



**Psychoeducation for bipolar disorder:
an exploration of the feasibility,
acceptability and impact of group and
internet-based interventions**

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Thesis submitted for the degree of Doctor of
Philosophy at Cardiff University

January 2014

DECLARATION

This work has not previously been accepted in substance for any degree and is not concurrently submitted in candidature for any degree.

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ACKNOWLEDGEMENTS

This thesis would not have been possible without the guidance of my dedicated supervisors Dr Danny Smith, Dr Sharon Simpson and Prof Ian Jones. I am very grateful for their excellent advice, support, encouragement, patience, and invaluable comments on my draft thesis chapters. Dr Smith and Dr Simpson were also independent reviewers for my systematic review.

My gratitude extends to the Medical Research Council and the BIG Lottery for funding this research, and to the BEP-Cymru team, who continue to provide a much appreciated service to people with bipolar disorder across Wales. I am also indebted to the BIPED trial team who conducted the quantitative research into the feasibility, acceptability and potential efficacy of Beating Bipolar, which I summarised at the beginning of Chapter 4.

I am thankful to Dr Fiona Wood and Dr Sarah Morgan-Trimmer for their expert advice on qualitative and mixed methods, and to Mr Ken Wann for double-coding the online forum data. Likewise, thank you to Dr Rebecca Playle for her expert advice on statistics.

I would like to acknowledge my friends who have traversed the rocky path to the PhD before me; these people have inspired me to follow in their footsteps and encouraged me along the way: Dr Cherry-Ann Waldron, Dr Joanna Crocker, Dr Eleri Owen-Jones, Dr Lucy Brookes-Howell, Dr Arianna Di Florio and Dr Leila Rooshenas.

Special thanks to everyone who has participated in my research.

Finally, I wish to express my love and deepest gratitude to my parents Margaret and Geoff Poole, who have supported me through difficult times and celebrated my achievements - thank you for always being there for me. I dedicate this thesis to you.

SUMMARY

Psychoeducation interventions are recommended for people with bipolar disorder to enable them to effectively self-manage their health, prevent relapse and improve their long-term outcomes.

Psychoeducation comprises expert information (on topics such as monitoring mood, lifestyle and medication) and is commonly presented by health care professionals in structured individual or group face-to-face sessions. This thesis reviewed the evidence from randomised controlled trials and qualitative studies that psychoeducational approaches in different formats may or may not be beneficial for patients with bipolar disorder, and consequently found the evidence base to be sparse, particularly with regard to the benefits and drawbacks of different formats of delivery.

This thesis explores the feasibility, acceptability and impact of a group-based psychoeducation programme for people with bipolar disorder in Wales (Bipolar Education Programme – Cymru) and a novel internet-based psychoeducation programme (Beating Bipolar) for participants of a randomised controlled trial. Adopting a pragmatic approach, and using both qualitative and quantitative research methods in a predominantly qualitative study, I explored and compared both interventions from the perspectives of patients and facilitators, using qualitative interviews, data from the Beating Bipolar online discussion forum and quantitative outcome data from questionnaires.

Findings principally describe the facilitators and barriers to delivery in different formats, what participants liked and disliked about the programmes, the potential impact of the programmes and recommendations for future use, and identify the potential therapeutic mechanisms of psychoeducation. Receiving social support from the groups and enhanced knowledge and understanding of bipolar disorder from the educational content and shared experiences were found to improve many participants' self-reported confidence in their ability to manage their bipolar disorder, and many made beneficial changes to their lifestyles, coping strategies and their attitudes towards medication and bipolar disorder in general as a result. Future research should focus on widening access to both interventions.

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Chapter 1: Introduction

1.1 Introduction to thesis

This thesis describes work carried out for a PhD sponsored by the Institute of Psychological Medicine and Clinical Neurosciences and the Clinical Epidemiology Interdisciplinary Research Group, School of Medicine, Cardiff University. It was jointly funded by the MRC and the Big Lottery.

This introductory chapter presents an outline of the thesis, introduces the research questions and aims and approaches, describes the interventions examined, and outlines recommended clinical guidelines for the maintenance treatment of bipolar disorder.

1.2 Rationale

1.2.1 Definition and prevalence of bipolar disorder

Bipolar disorder is a complex, relapsing mood disorder, characterised by episodes of depression and mania, and frequently comorbid with alcohol and substance misuse [1]. According to the DSM-IV, bipolar disorder is categorised into Type I (mania with or without depression), Type 2 (depression and hypomania with or without cyclothymia), and NOS (a category to include all other clinical presentations of bipolar disorder) [2]. Mania is characterised as an abnormally elevated or irritable mood and level of arousal, which may have psychotic features, such as delusions or hallucinations [3]. Hypomania is a less extreme form of mania, which commonly manifests in a decreased need for sleep, inflated self-esteem or grandiosity, racing thoughts, distractibility, increased talkativeness and involvement in risky activities such as promiscuity, gambling, unrestricted spending sprees or reckless driving [2]. Cyclothymia is the term for recurrent hypomania [1]. Rapid cycling is defined as a minimum of 4 episodes per year of mania or hypomania and major depression [1, 4].

Lifetime prevalence estimates of the bipolar disorder spectrum (as defined by the DSM-IV) are 1.0% for BP-I, 1.1% for BP-II, and 2.4% for sub-threshold bipolar disorder [5]. Compared with those without bipolar disorder those with the disorder have higher rates of disability and mortality, due to comorbid illness and suicide [6]. Costs associated with bipolar disorder include excess mortality and unemployment [6]. A recent study in the United States found that employees' non-adherence to their treatment for bipolar disorder resulted in greater indirect costs for their employers due to absence, short-term disability and compensation [7].

1.2.2 Clinical guidelines for the treatment of bipolar disorder

The National Institute for Health and Care Excellence (NICE) clinical guidelines recommend psychoeducation for the long-term management of bipolar disorder in addition to prophylactic medication [8]. The guidelines promote collaborative relationships between clinicians, patients, families and carers, and recommends clinicians to give patients, families and carers information at every stage of assessment diagnosis and treatment [8]. It also recommends advising patients on self-monitoring of symptoms, lifestyle and coping strategies [8]. Furthermore, it encourages patients, families and carers to join self-help and support groups [8].

Following an acute episode, NICE recommends individual structured psychological interventions to promote a healthy lifestyle and prevent relapses, specified as the following:

The therapy should normally be at least 16 sessions over 6–9 months and:

- include psychoeducation, the importance of a regular routine and concordance with medication*
- cover monitoring mood, detecting early warnings and strategies to prevent progression into full-blown episodes*
- enhance general coping strategies*
- be delivered by people who have experience of patients with bipolar disorder*

Excerpt from NICE clinical guidelines 38, p17 [8]

1.2.3 Psychoeducation for bipolar disorder

There is increasing evidence to suggest that the combination of evidence-based psychological interventions and medication is the most effective way of preventing relapses of bipolar episodes [9,

10]. Psychoeducation is a psychological intervention which has been shown to be effective in patients with bipolar disorder [9, 10]. Psychoeducation for bipolar disorder is a structured way of presenting information about the diagnosis, treatment and self-management strategies to patients, families and carers. Psychoeducation can be delivered in groups or one-to-one, face-to-face or online, and a range of media may be used in its delivery [10]. An internet-based intervention may be cost-effective and reach a greater number of people with bipolar disorder, whereas a group-based intervention facilitates peer support.

1.2.4 Potential therapeutic mechanisms of psychoeducation

There were about ten students in each class, and they loved meeting in his bright studio room. By and large, learning to paint was a pretext for their being there, and most of them were taking the class for the same reason he was giving it: to find satisfying contact with other people. All but two were older than he, and though they assembled each week in a mood of comradely good cheer, the conversation invariably turned to matters of sickness and health, their personal biographies having by this time become identical with their medical biographies and the swapping of medical data crowding out nearly everything else.

Excerpt from the novel "Everyman" by Philip Roth [11]

There are various theories as to how psychoeducation may work in terms of its therapeutic mechanisms. Psychoeducation in any format informs patients about their illness or long-term condition to equip them with the knowledge and skills to effectively manage their health, thereby improving their long-term outcome. The knowledge and skills gained through psychoeducation may improve patients' confidence in their ability to manage their health (self-efficacy) and their ability to monitor and regulate their cognitions and behaviour (self-regulation). Group psychoeducation may have enhanced therapeutic value for some patients as it offers social support; although some form of social support may be possible via an internet-based intervention. Social support, self-efficacy and self-regulation are discussed below as potential therapeutic mechanisms of psychoeducation for bipolar disorder.

1.2.4.1 Social support

Social support may operate in a number of ways, e.g. encouragement, motivation, feedback, empathy, improved self-efficacy, and may also provide an opportunity for role modelling. Social support can provide emotionally satisfying confirmation from others that one is loved, cared for, valued and a member of a community or support network [12]. It may take the form of appraisal support (helping others understand stressful events and suggest ways of coping), tangible assistance (providing material support), informational support (knowledge and advice) or emotional support (empathy, warmth, nurturing and reassurance) [12]. Studies have shown that social support effectively reduces depression and anxiety, and a lack of social support may be very stressful for people with high needs for social support [12]. In a qualitative study which explored how bipolar disorder impacts on patients' quality of life, themes emerged regarding routine, independence, stigma and disclosure, identity, spirituality and social support [13]. Participants ranked social support to be the most important factor in determining quality of life, followed by mental health [13].

Many people with long-term conditions may feel isolated as they do not know others who have the same condition or if their condition has impacted adversely on their work and social life. The latter is commonly the case for people with bipolar disorder, as their families, friends and colleagues may not be able to cope with their mood swings or the impact of them. A qualitative study of people with bipolar disorder by Michalak et al (2006) found that many interviewees reported that they had lost relationships with partners, friends and family members as a direct result of their bipolar disorder, particularly during hypomanic and manic episodes [13]. Another study found that the lives of many people with bipolar disorder were characterised by disruption, confusion, contradiction and self-doubt, and consequently stressed the importance of interventions which facilitate acceptance [14].

Group psychoeducation enables people to meet with others who have the same health condition, whereas internet-based psychoeducation may deliver social support through online forums or email. The peer support this provides may offer emotional support in terms of empathy, shared experiences and comradeship, informational support in terms of advising others from personal experiences, and appraisal support in terms of helping others to understand and come to terms with their stressful life events and sharing effective coping strategies and useful resources. Group facilitators may also contribute to psychoeducation groups in a pastoral sense as well as providing expert information and advice.

Social support is an important resource and may be of significant therapeutic benefit to patients. A study by House, Landis and Umberson in 1988 demonstrated that social support lowered the likelihood of illness, increased the speed of recovery from illness and reduced the risk of mortality due to serious disease [12]. Furthermore, from a health psychology perspective, disclosure of emotional experiences through confiding in others may help people express their feelings and find meaning in their experiences [12].

1.2.4.2 Promotes self-efficacy

Self-efficacy is the self-belief that one is capable of setting and achieving personal goals which have positive outcomes. Bandura's 1987 development of social cognitive theory stated that self-efficacy is the premise that by believing you are capable of a desired future state you are likely to set high personal goals and adapt your behaviour in order to achieve it [15].

Psychoeducation may provide an opportunity for patients to evaluate their circumstances, values and attitudes with expert information, advice and support. It may influence them to change any attitudes which lead to risk-taking behaviour (such as medication non-adherence or excessive spending) and place greater value on their health, which may in turn lead to enhanced health-promoting behaviour. Interactions with health care professionals may also enhance individuals' knowledge and self-efficacy and may help them set healthier goals.

Patients' motivation to improve their health, engage with relapse prevention techniques, set personal goals, improve their lifestyles and reduce their health-risk behaviour may be enhanced by information and/or social support provided by psychoeducation. Psychoeducation may inform, equip and empower patients to have sufficient self-belief in their capacity to effectively and skills to self-manage their condition and cope if and when they become unwell. Improved self-efficacy may occur through patients' interactions with others; i.e. via empathy, modelling, encouragement, etc.

1.2.3.3 Enhances self-regulation

Self-regulation is closely linked to self-efficacy in that if patients' confidence in their ability to take care of themselves is increased, they will be more able to self-monitor their behaviour and regulate their cognitions and behaviour to successfully organise and achieve their goals [15]. Self-regulation

is the process of controlling your thoughts and actions to achieve your goals. It involves cognitive regulation (controlling or modifying thoughts), emotional regulation, attentional control, good planning, and specific and valued goals [15].

Psychoeducation may prepare patients for negativity and low mood states which may interfere with their goal attainment by suggesting coping strategies. Monitoring mood through mood charts or diaries may help patients monitor and control their emotions. Similarly, cognitive behavioural techniques may assist with cognitive regulation. Additionally, patients are supported in creating their relapse signatures, emergency contact sheets and identifying their triggers and early warning signs, which enables them to plan their behaviour to reduce the likelihood of undesired outcomes.

A qualitative focus group study explored the personal experiences of self-management and recovery of people with bipolar disorder. Key themes related to taking responsibility for one's own wellness, building on existing self-management techniques (which may include techniques for self-regulation) and the importance of overcoming barriers to wellness, such as negativity, stigma and taboo [16]. Another qualitative study investigated the impact of bipolar disorder on patients' lives revealed that the patients interviewed typically reported a loss of autonomy and felt out of control, overwhelmed or flawed [17]. By learning how to take responsibility for their health patients may be empowered to positively value and take control of their health and their lives, thereby increasing their ability to self-regulate their cognitions and behaviour and maintain wellbeing.

1.3 Beating Bipolar: internet-based psychoeducation for bipolar disorder

In collaboration with patients with bipolar disorder, their families and health professionals the Bipolar Disorder Research Group at Cardiff developed an internet-based psychoeducational intervention called "Beating Bipolar" [18, 19]. This work has built on the success of group psychoeducation interventions for bipolar disorder (focusing on illness awareness, adherence to treatment, early detection of recurrence and lifestyle regularity), which have emerged as an effective treatment option for long-term management [10, 20-22].

Beating Bipolar involves a blending of different delivery mechanisms, with initial face-to-face delivery, followed by internet-based interactive delivery of factual content and ongoing support via an online forum [19]. The key areas covered are: i) the accurate diagnosis of bipolar disorder; ii) the

causes of bipolar disorder; iii) the role of medication; iv) the role of lifestyle changes; v) relapse prevention and early intervention; vi) psychological approaches; vii) gender-specific considerations; and, viii) advice for family and carers [19]. Each module contains interactive exercises to enable participants to actively engage with the material and maximise retention [19]. Example screen shots of the programme are provided in Figure 1 to illustrate the appearance of the modules. In the clinical trial, the Bipolar Interactive Psychoeducation (BIPED) study, [23] participants had an initial face-to-face consultation with a psychiatrist demonstrating how to use the programme, and were subsequently given access to each of the modules in turn every 2 weeks. They were encouraged to discuss the content of each module within the discussion forum [23].

The programme's content is similar in focus to Bauer and McBride's Life Goals Program [24] and Colom and Vieta's group psychoeducation intervention for bipolar disorder [25]. It was developed in three stages [18]. Firstly, literature searches were performed to identify the core content of the programme [10] and also to identify how to engage participants within an interactive environment [18]. The second stage of development involved a multi-disciplinary team of a psychiatrist, two psychologists and a web-designer to draft initial ideas for content and delivery [18]. In the final stage, three focus groups of service users and mental health professionals took place to inform the method of delivery and the content and the presentation of the modules, to provide a balance between service users' needs and recommendations based on clinical experience [18].

Figure 1. Example screen shots of Beating Bipolar



1.4 Bipolar Education Programme – Cymru (BEP-Cymru): group-based psychoeducation

The Bipolar Education Programme – Cymru, referred to as BEP-Cymru, is a manualised, group-based psychoeducation programme for people with bipolar disorder, delivered throughout Wales. BEP-Cymru is funded by the Big Lottery's Mental Health Matters programme and is provided by the BEP-Cymru project team based at Cardiff University, who developed the intervention. Beating Bipolar and BEP-Cymru were developed and delivered by the same research group and also had overlapping funding sources.

The programme comprises 10 group sessions delivered on a weekly basis to participants by two group facilitators, who have a background in psychiatry, mental health nursing or another related professional background. There are no more than 15 participants per group. Sessions are 2 hours in duration and are structured in the following format:

Presentation by facilitators - 30 minutes

Group exercise - 30 minutes

Break for refreshments – 20 minutes

Facilitator-led group discussion – 45 minutes

Summary by facilitators – 5 minutes

Its content is based on the psychoeducation programme by Colom and Vieta [22]. Table 1 is the BEP-Cymru training pathway, which lists each group session with their corresponding outcomes for participants (obtained from BEP-Cymru presentation slides).

Session	Outcomes
Introduction	Participants will: <ul style="list-style-type: none"> • Understand the goals of group psychoeducation for bipolar disorder. • Be aware of the rules for taking part in group sessions. • Know how the sessions will be conducted.
What is bipolar disorder?	Participants will: <ul style="list-style-type: none"> • Know how bipolar disorder is diagnosed. • Have a detailed understanding of the signs and symptoms of bipolar disorder. • Be able to construct their personal “life chart”.
What causes bipolar disorder?	Participants will: <ul style="list-style-type: none"> • Understand the importance of biological risk factors. • Understand the importance of environmental risk factors. • Appreciate that bipolar disorder is caused by a complex interaction of these factors.
Medications	Participants will: <ul style="list-style-type: none"> • Gain an increased knowledge of medication used in bipolar disorder. • Gain an improved understanding of the benefits and risks associated with medication. • Have a balanced attitude towards the use of drug treatments and a greater understanding of their own medication.
Psychological approaches	Participants will: <ul style="list-style-type: none"> • Have an increased knowledge of psychological approaches and an appreciation of their place in the treatment of bipolar disorder. • Understand that psychoeducation is an evidence based intervention for bipolar disorder. • Have brief experience of some CBT techniques.
Lifestyle	Participants will: <ul style="list-style-type: none"> • Understand how lifestyle can influence bipolar disorder • Be able to use simple methods by which these factors can be managed. • Appreciate the importance of lifestyle factors alongside medication use.
Monitoring mood and identifying triggers	Participants will: <ul style="list-style-type: none"> • Be able to effectively monitor their mood. • Identify their triggers for depression, hypomania or mania.
Early warning signature	Participants will: <ul style="list-style-type: none"> • Produce an Early Warning Signature for relapse which will include plans for intervening early to nip episodes of depression and mania in the bud. • Produce a contact sheet with information of all key clinical and support contacts recorded on it.
Friends and families	Participants will: <ul style="list-style-type: none"> • Have an increased knowledge of how partners, families and carers can help in managing bipolar disorder. • Have an increased ability to positively involve partners, families and carers in their care. • Have a better knowledge of the issues surrounding pregnancy and childbirth in women with bipolar disorder.
Bringing it all together	Participants will: <ul style="list-style-type: none"> • Reflect on good and bad aspects of the programme. • Identify useful insights and new skills learned during the programme that may be of lasting benefit.

Table 1. BEP-Cymru training pathway

Examples of the group exercises include:

- Splitting participants into smaller groups to rank a series of statements regarding the causes of bipolar disorder, following which all groups come together to discuss the rationales behind their ordering
- Asking participants to fill out a questionnaire on their attitudes towards medication, either individually or in small groups, for a facilitator to informally discuss with them during the process
- Asking the group to suggest “pleasurable activities”, which are then noted on a flip chart, following which participants receive handouts of a chart to record their pleasurable activities, their mood rating before and after the activity, and whether the activity was helpful and why

The sessions are held in hospital-based meeting rooms, community centres, arts centres or hotel conference suites. Desks and chairs are set-up in a horseshoe shape in the meeting rooms to maximise the potential for participant interaction. Presentations are interactive and include the video content and visual presentation slides. Participants are given handouts after each session containing key information on the topic of the day.

1.5 MRC framework for evaluating complex interventions and the mixed methods approach

Both Beating Bipolar and BEP-Cymru are complex interventions in that they include multiple interacting components; for example, information giving, social support, improving self-efficacy, challenging attitudes, planning, etc. Campbell et al, 2000, acknowledge that because evaluation of complex interventions is difficult, a phased approach to evaluation is recommended, requiring both qualitative and quantitative evidence [26]. Such a phased approach is described within the Medical Research Council’s (MRC) framework for the design and evaluation of complex interventions to improve health [26]. The sequential phases of developing randomised controlled trials for complex interventions are on a continuum of increasing evidence, although transition between phases may not necessarily be linear as new evidence may impact on the initial theoretical basis of an intervention, for example [26].

The first step is the theoretical stage which identifies evidence for the potential effectiveness of an intervention and culminates in the generation of the hypothesis [26]. The second step is referred to as Phase I, in which the components of the intervention are defined through statistical modelling or simulation, focus groups, surveys, case studies or descriptive studies [26]. The third step is Phase II, the exploratory trial, in which the intervention and outcomes are piloted, components of the intervention are described and the main trial is designed [26]. This phase includes testing for feasibility and acceptability; i.e., how feasible is the delivery of the intervention and how acceptable is it to patients and providers [26]. Phase III is the main randomised controlled trial and Phase IV is the assessment of the intervention in routine practice over the long term [26].

Beating Bipolar is the intervention of the BIPED randomised controlled trial, which is an exploratory Phase II trial. Preliminary work for developing the intervention was in line with the MRC guidance and consisted of a literature review [10] to assess the evidence for its suitability and effectiveness and a series of focus groups to inform the development of the intervention and pilot early versions of the programme [18]. A protocol was published for the exploratory trial [19]. My involvement with this trial was at the stage of assessing the feasibility and acceptability of the intervention from patients' perspectives and to explore the potential outcomes of the intervention by combining both qualitative and quantitative data. This is consistent with the aspects of evidence accumulation within Phase II of the MRC framework for the design and evaluation of complex interventions [26].

BEP-Cymru is not being evaluated as an exploratory trial; however, I have evaluated the intervention exploring its feasibility, acceptability and potential impact. I approached the evaluation of this intervention in a similarly exploratory manner as with Beating Bipolar, using a mixed methods approach.

For evaluating both interventions I have primarily used qualitative methods; however, integrating qualitative and quantitative methods within my PhD has provided richer data than would have been possible from either method alone – combining methods has become increasingly the optimal choice for evaluations of complex interventions [26-30]. Further details and rationale regarding my methods are provided within the methods chapter.

1.6 Aims of thesis

The thesis aims to address questions relating to the feasibility, acceptability and impact of internet-based and group-based psychoeducation for bipolar disorder from self-reported experiences of participants and group facilitators and questionnaire outcome data, and to explore and compare the different delivery formats of psychoeducation. Another aim was to systematically review the literature on psychoeducation for bipolar disorder for randomised controlled trials and qualitative studies in order to provide a context for my research. The main research questions and aims are detailed below.

Research question 1:

What can we learn from the literature on psychoeducation for bipolar disorder?

Aim:

- To review the evidence from randomised controlled trials and qualitative studies that psychoeducational approaches in different modalities may or may not be beneficial for patients with bipolar disorder

Research question 2:

How feasible and acceptable are internet-based and group-based face-to-face psychoeducation interventions for bipolar disorder?

Aims:

- To find out whether the interventions are feasible and acceptable to participants
- To explore the barriers and motivators to participant engagement, what participants like and dislike about the interventions, and ways in which the interventions may be improved
- To identify why some participants engage more with a psychoeducation intervention than other participants

Research question 3:

What is the impact of internet-based and group-based face-to-face psychoeducation interventions for bipolar disorder?

Aim:

- To identify benefits and drawbacks to participating
- To assess and explore impact via questionnaires and semi-structured interviews with participants, specifically relating to:

- Insight and understanding of bipolar disorder
- Attitudes to bipolar disorder
- Attitudes to medication
- Self-esteem
- Relationships
- Lifestyle
- Quality of life
- General functioning
- Self-regulation (the ability to develop, implement and flexibly maintain planned behaviour) [31, 32]
- Perceived health competence (sense of competence in effectively managing one's health) [33]
- Perceived extent of social support
- To identify the underlying therapeutic mechanisms of psychoeducation – i.e., which components of psychoeducation seem to be effective in inducing subsequent change in participants and the ways in which these components influence participants
- To identify why some participants may benefit from a psychoeducation intervention more than other participants

Research question 4:

When patients and facilitators describe their experiences of internet-based and group-based face-to-face psychoeducation interventions for bipolar disorder what is relevant to them?

Aim:

- To find out about patients' and facilitators' experiences of the psychoeducation interventions and what is relevant for them
- What are patients' and facilitators' "take home messages"

Research question 5:

What are the similarities and differences between internet-based and group-based face-to-face psychoeducation for bipolar disorder?

Aim:

- To explore the similarities and differences between views and experiences of psychoeducation of those who received the internet-based intervention and those who received the group-based intervention

- To gain insights into how the impact of psychoeducation may vary depending on the delivery format
- To explore participants' preferences for one mode of delivery over the other

Because my PhD is exploratory in nature, these research questions provided a flexible framework for my research enquiry with scope for exploring additional issues which emerged.

Chapter 2: Psychoeducation for bipolar disorder: a systematic review of randomised controlled trials and qualitative studies

2.1 Background

To date there has been a paucity of comprehensive critical reviews of studies examining the effectiveness and potential benefits of psychoeducation for patients with bipolar disorder [10, 34]. My aim was to review the evidence from quantitative and qualitative studies that psychoeducational approaches in different modalities may or may not be beneficial for patients with bipolar disorder. My objective was to review psychoeducation interventions (individual, online, and group-based) for bipolar disorder to include randomised controlled trials (RCTs) and qualitative studies.

This review provides a useful context for my assessments of the group-based and internet-based psychoeducation interventions for bipolar disorder – Beating Bipolar and BEP-Cymru.

2.2 Methods

2.2.1 Data sources and search strategy

A systematic review of the literature on psychoeducation for bipolar disorder was performed on 28 March 2012. Four electronic databases were searched: EMBASE, 1947-2012 March 26; OVID MEDLINE(R), 1946 – March Week 2 2012; Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations, March 27, 2012; and PsycINFO, 1806 to March Week 3 2012. The following limits were imposed on the searches: studies published since 1980 (before which time no studies on psychoeducation for bipolar disorder have been known to exist), in the English language (due to resource restrictions we were unable to translate studies for screening and inclusion), peer-reviewed, and RCTs and qualitative studies. We did not search the grey literature.

This first stage of our search strategy was as follows (key words in italics):

Search 1:	<i>relapse prevention</i> AND <i>bipolar disorder</i>	277 results
Search 2:	<i>treatment compliance</i> AND <i>bipolar disorder</i>	86 results
Search 3:	<i>psychoeducation</i> AND <i>bipolar disorder</i>	566 results
Search 4:	<i>family therapy</i> AND <i>bipolar disorder</i>	411 results
Search 5:	Searches 1 OR 2 OR 3 OR 4	1106 results
Search 6:	Remove duplicates within Search 5	812 results

We also searched OVID MEDLINE(R), 1946 – March Week 2 2012 and Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations, March 27, 2012 with MeSH (Medical Sub-Headings), limited to English language and 1980-current. The second stage of our search strategy was as follows:

Keyword: psychoeducation

Map term to subject heading: Bipolar disorder

Combine selections with: AND

Focus: Prevention and control

= 231 results

Map term to subject headings: *Bipolar disorder/ AND *Patient education as Topic/

= 60 results

Via these electronic searches we returned 812 results from searching keywords and 291 results from searching MeSH headings; totalling 1103 results. We then found a further 16 papers through hand-searching reference lists and contacting key authors; totalling 1119 papers for screening.

2.2.2 Study inclusion and selection

Studies were eligible for inclusion if they satisfied the following criteria:

- 1) Had original data;
- 2) All patients studied had bipolar disorder;
- 3) The intervention described was broadly psychoeducational;
- 4) The study had been published in English;
- 5) The study was a RCT or qualitative study;
- 6) The study reported patient focused outcomes.

Studies were excluded if:

- 1) The study sample was predominantly paediatric (patients under 12 years);
- 2) The study predominantly focused on bipolar disorder patients with comorbid conditions;
- 3) The study was only reported within a conference abstract;
- 4) Not written in the English language;
- 5) Unpublished;
- 6) Had non-randomised and non-controlled designs or were not qualitative;
- 7) In progress or no results reported within the paper or elsewhere (for protocol papers).

I screened titles and abstracts to create a shortlist of studies for potential inclusion. The shortlisted abstracts were validated by DS and SS who each checked half. Disagreements regarding inclusion or exclusion of studies were resolved through discussion. Of 83 shortlisted abstracts 10 were excluded. Seventy-three full papers were retrieved for further assessment. For independent assessments of study inclusion: I assessed all papers, DS and SS assessed half each, and again disagreements were resolved through discussion. Following this process 35 studies were excluded (on the basis that the sample was predominantly paediatric, the designs were non-randomised and non-controlled or the study was only reported via a conference abstract); retaining 34 quantitative and 4 qualitative full text papers for data extraction. Following advice from my thesis examiners, a further thirteen papers have been subsequently excluded because the studies described broader psychotherapy applications (where psychoeducation was only a small or component part of the intervention). See the subsection for included studies within the results section for further details.

2.2.3 Data extraction and quality assessment process

All 38 papers identified for data extraction retained their study identification numbers allocated for the first screening. Detailed data extraction and quality assessment templates were used for reviewers to critically assess RCTs and qualitative studies – different forms were designed for both types of study (see Appendices 1 and 2 for the RCT form and the qualitative form, respectively). The data extraction tool for RCTs comprised details of the study, characteristics of the intervention(s), participant characteristics, outcome measures, and results. The quality assessment tool for RCTs included queries for the following: sample size and power calculation, participants withdrawn or lost to follow-up, number included in analysis, baseline comparability and maintenance of comparable groups, randomisation process described, blinding of outcomes, statistical methods and estimates of variance for main results. This tool was based on the CONSORT checklist of information to include

when reporting a randomised trial [35]. Items within the checklist focus on the quality of reporting, the trial design, clarity and minimisation of bias within the methods and results, limitations, generalisability and interpretation of findings [35]. The data extraction tool for qualitative studies comprised details of the study, characteristics of the intervention(s), participant characteristics, and findings. The quality assessment tool used for qualitative studies comprised the CASP [36] checklist and also included questions relating to aims and objectives, the authors' interpretations of findings, inclusion of quotations to appropriately support findings, and appropriate attention to outliers. The CASP is a brief, commonly used quality checklist which focuses on rigour, key research methods, credibility and relevance [36].

Data extraction and quality assessment were performed for each study by two independent reviewers (DS or SS, and me). Study quality was rated as good, fair or poor, according to the extent to which the studies satisfied the criteria within either the qualitative or quantitative quality assessment tool. Ratings are by their nature subjective, but we defined the minimum criteria for each as follows:

- Good quality: must report at least four of these below to include power calculation, loss to follow-up and intention-to-treat
- Fair quality: must report at least three of these below
- Poor quality: where two or less of these are reported
 - Sample size and power calculation
 - Participants withdrawn or lost to follow-up
 - Number included in analysis
 - Baseline comparability and maintenance of comparable groups
 - Randomisation
 - Blinding of those conducting outcome assessment
 - Intention-to-treat
 - Estimates of variance for main results

Where two reviewers disagreed upon study characteristics or quality, agreement through discussion was sought amongst all three reviewers. Meta-analysis was not possible due to heterogeneity within study design, intervention and outcomes. Hence, we report a narrative synthesis of included studies.

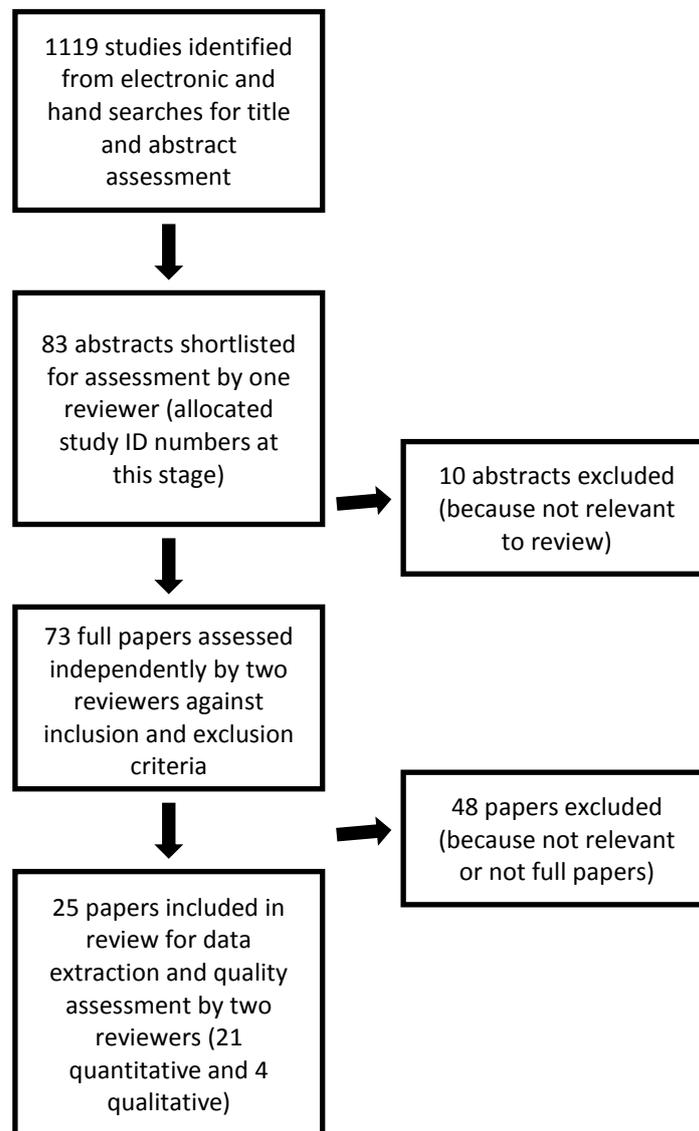
2.3 Results

2.3.1 *Included studies*

I screened 1103 abstracts retrieved from four electronic databases and 16 abstracts identified through hand-searching through reference lists for potential relevance to the literature review. I shortlisted 83 abstracts for independent review against the inclusion and exclusion criteria, and rejected 10 abstracts at this stage because they were not relevant. Seventy-three full papers were read in detail and assessed for inclusion against the inclusion and exclusion criteria by myself and one independent reviewer. After excluding 35 of these (because they did not fulfil the inclusion or exclusion criteria or because they were not full papers - i.e. they were protocols or conference abstracts), two reviewers independently extracted data and performed quality assessments of the 38 papers to be included (34 quantitative and 4 qualitative).

A further 13 papers have been subsequently excluded from this review because the studies reported broader psychological therapy applications – where psychoeducation was only a small or component part of the intervention – leaving 21 quantitative and 4 qualitative papers eligible for assessment. These 13 studies were excluded because they were studies of Cognitive Therapy, Cognitive Behavioural Therapy or family therapy where psychoeducation was a small component of the intervention. The exclusion of these papers benefits the review by providing a more specific focus on psychoeducation. See Figure 2 for a summary of the study selection process.

Figure 2. Study selection process flowchart



2.3.2 Quality assessment of studies

Only nine studies [23, 37-43] (of which three were qualitative studies embedded within RCTs [41-43]) had published corresponding *a priori* protocols [19, 44-47]. Of the RCTs, eight studies were rated as good [37-40, 48-51], seven were rated as fair [23, 52-57] and six were rated as poor quality [58-63]. Half the studies (11 of 21) did not report their power calculations [48, 49, 53, 55, 56, 58-63] nor did many report blinding for outcome assessors [52-56, 58-63]. Ten studies did not state that they followed the intention-to-treat principle [48, 52, 54, 57, 59-63] (i.e., not all participant data were analysed regardless of adherence to the protocol or continuation in the trial which could lead to bias). Thirteen studies were unclear regarding their method of generating randomisation [40, 51,

52, 55, 58-62]. Only half the studies clearly stated numbers of participants withdrawn or lost-to-follow up [23, 38-40, 50, 51, 54-58, 60, 61]. However, the vast majority of studies described the intervention examined in reasonable detail, had comparable groups at baseline and reported main outcomes. With regard to the four qualitative studies, two were of good quality [42, 43], one was rated as fair quality [41] and one was rated as poor quality [64]. I acknowledge that the publication of qualitative studies in medical journals offers less space for methodological detail than would be offered in social science journals. However, the study of poor quality offered very little information regarding its methods and no indication of rigour [64].

2.3.3 Summary of findings

The findings are split by the delivery format of the psychoeducation: Group-based patient only psychoeducation, Individual face-to-face psychoeducation, Caregiver or family psychoeducation and Internet-based psychoeducation. For detailed information on all 25 papers please refer to Table 3 for RCTs (Appendix 3) and Table 4 for qualitative studies (Appendix 4).

2.3.3.1 Group-based patient only psychoeducation

In most studies of group-based psychoeducation delivered to outpatients, a manual-based programme of topics relating to bipolar disorder and self-management of symptoms was provided via weekly sessions of approximately 90 minutes, which were facilitated by a health care professional.

We found 11 RCTs assessing group-based patient only psychoeducation [38-40, 48, 49, 51, 52, 54, 56, 57, 59, 61]; however, only 8 of 11 were rated as good quality. Because the majority of studies lacked power calculations and many studies of fair quality did not state they had followed the intention-to-treat principle the evidence these studies provide is weak. The key studies for group-based psychoeducation which were rated as being good quality were the studies by Colom et al, 2003 [48], Colom et al, 2009 [49], Simon et al, 2005 [38], Simon et al, 2006 [38], and Bauer et al, 2006 [40, 51]. These studies are discussed in detail below.

Colom et al, 2003, [48] delivered 20 weekly group psychoeducation sessions to patients in the treatment arm of the study. The meetings were structured according to the Psychoeducation

Manual for Bipolar Disorder [22], and content focused on illness awareness, adherence to treatment, early detection of prodromal symptoms and recurrences, and lifestyle regularity. The control group received 20 weekly group meetings with the same psychologists who led the groups in the treatment arm, but there was minimal psychoeducational content within the meetings. Sixty patients, who met the DSM-IV criteria for bipolar disorder and had been euthymic for the previous six months, were randomised to receive the intervention and 60 randomised to the control condition. They assessed number of recurrences, time to recurrence and number and duration of hospitalisations as their main outcome measures. They found that the intervention group had significantly fewer relapsed patients, recurrences per patient and greater time to recurrences. The intervention group also had fewer and briefer hospitalisations. A five-year follow up was conducted for these patients in 2009 [61]. Data for 50 participants in the treatment arm and 49 participants in the control arm were available and showed that the intervention group had longer time to recurrence, fewer recurrences, spent less time acutely ill and had lower median number of days hospitalised. Although these results found significant effects of the intervention, it should be noted that although the studies were of relatively good methodological quality a power calculation was not stated within either paper and there are no protocols published for these studies.

Bauer et al, 2006, [40, 51] developed the Bipolar Disorders Programme intervention, which comprised group psychoeducation via the Life Goals Program, clinician support via simplified clinical practice guidelines, and improved information flow, access to and continuity of care from nurse care coordinators. The Life Goals Program focused on personal symptom profiles, early warning symptoms and triggers for self-management. The control arm received treatment as usual. Participants were outpatients with a diagnosis of bipolar disorder types I or II, and were acutely ill and highly comorbid. Three-hundred and thirty participants were randomised and outcome data were collected for 306 participants – 157 in the treatment arm and 149 in the control arm. The main outcomes were clinical outcome, functional outcome, quality of life, social adjustment and service use. Assessments after six months revealed that the treatment group had a significant reduction in weeks of a bipolar episode, significantly improved social functioning (specifically relating to work, parental and extended-family roles) and significantly improved mental quality of life. The treatment group also had significantly higher treatment satisfaction. This was a well-designed and well conducted study, for which an a priori protocol has been published [47], although one drawback is the relatively short follow-up period.

Simon et al, 2005, [38] conducted a trial to evaluate group psychoeducation (adapted from Bauer and McBride's Life Goals Program) and monthly telephone monitoring of mood and symptoms by trained nurse care managers in a community setting. The group programme consisted of five weekly then twice-monthly sessions for two years. Most patients had some bipolar symptoms at baseline, and all had a diagnosis of bipolar disorder type I or II. Participants in the control arm received treatment as usual. Data were analysed for 441 participants – 212 in the treatment arm and 229 in the control arm). Participants were assessed every three months for 12 months for manic and depressive symptom severity, which was the main outcome measure. Results showed that the psychoeducation group had significantly lower mean mania ratings at 12-month follow-up and a greater decline in depression ratings. These findings are robust in the context of the good design [46], conduct and reporting of the RCT. The authors conducted an additional year's follow-up for 331 available participants, 156 of whom were randomised to the treatment group and 175 to the control, and published their findings in 2006 [39]. After two years follow-up, the psychoeducation group had significantly lower mean mania ratings and less time with significant mania symptoms.

There was one qualitative study examining group-based psychoeducation; however, it was of poor quality [64]. The authors provided very little detail of how they conducted the study in their methods section. The sampling strategy was not mentioned, nor the setting or how the interviews were conducted or recorded. There is also no indication of a rigorous analysis as there is not an in-depth description of the analytic process, and the findings lack explicit, detailed exploration of themes. Despite the limitations of this study, its findings may provide an insight into the experiences of group psychoeducation from the perspectives of service users. The sample comprised outpatients in remission who met criteria for bipolar disorder according to the DSM-IV. Semi-structured interviews were conducted with 11 participants and the data were analysed using IPA procedures [65]. Although the authors do not describe their IPA procedures, IPA (Interpretative Phenomenological Analysis) is acknowledged to be a cyclical process with specific stages of analysis [66], which enables rigorous exploration of subjective experiences [67]. This thematic analysis goes beyond a purely descriptive level of analysis to the level of interpretation [66]. Participants received group psychoeducation for bipolar disorder delivered by a clinical psychologist and a mental health nurse, which comprised eight weekly sessions of 90 minutes. Sessions included an overview of bipolar disorder and focussed on treatment, relapse prevention, coping with psychosocial stressors, and cognitive and behavioural strategies. The authors reported that three main themes emerged from the data: the treatment of bipolar disorder, comparison with and perception of others, and learning from the group. Pertaining to the theme of the treatment of bipolar disorder, participants

had differing views on the health service's approach to the illness, many expressed either reluctance or acceptance towards taking medication, and some described the trauma of hospitalisation. Regarding the theme "comparison with and perception of others", participants compared themselves to other group members, and recognised that others shared similar experiences and issues. They also acknowledged the friendship and respect of others and felt a heightened sense of self-esteem as a result. Relating to the theme "learning from the group" the programme helped some participants accept their diagnosis of bipolar disorder and learn cognitive-behavioural coping strategies for managing depression and mania.

2.3.3.2 Individual face-to-face psychoeducation

Two RCTs examined the effects of individual face-to-face psychoeducation for patients, which were rated as good quality [37, 50]. One study compared seven individual psychoeducation sessions with 13 sessions of Cognitive Behavioural Therapy (CBT) plus psychoeducation; however, this study was rated as poor quality [60].

Perry et al, 1999, [50] conducted an RCT to determine the efficacy of teaching patients to identify early signs of relapse. Outpatients diagnosed with bipolar disorder Type I or II received 7-12 treatment sessions with a research psychologist who taught them to identify early signs of relapse and obtain treatment or routine care. Thirty-four participants were randomised to the treatment arm and 35 to the control arm. They were assessed every six months for 18 months, and the main outcome measures were time to first manic or depressive relapse, number of manic or depressive relapses and social functioning. Results showed that the treatment group had a significantly longer time to first manic relapse and fewer manic episodes. The treatment also significantly improved overall social functioning and rates of employment. Although the sample size for this study appears small, a sample size calculation was reported and the analyses were intention-to-treat.

Lobban et al, 2010, [37] conducted an RCT to assess the feasibility and effectiveness of training Community Mental Health Teams (CMHTs) to deliver enhanced relapse prevention (ERP), also referred to as psychoeducation to teach patients to recognise early warning signs of manic and depressive episodes. A protocol was published for this research [44] and two qualitative studies which were embedded within this RCT have also been published and all studies have been rated as being of good quality [42, 43]. The ERP intervention was provided by CMHT workers (Care Coordinators) who were trained for the purposes of this research study to offer it to their patients

with bipolar disorder. ERP content included early warning signs, coping strategies, action plans, how to respond with services to different stages of relapse, and involving a friend or relative. Six one-hour manual-based training sessions of psychoeducation for bipolar disorder were provided by care-coordinators. For the main RCT 23 CMHTs and 96 patients with bipolar disorder who had no major episode in the previous four weeks were recruited. The intervention arm had 11 CMHTs and 56 patients and the control arm had 10 CMHTs and 40 patients. The primary outcome was time to recurrence of an episode of mania, hypomania or depression. After one year, no significant differences were found between the groups in terms of time to relapse, although treatment increased median time to the next bipolar episode by 8.5 weeks. These findings appear to provide some evidence for limited benefits of relapse prevention provision to service users by CMHTs.

The first qualitative study published as part of the research programme above, by Pontin et al in 2009, aimed to explore the value to service users of ERP for bipolar disorder from service users' and mental healthcare professionals' perspectives [42]. The researchers conducted semi-structured interviews with 21 Care Coordinators (CCs) and 21 service users (SUs). Purposive sampling was used to ensure a range of views from participants in the intervention arm and the control arm of the study. To ensure a spread of views, SU participants were selected on the basis of whether or not they had experienced a relapse since baseline and their length of diagnosis, and CC participants were selected on the basis of how many clients they had trained in the intervention and their professional background. The researchers employed a grounded theory approach [68] to analysing the data, and developed conceptual categories from the data by thematic analysis. Reliability of coding was ensured in that all interviews were read by at least two researchers. Furthermore, they increased the trustworthiness of the analysis by triangulation. Investigator triangulation was achieved through the development of the coding framework by researchers from different disciplines. Data triangulation was achieved by the investigation of both SU and CC perspectives which were categorised as themes in the final analysis if they were independently identified by both groups. The authors also strived for "catalytic validity" in that their findings should have the potential to change clinical practice or research [69].

They found that ERP improved both SUs' and CCs' understanding of bipolar disorder, developed their ways of managing or working with bipolar disorder, and enhanced working relationships. SUs learned about early warning signs and coping strategies, had a greater acceptance of diagnosis and medication adherence, felt more empowered, felt distressed about discussing past illness episodes, had more contact with their CC, and their trust in services increased. However, some SUs

experienced distress when reviewing their illness episodes. CCs increased their knowledge of bipolar disorder, had increased competence and confidence in working with patients, acquired new skills and strategies, learned more about the SU perspective and experience of bipolar disorder, had a greater sense of purpose, had more contact with SUs and created concise and individualised action plans. However, they felt that ERP added a burden to their workload and time, and increased SU dependency on them individually rather than on the service as a whole. This study's methods were detailed, demonstrating rigour and trustworthiness. These findings provide a valuable insight into how the provision of enhanced relapse prevention for bipolar disorder in case management by Community Mental Health Teams is experienced and valued by both service users and their mental health care professionals.

2.3.3.3 Caregiver or family psychoeducation

There were five RCTs which focused on caregiver or family psychoeducation: two were rated as fair quality [53, 55] and three were rated as poor quality [58, 62, 63]. I will describe the studies which were rated as fair quality only, as these studies represent the best available evidence on caregiver or family psychoeducation.

Perlick et al, 2010, [53] investigated the effectiveness of Family-Focused Treatment – Health Promoting Intervention (FFT-HPI), a manualised psychoeducation intervention in which caregivers of patients with bipolar disorder received either FFT-HPI or brief education about bipolar disorder and health problems. The intervention comprised 15 weekly group sessions of 45 minutes duration, led by two experienced clinicians trained in FFT and CBT. Sessions covered psychoeducation, goal setting and behavioural analysis of self-care barriers, and educational videos and reading materials were provided. The control group received a Health Education intervention (HE), which comprised eight 20-25 minute DVDs on the most common health problems experienced by caregivers. Primary caregivers and corresponding patients with bipolar disorder types I or II who were experiencing physical and mental health problems were recruited. Data were analysed for 43 caregivers (FFT-HPI: 24, HE: 19) and 40 patients (FFT-HPI: 22, HE: 18). Primary outcome variables for caregivers were depressive symptoms and health behaviour, and for patients they were symptoms of depression and mania. They found that after six months caregivers receiving FFT-HPI had significantly fewer depressive symptoms and reduced health risk behaviour. Patients associated with caregivers in the intervention arm also had fewer depressive symptoms. These results should be viewed with caution due to the limitations of the study design. The sample size for this study is small and there is no

power calculation. It's also not clear exactly how many participants withdrew or who were lost to follow-up and outcomes were not blinded.

Reinares et al, 2008, [55] assessed the efficacy of group psychoeducation for caregivers of euthymic patients with bipolar disorder. Caregivers in the psychoeducation group received 12 weekly 90-minute group psychoeducation sessions in a hospital setting. Patients did not attend. It included structured information about the nature of the illness, skills training for its management, the role of the family and the importance of reducing feelings of guilt. Caregivers received written summaries of topics, and groups were conducted by a psychologist with relevant experience. Caregivers of patients in the control group did not receive any specific intervention. Patients with bipolar disorder met DSM-IV criteria for bipolar disorder I or II and were euthymic at the intervention onset. The primary outcome measure was time to any mood recurrence, and participants were followed-up for one year. They found that the intervention group had a significantly longer time to recurrence of any mood episode than the control group. Additionally they found that the intervention group had fewer patients with mood recurrences and longer relapse-free intervals. Study limitations included no power calculation or blinding of outcomes and the method of randomisation wasn't clear. However a significant difference between groups for time to recurrence of any mood episode at 1 year follow-up is notable, because the follow-up period is relatively long.

The qualitative study by Peters et al, 2011, [12] was nested within a RCT [6] and rated as good quality. The intervention is as described above, referencing the paper by Lobban et al, 2010 [6]. This study aimed to investigate the perceived values and barriers of involving relatives in relapse prevention from the perspectives of service users, their relatives and Care Coordinators. Semi-structured interviews were conducted with 21 Care Coordinators (CCs), 21 service users (SUs) and 10 relatives. The authors adopted a grounded theory approach [52] to analysing the data, developing conceptual categories. Emerging themes were explored during data collection and developed in further interviews, which were conducted in parallel until thematic saturation was achieved. The interviewer analysed all the data, which was separately analysed by at least one other researcher for reliability. Findings were discussed within a multidisciplinary team for trustworthiness. Like the qualitative study corresponding to the same trial by Pontin et al, 2009, [11] this study was highly rigorous in its design and conduct and it provides trustworthy evidence. The authors examined both the values of and barriers to involving relatives in relapse prevention (RP) for patients with bipolar disorder. They found that RP increased relatives understanding of bipolar disorder, triggers and early warning signs. Relatives recognised triggers and early warning signs that SUs were unaware of,

and felt empowered, less anxious about a relapse and more equipped to intervene. Novel information was shared between SUs and relatives which led to increased understanding; although sometimes information was withheld because relatives were present. Regarding the barriers and drawbacks to involving relatives in RP: some relatives lacked the time to be involved, some SUs didn't have an appropriate family member to involve, some SUs wanted to keep their illness private, either due to stigma or not wanting to burden their relatives, and some relatives felt uncomfortable about "intruding" on the established CC and SU relationship. Negative aspects reported from the perspectives of CCs included their difficulty in maintaining SU confidentiality, and RP with relatives was viewed as a professional burden, with the addition of relatives increasing their caseloads. Some CCs also found it difficult to manage family dynamics, and reported that keeping the focus on SUs was difficult at times.

2.3.3.4 Internet-based psychoeducation

Only two papers relate to internet-based psychoeducation for bipolar disorder: the quantitative paper for the BIPED trial, which was rated as fair quality [23], and the qualitative paper by Nicholas et al, 2010, [41] which was also rated as fair quality. Both studies have published *a priori* protocols.

Smith et al, 2011, [23] conducted an exploratory RCT to examine the acceptability, feasibility and efficacy of an internet-based psychoeducation programme for bipolar disorder. The programme comprised eight online, interactive modules to be completed by patients on an individual, fortnightly basis, with peer discussion available via an online forum which was moderated by the first author, a Consultant Psychiatrist. Modules covered diagnosis, causes of bipolar disorder, medication, lifestyle, relapse prevention, psychological approaches and advice for families and carers. There was a waiting list control group. Participants were debriefed on how to use the programme in an initial face-to-face consultation with the first author. All participants met the DSM-IV criteria for bipolar disorder and were in remission when recruited to the trial. Data for 37 participants were analysed (17 participants in the intervention arm and 20 in the control arm). The primary outcome measure was quality of life score at 6 months following the intervention. The intervention was feasible to deliver but there was no significant difference between groups on the quality of life measure (total WHOQOL-BREF score); however, the intervention group showed a marginally significant improvement in psychological quality of life: an increase from baseline to follow-up in the intervention group compared with a decrease from baseline to follow-up in the control group. The finding that there was no difference between groups on the main outcome measure quality of life

may not be generalised beyond this study, as the study was not adequately powered. No power calculation was conducted.

The qualitative study by Nicolas et al, 2010, [41] was embedded within a RCT, which is yet to be published. The aim of the study was to identify predictors of attrition and explore reasons for non-adherence to an online psychoeducation programme for bipolar disorder, and hence it had a quantitative component (for identifying predictors of attrition). Participants in the trial were randomised to receive either an online bipolar education programme alone (BEP) or with email support from informed supporters (BEP + IS) or a control condition which consisted of eight online text-based modules about bipolar disorder, of no more than two pages in length, with a brief quiz and a mood chart to complete. BEP comprised eight online modules delivered weekly with associated workbooks for participants to develop their “stay well plan”. Modules were approximately 30 minutes, presented via a lecture-style slide presentation with voice narration, and topics included: causes of bipolar disorder, medications and psychological treatments. Informed supporters were expert patients with bipolar disorder trained to provide email support under supervision from the research team. Participants were recruited if they had received a diagnosis for bipolar disorder by a general practitioner or a psychiatrist in the previous 12 months. Semi-structured interviews were conducted with 39 participants (BEP: 16, BEP + IS: 9, control: 14) who met criteria for non-completion (i.e. they returned three or fewer completed workbooks). Thematic analysis was used to identify patterns in participants’ reasons for attrition. Interviews were analysed by two researchers and discrepancies in theme identification were resolved through discussion. 358 participants were included in the quantitative analysis to identify predictors of attrition. The number of workbooks completed was the outcome measure. They found that 26.5% returned three or fewer module workbooks, and adherence was significantly higher in BEP + IS compared with BEP alone. These results signify the importance of peer support in enhancing programme adherence and completion rates. The significant predictors of attrition identified were: young age, male gender and recruitment via a clinic. Unfortunately, these predictors of attrition were not subsequently explored within the qualitative interviews, either through purposive sampling or direct questioning, which may have offered a useful triangulation of findings. Regarding participants’ reported reasons for non-adherence, the most common theme for discontinuation was being in an acute phase of the illness – those in a depressive phase lacked energy and motivation to complete, and those in a manic phase became distracted by their symptoms. Many didn’t want to think about their illness and found the weekly information confronting or overwhelming. A few regarded the information to be too basic or simplistic, and were aware of much of the content beforehand. Some expected more

tailored information and were dissatisfied with its generality. Some didn't feel the need to continue with it when well, but others said they would re-access the programme if depressed. A number of participants did not view the programme as a priority or lacked motivation to complete it. Although the methods section within this paper was brief, it appears to be a relatively well conducted study as two researchers coded the data in parallel and resolved disagreements through discussion. The findings are presented clearly and they offer insights into why patients may not choose to undertake or continue with an internet-based psychoeducation programme for bipolar disorder.

2.4 Discussion

2.4.1 Strengths and limitations

This review provides the first systematic assessment of the evidence from both RCTs and qualitative studies for the potential efficacy of psychoeducation for bipolar disorder in different formats. Strengths of this review include: four electronic databases and reference lists were searched; identified studies were independently assessed by two independent assessors for inclusion and quality rating; and, data were extracted using data extraction tools based on either the CONSORT checklist (for RCTs) or the CASP checklist (for qualitative studies). This review may have benefitted from including unpublished studies, grey literature and additional databases within the search strategy. Because the included studies had heterogeneous outcome measures it was not possible to conduct a meta-analysis.

Overall, the quality of data in this area lacks methodological rigour. This review of different psychoeducational approaches includes only eight RCTs which were rated as good quality and seven which were rated as fair quality and some of these were borderline poor. Furthermore, only nine studies had published corresponding *a priori* protocols, of which three were qualitative studies embedded within RCTs. The main outcomes of the studies were heterogeneous, so a meta-analysis could not be performed. As reported in the results section, the majority of RCTs did not report their power calculations or blinding of outcome assessors. Additionally, few studies stated a primary outcome. Power calculations are based on one outcome yet several outcomes are reported in most studies; therefore, they were not necessarily powered for all outcomes. Many were unclear regarding their method of generating randomisation and rarely stated number of participants

withdrawn or lost to follow-up clearly. Crucially, 48% of studies did not adhere to the intention-to-treat principle; they did not include all eligible participants in the analysis to ensure validity of the results and avoid bias [70]. This highlights the lack of good quality, rigorous evidence on this topic. The good quality RCTs are of individual face-to-face psychoeducation [37, 50] and group-based psychoeducation [38-40, 48, 49, 51].

Regarding the qualitative studies on this topic two studies examining one-to-one and caregiver psychoeducation for bipolar disorder were rated as good quality [42, 43] and one study which explored non-adherence to an internet-based psychoeducation programme was rated as fair quality [41]. These studies provide a good starting point for understanding patients' and caregivers' experiences of psychoeducation and their motivation to undertake it, which may be beneficial for clinicians and for the development of psychoeducation interventions in the future. However, there is clearly a lack of good evidence for the benefits and drawbacks of psychoeducation from patients' perspectives, especially for group and internet-based psychoeducation, the former of which there is only one qualitative study which is rated as poor quality [64].

2.4.2 *Synthesis of the main findings from qualitative studies*

Although each of the four qualitative studies in this review had a different focus, a few themes were identified across studies. Patients reported learning coping skills and strategies through psychoeducation [42, 64] and caregivers were able to recognise triggers and early warning signs which the patients were not aware of [43]. Patients and caregivers felt empowered from the knowledge gained through psychoeducation [42, 43], and psychoeducation helped some patients accept their diagnosis [42, 64]. Some patients felt distressed about discussing past episodes [42] or felt confronted or overwhelmed by the information and didn't want to think about their illness [45]. Medication adherence increased for some participants [42, 64]. Psychoeducation enhanced relationships: between group members as they acknowledged the friendship and respect of others in the group [64], between service users and care coordinators as they increased their knowledge and understanding of bipolar disorder, and between relatives and patients with bipolar disorder who shared novel information which led to increased understanding [43]. Service users and care coordinators had more contact with each other and developed their ways of working together [11]. However, psychoeducation within routine care was perceived by care coordinators as an added burden to their workload and time [42], and the addition of involving relatives in relapse prevention as increasing their caseload [43].

2.4.3 Synthesis of the main findings from RCTs of different psychoeducational approaches

2.4.3.1 Group-based patient only psychoeducation

The following findings regarding the benefits of group-based psychoeducation for patients with bipolar disorder are extracted from papers rated as good quality – no adverse effects of interventions were identified. Group-based psychoeducation for patients may reduce recurrences of bipolar episodes [48, 49], and time spent in a bipolar episode may be reduced [40, 49, 51]. Patients may also have fewer and briefer hospitalisations [49]. Severity of depression and mania may be reduced after one year [38], and after two years the severity and duration of manic symptoms may be reduced [39]. Social functioning and mental quality of life may also be improved [40, 51].

2.4.3.2 Individual face-to-face psychoeducation

Two studies rated as good quality demonstrated that individual face-to-face psychoeducation may increase the time to the next bipolar episode by 8.5 weeks [37] and may result in a longer time to a manic relapse and fewer manic episodes [50]. It may also improve social functioning and rates of employment [50].

2.4.3.3 Caregiver or family psychoeducation

From the RCTs rated as fair quality it can be concluded that caregiver or family psychoeducation may result in fewer depressive symptoms both for patients and caregivers [53], delay recurrence of a mood episode [55] and prolong the relapse-free interval for patients [55], and patients may have fewer relapses [55].

2.4.3.4 Internet-based psychoeducation

Only one RCT rated as fair quality has been published on internet-based psychoeducation for bipolar disorder so far [23]. It found that the intervention group showed a marginally significant improvement in psychological quality of life. At the moment we cannot confidently say much about the effectiveness of internet-based psychoeducation for bipolar disorder.

2.4.4 Implications for further research

There is a need for additional good quality RCTs and qualitative studies in this area to contribute to the currently limited evidence base. In particular, further RCTs should investigate internet-based psychoeducation, caregiver and family psychoeducation and individual face-to-face psychoeducation, for which there is very little good quality evidence. RCTs should consider key design elements to improve methodological quality including sample size calculations, intention-to-treat analyses etc. Authors should always publish *a priori* protocols and follow CONSORT guidelines for reporting clinical trials [35]. As yet, no firm conclusions can be made about the effectiveness of one mode of psychoeducation delivery over another as there is little good quality evidence available.

More in-depth qualitative studies need to be conducted to demonstrate how these interventions are experienced by patients, relatives and those delivering the interventions. This would enable exploration of the value of the interventions from different perspectives and exploration of the barriers to benefitting from or undertaking the interventions, as well as delivering them in practice. It would also facilitate assessment of feasibility, acceptability and reach, and the personal impact of psychoeducation from patients' perspectives. All of this information would help enhance and promote psychoeducation interventions.

From the qualitative studies it appears that the therapeutic relationships between individuals involved in the interventions may be an active ingredient in psychoeducation [42, 43, 64] as well as the material itself, although further research should explore the effective mechanisms of psychoeducation for bipolar disorder in greater depth and the promise of linking qualitative and quantitative data together in a mixed methods approach is yet to be fully exploited [10].

Smith et al, 2010, [10] in their review of the literature of psychoeducation for bipolar disorder suggest the following for future research considerations: "How do group and internet-based interventions compare? Which patients are most likely to respond to psychoeducation? Should resources be targeted at high-risk groups? Is it necessary for patients to be in clinical remission for psychoeducation to be given? Is there a role for expert patients in the delivery of psychoeducation?" [10].

In addition to these considerations, I have contributed my own in response to my understanding of the current literature on this topic:

- How acceptable are group-based and internet-based psychoeducation interventions for bipolar disorder?
- How do patients describe their experiences of psychoeducation for bipolar disorder?
- How do patients perceive the impact of the psychoeducation they receive for bipolar disorder?
- What are the similarities and differences between group-based and internet-based psychoeducation for bipolar disorder, in terms of how patients engage with the material and the process of learning?
- How do patients use what they learn from psychoeducation effectively?
- Are different psychoeducational approaches suited to different people?

Although I will not be addressing all the questions noted above, these gaps in our knowledge were the starting points for my PhD research on this topic.

Chapter 3: Methods: aims and approaches

3.1 Introduction and methodological aims

This exploratory study aims to evaluate internet-based and group-based psychoeducation interventions and explore their potential effectiveness as well as seeking to understand how these interventions are experienced by participants. A mixed methods approach consistent with that described within the process evaluation literature for complex interventions in health care is considered most appropriate.

Mixed methods research refers to studies which integrate one or more quantitative and qualitative techniques for data collection and/or analysis [71]. It employs a range of different methods and draws on expertise from many disciplines, as appropriate to the research question [72]. My challenge is to find a way of sensitively mixing these methods in the most effective and methodologically legitimate way. In this chapter I will describe my approach to combining qualitative and quantitative methodological approaches, and explore the philosophical and practical realities of my approach.

My overarching methodological aim is to produce robust evidence that has been rigorously analysed, is valid, as neutral and unbiased as possible, and clearly defensible in terms of how interpretations have been reached.

I will use both qualitative and quantitative research methods to comprehensively evaluate the feasibility, acceptability and impact of internet-based and group-based psychoeducation interventions. As my primary research questions seek to explore the nature of these interventions and how they are directly experienced by patients and group facilitators (please refer to Chapter 1, section 1.2), qualitative research takes precedence over quantitative research.

I have adopted a pragmatic approach to combining different methodologies in a single study, as both qualitative and quantitative research methods may be seen as complementary strategies existing within the research “tool-kit” [72], and not opposing strategies of research enquiry. This view

resonates with the methodological approach of *pragmatism* which favours choosing the most appropriate method for addressing specific research questions rather than focussing too much on the underlying philosophical debates (Seale, 1999, as cited in [72]), which otherwise may constrain valid enquiry.

Within this chapter I will fully describe and justify the methodological approaches adopted within this study and the mixed methods research strategy for the PhD as a whole. This chapter serves as the overarching context for the individual methods sections, which are written in specific detail within the literature review, BIPED and BEP-Cymru chapters.

3.2 Differences between qualitative and quantitative research approaches

There are fundamental differences between the approaches and functions of qualitative and quantitative research. Quantitative methods work best when examining specific factors which are subject to variation at specific time points using numbers, whereas qualitative methods are useful for gaining insights into processes and events [71]. Quantitative data provide a general understanding of a problem, which arises from examining a relatively large number of people and measuring their responses to certain key variables; whereas, qualitative data provide a detailed understanding of a problem, which usually arises from exploring the perspectives of a few individuals in great depth [73]. When patients' or providers' narratives or lived experience are sought qualitative data collection techniques are most appropriate [71].

Qualitative data collection is an iterative process, whereas quantitative data collection is linear in its use of questionnaires or measurements [71]. The basis of qualitative research is usually "antipositivistic" or "inductive", which means that instead of searching for truths the investigator seeks valid and rigorous meanings and interpretations [71]. In contrast, quantitative research may be considered "reductionist" or "deductive" – starting with hypotheses based in theories which are then proved or disproved according to data gathered in response to those hypotheses [71]. The "inductive" qualitative approach is used to explore data and potentially generate theories, and the "deductive" quantitative approach is used to test theories.

Borkan emphasises the distinction between qualitative and quantitative research in this way:

“...quantitative research and its data collection tools allow the researcher to infer only about that which he or she is examining (you “see” only what you are “looking at”) whereas qualitative methods can expand the gaze to key elements that were never elucidated or even previously considered” [71]

3.3 Rationale for a mixed methods study

Borkan’s point is consistent with the “zoom lens” analogy proposed by Onweugbuzie and Leech, who suggest that by conducting mixed methods studies researchers are able to combine empirical precision with descriptive precision [74]. By employing a pragmatist lens (i.e., using both qualitative and quantitative techniques) rather than using a single lens (i.e., monomethod studies) one can “zoom in” to fine detail or “zoom out” to indefinite scope (Willems and Rauch, 1969, as cited in [74]).

I have chosen to conduct a mixed methods study because it offers the best approach for addressing my research questions; however, mixing methods can be challenging and lead to disjointed and unfocused research when not undertaken with a specific justification for doing so [73, 75].

Bryman (2006, as cited in [73]) provides a detailed examination of researchers’ reasons and practices for combining methods, which builds on the more general reasons for mixing methods by Greene et al. (1989) [76]. From these two key sources I have identified the main rationale for mixing methods within my study as the following:

- a) In this study, I apply qualitative and quantitative methods to the same questions. The methodological goal of *complementarity* refers to seeking enhancement and clarification of the findings from one method with the results from the other method [76]. Through complementarity different aspects of a phenomenon may emerge (Creswell, 1994, as cited in [29]); for example, qualitative data may add depth of understanding to quantitative findings (Bryman, 2006, as cited in [73]). The aim of complementarity is to connect aspects of a social phenomenon that complement or contradict each other, rather than validate [75, 77].

- b) When qualitative and quantitative methods are combined a more comprehensive account of my domain of enquiry may be formed, consistent with the methodological goal of *completeness* (Bryman, 2006, as cited in [73]).
- c) Quantitative data (such as number of modules completed, number of sessions attended or time since diagnosis) has facilitated qualitative sampling of participants for the qualitative interviews (consistent with Bryman, 2006, as cited in [73]).

These reasons for undertaking mixed methods research for this study have guided my approach to linking data analytically [75].

I selected methods on the basis of their ability to answer different aspects of my research enquiry and to give a better sense of the “whole”. My literature review appraises evidence from both randomised controlled trials and qualitative studies that psychoeducation for bipolar disorder is beneficial to patients, and it provides the platform from which to guide the questions posed within my study. In particular, the review highlights the dearth of qualitative studies to explore the experiences of patients who have received psychoeducation for bipolar disorder and the need to explore the feasibility, acceptability and impact of a new group-based and an internet-based psychoeducation programme for bipolar disorder from patients’ perspectives and group facilitators’ perspectives. For this reason, my study is primarily a qualitative investigation into patients’ experiences, with an additional quantitative component to explore the various ways in which the interventions may have impacted on patients over time (which may serve to corroborate or conflict with qualitative findings).

3.4 The pragmatic paradigm or worldview

It is important to define the basic set of philosophical assumptions which underpin any study in order to guide research enquiries. Philosophical assumptions include: an ontological position (i.e., what can be “known” about the world), an epistemological position (i.e., how knowledge can be acquired) and methodology (i.e., the process of research – a strategy, plan of action, or a research design which incorporates the methods [73]). Differing *paradigms* or *worldviews* (terms which are used interchangeably) shape the underlying philosophical assumptions of research in different ways. Thomas Kuhn (1970, as cited in [73]) coined the term “paradigm” as a set of “generalizations, beliefs and values of a community of specialists”.

There are three predominant paradigms in research:

- a) *Positivism* is commonly associated with quantitative approaches and is based on cause-and-effect rationales, measurement of variables and theory testing (Slife and Williams, 1995, as cited in [73]).
- b) *Constructivism* is often associated with qualitative approaches and concerns the meaning of phenomena via participants' subjective views, which are shaped by participants' social interactions and personal histories [73] and through the interpretation of the researchers. Positivists tend to verify theory whereas Constructivists generate theory.
- c) *Pragmatism* is typically associated with mixed methods research – it focuses on the consequences of research in real-world practice, on the importance of the research question over the methods, and on the use of multiple methods of data collection to address the research problems [73]. Tashakkori and Teddlie (2003a, as cited in [73]) noted that many authors embraced pragmatism as the most appropriate paradigm for mixed methods research.

Hence, pragmatism is well suited as the predominant paradigm for my study; it draws on the strengths of different philosophical approaches which are viewed as complementary rather than conflicting. I am combining both qualitative and quantitative data by way of “what works” to address the components of my research enquiry, and also combining multiple stances in terms of both deductive (i.e., testing *a priori* theory) and inductive thinking (i.e., starting with participants views and building up to patterns, theories and generalisations) [73].

3.5 Ontological position

The *ontological* position in social research refers to what we can “know” about the social world; whether there is a common social reality or multiple realities[72]. It is important for researchers employing qualitative methods to define and justify their ontological position [72], because researchers may take different positions, and consequently conduct their research and frame their findings in different ways.

The *realist* perspective holds that reality exists independently of our beliefs and understanding [72]. At the other end of the ontological spectrum is the position of *idealism*, which negates the existence of an external reality which is independent of our beliefs and understanding - idealists opine that reality is only knowable through the socially constructed meanings [72].

An ontological perspective which sits between these two extremes is the position of *subtle realism* (Hammersley, 1992, as cited in [72]), which is also referred to as *critical realism* [72]. Proponents of subtle realism accept that the social world exists independently of subjective understanding, but is only accessible to us via the respondents' interpretations, which may be further interpreted by the researcher [72]. Subtle realism holds that reality is multifaceted and can be captured by diverse perspectives which illuminate the various ways in which reality may be experienced [72], balancing the objective with the subjective. The aim of subtle realism is to convey as full a picture as possible of a multifaceted reality [72], so it is a useful perspective for mixed methods research which collects different types of data which complement each other to achieve a rich and detailed understanding of phenomena. Pragmatism draws on subtle realism to define the nature of singular and multiple realities from multiple perspectives.

3.6 Epistemological position

In conjunction with the ontological position in qualitative research, the *epistemological* position - "how it is possible to find out about the world" [73] - is equally important to acknowledge because it indicates how a researcher approaches a research question and the assumptions about how data are collected and analysed.

Using quantitative research, *Positivists* objectively collect data whilst maintaining distance and impartiality and strive for reliability and validity [73]. These aspects of the scientific method have been adapted to suit some qualitative research studies [72]; however, most qualitative researchers are *Interpretivists* who are less concerned with objectivity and neutrality [72, 73] and more focussed on "immersing" themselves in the data in order to gain insights and facilitate inductive reasoning.

Because this research is mixed methods the epistemological position taken in this instance combines the perspectives of *positivism* and *interpretivism*, consistent with the pragmatic worldview [73].

3.7 Methodological approach

The methodological approach relates to the underlying logic, or ways of thinking about the data: whether data are interpreted from a prior frame of understanding (i.e., deductively) or not (i.e., inductively) [29]. Data for this study are not limited to inductive or deductive reasoning, as both types of reasoning can be complementary to each other [29]. This perspective is also consistent with the methodological goal of complementarity and the overarching pragmatic approach.

Pragmatism is concerned with choosing the appropriate method for addressing specific research questions [72]. Within this approach the focus is ensuring a suitable fit between the research methods used and the research questions posed – quality and rigour in research practice is sought through choosing the right research “tools” for the research enquiry, rather than limiting the practice through only using methods which are philosophically consistent [72]. This approach ultimately seeks to address pragmatic considerations through complementary extension – using different forms of evidence to build greater understanding and insight of the social world than is possible from one approach alone [72].

A criticism of pragmatism is that through mixing methods analytical clarity may be compromised, as each method relies on different assumptions in data collection and procedures may be difficult to reconcile when interpreting findings [72]. To address this concern, assumptions should be made clear from the outset, each method should be adequately justified, and the study design, data collection process, analyses and interpretation of findings should be explicit and transparent.

Rather than attempting to settle philosophical differences, the pragmatic approach reflects on how to conduct and analyse data based on what the researcher is interested in knowing about [78]. This approach is ideally suited to my research, which is predominantly qualitative in nature, and seeks to address specific questions. Research questions relating to the impact of the interventions on clinical measures differ from questions relating to how participants elect to describe their experiences of the interventions and the aspects which have personal relevance for them (consistent with *phenomenology*, a philosophy by Edmund Husserl concerned with charting how people experience phenomena [78], which I will describe in greater detail in section 3.7.1 below).

3.7.1 *Overarching methodological approach to qualitative interviews*

Conduct of the interviews was influenced by the methods of phenomenology, which aims to understand social phenomena from the perspectives of those who have experienced the phenomena directly [78]. Phenomenology assumes that the important reality is what people perceive it to be [78]. Essentially, the qualitative interviews were designed and conducted to obtain access to the phenomenon which participants have encountered through their direct experience (participation in the psychoeducation programmes). From these interviews central themes of participants' experiences of their "life world" were elicited, and meanings were explored and interpreted. The "life world" in qualitative interviews refers to the everyday lived world of the interviewee and his or her relation to it [78]. In the context of phenomenology, rich and detailed descriptions of participants' first-hand experiences of a phenomenon are sought. Interviews usually begin with an open-ended "life-world evoking question" to elicit the aspect of the experience which was most pertinent to them [79].

3.7.2 *Overarching methodological approach to quantitative data*

Questionnaires were administered to participants of both interventions primarily to explore the impact of the interventions over time. Outcome measures assessed factors such as participants' quality of life, depressive and manic symptoms, social functioning and self-efficacy. Due to small sample sizes analyses were exploratory. Statistical tests were selected on the basis of their appropriateness to each research question and the type of data collected (i.e., continuous, ordinal or categorical).

3.8 *Mixed methods approaches*

3.8.1 *Process evaluation*

It is important not only to gain understanding of the outcomes and effectiveness of interventions, but also how and why the interventions have had the effects they have had [27], which entails a mixed methods approach. Key components of process evaluations for public health interventions and research have directly influenced my research questions and the ways in which I address them.

I describe the key process evaluation components which relate to this study below – the questions to be addressed and the methods employed to assess them.

I address the feasibility and acceptability of the psychoeducation programmes from the perspectives of patients and facilitators, and the extent to which patients engaged with the programmes primarily through conducting qualitative interviews with those who accessed or attended the programme well and those who dropped out. Exploring participants' engagement with an intervention is a key component within a process evaluation. Baranowski and Stables, 2000, as cited in [27], differentiate between initial use and continued use of programme materials and recommended resources. Follow-up qualitative interviews with participants of Beating Bipolar assessed their continued use of activities from the programme, and I assessed participants' engagement with the Beating Bipolar online forum by examining computer usage data.

In a process evaluation, an intervention's reach is also concerned with which subgroups of participants actually participate [27]. For both Beating Bipolar and BEP-Cymru I explored reach through the qualitative interviews, and considered their age, gender, access to transport, access to a personal computer, and their mood during the programme. Baranowski and Stables (2000, as cited in [27]) recommend exploring barriers encountered in reaching participants. Through the qualitative interviews I have explored both facilitators and barriers to using the programmes, and also participants' suggestions for improving the programmes.

Clearly, in a process evaluation it is important to consider the context of an intervention. For example, I considered context with regard to how and where programmes were delivered and by whom. Contamination, in this case, is the extent to which participants receive interventions from outside the programme which might overlap with the content of the psychoeducation (Baranowski and Stables, 2000, as cited in [27]). I explored the extent to which participants received other interventions, guidance or support from sources outside the programmes, and the nature and impact of those experiences, through the qualitative interviews. I asked participants specifically about their existing social support networks, their previous knowledge of management techniques for bipolar disorder, their prior involvement in other bipolar disorder support or self-management groups, and the accessibility of the psychoeducation intervention from their perspectives. These contextual factors are important to consider as they may affect the impact of the programme for participants. Prior knowledge of how to manage bipolar disorder may limit the extent to which they

can benefit from the intervention, their insight and attitudes to bipolar disorder and medication, and their perceived competence in their ability to manage their condition.

Fidelity refers to the extent to which an intervention was delivered as planned, representing the quality and integrity of the intervention as conceived by the developers [27]. As fidelity is a function of the intervention providers, I assessed the fidelity of the BEP-Cymru programme implementation through interviews with the programme facilitators, two of whom also led the development of the programme. Ideally, one would employ at least two independent assessors to observe BEP-Cymru group sessions and rate fidelity on the match between the delivery of each session and the pre-specified plan for each session using checklists. This was not possible, however, due to time and resource constraints. As Beating Bipolar is an online intervention, the programme was presented uniformly to each participant through its unchanging computerised interface, exactly as the programme developers intended. Hence, fidelity assessments were not relevant for Beating Bipolar, due to the unchanging nature of its educational component.

3.8.2 *Mixed methods exploration of the data*

Both qualitative and quantitative data were gathered concurrently and brought together in the results and interpretation of the results, which is consistent with a mixed methods design recommended by Creswell et al., 2004 [28]. I conducted a parallel mixed analysis in a predominantly qualitative study. Priority has been given to the qualitative research because I am primarily interested in participants' direct experiences of psychoeducation interventions and the meaning and impact of those experiences from their perspectives.

According to Onweugbuzie & Leech (2004), in parallel mixed analysis the following conditions should hold [74]:

- a) Quantitative and qualitative data analysis should occur separately*
- b) Neither type of analysis builds on the other at the analysis stage*
- c) The results from each type of analysis are neither compared nor consolidated until both sets of data analyses have been completed*

In this study thematic analysis was employed for all qualitative analyses. More detail on the methods of both qualitative and quantitative analyses is given in Chapters 4, 5, 6, 7, 8 and 9.

Chapter 4: Feasibility, acceptability and impact of a novel, internet-based psychoeducation programme for bipolar disorder

4.1 Background

In this chapter I will present my qualitative analysis of the feasibility, acceptability and impact of a novel, internet-based psychoeducation programme for patients with bipolar disorder, called “Beating Bipolar”. These qualitative data were obtained as part of an exploratory trial of Beating Bipolar (BIPED).

When I began my PhD in February 2010 I assisted the BIPED trial team by conducting half the participant interviews for the outcome assessments at six months’ follow-up. Arianna di Florio conducted the other half of these outcome assessment interviews. I inputted these outcome data into SPSS using SPSS syntax and cleaned the data. I performed a preliminary exploratory analysis of the data and DS performed the main analysis which is reported in the paper [23]. Findings from this analysis are reported here for illustration only, rather than for inclusion within my analysis plan. My qualitative studies within the BIPED trial complement the trial’s quantitative findings by providing a more in-depth account of how the intervention may have impacted on participants and commentary on the feasibility and acceptability of the intervention from participants’ perspectives. To present to the background to this research, I will begin by summarising the results of the trial; the paper of which has been published in *Bipolar Disorders* [23].

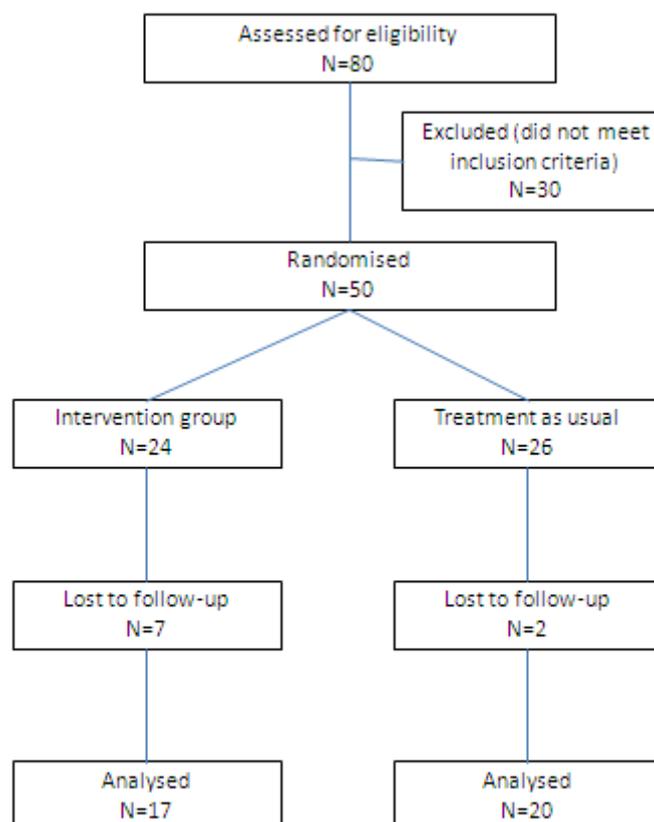
In collaboration with patients with bipolar disorder, their families and health professionals, the BIPED trial team developed an internet-based psychoeducational intervention called “Beating Bipolar” [18]. Beating Bipolar built on the success of group psychoeducation interventions for bipolar disorder, which have emerged as an effective treatment option for long-term management [10, 20-22], and involved a blending of different delivery mechanisms; internet-based delivery of factual content with interactive exercises and an online forum designed to provide ongoing support [19]. In the clinical trial [23] participants were given access to each of the modules in turn every two weeks and were encouraged to discuss the content of each module within the forum. The BIPED trial team undertook an exploratory randomised trial to examine efficacy, feasibility and

acceptability of the Beating Bipolar intervention [23]. BIPED was a phase II randomised controlled trial, carried out between March 2009 and September 2010 [23].

Participants between the ages of 18 and 65 with a diagnosis of bipolar disorder were recruited from multiple health care sources across South Wales [23]. Participants were included if they satisfied criteria for being in clinical remission during the three month period preceding recruitment, and were randomised to either the Beating Bipolar intervention plus treatment-as-usual or treatment-as-usual [23]. Outcomes were assessed 6 months following the end of the intervention [23].

Fifty participants satisfied the inclusion and exclusion criteria (Figure 3) [23]. Seventeen participants from the intervention arm and 20 participants from the control arm presented for follow-up assessments [23].

Figure 3. CONSORT diagram [23]



Outcome assessments were conducted 6 months following delivery of the intervention via face-to-face structured interviews. Assessors were blinded as to whether participants had received the intervention or not. The primary outcome was improvement in quality of life, which was measured

by the World Health Organisation Quality of Life - Brief version (WHOQOL-Bref) questionnaire [23, 80]. The WHOQOL-Bref is a reliable, valid and widely-used measure of quality of life for psychiatric outpatients, and comprises 4 broad domains: physical health, psychological health, social relationships and environment [23, 81]. Secondary outcome measures assessed general functioning, insight, current depressive and manic symptoms, and the number and severity of bipolar episodes experienced during the 10 month period since the beginning of the trial. These outcome measures were compared between groups.

WHOQOL-Bref scores were compared between the intervention and control groups while controlling for baseline WHOQOL-Bref scores using analysis of covariance (ANCOVA) [23]. Secondary outcome measures were analysed similarly, and were also controlled for baseline scores [23]. There were no statistically significant differences within or between groups between scores on any of the baseline and outcome measures, with the exception of the psychological health subsection of the WHOQOL-Bref where there was a marginally significant difference: an increase of 8.1 units from baseline to follow-up within the intervention group compared to a decrease of 5 units from baseline to follow-up within the control group ($p=0.05$) [23]. Hence, we found that the programme may have impacted on participants' psychological quality of life; specifically regarding: body image, positive and negative feelings, self-esteem, spirituality, learning, memory and concentration.

Regarding compliance to the programme, 2 thirds completed more than 75% of the programme; however, only 4 out of 24 participants contributed to the forum on a regular basis.

It is possible that the small sample size of the trial made it difficult to detect differences between groups on the outcome measures. Furthermore, we cannot anticipate the long-term impact of the intervention from the brief follow-up period of 6 months.

The focus of this aspect of my thesis is to explore beyond these quantitative results to understand participants' experiences of using the programme. This qualitative study addressed the feasibility, acceptability and impact of the intervention from the perspectives of participants in the intervention arm of the trial.

4.2 Method

4.2.1 Participants

Participants were purposively selected on the basis of their level of engagement with the programme because we sought feedback from those who completed all or most of the programme and also from those who chose not to complete the programme. These participants were approached initially by letter followed by a telephone call to arrange a suitable time for interview. Prior to selecting participants for interview we collected computer-generated programme usage information. We considered those participants who completed more than half the programme to be “high users”, and those participants who completed less than half the programme to be “low users”.

Semi-structured interviews covered a number of key areas (see Appendix 5): the implementation and receipt of the intervention, the acceptability and perceived usefulness of various components of the intervention, the impact of the programme and recommendations for its improvement.

4.2.2 Theoretical framework

The qualitative methodology employed for this research is consistent with a pragmatic approach (see Chapter 3). The focus of this approach is ensuring a suitable fit between the research methods used and the research questions posed [72]. Conduct of the interviews incorporated aspects of phenomenology, which aims to understand social phenomena from the perspectives of those who have experienced the phenomena directly [78], and also questions relating to the feasibility and acceptability of the intervention, which is consistent with key objectives stated within the process evaluation literature [27].

Thematic analysis was chosen because it is a widely used qualitative analytic method for identifying, analysing, and reporting patterns or themes within data, and organising and describing data in rich detail [82]. Braun and Clarke, proponents of thematic analysis, state the importance of matching the theoretical framework and methods with what the researcher wants to know [82], which also reflects the principal tenet of pragmatism. Grounded theory was not deemed to be an appropriate strategy as it aims to obtain one core category – the essence of the findings – which becomes the theory to connects all the data [83]; whereas I wished to explore many aspects of participants’

experiences with a view to understanding the feasibility, acceptability and impact of the intervention, which are more specific and pragmatic concerns better suited to semi-structured interviews and thematic analysis. Interpretative Phenomenological Approach (IPA) was also considered as it is concerned with how people find meanings in their experiences; however, IPA questions are open and aim to explore a primary research question, rather than many, and the sample is intended to be homogenous. Furthermore, because IPA analyses are very complex and in-depth, studies commonly become unmanageable if more than six participants are studied. I rejected IPA for this study because I wished to interview a heterogeneous sample and explore many factors which may have affected participants' engagement with the programme, the acceptability of the programme and its potential impact.

Thematic analysis enables researchers to describe patterns within the data which are not theoretically bound [82]; so, for this research project, thematic analysis enabled me to explore all patterns within the data without theoretical restriction. As a method linked with the ontological perspective of critical realism, thematic analysis reports on participants' lived experiences and the meanings derived from those experiences. Consistent with my overarching methodological approach of phenomenology, rich and detailed descriptions of participants' experiences of psychoeducation for bipolar disorder could be fully explored using thematic analysis, focussing on the material itself rather than how the material may fit with theoretical constructs. Using thematic analysis to analyse semi-structured interviews enabled emerging themes to be identified, coded and analysed according to a flexible and evolving framework. The entire data set could be coded using an inductive approach; however, often participants' responses within semi-structured interviews reflect the questions being asked and so the coding framework tends to take the shape of the topic guide or interview schedule. A drawback of using thematic analysis for analysing data from semi-structured interviews is that many of the emerging themes may simply mirror the questions asked and not lead to further exploration and interpretation. However, as a recursive process, thematic analysis facilitates immersion in the data and comprehensive theme identification and review. Braun and Clarke present a step-by-step guide to conducting thematic analysis [82], which is a straightforward and intuitive process for researchers to replicate.

4.2.3 Analysis

Data were transcribed verbatim and transcripts were coded and analysed. I employed thematic analysis techniques where transcripts were closely examined to identify themes and categories [72,

82, 84]. Initially, I familiarised myself with the data by listening to the interviews whilst reading the transcripts. I also maintained a reflective journal of my impressions of the interviews to aid reflexive thinking and identify salient themes.

Employing a semi-structured interview schedule provided a focus for the interviews and the themes which consequently emerged to some degree reflected the questions asked. I identified themes as being salient responses which related to our research questions and may also occur as patterned responses within the data. The coding framework developed in a responsive manner to the themes elicited within each interview and was systematically reviewed and refined as it was applied to the data. Patterns within and across themes were explored throughout the analytic process.

The main coding categories to some extent reflected the questions asked during the interviews as well as emerging trends in the data evident from the prevalence of certain categories and the reiteration of particular points of view. Agreement on concepts was sought between members of the research team to ensure reliability, and the interviews and coding framework were scrutinised until no new insights emerged from the data. DS, SS and I each read four different manuscripts and made notes to inform the coding scheme. The coding framework was discussed throughout its development within our fortnightly meetings to ensure that concepts were appropriately identified and described. There were no notable disagreements between researchers regarding the identification and description of concepts within the analysis.

The interviewing was iterative; where new themes emerged I incorporated them into the interviews. Interviews continued until all the themes were saturated. Analysis was supported by the use of the qualitative analysis computer software NVivo version 8 [85]. Please refer to Appendix 10 for annotated extracts from my analysis; included to demonstrate my application of coding.

4.3 Results

4.3.1 *Characteristics of the sample*

Twenty participants from the intervention arm of the trial were invited to take part in the interviews. Fourteen were high users of the programme (13 completed all 8 modules; 1 participant completed

modules 1-6) and 6 were low users of the programme (1 participant completed 3 or 4 modules; 2 participants completed the first 2 modules; 3 participants only attempted the first module). Of the high users 8 were male and 6 were female, and of the low users 5 were female and 1 was male. Participants' age range was between 20 and 65 years (see Table 5.)

	High users	Low users
Age range	20-65 years	20-65 years
Male	8	5
Female	6	1
Total	14	6

Table 5. Characteristics of interview participants

Participants stated that they were motivated to participate in the trial for the following reasons: to contribute to research which may help others with bipolar disorder in the future, to learn more about bipolar disorder, to help with their self-management of bipolar disorder, because they were curious about the intervention, to inform their voluntary work helping others with bipolar disorder, and because no information on bipolar disorder was readily available to them when they were diagnosed.

Some participants reported being involved with other non-pharmaceutical interventions for bipolar disorder, specifically: informal monthly support group meetings organised by the Manic Depression Fellowship (MDF), a 2-week self-help group course run by the MDF and cognitive behavioural therapy (CBT) for bipolar disorder. Three high users of the programme said that they volunteered as mentors for others with bipolar disorder.

In this chapter I explore the main themes which relate to feasibility, acceptability and impact.

4.3.2 Feasibility

4.3.2.1 Accessibility and flexibility

Computer literate participants who had access to a private computer and were well enough to engage with the programme found the programme feasible to undertake and complete.

I mean it's marvellous these computers but they're not the end of everything, but I think you should offer an alternative for the not so bright.

PID2, female, low user

Many participants valued the programme's ease of use and access, and commented that it ran smoothly online. Participants specifically liked being able to access the programme in their own time, at their own pace, and having the option to revisit modules. Some commented that they appreciated having the option to share content by inviting others to look at the programme.

You can share it and invite other people to sort of look of bits of it with you as well, you couldn't really invite someone along to a group meeting, could you [...] I felt able to engage with it when it was just me and the computer... because in a way I'm very familiar with engaging with the computer.

PID71, female, high user

Eighteen participants stated that they regarded themselves to be competent in using a computer. Two participants (1 low and 1 high user) reported not being sufficiently computer literate to engage fully with the programme; the high user completed all the modules, but couldn't access the forum because she regarded it to be too technical for her. Only 5 participants reported difficulties with accessing the programme because of either a reluctance to use a computer or issues surrounding arrangements to access a computer.

4.3.2.2 The effect of illness on engagement with the programme

The mood of some participants at the time of undertaking the programme affected their engagement with it. For some, their low mood was a motivation to engage more fully with the programme because of a desire to find meanings and solutions for their depressive symptoms. Others reported that low mood compromised their concentration and ability to engage fully, either because confronting the illness made them feel low or they feared experiencing an episode of the illness through learning about bipolar disorder when well. One participant who completed the programme reported that the programme triggered a depressive episode because he confronted his illness, whereas he tended to forget about it when he was feeling well.

I got depressed when I was doing it because, like, it brings it home that you're ill, cos you can forget about it, you know. [...]and I got the same symptoms as people who was on there[...] it just brings it home to you then, you know, and you tend to forget about it in real life and you just hide away when you're ill and come out smiling and happy when you're OK.

PID47, male, high user

Of the 7 participants interviewed who did not complete all the modules (6 low users and 1 high user) 4 participants reported experiencing difficulty with concentrating on the programme due to their poor attention and distractibility. Three participants became ill during the programme, and reported that as a result they were distracted from the programme and lost the motivation to complete it.

4.3.2.3 The importance of accessing the programme in a private environment

The majority of participants accessed the programme from their homes and found this to be acceptable; however, several participants noted that accessing the programme in a private environment was important. Five participants accessed the programme in a public venue, such as a library, hospital, internet café or university. Two participants (low users) who used a public computer felt that their privacy was compromised. Four participants specifically appreciated the privacy and anonymity of the online programme.

[...] it seems to be more personal [than a group-based intervention] and you can work through it at your own time and more honest really. [...] I mean I've been to a couple of [...]

Manic Depressive Fellowship [...] meetings and I just sort of sit there very quiet and take it all in and listen, but I don't contribute very much.

PID71, female, high user

4.3.2.4 Characteristics of some patients which may prevent them from fully benefitting from internet-based psychoeducation

Participants were asked whether they could suggest any characteristics of patients with bipolar disorder which may prevent them from fully benefitting from the online psychoeducation programme. The characteristics that participants suggested which may prevent some patients from fully benefitting from the programme included: lack of experience of using a computer, patients who are too ill, patients who have not accepted their condition, patients without access to a computer, visual impairment or deafness, poor comprehension of the English language, poor attention span, co-morbid psychiatric conditions, and a fear of sharing personal information online.

4.3.3 Acceptability

4.3.3.1 Highlights of the programme

4.3.3.1.1 Professional appearance and usability

Many participants commented that the programme's interface was professional and clear.

I thought it was basic. Basically done, but again I think that's good, it was basic and it was clear. I wouldn't like to see it all with flash animations and things to be honest.

PID61, male, low user

Participants found the pace of the modules acceptable, and most felt that the gap of 2 weeks between modules was appropriate.

[...] it means you can do it at your own pace because if you've got a group of people trying to learn something, there's some people get it straight away and there's some people who may not get it straight away, and you know it's hard to get the pace right for everybody and it would end up being a compromise.

PID76, female, high user

A few participants reported feeling impatient to receive the next module at times, but expressed their appreciation that the time between modules enabled them to engage with new concepts and knowledge.

I think it would have been nice to have it a bit more often, like perhaps once a week, but I think as well if I'd been newly diagnosed I might want that two weeks to think about what was said in one module before going on to the next.

PID49, female, high user

Some participants found the pause, rewind and fast-forward function frustrating to use because the programme did not permit the user to rewind or fast-forward to specific points within the module segments. Participants suggested that instead there should be a time bar or scroll bar with which you could drag the play of the clip forwards and backwards without jumping to the next or the previous segment.

You couldn't sort of rewind within the segment, you'd have to go back to the one that was before, and there must have been something that I wanted to watch that had a particularly long segment before, so, in order to look up, it was probably around the medication [...] but wherever it was I just remember that one day of thinking how frustrating that I couldn't just sort of drag a bar back, you know, 15 seconds into the presentation just to hear again what had been said, and I had to go back to the previous section [...] to run back into it again.

PID14, male, high user

One participant suggested that it would be helpful to have written module summaries for users to be able to easily refer to without having to go through the modules again, and to keep as a reminder of the programme's content.

[...] perhaps a leaflet or something to go with it that we could keep to remind us of the modules and what was in it maybe [...] something that we could print out that we could keep close to hand because logging on and sitting and trying to find that bit in the video where he said this and he said that, you know, at the end where they recap and say "right ok, this is what we've looked at", perhaps something like that in written form [...] so that we can think "Oh! Gosh! Yes! Now I know that that's on module four and it was on such and such a section".

PID50, female, high user

4.3.3.1.2 Clarity and quality of content

Seventeen participants reported that they would recommend Beating Bipolar to others, primarily because of the information it provides. Many participants reported that the information presented within the modules was relatively easy to follow, comprehensive and of good quality.

I enjoyed the clarity of the content and the way there was a lot of [...] information available at many levels [...] at every level of possible understanding, and it was very up to date as well.

PID63, male, high user

Regarding recommending the programme to others, some participants acknowledged that the programme would not suit everyone.

If they're willing to do the whole thing then yeah, and if they wanna know about it, you can't force anybody to do it, but I mean if you sit someone down for half an hour a week, um, that's not too much you're asking of them. They could learn without realizing it, do you know what I mean, you can't force them and they've got bipolar and they just don't wanna do it, they just don't wanna do it, they'll just stay in bed, won't they, under the duvet. I like

filling in forms, I like ticking boxes and answering questions, I like all that. Other people don't. It's [...] subjective not objective.

PID2, female, low user

Some participants felt that the information presented was too basic and suggested that the programme should provide links to other resources, such as books or websites, for those who wished to find out more.

The only thing is for me you know I've studied to quite a high level, I'm used to quite in-depth information and it's [...] fairly basic information. I wanted references to find out more and stuff. [...] links to further reading or recommendations for books if you want to know more on the subject.

PID76, female, high user

Some participants felt that patients could learn more from the programme than they could from an appointment with a psychiatrist, because they felt that some psychiatrists may have a tendency to assume that their patients have a realistic concept of what bipolar disorder is, and may forget that some may be frightened of their diagnosis due to prior familiarisation with unfavourable stereotypes or the stigma associated with bipolar disorder. They also commented that the programme offers valuable continuity of care for patients.

[...] the psychiatric professionals are used to dealing with people like me every day of their life, [but] that day might be the only time I've ever met one of them, so they're doing something that they've done a thousand times before, this is the first time I've ever done this. That's what gets forgotten. The assumption that people are going to know what bipolar is, the assumption that they're going to know what mania means, the assumption, you know, traditionally the word manic depressive conjures up an image of a knife wielding maniac. Thankfully it's now beginning to start to conjure up an image of Stephen Fry, which is much more acceptable, but the healthcare professionals forget that the person sitting in front of

them may only have read a novel about the knife wielding maniac, so they need to know that it's not all doom and gloom.

PID50, female, high user

4.3.3.1.3 Defining bipolar disorder and identifying triggers

Five participants found the 2 introductory modules to be very helpful, which describe bipolar disorder and explain what causes it. The information provided within these modules was described as being concise and memorable, and the graphics helped to illustrate the explanations.

I thought the diagnosis at the start was particularly strong and how your mood changes and the diagram, the graphics for showing the brain and how different portions of the brain function, I thought that was pretty well explained, and it must have been pretty well explained because I can still remember it now, you know, it stuck in my mind.

PID52, male, high user

The mood thermostat analogy was particularly helpful for some participants to conceptualise bipolar disorder, and enabled them to describe their illness in simple terms to others.

The mood thermostat has been brilliant, that's been really good in trying to explain to people who don't know what I've got what it is, you know, the actual words 'mood thermostat', my mood is like a thermostat, it goes up and it goes down and I've got no control. It's only medication that acts like my little boiler, and controls it.

PID50, female, high user

Some participants found the information on triggers and risk factors to be particularly useful for identifying when one's mood is changing.

I was taught a lot about insight and what signs to look for and if the illness was creeping up again.

PID2, female, low user

One participant struggled with the cognitive behavioural aspect of identifying triggers as she reported finding difficulty with identifying a thought behind a feeling.

I struggle with CBT because what a lot of, well for me personally it doesn't always start with thought. Mine will often begin with a feeling - I just wake up with a feeling of impending doom. That then gives me a very bad thought, therefore my behaviour becomes awful. Some days I will wake up and I've got a feeling of 'I feel great', there's no thought behind it. I think for me my feeling comes first, so it's really hard to CBT somebody when the feeling is there but not the thought [...] I can't identify a thought behind a feeling sometimes. [...] You know, that is sometimes difficult, well it is very difficult for me.

PID50, female, high user

4.3.3.2 Low points of the programme

4.3.3.2.1 Dislike of actors' acting

Although some participants reported that they appreciated the videos of the "talking heads", one theme concerned the appropriateness of using actors and the quality of the acting within these video clips. Many participants felt that these clips were scripted, rather than from personal experience, and would have preferred either more convincing and naturalistic acting or people with bipolar disorder speaking from their own experiences.

I did feel a little bit like it was actors rather than people who have actually experienced it at points. [...] it came across as though it was scripted rather than personal experience.

PID7, female, low user

I didn't like the staged-ness [...] you could tell they'd done it so many times they were probably on take 500 because someone had forgotten their lines, and it lost a little bit of its authenticity, [...] and I think perhaps it might be better to get the actors out of there and get the real ones in there because we felt we could spot them, as people who have got it.

PID50, female, high user

4.3.3.3.2 *Difficulty with the interactive "life chart" exercise*

Another theme emerged with respect to one of the interactive exercises within the programme in which participants were invited to complete an online "life chart" documenting their pattern of relapse. Seven participants criticised it as being too restrictive and difficult to complete; for example, when their pattern of illness was predominantly mixed affective or where they had experienced a large number of relapses. Some participants also found it difficult to remember when past episodes had occurred. One participant found it emotionally difficult to remember past episodes, and was reluctant to recall her difficult experiences because she was scared that the act of remembering may trigger a depressive episode.

I can remember a timeline [...] that did kerfuffle me a bit, remembering back all the bad stuff, wasn't good. [...] I've done some stupid stuff, overdoses and stuff, and I've got a little girl now I can't be thinking about stuff like that. And I can't afford to be, I mean my best mate died in January and I can't grieve over her cos I'm too scared of sinking in that hole again [...]

PID33, female, low user

It was suggested that the timeline should allow for more detail, such as memos for highlighting the triggers next to key episodes of the illness, and should enable the depiction of periods of wellness via a horizontal line, rather than solely depicting ups and downs.

4.3.3.3.3 *Lack of activity on the forum*

Many participants described the forum as being too quiet and lacking the critical mass for worthwhile conversations or an incentive to log in to it regularly. They felt that it would benefit

from more input from medical professionals. It was suggested that the forum moderator could ask specific questions as conversation starters for each topic, and that suggestions for topics to be discussed within the forum could be presented at the end of each module.

I think initially there was only two of us putting things back and forth and I think once we realized we were the only two we quickly retreated as well. [...] I found it really quiet to be honest, that's the best way to describe it [...] if there could be some external, you know, perhaps somebody running the programme to kick the topics off, as opposed to just sort of saying 'please discuss', ask proper questions [...] get somebody who's in charge there or involved in the project to be specific to get the conversations starting.

PID50, female, high user

[...]it was kind of similar to a lot of bipolar forums that I've been on before so I was seeing same sort of stuff as I'd seen before. [...] various sorts of ones with people with bipolar which just comes down to people listing their medication and people saying 'oh! That's a terrible one' or 'that's a good one' and no one really agrees. [...] I think input from professionals would be nice. [...] Maybe some suggestions for topics at the end of each section of the course that you do.

PID71, female, high user

The reasons given by participants for not using the forum included: not being sufficiently computer literate to access the forum, not being aware of the forum, not wanting to engage with bipolar disorder when feeling well, being too busy, and anticipating feeling miserable because of communicating with others with bipolar disorder.

Some participants observed the forum without contributing to it because they were unfamiliar with communicating via the internet and would have felt self-conscious in doing so. Many who chose to participate in the forum only participated rarely because they lacked confidence in communicating with others within the context of the forum. Some participants who were reluctant to use the forum reported that they would have felt more comfortable with discussing the modules in a face-to-face group context.

I would have preferred it if the modules [...] were played to a bigger audience. So instead of me accessing it via my PC, I mean a group of people who are suffering from bipolar, played the modules or had the module played to them or viewed it, [...] however you wanna put it, and then discuss it openly in a meeting, [...] after each module or after two or three modules. Because I would be willing to attend that sort of group.

PID78, male, high user

Two participants expressed their uncertainty of the purpose of the forum. One participant suggested that there should be a separate chat stream within the forum to enable only relevant topics to be discussed within the main body of the forum.

I wasn't sure whether the function of the forum was to sort of generate a network of self-help, or whether it was there to provide information or discussion, or just for people to [...] articulate what it was that they felt, so I wasn't totally clear what the network was for [...] I just don't whether that's the sort of thing, for me at any rate, I think a lot of that depends on how comfortable you are about sort of having that type of discussion on the computer, which I might be through emails with people but then it would probably be with people I knew well.

PID14, male, high user

4.3.3.3.4 Presentation of lithium within the medication module

Some participants reported a strong dislike of the presentation of Lithium within the medication module. They felt that Lithium was presented too often without discussion of the serious problems relating to Lithium use, and that it shouldn't be presented as the drug of choice for bipolar disorder. Many participants felt that other drugs were either not discussed or not discussed enough. Participants suggested that instead of highlighting Lithium as a main drug the module should present a more in-depth drug review.

The one criticism I would have is that they were pushing Lithium rather too much. [...] I thought well maybe that's a little bit biased, you know, that there are a lot less side effects with some, so I thought maybe it was some sort of um pharmaceutical company that was involved with that [...] if you could sort of try and do perhaps a bit of a drug review with the

side effects that people are likely to suffer from [...] it was almost like it was a Lithium show sort of thing.

PID44, female, high user

4.3.3.4 Group versus computer-based formats

4.3.3.4.1 Preferences for alternatives to the computer-based format

Although overall most participants found the programme acceptable, some commented that they would have preferred an alternative to the computer-based format as they were resistant to using a computer. Two participants commented that because they belong to an older generation they prefer face-to-face communication over online communication.

I suppose I just like more face to face stuff, [...] I mean I'm 63, it's the younger generation that's much more accepting of this technology and they use it for everything, but I think I just prefer more face to face stuff.

PID53, female, high user

Some participants would have preferred to have read the information and others would have preferred the social interaction of a face-to-face psychoeducation group.

I didn't like the fact that I had to watch, watch and listen, um, you know it's almost like watching a TV programme, you know, I'd have to watch a presentation or people talking. I much prefer to read information. [...] I watch very little television, I mean 15 or 20 minutes my attention span's filled and that's about it.

PID61, male, low user

All participants were asked whether they would prefer internet-based or group-based face-to-face psychoeducation for bipolar disorder (where there may be up to 15 people with bipolar disorder

learning together under the direction of a clinician). Of those who stated a preference, eight said that they would prefer Beating Bipolar and eight preferred a group-based intervention.

4.3.3.4.2 Internet-based psychoeducation lacks the sociability of group-based learning

Eight participants stated a preference for the sociability of group-based learning, and commented that they would be more stimulated by learning with and from others through group work than by learning on their own. Some suggested that the opportunity to exchange experiences of bipolar disorder within a group may provide social support, an opportunity to make friends and learn from others' experiences, and may reduce any feelings of isolation.

Personally I'd be more sort of geared towards learning with others and learning from others. [...] it's just because I don't ever talk about it in my day to day life with anyone so it's nice to be able to have people you can openly talk about it to.

PID7, female, low user

Some participants would have preferred to discuss topics within a classroom environment, rather than via an online forum. One participant commented that he would have felt more reassured by seeing others' reactions within a face-to-face meeting and by being present to defend his views in person.

If my daughter was in the same situation, you know, I think she might choose the computer so I think it's something to do with how comfortable and how familiar you are about exposing yourself or talking about how you feel, you know, there's something more comfortable about me doing it when I can see the reaction of the other person across the other side of the table [...] cos you don't really know [...] whether you'll be able, or 'look at that! He can't even spell properly!' or whatever [...] I don't mind being critiqued, but I just like the opportunity to be there so I have the opportunity to defend myself.

PID14, male, high user

4.3.3.4.3 Groups of people with mental illness are unappealing

All eight participants who stated a preference for online as opposed to group-based psychoeducation reported that group meetings for people with mental illness were unappealing, and that they would not find support group meetings to be useful.

I don't like groups of people, and groups of people who are mentally ill just don't appeal to me at all. ... I don't go to support groups, I don't find those sorts of things useful, reminds me too much of hospital.

PID24, female, low user

I don't like the idea of sitting in a room with manic depressives, I just don't like the room, I don't like the thought of it. It's just so miserable. A room full of people like me ... no.

PID33, female, low user

Five participants reported that they do not see themselves as being mentally ill, or do not identify with others with mental illness, and hold the view that others with mental illness are more "ill" than they are.

Online [...] it's more flexible, you don't have to take time out of work or anything, um, and I think everybody is at a different stage, everybody has different [...] times. I don't identify with a group of people with bipolar [...] I'm not a big one for self-help groups. You know, I just kind of think, 'no, no, no, I'm not that ill, I don't need that'.

PID76, female, high user

Some participants considered that attending a group meeting with people with bipolar disorder would be depressing and frightening. Two participants who related their previous experiences of attending group meetings with others who had bipolar disorder remarked that seeing others who were more ill than they were reminded them of how unwell they could become, and were frightened to think that they may deteriorate to the level of those who appeared to be heavily medicated or looked very unwell.

I can't say everybody's the same, my own opinion, the thought of going into a room with fifteen people who've got bipolar would frighten the life out of me [...] It frightens you. It frightens you to think you might deteriorate to that level, you know. I just thank God, cross my heart, that I have not dropped so low that I could be hospitalized or anything, but I've seen people who have been hospitalized and it's not a nice sight [...] The heavily medicated, they look like zombies, you know, and I just thank God it hasn't happened to me yet.

PID47, male, high user

One participant said that she stopped attending group self-help sessions for bipolar disorder because meeting with others who were particularly ill and heavily medicated reminded her of how ill she could be and made her feel worse.

I stopped going because there were people there who were fresh out of hospital, up to their eyes on medication which didn't suit them, well, comatose for want of a better word, I know that sounds awful but I'm not saying anything that I don't feel to be true. I've got the same illness as them, I've got every sympathy with them, but I don't want to be reminded of what I could be as well, so it was no good for me, I need to be with people who are not ill-er than I am. I can't, because it makes me more ill, so I had to stop going, and I did.

PID50, female, high user

Three participants suggested that group-based psychoeducation for bipolar disorder may be disruptive as some participants may dominate the group and become absorbed with discussing their negative experiences. They commented that the dynamics of the group may affect the objectivity of one's experience of the material presented.

Sometimes if you've got people with the same illness you can drag each other down.

PID2, female, low user

My concern [...] having a whole bunch of people is that we all get down into the dirt, you know, [...] as I know from my own experience in teaching, you will have one or two vociferous

ones in the group and um who will [...], even with the best facilitator in the world, will church out their experiences [...] and it can be less satisfying and objective for the others whereas in an online version it's just you. It's you, and you can engage, and again with the forum you can engage if you so wish.

PID52, male, high user

4.3.3.4.4 Internet-based psychoeducation is more acceptable than group-based psychoeducation for those newly diagnosed

Some participants suggested that online psychoeducation would be more acceptable than group-based psychoeducation for those who were newly diagnosed with bipolar disorder. In addition to the perception that meeting with a group of people with mental illness may not appeal to those in the early stage of their illness, online psychoeducation can provide anonymity and an opportunity to take a break from the programme if they felt uncomfortable or lacked concentration.

In the beginning I would have preferred to gone online. That is because from doing an online programme I would realize that they don't all sit there in straitjackets, um, I would realize that they're normal people. [...] in the beginning if anyone had said you're going to go to sit in a group with a load of other people with bipolar I would have gone 'not on your nelly'. The anonymity of the online thing is absolutely perfect [...] Frightened to death [...] if I saw, I just mentioned two people there, had they been there on my first meeting I would not have gone back again. I would have been too frightened [...] Now I'd be happy to go to a group but not newly diagnosed.

PID50, female, high user

4.3.4 Impact

4.3.4.1 Minimal contribution to existing knowledge for those with a long-standing diagnosis

The majority of participants reported benefitting from the programme. Some commented that the programme reinforced or consolidated their existing knowledge of bipolar disorder, although almost

all participants were not newly diagnosed with bipolar disorder and 13 participants reported that the programme minimally contributed to their understanding of bipolar disorder.

Well, a lot of what it was telling me I already knew. I mean, I had the diagnosis for over 20 years and I've done a lot of research on my own behalf, so a lot of actually what was being said I already knew.

PID24, female, low user

4.3.4.2 Potential greater impact for those with a recent diagnosis

Many participants felt that the programme would be particularly useful for those who were more recently diagnosed. Some expressed that they would have appreciated the programme in the early stages of their illness as they didn't have sufficient information on bipolar disorder available to them at that time.

I think it would be most useful for someone who was newly diagnosed, but for somebody like me it wasn't really teaching me anything I didn't already know. [...] in newly diagnosed people I think it would be very helpful.

PID24, female, low user

One participant commented that the mode of presentation is helpful for newly diagnosed participants because it enables them to access as much information as they are ready to absorb when it suits them.

I remember when I was first diagnosed there was absolutely nothing. [...] the programme is exactly what I needed when I was first diagnosed, but I had to go looking for that information myself. [...] Had that, something like that been out, not a book, you can't concentrate on a book when you've just been delivered this news, no good at all, to have somebody there, not face to face, but so you can switch it off when it becomes uncomfortable, it would have been worth its weight in gold, and, like I say, I would have paid for it. [...] because you go through different elements of concentration and taking things in. There's certain times in your life when someone will start talking and after 30 seconds you've

just switched off. Yet you could be missing something that could really help you along, particularly in the early days, there's a lot you don't want to know, you're too frightened to know 'so don't bother telling me, thank you very much', so it is nice to get into that sort of thing and think 'right, ok, I'm ready to look at it now'.

PID50, female, high user

One participant commented that he would continue to log in to the website to refresh his memory because, as someone who had been recently diagnosed with bipolar disorder, there was much within the programme for him to remember and continue to learn about as his behavioural patterns changed.

I was only diagnosed fairly recently so I still, as far as I'm concerned, don't know enough, so when, I dunno, your behavioural pattern changes or, um, something else that's perhaps is linked to bipolar happens, it would be nice to go in there and think 'oh right, that's why this is happening' or 'that makes sense'. [...] As a refresher if you like. Because it's basically written by people who've studied bipolar perhaps and [...] because it was a study of people with bipolar, it beats going to the library and getting a book on it or pulling up something off the internet.

PID78, male, high user

4.3.4.3 Greater knowledge of bipolar disorder

Even though the programme contributed minimally to most participants' understanding of bipolar disorder many participants reported that they had learned something new as a result of the programme. As a result of the lifestyle module some participants recognised what may trigger an episode of bipolar disorder, such as stress, alcohol, and lack of sleep or moderate exercise. Two participants remarked that the programme (particularly the introductory module) had contributed to a greater acceptance of the illness.

I think maybe it impacts perhaps indirectly in so much as it has facilitated, although I can still feel desperate at times, [...] I accept it far more perhaps than I used to, I realize that it's not being, you know, a complete and utter shit basically, it is actually because I've got a mood

swing and you know or things aren't as stable as they ought to be and that you know it will pass, which is again part of the learning curve I guess.

PID52, male, high user

Nine participants remarked that they would continue to log in to the website as a useful resource for revisiting modules.

4.3.4.4 Improved self-awareness

Many participants expressed the view that the programme encouraged them to think about self-management techniques, how to monitor their thoughts and feelings, and how to regulate their behaviour.

I feel now that I would be more aware of the changes in me, but that's only a feeling because of course I haven't had another episode to actually put that to the test. [...] So I do feel in that sense [...] it's been a good experience to do this, to actually recognize when my thought processes, you know, might be going off track.

PID53, female, high user

I can certainly recognize that, if given the opportunity to do loads and loads and loads, I mean, it's nice to do so, but I recognize that I need to balance things a bit sometimes. If, for example, I wake up about 6 o'clock in the morning, send off about twenty-five emails and then start phoning as soon as people are up at nine o'clock, and that kind of thing, I recognize that it's not ultimately in my best interest to carry on functioning at that level, it's best to just deliberately back down a bit.

PID63, male, high user

Some participants felt that the programme enabled them to reinterpret aspects of their life and illness.

I think it's sort of marginally therapeutic to actually be doing it, um, it gave me an insight into, you know, bipolar disorder and also impacted, gave me a way of reinterpreting some of the things that have happened during my life in a way that made them easier to accept I think, so that was good.

PID14, male, high user

[...] it gave me [...] different ways of thinking [...] so I can express myself differently, um, whereas perhaps prior to it I had my own little way of dealing with everything, it has given me different thoughts, you know, it's given me something to think about.

PID50, female, high user

4.3.4.5 Behaviour change as a result of the programme

Some participants adapted their health behaviour, lifestyle or routine as a result of the programme; specifically because of the modules on lifestyle changes and relapse prevention. Since undertaking the programme, some participants reported implementing the following changes: creating and maintaining a regular routine, quitting smoking, reducing alcohol consumption, adjusting their sleeping patterns, and exercising more. Participants who reported implementing these changes were all high users of the programme.

I used to be a fitness fanatic in my younger days, so I started doing that and like I say I stopped smoking after forty years and, you know, it was all working, that part of it is very helpful.

PID47, male, high user

As a result of the programme two participants stated that they created a regular routine to maintain their wellbeing.

I discipline myself better, you know, I can, even when, I haven't been really ill for a long time now, but when I have been ill I used to find it difficult to discipline myself [...] getting a routine made me feel better because it made you do, made you get off your fat arse, sorry

for saying it like that, made you get up and do it. And I stuck to the routines and I started swimming, and even when I'm paranoid and can't go out of the house I still went. You know, I mean it did help me in a lot of ways like that [...] sometimes you just wanna sleep 24 hours a day, you don't want to go anywhere, or do anything, just sleep. When I do feel like that I force myself up at six o'clock in the morning or whatever and I seem to be sticking to a better routine than I used to.

PID47, male, high user

Two participants reported reducing their alcohol consumption as a result of the programme.

Um ... what triggered me to not drink as much ... I think partly knowing that it can be a trigger for things and I know sometimes if I suddenly feel like I wanna go out and have a drink that's usually a bad sign.

PID71, female, high user

One participant reported intending to return to work after being a housewife for 13 years.

I'm thinking about going back to work which has been a big sort of change because I haven't worked for 13 years [...] but I'm really thinking about doing some voluntary work to start with and get back into the workforce. [...] So that's been a help with the modules at the beginning and then really thinking about perhaps doing a part time job, after the voluntary work obviously, and that's been a good result I think.

PID44, female, high user

As a result of the programme two participants stated that they ensure they have enough sleep by going to bed earlier.

I go to bed a lot earlier than I used to. [...] going to bed early is no longer an issue for me. [...] I'm turning into an old fart, so I find it difficult to want to be up beyond eleven o'clock, you know, so it's not uncommon to find me in bed at half past ten now.

PID52, male, high user

Two participants reported exercising more as a result of the programme.

I probably spend four days a week in the gym whereas I didn't before, I didn't go at all.

PID78, male, high user

4.3.4.6 Change in attitudes towards medication

Six participants reported being more medically informed as a result of the medication module and subsequently changing their attitudes towards taking medication. Two participants reported being more confident to try medication and more willing to experiment with medication.

I was very resistant to the idea of medication although I'd sort of reluctantly agreed to it, and it did, I did feel much more confident in the idea of medication, and more willing to, you know, experiment, or try that as a solution.

PID14, male, high user

One participant commented that now she takes her medication regularly rather than sometimes skipping her medication and thinking that she will cope.

[...] the only thing I have done is make sure that I take my medication regularly, rather than leave it and think "well I'll cope", you know? It's tempting to do sometimes and I realize that it's not very beneficial to do it so that sort of compounded my resolve to do that.

PID44, female, high user

4.3.4.7 Facilitation of greater understanding and support from others

Twelve participants chose to share the content of the programme with others, mostly through showing others the website. Many participants who shared the content of the programme with a

family member, partner or friend reported that doing so was useful because it facilitated communication, understanding and support. The first two modules on diagnosis and aetiology were commonly shared with partners. Additionally, some participants also shared the module on partners, families and carers.

I tried to engage my wife. Because there was a section [...] at the beginning of it, quite early on in the modules, that I said 'you really need to look at this because it might help you understand [...]', she's a GP my wife, but I said 'it might help you understand where I'm coming from when things are not right, and I am behaving erratically or [...] somewhat short fused [...], this might help you out', and she did have a look at the module and she thought it was quite useful.

PID52, male, high user

[...] we were on holiday recently with my in-laws and I just couldn't face another day, um going out with a couple of them, you know, and I was able to, um, in previous years I've not been able to repel that burden of responsibility and I've just said now, 'you guys go off for the day I'm going to spend the day on my own reading at home' [...] So, yeah and it was a good thing and the family are more accepting of that now. [...] being able to realize that there [...] are plenty of times when I want to be involved and I want to be part of things and I realize that I don't have choices in some matters pertaining to, you know, to my wife and children, you know, but there are other things I can opt out of without anybody getting upset or what have you. And so they've adapted and I've adapted. [...] My family [...] is very understanding in that respect.

PID52, male, high user

One participant reported that work colleagues with whom he has a close relationship are more aware of what triggers his bipolar disorder, and are able to identify when he is vulnerable to experiencing a depressive episode in order to make him aware of this.

[I] know my triggers, um, such as stress and sleep, exercise, alcohol intake, and so do my family now, and so do my work colleagues which is great. [...] They, the ones that I'm very

close to in work, can pick up on when I'm perhaps even heading for a low, before, well, not before I do, but at the same time that I can see it, they will point it out to me.

PID78, male, high user

4.4 Discussion

4.4.1 Main findings

We identified several key themes within each domain of enquiry (see Table 6).

<p>FEASIBILITY</p> <p>Accessibility and flexibility The effect of illness on engagement with the programme The importance of accessing the programme in a private environment</p>
<p>ACCEPTABILITY</p> <p>Professional appearance and usability Clarity and quality of content Dislike of actors' acting Difficulty with the interactive "life chart" exercise Lack of activity on the forum Presentation of lithium within the medication module Preferences for alternatives to the computer-based format Internet-based psychoeducation lacks the sociability of group-based learning Groups of people with mental illness are unappealing Internet-based psychoeducation is more acceptable than group-based psychoeducation for those newly diagnosed</p>
<p>IMPACT</p> <p>Minimal contribution to existing knowledge for those with a long-standing diagnosis Potential greater impact for those with a recent diagnosis Greater knowledge of bipolar disorder Improved self-awareness Behaviour change as a result of the programme Change in attitudes towards medication Facilitation of greater understanding and support from others</p>

Table 6. Main themes within each domain of enquiry

4.4.1.1 Feasibility

The implementation of the programme was found to be feasible for those who had access to a computer and were willing and sufficiently able to use a computer. The programme was commended on its accessibility and ease of use. Some participants specified that they required privacy when accessing the programme and others commented that they needed to be well enough to undertake the programme in order to concentrate on it. This confirms the finding of a recent study examining the predictors of attrition of an online bipolar education programme, where the most common theme arising from interviews was that the nature of the illness made it difficult for some participants to continue their involvement with the programme [41]. Akin to our findings, this study discovered that many participants who suffered an acute phase of the illness during the course of the programme could not complete the modules – particularly if they were experiencing a depressive episode and lacked sufficient energy or motivation to complete the programme [41]. The authors of this study also found that several participants reported not completing the programme due to not wanting to think about their illness or because they didn't feel the need to participate in the programme once their mood had stabilised [41], which mirrors our finding that some participants preferred not to engage with their illness or the programme when well.

4.4.1.2 Acceptability

The programme was found to be acceptable to participants, who were satisfied overall with the content and presentation of the programme and made suggestions for improvements. The presentation of the programme was reported to be professional and clear, and the pace of the modules and the time between modules was regarded as acceptable. Revisions of the programme should focus on the use of actors, the forum, the life chart exercise, and the content of the medication module. An alternative format of the programme, such as group-based psychoeducation or a psychoeducation manual for patients, should be offered for those who are resistant to using a computer, perhaps especially for older individuals who may not be familiar with using the internet.

We found that many participants who preferred internet-based psychoeducation for bipolar disorder felt that interacting with groups of people with mental illness was an unappealing prospect; as they did not identify with people who have a mental illness, may be frightened or upset by witnessing others with an apparent worse case of the illness and anticipated that some group members may be disruptive. Additionally, we found that some participants regarded online

psychoeducation as more suitable than group-based psychoeducation for those newly diagnosed; due to the accessibility, flexibility, privacy, and anonymity of online psychoeducation, and the stigma associated with groups of people with mental illness. This finding supports the results of a study of computerised cognitive behavioural therapy (CCBT) for depression, in which freedom and anonymity were found to be motivating factors contributing to adherence to online self-help [86]. Despite this appreciation for anonymity, however, many participants of this study reported a preference or need for social support to complete CCBT successfully; either to create sufficient discipline to adhere to CCBT, to have personal contact, or to receive feedback or explore the course in greater depth through personal support [86].

Participants who expressed a preference for group-based face-to-face psychoeducation preferred the sociability of group-based learning; many of whom were also resistant to using a computer. This finding relates to the limitations within the forum; which was not as effective as we had hoped in providing adequate or appropriate peer and social support. A key insight from the focus groups which were held at the outset to develop the content and format of this intervention was that social support for those with bipolar disorder delivered via an online forum was desirable [18]. The purpose of the forum was to enable participants to discuss their experiences of the modules and their illness with a view to enhancing their learning experiences and reducing any feelings of social isolation or stigma [18]. It is apparent that the forum did not serve this purpose, perhaps because of its lack of critical mass (only half of all trial participants in the intervention arm contributed to the forum [23]), its lack of input from professionals, and because for some it was not viewed as an appropriate medium for social support. Previous research has found that the time since diagnosis for online forum participants was less than that for face-to-face support group participants [87-89]. A study comparing peer support modalities among breast cancer patients found that online forums primarily facilitate emotional expression and advice, whereas face-to-face support groups mainly enable insight and emotional support [88]. With regard to these findings, our online forum may have been better suited to those more recently diagnosed, for seeking advice and expressing their feelings.

4.4.1.3 Impact

Participants' capacity to benefit from the programme was reduced for those who were not newly diagnosed with bipolar disorder. For these participants the programme minimally contributed to their existing knowledge of bipolar disorder. An important finding was that many participants

regarded the programme to be most beneficial for those recently diagnosed. The programme was found to impact to some degree upon some participants' insight into their illness – specifically, their knowledge of self-management techniques, their self-awareness, and their acceptance of their illness. Furthermore, the programme was found to impact upon some participants' health behaviours, lifestyles and personal routines, and their attitudes towards medication. Many participants chose to share the content of the programme with others, which they reported as having contributed to the quality of their personal relationships through enhanced communication and understanding.

4.4.2 Strengths and limitations

This study is the first qualitative enquiry to comprehensively evaluate an online psychoeducation programme for bipolar disorder. Interviews enabled both high and low users of the programme to elaborate on their experiences of it, which gave us insights into how the programme was experienced, what was considered to be effective, and areas for improvement. Respondents commented on contextual factors which might influence the acceptability and efficacy of the intervention in practice, as well as fidelity of delivery.

The main limitation of the study is that the majority of participants recruited for the trial were not recently diagnosed with bipolar disorder and were already familiar with much of the material presented. This affected the extent to which some participants were able to benefit from the programme, and may have affected the outcomes of the trial [23].

Furthermore, the format of the semi-structured interview may have restricted participants' responses. It was useful to enquire about specific aspects of the programme for the process evaluation, but prior to asking these direct questions a better interviewing technique would have been to ask very open-ended questions from the outset to enable participants to describe their experiences of the programme more freely. This would have been more in-keeping with the phenomenological approach.

Participants may have forgotten aspects of the programme in the six to eight months between receiving the intervention and being interviewed. This follow-up period facilitated exploration of the longer term impact of the intervention; however, details relating to the specific content of the programme had been forgotten by some participants, particularly by low users of the programme.

4.4.3 Future research and clinical implications

An online psychoeducation package for bipolar disorder, such as “Beating Bipolar”, is feasible and acceptable to patients who are amenable to computerised learning and have access to a computer, and it may be particularly suited to early intervention. Ideally, alternative formats should be available to patients who would prefer either written materials or a group-based, face-to-face learning environment. Future research should evaluate an intervention of this kind specifically targeted at those who have been recently diagnosed with bipolar disorder and explore optimal ways to provide, and alternatives to, online forums for providing peer and social support within internet-based psychoeducation. Overall, internet-based interventions of this kind have considerable potential to deliver high-quality self-management and psychoeducational support for mental health problems such as bipolar disorder at relatively low cost.

Chapter 5: How patients contribute to a web-based psychoeducation forum for bipolar disorder

5.1 Introduction

Online resources which provide health information are increasing in number and popularity [90, 91]. Accessing online health information has an empowering effect as patients and caregivers take an active role in managing their health and receiving peer support [90]. ‘Expert patients’ manage their condition by developing knowledge relevant to managing their health [92] and making informed decisions regarding their treatment [93]. A survey of 3001 adults in the United States revealed the following statistics for the 74% of adults surveyed who used the internet [91]:

- 34% had read someone else’s commentary or experience about health or medical issues on an online news group, website or blog [91]
- 18% had gone online to find others who might have health concerns similar to theirs [91]
- 6% had posted comments, questions or information about health or medical issues on a website [91]
- 4% had posted their experiences with a particular drug or medical treatment [91]

Although there is an understanding of trends in seeking health information online in broad terms, research upon the use of online discussion forums for people with bipolar disorder is minimal [94-96]. A German study analysed two forums for patients with bipolar disorder examining 1200 contributions of 135 users, according to “fields of interest” and “self-help mechanisms” [94]. The authors found that patients mostly discussed their social networks, symptoms of the illness and medication, primarily in order to share their emotions [94]. They also identified disclosure, group cohesion, empathy and support to be the main self-help mechanisms [94].

A Spanish study of an online forum for bipolar disorder focussed solely on exploring contradictions between the first posts of a new user and other member’s replies giving unsolicited advice [95]. The authors used conversation analysis to examine the sequential features of communication [95]. The main finding from this study was that there was commonly an apparent mismatch between what the

new user appealed for and the responses given by other users [95]. New users who sought accounts of others' experiences, reassurance or basic information were given unsolicited advice by existing members [95], which the authors interpret as being instructive and a way of asserting the culture of the group.

Cultural differences may account for some differences between the ways users of both studies typically communicate within the forums. To our knowledge no research has been conducted into how British patients use a forum for bipolar disorder. We sought to explore participants' contributions to a web-based psychoeducation forum which was part of the Beating Bipolar trial [23]. Twenty-four participants, who were allocated to the intervention arm of the trial, were provided with user accounts to access the forum. The forum was moderated by Dr Smith and forum thread topics could be initiated by all users. This qualitative study aimed to explore contributions to this forum during the 14 weeks within which participants accessed the Beating Bipolar psychoeducation modules. The aims were to identify topics which individuals with bipolar disorder raised or discussed in the forum which seemed to be important or relevant to them, and to explore how they engaged with the forum and with other users.

5.2 Methods

5.2.1 Methodology

Research into computer-mediated communication (CMC) has shifted in its epistemological focus from viewing CMC as a research "tool" [97] to recognising CMC as a site of investigation and a culture to be explored [98, 99]. As an adaptable methodology appropriate for the study of online communities and cultures, "virtual participant observation" [100] (also referred to as "online ethnography", "netnography" and "virtual ethnography") is increasingly used within many disciplines; including sociology, philosophy, psychology and economics [97, 99, 101, 102]. To reflect the values of ethnography, proponents of virtual participant observation state the importance of providing a Geertzian "thick description" [14] through immersing the researcher in the life of the online community or culture [8, 9]. This immersion in the life of the community may be achieved through directly participating in an online forum or through combining different research methods [15], to include interviews or focus groups, for example.

Although this study is not strictly ethnographic, because I did not immerse myself in the life of the online community through directly participating in the forum as the researcher, DS participated in the forum as a Psychiatrist and researcher to initiate topics for discussion. Furthermore, in Chapter 9 I combine findings from this virtual observation study with findings from qualitative interviews with the same Beating Bipolar participants (described in full in Chapter 4) to more fully understand how patients contribute to the forum and the barriers and facilitators to them doing so.

In this research, DS “announced” his online presence within the online forum as “Dr Smith”, who was known to participants as a Psychiatrist and a researcher of the Beating Bipolar psychoeducation programme. DS contributed posts within the forum, and in this sense became immersed within the online community as a participatory member (in the sense that he took part in the forum on a fortnightly basis).

5.2.2 Data collection and analysis

Forum usage data were obtained from the software company who created a database to record this information to explore how many users posted contributions or created new topic threads and how often. Written data were extracted from the forum into a text document which was consequently uploaded to the qualitative analysis software programme NVivo 8.

To study the way participants used language to convey meaning and construct their identities discourse analysis [103] was used in conjunction with thematic analysis [82], the latter chosen because of its flexibility and applicability to various types of data and theoretical frameworks.

Discourse analysis examines text or spoken language to identify underlying social structures which may be implied through metaphors, word choice or speech patterns for emphasis, for example [104]. Discourse analysis is intrinsically linked to thematic analysis - linguistic considerations are taken into account as the researcher analyses the data for recurring themes and categories.

According to discourse analysts, discourse pertains to themes which relate to identity in particular [104]. In the present study, I wished to see how identity is constructed within the group of Beating Bipolar forum users in terms of how they interact with each other and what they discuss as being important to them. I conducted thematic analysis of forum posts, which also considered patients’ discourse in terms of the language they used to convey meaning in the experiences they described.

A mostly inductive approach to analysis was chosen whereby themes were identified as they emerged from the data, rather than being driven by the headings of the topic threads. Three members of the research team read the forum data (DS, KW and I) for initial impressions. KW is Ken Wann, who helped with this data analysis for his project as an undergraduate medical student. DS and I made notes of our impressions of the forum, which facilitated reflexivity, orientation to and immersion in the data. I developed an initial coding framework for data analysis when I read through the forum posts prior to coding using NVivo. This framework was discussed with the team prior to conducting in-depth analysis, for which it provided the structural ground for coding – the framework was inputted into NVivo as parent nodes (or top-level headings) with child nodes (potential sub-categories, which were subject to alterations as coding proceeded) beneath. Top level headings for emerging themes within the coding framework were: “What do people say?”, “How do people say it?” and “How do people engage with others?” KW and I independently coded the data according to the coding framework, which was developed and refined through discussion during the analytic process. Hence, the whole data set was double coded for consistency and agreement of interpretation for emerging themes. Where there were any uncertainties, consensus was achieved through discussion. We identified the main themes and sub-themes, and interpreted users’ interactions with each other.

Participants of the trial consented for us to assess the acceptability of the forum within our research; unfortunately, however, consent was not obtained for us to use quotes from the forum.

5.3 Results

5.3.1 *Participation within the forum*

Of the 24 participants who were provided with exclusive access to the forum 13 (54%) contributed at least once to the forum and 10 (41.7%) created a new topic for discussion. One hundred and twenty seven posts were generated in total, 92 (72.4%) of which were contributed by four participants (16.7%) who dominated the forum.

5.3.2 Key themes

The key themes identified within the analysis were: medication, employment, social stigma, social support, coping strategies, insight and acceptance, the life chart, and negative experiences of health care.

5.3.2.1 Medication

Medication was the predominant topic for discussion. 44 of 127 posts (34.6%) related to medication. Participants mostly discussed the side-effects of medication from their personal experiences and the trial and error process of finding the right combination of medication. Many participants described their experiences with Lithium, and weight gain was a particular concern.

One participant said that after 15 years she has now come to terms with the illness and takes Lithium “religiously”. She tries to ignore the side effects because without the medication she feels she would be ill again. Another participant responded to this post to say that he felt encouraged by this person’s experience of Lithium and would start a new topic thread for people to share their experiences of different combinations of medication.

One participant said that she put on a lot of weight and became really lethargic when taking Lithium for six years and felt very unhappy. A couple of participants commented that despite the side effects being on Lithium enabled them to lead a balanced life.

As a result of viewing the medication module, one participant reported feeling frustrated that his doctor would only prescribe him antidepressants in spite of the fact that he doesn’t respond well to them.

5.3.2.2 Employment

Employment was the next most popular topic for discussion, with 30 posts (23.6%). Participants mostly expressed difficulty in securing or holding down a job. Stigma regarding mental health issues was noted by a number of participants, and some participants gave personal accounts of prejudice or discrimination in the workplace. Advice was sought regarding how to get a job and many

expressed their frustrations and dissatisfaction with being unemployed or with their current job. Boredom, self-esteem and financial issues were key sub-themes.

One participant said that he lost three jobs as a result of his behaviour during manic episodes. Another participant remarked that she had to give up a very well-paid job because of the illness. Some participants commented that their careers have ended due to their bipolar disorder, and sought advice from other forum users regarding potential work opportunities.

Some participants remarked upon the issue of explaining gaps in their employment histories. One participant tried to hide his bipolar disorder from his employer for 15 years. Another participant complained that in his experience employers do not risk employing a person with bipolar disorder because they cannot afford to cover months of sick leave.

One participant commented that she felt that his only way back into work would be via the voluntary sector. She expressed a desire to do something to stimulate her brain again and give her life purpose. Another participant recommended doing administrative work, because it had improved her self-esteem, confidence and CV.

The Disability Discrimination Act was cited by a couple of participants. One participant remarked that although legally employers need to make adjustments for the condition what happens in practice may vary.

5.3.2.3 Social stigma

Stigma was a key theme which pervaded many topic threads. Participants discussed how bipolar disorder is perceived by others. The portrayal of bipolar disorder in the media was discussed and participants felt that more accurate examples in the media may improve public awareness of bipolar disorder and reduce social stigma. Participants expressed their fear of disclosing their bipolar disorder, and some reported concealing their illness from others because of stigma. Some felt stigmatised by friends and family, insecure and ashamed of themselves.

One participant revealed that she wouldn't disclose her bipolar disorder to anyone other than close friends and family because of she feels that others have preconceptions, misunderstandings or

stereotypes of the condition. Another participant reported feeling stigmatised and misunderstood by his family and friends.

One participant said that she was told not to tell anyone about her bipolar disorder because of the stigma, the possibility of losing her job and having her children taken into care. She reported feeling dazed, frightened, insecure and ashamed.

Some participants recommended television screenings which address the issue of stigma surrounding mental health. Regarding bringing the issue of bipolar disorder into public awareness, the celebrity Stephen Fry was mentioned by some participants. One participant said that the portrayal of a character with bipolar disorder in the soap opera “Eastenders” was particularly realistic. One participant provided a link to the “Like Minds” television commercials in New Zealand which aim to reduce stigma and raise awareness of mental health conditions. Another participant remarked that he wished that British television would screen similar commercials. He related that he makes light of the illness through humour in the hope that others may accept mental health problems without fear or prejudice.

5.3.2.4 Social support

Participants sought advice and support from others via the forum as well as providing it. Some participants invited others to coffee mornings and self-help groups organised by the Manic Depression Fellowship charity. Some participants revealed difficulties in communicating with family members about their bipolar disorder or struggling to rely on others in times of need. Other participants expressed their gratitude for having supportive families they could rely upon, and some acknowledged that their partners or children looked after them when they were ill. Responsibility was a key sub-theme: participants reported either relinquishing their responsibilities when they were very ill or feeling unable to.

One participant commented on the importance of having social support, but lamented that she doesn't feel comfortable with relying on others. Another participant said that her children have looked after her when she was incapable because of the illness, which gave rise to feelings of humiliation, shame and guilt.

5.3.2.5 Coping strategies

Participants shared their personal coping strategies for dealing with boredom, staying well and managing personal relationships. Exercise, routine, sleep and diet were mentioned most frequently.

The importance of a regular sleeping pattern was cited by some participants as a coping strategy. Those who worked shifts felt that this contributed to their becoming unwell. One participant who worked shifts reported drinking alcohol after a late shift and waking up at intervals throughout the night.

Some participants stated the importance of exercise; either to burn off excess energy or to improve low mood. The responsibility of being a member of a sports team motivated one participant to reliably engage with his sports practice even when becoming ill. The discipline of this regular commitment to exercise enabled him to cope when he lacked energy. This participant also recommended writing things down in a diaries, lists or letters to release pressing thoughts and regain focus. Listening to music is another coping strategy used by this participant, who said his mood can be affected by it, either to induce calm or excite. Another participant also reported lifting his mood through listening to music.

Some participants stated that the engaging with the routine of work was their best coping strategy. Others mentioned that they tried to maintain a healthy diet, but struggled with their cravings for unhealthy, sugary food.

Regarding coping strategies for managing personal relationships, one participant mentioned using code words with his partner to non-aggressively communicate warning signs of the illness. Another participant is wary of exposing herself to the emotional distress of others; such as a crying baby, her daughter's emotional outbursts or televised aggression.

5.3.2.6 Insight and acceptance

Through a greater personal understanding of bipolar disorder some participants reported their increased self-esteem and a greater acceptance of the illness. Some participants commented that the programme helped them gain insights into themselves and the trajectory of their illness.

One participant remarked that she thought she had a good insight into bipolar disorder prior to the programme, but has since learned new things and hopes to be able to accept the illness more. Another participant commented that he felt that he was learning more about bipolar disorder and could understand himself better.

One participant said that she was finding the programme and the forum to be very useful, despite her minimal contribution to the forum. She said that her episodes have become more seldom, she has made improvements to her lifestyle and can now accept what she cannot change. She goes on to explain that now her employer and colleagues are fully aware of her condition.

Another participant said that she had recently begun to think of bipolar disorder as a problem with her neurotransmitters and a flaw in her make-up rather than a disorder with extreme moods or a mental illness.

5.3.2.7 Life chart

The life chart exercise was the most discussed aspect of the Beating Bipolar programme due to participants' difficulties with completing it. Participants felt that it was too simplistic and they needed to be able to add labels and notes regarding what medication they were taking and what triggered their highs and lows. Participants also needed the chart to begin before age 15 (if they felt that their bipolar disorder began at an earlier age), include the option to report a combination of medication, enable mixed episodes and rapid cycling to be represented graphically, to show age at each point along the timeline, and to be able to select individual months or seasons. Some reported that the life chart was useful for explaining their illness to others and remembering events in greater detail.

One participant commented that he was finding it difficult to remember events, especially when highs and lows occurred around the same time. He suggested that it would be helpful if he could draw a wiggly line with the mouse.

One participant said that it would be useful if one's exact age could be shown within a box which would appear as the cursor hovered over each point on the timeline. Another participant requested to be able to specify months within the timeline because her mood corresponded with the yearly seasons.

Some participants complained that they were not able to note on the chart when they were taking multiple medications at any one time. Which single medication to record or which mood to record if one's moods were changing rapidly were also issues discussed, and one participant struggled to record mixed states or periods of rapid cycling.

5.3.2.8 Negative experiences of health care

Participants described their negative experiences of health care. Some participants who had initially been misdiagnosed revealed the implications of their misdiagnosis for obtaining appropriate treatment, experiencing severe relapses and employment.

One participant was diagnosed as having bipolar disorder by a General Practitioner (GP) who consequently referred him to a Psychiatrist. The Psychiatrist refused to provide a diagnosis of bipolar disorder based on a single manic episode and refused to prescribe the medication which was previously prescribed to him by his GP. It took seven years before this patient received a diagnosis of bipolar disorder from another Psychiatrist, who recognised his mania developing.

Another participant had received misdiagnoses from GPs, and had consequently taken medication which exacerbated the illness, until a Psychiatrist reluctantly gave him a diagnosis of bipolar disorder. Due to his diagnosis he had to retire from his career and has since struggled to gain employment.

Participants highlighted difficulties in accessing a Psychiatrist and a lack of continuity of care. Some related their experiences of doctors not listening to their concerns about medication or diagnosis, or doctors criticising them for independently researching their illness. Some also felt that medical practitioners should increase their knowledge and understanding of bipolar disorder.

One participant related that with the support of a good mental health team many people with bipolar disorder can lead happy, healthy and productive lives.

5.3.3 Participants' use of language

5.3.3.1 Personal narratives

Participants frequently provided personal narratives relating to their history of bipolar disorder, life experiences and backgrounds. These narratives were often confessional and contained anecdotes, metaphors, emotive language and humour. Participants typically used a narrative style when describing their experiences with health care professionals, medication and relationships with others. For example, participants would tell their story about how they came to be diagnosed with bipolar disorder and how they came to be on their current medication, or would relate their story of their careers and how they came to be unemployed or retired as a result of the condition. Many of these narratives did not explicitly invite comments or advice from others; they appeared to be stories offered for the sake of sharing.

5.3.3.2 Humour

Participants used humour frequently within their posts. Humour was used for self-depreciation, irony or sarcasm, and some participants used abstract or surreal metaphors to amuse. Many emoticons, abbreviations and colloquialisms were also used.

One participant joked that while his family sit down to have their cereal in the morning he has a bowlful of antipsychotic and antidepressant medication. Another participant referred to the implications of his weight gain (which resulted from the side effects of his medication) on finding a girlfriend. With humour he remarked that not many women want to date an overweight man.

Some participants used metaphors which related to their perceptions of their careers or job prospects being worthless or discarded. Participants wrote of their careers "being binned" or having "fallen apart". A couple of participants consequently regarded themselves as being "on the scrapheap" or "scrapheaped". One participant said that she felt as though her brain was "rotting quietly away" with lack of use.

Some participants illustrated happy or miserable smiling faces, "☺" or "☹", following their own comments of a confessional nature. For example, one participant disclosed that a significant

problem of hers was an eating disorder. She ate to cope with emotions and regarded her eating to be an addiction. She revealed that after years of trying to overcome her eating disorder she has been unable to “break the cycle ☹ ☹ ☹”.

Abbreviations used included “CPN” for “Community Psychiatric Nurse”, “BD” for “bipolar disorder” and “LOL” for “laugh out loud”.

5.3.4 *How participants engaged with each other*

Participants shared their experiences via the forum and engaged with each other in a respectful manner. Some commented on others’ posts and some provided stand-alone narratives. Participants regularly sought and offered advice, and expressed encouragement and empathy. Some participants invited others to contribute to topics or to meet face-to-face. Links to external resources were also provided within some posts.

5.4 Discussion

5.4.1 *Main findings*

Only half the participants contributed to the forum and only four participants contributed regularly, which suggests that the forum lacked the impetus for participants to continue to contribute, despite some input from DS. Participants used the forum to share and discuss what was relevant for them, to seek and offer advice, and to offer suggestions for improving the programme. Posts were often personally revealing yet at the same time usually carefully considered. Participants were respectful of each other and their suggestions were often constructive and given in a supportive way.

The main themes which emerged from the forum posts were: issues regarding medication and employment, stigma, social support, coping strategies, insight and acceptance, the life chart exercise, and negative experiences of health care. Participants also provided personal narratives of their experiences, which often contained emotive language and humour.

Participants' experiences of the forum, their reasons for not contributing and their suggestions for its improvement were explored within one-to-one qualitative interviews (see Chapter 4, [105]). Key observations from these interviews were: the lack of critical mass within the forum for worthwhile conversations, feeling put off by contributors who dominated topic threads, requiring reminders to log in regularly and needing more input from health care professionals for new topics for discussion [105].

5.4.2 *Strengths and weaknesses*

The way patients use self-help forums for bipolar disorder is an under-researched area. This study offers insights into how patients used the forum, topics which they feel are relevant to them following an education programme for bipolar disorder and how they interact with each other within an online community. The methodological approach of virtual participant observation is less obtrusive than interviews and has provided insights into how these patients shaped this online culture. By incorporating aspects of discourse analysis, the study revealed how participants commonly used humour in the form of metaphors or emoticons to convey emotionally sensitive issues and used a narrative style to self-disclose their personal stories to others.

Had there been more contributors and contributions to the forum this study would have had a richer data set on which to draw conclusions. Another weakness of this study is that we had not obtained consent from participants to use quotes from the forum. Unfortunately, it was not feasible within the scope of this research project to obtain the necessary consent in retrospect. A more in-depth discourse analysis may have also considered language structure, such as sentence length or word position [103], however this level of detail was considered to be beyond the scope of this study.

5.4.3 *Findings in relation to other studies*

The predominant topic of medication within this forum was also one of the most discussed topics within studies of two German language forums for patients with bipolar disorder [94, 96], which also cited patients' social networks and symptoms as key topics. The studies inferred that participants' main interest in contributing to a forum for bipolar disorder was to share emotion; as they identified disclosure, empathy and support to be the main self-help mechanisms [94, 96]. In our study, we identified much use of emotive language within participants' narratives as well as humour. It may be

that participants' frequent use of humour enabled them to communicate personal, emotionally-charged issues in a less intense way, thereby diffusing any awkwardness and facilitating ongoing social interaction.

Regarding the use of emoticons in internet forums, previous research has found that individuals "become" the text they write and the use of emoticons and expressive or "messy" texts can intensify interaction and push the boundary of what is possible in a textual conversation [101]. Participants' use of humour, emoticons and abbreviations formed their social "netiquette"; textual conventions which were to be adhered to in order for participants to "fit in" with their online community [97].

Other studies of internet forums have also found the exchange of information to be a key feature [106-108]. In an ethnographic study of an internet forum for obese and overweight people, researchers found that users exchanged a lot of information, including exercise tips, diets and progress reports, alongside discussions of a weight-loss drug and its side-effects [107]. Similarly, we found that patients exchanged much information relating to their coping strategies for dealing with bipolar disorder, and discussed exercise and dieting alongside other coping strategies such as the importance of maintaining a routine and a regular sleeping pattern.

A qualitative study of problems reported on an online depression support forum based in Australia presented six broad themes: "understanding depression", "disclosure and stigma", "medication", "treatment and services", "coping with depression" and "comorbid health problems" [109]. Akin to our finding that participants expressed their reluctance to confide in colleagues and their fear of the consequences of self-disclosure, this study also revealed these concerns; however, the study also noted participants' self-stigmatisation – participants blaming themselves for their condition and considering it to be a personal failing [109]. The BIPED forum did not present such self-stigmatisation, perhaps because the forum was delivered as part of a psychoeducation trial and its participants had greater insights into their illness. Another finding of the depression forum study revealed an insight into participants' reservations regarding seeking information from health care professionals; professionals may be perceived to lack the necessary skills or knowledge, lack sufficient time or be unavailable, and patients may fear a negative interaction with them [109]. Our study similarly highlighted participants' negative experiences of health care, such as difficulties in accessing a Psychiatrist and doctors not listening to their concerns about medication or criticising them for researching their illness. These prior negative experiences may lead patients to seek

information and support from non-medical sources, as they may expect empathy, respect and knowledge from patient support groups and forums.

Our finding that only 54% of participants contributed at least once and only 16.7% of participants contributed regularly to the forum highlights the discrepancy between participants who wish to merely observe an online forum and those who wish to actively participate in it. This finding is explored further in Chapter 4, as participants were asked to comment on their experiences of the forum within the semi-structured interviews. Their reasons for engagement and non-engagement were explored, and a synthesis of my research findings is presented in Chapter 9.

5.4.4 Conclusions

Internet-based psychoeducation is a more private experience than face-to-face group psychoeducation for bipolar disorder and in some instances may present less scope for enhancing social support. It may be most beneficial to those who lead busy lives, who are newly diagnosed or who are disinclined to socialise with others in the context of a group healthcare programme [105]. Online forums may be a cost-effective and pragmatic option for enhancing peer support for people with bipolar disorder, especially if provided in conjunction with an internet-based psychoeducation programme. They may provide patients with the opportunity to share their experiences and disclose and explore issues related to their illness anonymously. Although 13 of 24 participants in the intervention arm of the BIPED trial contributed to its forum, only four contributed on a regular basis. This forum would have benefitted from many more regularly contributing users to offer a greater support network with more diverse views and experiences. Further research is needed to explore how to optimally engage patients in using online healthcare forums.

Chapter 6: Feasibility, acceptability and impact of a group-based psychoeducation programme for bipolar disorder: a quantitative analysis

6.1 Introduction

I wished to explore the feasibility, acceptability and impact of a group-based psychoeducation programme for bipolar disorder (BEP-Cymru) for group participants. For details of the content and delivery of BEP-Cymru please refer to Chapter 1.

We have previously published quantitative data from the Beating Bipolar trial [23]. Since we wished to compare results from this trial and the group-based BEP-Cymru study we used similar outcome measures for participants of BEP-Cymru.

The primary aim for this chapter was to explore changes within group participants' outcome data across two time points from baseline; at 10 weeks (immediately following the intervention) and after three months. These data mostly assess the impact of the intervention; however, assessments of the feasibility and acceptability of the intervention were also captured in a post-course survey.

Results of this exploratory analysis will be assessed alongside the qualitative findings from interviews with patient participants and group facilitators in the comparative mixed methods chapter (Chapter 9).

6.2 Methods

Ethical approval was obtained for this PhD project from the Cardiff and Vale Research Review Service (CaRRS) on 13 April 2011 (Project ID: 11/MEH/5087).

6.2.1 Patient inclusion and exclusion criteria

All participants who took part in the BEP-Cymru programme were eligible for inclusion if they had a diagnosis of bipolar disorder and were able to provide informed consent to take part. Participants were excluded if they were unable to provide informed consent or had insufficient English language skills to comprehend the assessment materials.

6.2.2 Recruitment and consent

The BEP-Cymru programme recruits people who have a diagnosis of bipolar disorder and who are 18 years of age or over.

All participants of BEP-Cymru are initially screened by a psychiatric nurse to ensure that they have bipolar disorder and are able to take part in the group programme. Participants are then asked to complete assessments at baseline, immediately following the intervention (at 10 weeks) and three months following participation in the intervention, for the purpose of evaluating BEP-Cymru for its funder the Big Lottery. Assessments at baseline and 10 weeks are conducted within the first and last sessions of the group programme, and assessments at three months are posted to participants along with a stamped addressed envelope. For my PhD project, I obtained consent from patients to use this routinely collected data.

All participants of BEP-Cymru were invited to take part in this study by letter along with the patient information sheet and consent form. These were sent to prospective participants at least a week prior to their first group session by post. If prospective participants were interested in taking part in the study they had at least a week to contact me by telephone to ask any questions about the study or the nature of the data to be collected. It was made clear that if they choose not to participate in the research study it would not affect their participation in the programme or their medical care in any way. Initially, we expected to obtain consent from some participants by post, but it turned out that all consent was obtained face-to-face. For those who were willing to take part, their informed consent was obtained at their first group session, where I was able to answer any questions regarding involvement in the study.

6.2.3 Quantitative outcome assessments

For participants who consented to participate in the study I obtained access to their routinely collected outcome data. Participants self-completed the outcome assessment questionnaire packs in the first and last group sessions and at home for the final assessment. Facilitators routinely supervise baseline and 10-week outcome assessments face-to-face at the first and last group sessions and I was also present at these sessions to answer any queries participants had in relation to the questionnaires. Each questionnaire pack took up to 40 minutes to complete.

Table 7 describes the questionnaires included within the questionnaire packs. The 10 week and three month assessments omit the demographic details questionnaire and questions relating to participants' history of bipolar disorder. The 10 week questionnaire pack also includes a survey to assess participants' satisfaction with different aspects of BEP-Cymru and any suggestions for its improvement. Please refer to Appendix 6 for copies of the baseline, 10 week and three month questionnaire packs.

Questionnaire	Data collected / Measures	Time point at which data was collected
Demographic details questionnaire	Name, date of birth, age, gender, contact details, contact details of GP, contact details of psychiatrist/Community Mental Health Team, ethnic origin, marital history, highest educational level, employment status, whether has diagnosis of bipolar disorder, current medication	Baseline
WHOQOL-BREF [80]	Quality of life	Baseline, 10 weeks and 3 months
Functioning Assessment Short Test (FAST) [110]	Autonomy, occupational functioning, cognitive functioning, financial issues, interpersonal relationships, leisure time	Baseline, 10 weeks and 3 months
BDI (self-rated depression scale) [111]	Presence and degree of depressive symptoms	Baseline, 10 weeks and 3 months
ASRM (self-rated mania scale) [112]	Presence and degree of manic symptoms	Baseline, 10 weeks and 3 months
SSRQ self-regulation questionnaire [32]	Ability to regulate behaviour to achieve desired outcomes	Baseline, 10 weeks and 3 months
Perceived Health Competence Scale [113]	Self-efficacy regarding health-related behaviour	Baseline, 10 weeks and 3 months
Oslo 3-items social support scale [114]	Perceived extent of social support	Baseline, 10 weeks and 3 months
Knowledge and attitudes questionnaire	Knowledge of bipolar disorder Attitudes to medication Attitudes to the group format of the programme Techniques used to self-manage bipolar disorder	Baseline, 10 weeks and 3 months
Wellness questionnaire (clinical status questionnaire, based on MINI [115])	Number, duration and severity of manic, hypomanic and depressive episodes	Baseline, 10 weeks and 3 months
Modified SAI (insight into illness questionnaire, pertaining to attitudes towards bipolar disorder) [116]	Insights and attitudes relating to bipolar disorder	Baseline, 10 weeks and 3 months
Post-course survey	Feasibility and acceptability of BEP-Cymru	Baseline, 10 weeks and 3 months

Table 7. Quantitative outcome assessments

The demographic details questionnaire included routine questions (Table 7). The World Health Organization Quality of Life questionnaire (WHOQOL-BREF) [80], Functioning Assessment Short Test (FAST) [110], Becks Depression Inventory (BDI) [111], Altman Self-Rating Mania scale (ASRM) [112], Short Self-Regulation Questionnaire (SSRQ) [32, 117], Perceived Health Competence Scale (PHCS)

[33, 113] and Oslo 3-items social support scale [114] are reliable and valid in this population. The WHOQOL-BREF is a validated and widely-used measure to assess quality of life, and incorporates four domains: physical health, psychological, social relationships and environment [80]. The FAST is a validated measure to assess functioning, and incorporates six domains: autonomy, occupational functioning, cognitive functioning, financial issues, interpersonal relationships and leisure time [110]. The BDI and ASRM are self-rated scales to measure the presence and degree of depressive and manic symptoms, respectively [111, 112]. The SSRQ is a validated measure to assess the ability to adapt one's behaviour to achieve goals [32]. The PHCS is a validated questionnaire to assess self-efficacy regarding health-related behaviour [33]. The Oslo 3-item social support scale consists of three questions to assess the perceived extent of one's social support [114]. The reason I decided to include measures of behavioural self-regulation, self-efficacy and social support was because we theorised that these might be potential therapeutic mechanisms of the intervention, and therefore psychoeducation may improve scores on these measures.

The Knowledge and Attitudes Questionnaire was designed for BEP-Cymru because validated questionnaires to enquire about knowledge of bipolar disorder, attitudes towards medication or attitudes towards health education interventions could not be found. The Wellness Questionnaire was also designed for BEP-Cymru and was based on the MINI International Neuropsychiatric Interview [115], which is routinely used to identify bipolar episodes in clinical practice. The MINI is not suitable for patients' self-completion, so although it asked similar questions to the MINI psychiatric assessment to cover the number, duration and severity of manic, hypomanic and depressive episodes, the questions were different (reformatted and simplified) to facilitate self-completion. Both the Knowledge and Attitudes questionnaire and the Wellness questionnaire were piloted with a group of participants, who were invited to comment on the wording or meaning of the questions within the questionnaires if any were unclear and needed rephrasing. Following this piloting no questions were subsequently altered.

The Schedule for the Assessment of Insight (SAI) questionnaire [116] was modified by DS from an existing insight scale for psychosis so that it was more relevant to people with bipolar disorder, for the Beating Bipolar trial assessments [23]. This was necessary there was no currently available scale for insight in bipolar disorder [23]. Participants of the Beating Bipolar trial completed this assessment as intended (by circling one answer for each question and not skipping any questions), although it was not piloted beforehand.

I designed the post-course survey to assess participants' satisfaction with specific aspects of the programme, its feasibility, acceptability and ways in which it could be improved. I handed out the questionnaires at participants' first group session of BEP-Cymru and told them that they were free to ask me anything regarding the questionnaires, especially if any instructions, phrasing or layout were unclear or confusing.

Table 8 summarises the reported psychometric properties for the measures included in my analysis.

Outcome measure	Sample evaluated in	Validity	Reliability		Ref
			Test-retest, <i>Intraclass Correlation Coefficients (95% CI)</i>	Internal consistency <i>Cronbach's alpha</i>	
WHOQOL-BREF	229 adult psychiatric outpatients (45% with a DSM-IV-TR Mood Disorder; 30.6% with an anxiety disorder; 19.2% with a psychotic disorder; 5.2% with other psychiatric disorders), in Italy	Construct validity: Mean values for each of the four domains were significantly higher in a control sample than in the psychiatric sample ($p < 0.001$)	Physical: 0.92 (0.85-0.96) Psychological: 0.94 (0.88-0.97) Social relationships: 0.89 (0.80-0.93) Environment: 0.80 (0.75-0.85)	Physical: 0.82 Psychological: 0.81 Social relationships: 0.71 Environment: 0.76	[118]
	533 adult psychiatric outpatients (23.8% with Axis I Mood Disorder according to DSM-IV; 76.2% with other psychiatric disorders), in the Netherlands	Content validity: 25 of 26 questions presented a normal distribution of scores, 1 question was excluded from further analysis: "How healthy is your environment?" (skewness 0.20; kurtosis 0.75) Construct validity: Symptoms Check List-90 and Perceived Social Support Scale were statistically significantly correlated with all WHOQOL-Bref domains	Not reported	Physical: 0.80 Psychological: 0.74 Social relationships: 0.66 Environment: 0.73	[81]
FAST	101 patients with DSM-IV TR bipolar disorder and 61 healthy controls, in Spain	Concurrent validity: Statistically significant correlation with Global Assessment of Functioning (GAF) scale ($p < 0.001$)	0.98, $p < 0.01$	0.909	[110]
BDI	139 psychiatric inpatients and 270 psychiatric outpatients (mixed diagnoses), in the USA	Content validity: Compared with DSM criteria for depression Concurrent validity: with clinical ratings: $r = 0.66$	0.48, $n = 91$, n.s.	0.93	[119]
ASRM	105 psychiatric inpatients (34 of which had bipolar disorder), in the USA	Concurrent validity: Statistically significant correlation with both the Clinician-Administered Rating Scale for Mania (CARS-M) and the Mania Rating Scale (MRS) ($p < 0.001$)	Factor 1 (mania): 0.86, $p < 0.001$ Factor 2 (psychosis): 0.80, $p < 0/001$ Factor 3 (irritability, labile mood, racing thoughts and distractibility): 0.89, $p < 0.001$	Factor 1: 0.79 Factor 2: 0.65 Factor 3: 0.65	[112]
SSRQ	377 undergraduate students in the USA	Content validity: Factor analysis was conducted for the 63 items of the validated self-regulation questionnaire (SRQ) and a single-factor solution was chosen (accounting for 43% of the variance) – reducing the SRQ to 31 items which loaded to the factor and were then assessed for internal consistency Concurrent validity: with SRQ: $r = 0.96$	0.94, $p < 0.0001$	0.92	[117]
PHCS	Sample from 5 independent studies (238 rheumatoid arthritis patients; 100 university staff; 186 psychology undergraduates; 54 psychology undergraduates; 528 cadets), in the USA	Construct validity: Mean values were significantly lower in the patient sample than in the other 4 samples combined ($p < 0.001$) Concurrent validity: Consistently correlated with indicators of health status within samples, range between 0.4 and 0.5	Rheumatoid arthritis sample: 0.60 (2.5 years) Undergraduate Sample ($n = 54$): 0.82 (1 week) Cadets sample: 0.59 (4 months)	Range between 0.82 and 0.90 across samples	[33]
	320 primary care patients, in the UK	Construct validity: Mean values were significantly lower	Not reported	0.91	[113]

		for those with a long-term illness than for those without a long-term illness ($p < 0.001$) Concurrent validity: Statistically significant correlations with the each of the scales of the Short Form 36 (SF-36) ($p < 0.001$)			
Oslo 3-item social support scale	1717 adults from different types of neighbourhoods (suburban, industrial, rural and coastal) in Norway	Content validity: Factor analysis was conducted for the 25 items of the mental health measure the Hopkins Symptom Checklist (HSCL-25) and 3 single items were identified as being significantly associated with HSCL-25. These 3 items were considered to be the best predictors of mental health covering different fields of social support Concurrent validity: Statistically significant correlations with HSCL-25 ($p < 0.001$) and BDI ($p < 0.001$)	Not reported	Factor 1 (neighbourhood): 0.78 Factor 2 (family/friends): 0.72	[114]
Knowledge and attitudes questionnaire	15 people with a diagnosis of bipolar disorder in the UK	Face validity: Questions piloted with a group of 15 outpatients with bipolar disorder for comprehension and acceptability	Not conducted	Not conducted	N/A
Modified SAI	Not conducted	Face validity: The Modified Schedule for the Assessment of Insight questionnaire was modified from an existing insight scale for psychosis (Schedule for the Assessment of Insight) so that it was more relevant to people with bipolar disorder	Not conducted	Not conducted	N/A

Table 8. Summary of reported psychometric properties of outcome measures included in analysis

6.2.4 Statistical analyses

Within-group analyses were conducted using non-parametric techniques which were suitable because the sample was very small [120] (although 25 questionnaire packs were returned at the three time points, missing data due to unanswered questions within some questionnaires meant that for some measures up to 15 of the 25 respondents yielded missing data). In addition to this reason for using non-parametric tests, there was strong non-normality within the data (please refer to Appendix 7 for two examples of non-normal distribution of the data, depicted via histograms and significant results of the Kolmogorov-Smirnov statistic) [120].

To conduct exploratory analyses of outcomes at 10 weeks and 3 months for ordinal data the Friedman Test was used. The Friedman Test is the non-parametric equivalent of the one-way repeated measures ANOVA, and is used when the same sample of participants are assessed at 3 time points. If a statistical significance was found by using the Friedman Test, then the Wilcoxon Signed Rank Test was used as a post-hoc test to identify the time points between which the statistically significant difference in outcome occurred. The Wilcoxon Signed Rank Test is the non-parametric alternative for the paired samples T Test, and is used when comparing participants' scores at two time points.

For dichotomous categorical variables at baseline, 10 weeks and three months Cochran's Q test was used, for which there is no parametric alternative.

All variables were considered to be outcome measures. However, the variables which measured social support, self-efficacy and self-regulation were also considered to be potential therapeutic mechanisms of psychoeducation.

I performed a bivariate correlation analysis using Spearman's Rank Order Correlation (ρ) to explore the strength and direction of relationships between potential explanatory variables (independent variables) and outcome variables (dependent variables). Spearman's ρ is the non-parametric equivalent of the Pearson product-moment correlation coefficient for continuous variables.

I hypothesised that the following variables may be explanatory variables:

- Age at baseline
- Length of diagnosis in years at baseline
- Baseline knowledge of managing bipolar disorder (measured by Knowledge and Attitudes question: “How much do you think you know about managing your bipolar disorder?”)
- Baseline perceived social support (measured by the Oslo question: “How many people are so close to you that you can count on them if you have serious problems?”)
- Baseline self-regulation (measured by the SSRQ)
- Baseline self-efficacy (measured by the PHCS)

These potential explanatory variables may have a relationship to the main outcome variables:

- Knowledge of managing bipolar disorder at 3 months (measured by Knowledge and Attitudes question: “How much do you think you know about managing your bipolar disorder?”)
- Self-regulation score at 3 months (measured by the SSRQ)
- Self-efficacy score at 3 months (measured by the PHCS)
- Perceived social support at 3 months (measured by the Oslo question: “How many people are so close to you that you can count on them if you have serious problems?”)
- Presence and degree of depression at 3 months (measured by the BDI)
- Presence and degree of mania at 3 months (measured by the ASRM)
- Functioning at 3 months (measured by the FAST)
- Quality of life at 3 months (measured by the WHOQOL-BREF)

I used the software PASW Statistics 18 (SPSS Inc) for data analysis.

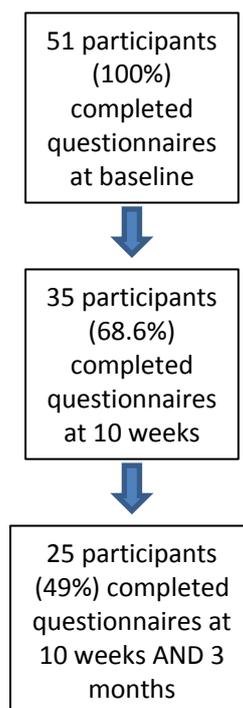
6.3 Quantitative results

6.3.1 Sample characteristics

Fifty-one participants provided baseline data, of which 35 completed questionnaires at 10 weeks. Although 31 participants completed questionnaires at three months, only 25 participants completed questionnaires at 10 weeks and three months.

The flowchart below (Figure 4) depicts how many returned questionnaires at each stage.

Figure 4. Flowchart to depict questionnaire completion



All participants were sent three month questionnaires regardless of whether they completed a questionnaire at 10 weeks. Therefore, of the 31 participants (60.8%) who completed questionnaires at three months only 25 (49%) had completed questionnaires at both 10 weeks and three months. Sixteen participants (31.4%) did not return questionnaires at 10 weeks, and 26 participants (51%) did not return both their 10 week and three month questionnaires.

Below is a table of baseline characteristics of the 51 participants.

Characteristic		Missing (%)	Total (%)
Age, median (range)	42.5 (20-72)	0 (0)	51 (100)
Gender, N (%)	Female: 40 (78.4)	Male: 11 (21.6)	0 (0) 51 (100)
Group location, N (%)	South Wales: 35 (68.6)	North Wales: 16 (31.4)	0 (0) 51 (100)
Ethnicity, N (%)	Caucasian: 46 (90.2)	Non-Caucasian: 5 (9.8)	0 (0) 51 (100)
Marital history, N (%)	Has married/lived as married: 32 (62.7)	Has never married/lived as married: 19 (37.3)	0 (0) 51 (100)
Highest educational level, N (%)	Up to age 16: 11 (21.6)	Post age 16: 40 (78.4)	0 (0) 51 (100)
Employment, N (%)	Currently in paid employment: 12 (23.5)	Currently unemployed or retired: 39 (76.5)	0 (0) 51 (100)
Diagnosis of bipolar disorder, N (%)*	Has diagnosis of bipolar disorder: 49 (96.1)	Without diagnosis of bipolar disorder: 0 (0)	2 (3.9) 49 (96.1)
Whether learned techniques to self-manage bipolar disorder prior to BEP-Cymru, N (%)	Yes: 26 (51)	No: 25 (49)	0 (0) 51 (100)
Previously learned techniques to manage bipolar disorder in a face-to-face group-based setting, N (%)	Yes: 14 (27.5)	No: 37 (72.5)	0 (0) 51 (100)
Previous techniques learned in a face-to-face group-based setting helped in self-managing bipolar disorder, N (%)	Yes: 10 (71.4)	No: 4 (28.6)	0 (0) 51 (100)
Taking medication for bipolar disorder, N (%)	Yes: 48 (94.1)	No: 3 (5.9)	0 (0) 51 (100)
Episode(s) of mania in past 6 months, N (%)	Yes: 28 (54.9)	No: 22 (43.1)	1 (2) 50 (98)
Hospitalised for mania in past 6 months, N (%)	Yes: 3 (10.3)	No: 23 (79.3)	3 (10.3) 48 (89.7)
Episode(s) of hypomania in past 6 months, N (%)	Yes: 25 (49)	No: (49)	1 (2) 50 (98)
Episode(s) of depression in past 6 months, N (%)	Yes: 40 (78.4)	No: 11 (21.6)	0 (0) 51 (100)
Hospitalised for depression in past 6 months, N (%)	Yes: 4 (10)	No: 36 (90)	0 (0) 51 (100)
Length of diagnosis in years, Median (range)	5 (0.2-60)		0 (0) 51 (100)

* Although all participants were screened for having bipolar disorder prior to their participation in the group programme, some did not provide a response to the question of whether they had a diagnosis of bipolar disorder within the questionnaire – hence the missing data

Table 9. Characteristics of the sample at baseline

6.3.2 Results

The areas assessed were:

- Knowledge and attitudes
- Mood
- Quality of life and functioning
- Insight, self-regulation and perceived health competence
- Perceived social support
- Feasibility and acceptability of BEP-Cymru

6.3.2.1 Data completeness

Some questions were not answered so had to be recorded as missing data. This was a problem to a greater or lesser degree in the following questionnaires: Knowledge and attitudes, FAST, modified SAI, SSRQ, PHCS and the OSLO social support scale.

Most notably, many participants seemed to struggle with the layout of the SSRQ as the lines for each question and its responses were very close together; hence, some responses were missing or participants gave two responses to the same questions. Participants also appeared to be confused by the negative framing of some of the questions within the SSRQ, as for many questions responses were crossed out and the opposite responses was circled. This may be because this questionnaire was not validated specifically for people with bipolar disorder.

Many participants did not complete the occupational functioning section of the FAST questionnaire because they were unemployed; hence, overall functioning scores could not be computed for these participants.

Upon closer inspection during data analysis I realised that the Wellness questionnaire, which was based on the MINI psychiatric assessment and assessed presence, frequency and degree of manic, hypomanic and depressive episodes, asked about incomparable time frames. The baseline questionnaire asked about episodes in the preceding six months, the 10 week questionnaire asked about the preceding 10 weeks and the three month questionnaire asked about the preceding six months. Because of these incomparable time frames I couldn't analyse these data. This

questionnaire has now been altered for use with future groups of BEP-Cymru to ask about episodes in the prior three month period, and is only included within the baseline and three month questionnaire packs.

When scoring the WHOQOL-BREF we realised that question 19 was missing from the questionnaire. Hence, for each participant we calculated the mean score for all scores within its domain, which was the “psychological” domain, and substituted this mean score for the missing item. This approach was consistent with recommendations for substituting missing data within the scoring procedure of the WHOQOL-BREF [80].

6.3.2.2 Knowledge and attitudes

Outcome	N	Percentiles: 50 th (25 th - 75 th) at baseline	Percentiles: 50 th (25 th - 75 th) at 10 weeks	Percentiles: 50 th (25 th - 75 th) at 3 months	Sig.
Rating on 4-point Likert scale of knowledge of managing bipolar disorder*	22	2 (2-3)	3 (2.75-3)	3 (2-3)	p = 0.009
Regularity of taking medication on a 5-point Likert scale**	24	4 (4-4)	4 (4-4)	4 (4-4)	p = 0.717
Rating on 5-point Likert scale of extent to which group healthcare programmes are helpful***	21	3 (2-3)	4 (3-4)	3 (3-4)	p = 0.008
Rating of preference for learning about bipolar disorder in a group or one-to-one^	23	3 (2-3)	4 (3-5)	4 (2-4)	p = 0.003

* 1=Nothing 2=Very little 3=A moderate amount 4=Quite a lot
 ** 1=Never 2=Seldom 3=Sometimes 4=Most of the time 5=Always
 *** 1=Not at all 2=A little bit 3=Quite 4=Very 5=Extremely
 ^ 1=Strongly favour 1-to-1 2=Favour 1-1 3=No preference 4=Favour group 5=Strongly favour group

Table 10. Knowledge and attitudes: outcomes for analyses conducted using the Friedman Test

As Table 10 shows, there was a statistically significant difference in participants’ ratings of their **knowledge of managing their bipolar disorder** on a 4-point Likert scale across the three time points; $\chi^2 (2, n = 22) = 9.5, p = 0.009$. Inspection of the median values showed an increase in ratings from baseline (Md = 2, “very little”) to 10 weeks post-intervention (Md = 3, “a moderate amount”), which was sustained at three months’ follow-up (Md = 3, “a moderate amount”). The post hoc test confirmed this observation, showing that the increase in ratings between baseline and 10 weeks was significant, $z = -3.254, p = 0.001$, with a medium effect size ($r = 0.369$). No difference between ratings at 10 weeks and three months was observed, $z = -1.414, n.s.$

Participants' ratings of **how regularly they took their medication** did not differ significantly across the three time points.

Participants' ratings on a 5-point Likert scale for the **extent to which they perceived group healthcare programmes to be helpful** to them were found to statistically differ between the 3 time points; $\chi^2 (2, n = 21) = 9.632, p = 0.008$. Post-hoc tests were subsequently conducted, and revealed that the increase between participants' ratings from baseline to 10 weeks was statistically significant, $z = -2.818, p < 0.01$, with a medium effect size ($r = 0.325$). The median rating of the perceived helpfulness of group healthcare programmes increased from baseline (Md = 3, "very" helpful) to 10 weeks (Md = 4, "extremely" helpful). No statistically significant difference between ratings at 10 weeks and three months was found, $z = -1.508, n.s.$

Participants rated their **preferences for learning about bipolar disorder in a group context or on a one-to-one basis**. There were statistically significant differences between participants' preferences across the three time points; $\chi^2 (2, n = 23) = 11.727, p = 0.003$. Post-hoc tests were subsequently conducted, and revealed that the difference between participants' preferences from baseline to 10 weeks was statistically significant, $z = -3.714, p < 0.001$, with a medium to large effect size ($r = 0.41$). The median preference of "no preference" for learning context at baseline significantly differed from the median preference of "favour group learning" at 10 weeks. No statistically significant difference in preferences between 10 weeks and three months was found, $z = -1.483, n.s.$

Outcome	N	Yes/True : No/False (baseline)	Yes/True : No/False (10 wks)	Yes/True : No/False (3 mths)	Sig.
Number of participants taking medication	25	24 : 1	24 : 1	24 : 1	$p = 1$
"Taking medication for bipolar disorder has not been suggested to me"	25	0 : 25	1 : 24	1 : 24	$p = 0.368$
"Taking medication helps to keep my mood stable"	25	21 : 4	20 : 5	20 : 5	$p = 0.895$
"I take my medication regularly as prescribed"	25	20 : 5	24 : 1	22 : 3	$p = 0.91$
"Taking medication does not help to keep my mood stable"	25	5 : 20	5 : 20	4 : 21	$p = 0.895$
"I don't like taking my medication"	25	10 : 15	14 : 11	10 : 15	$p = 0.102$
"I suffer from side effects of my medication"	25	17 : 8	20 : 5	17 : 8	$p = 0.325$
"Side effects from my medication are tolerable"	25	14 : 11	16 : 9	12 : 13	$p = 0.223$

Table 11. Attitudes towards medication: outcomes for analyses conducted using Cochran's Q Test

There were no significant differences between the three time points in the number of participants taking medication for bipolar disorder, the regularity of taking medication for bipolar disorder, or in attitudes towards taking medication (Table 11).

6.3.2.3 Mood

The 35 respondents who completed questionnaires at 10 weeks reported on their mood during the course. Twenty-two reported experiencing a depressive episode during the course and five were unsure as to whether they had experienced a depressive episode during the course. Fourteen reported experiencing a manic episode during the course and three were not sure whether they had experienced a manic episode. Six reported that their mood during the course was more stable than usual, four reported that their mood was less stable than usual and 25 reported that their mood was the same as usual. Table 12 below summarizes these data.

Depressive episode since course began, N (%)	Yes: 22 (62.9)	No: 8 (22.9)	Not sure: 5 (14.3)
Manic episode since course began, N (%)	Yes: 14 (40%)	No: 17 (48.6) Not sure: 3 (8.6)	Missing data: 1 (2.9)
Mood during course, N (%)	Less stable: 4 (11.4)	More stable: 6 (17.1)	Same as usual: 25 (71.4)

Table 12. Summary of participants' self-assessments of mood during 10-week course

Presence of mania and depression at the three time points was assessed using the ASRM and BDI measures, respectively. The Friedman Test did not reveal any statistically significant differences between the three time points for presence of mania or depression, as Table 13 shows.

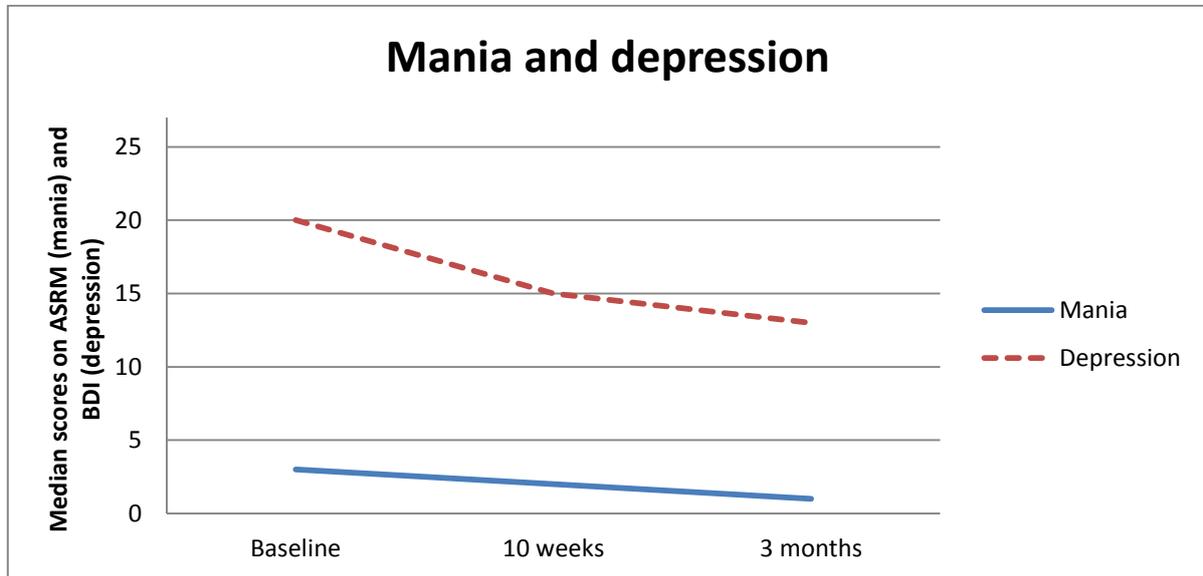
Outcome	N	Percentiles: 50th (25th-75th) at baseline	Percentiles: 50th (25th-75th) at 10 weeks	Percentiles: 50th (25th-75th) at 3 months	Sig.
ASRM score for presence of mania*	25	3 (0-5.5)	2 (1-5.5)	1 (0-5.5)	p = 0.665
BDI score for presence of depression*	25	20 (8.5-26)	15 (9.5-26)	13 (8.5-26.5)	p = 0.364

* The higher the score the greater the presence of mania or depression

Table 13. Mania and depression: outcomes for analyses conducted using the Friedman Test

Despite no significant differences across the time points, a trend for a decline in the presence of both mania and depression across the three time points can be observed, as Figure 5 shows.

Figure 5. Line chart to show medians of mania and depression scores at baseline, 10 weeks and three months



The standard thresholds for assessing degree and presence of depression on the BDI are as follows [121]:

- 0–9: indicates minimal depression
- 10–18: indicates mild depression
- 19–29: indicates moderate depression
- 30–63: indicates severe depression.

The trend observed from median scores on the BDI indicates that although participants' scores may not have improved enough to achieve statistical significance across the three time points the results are clinically significant. The median score of 20 at baseline indicates moderate depression, which drops to median scores of 15 and 13 at 10 weeks and three months, respectively, which indicates sustained improvement from moderate to mild depression.

6.3.2.4 Quality of life and functioning

Outcome	N	Percentiles: 50 th (25 th - 75 th) at baseline	Percentiles: 50 th (25 th - 75 th) at 10 weeks	Percentiles: 50 th (25 th - 75 th) at 3 months	Sig.
Overall WHOQOL-BREF score for quality of life*	25	206 (157-238)	212 (153-259.5)	219 (156-273)	p = 0.931
WHOQOL-BREF sub-score "physical health" *	25	50 (38-66)	44 (31-63)	50 (34.5-63)	p = 0.341
WHOQOL-BREF sub-score "psychological" *	25	44 (34.5-56)	50 (31-56)	44 (31-69)	p = 0.588
WHOQOL-BREF sub-score "social relationships" *	25	50 (31-62.5)	50 (31-69)	50 (31-75)	p = 0.732
WHOQOL-BREF sub-score "environment" *	25	63 (50-75)	63 (50-75)	63 (50-81)	p = 0.418
Overall FAST score for functioning**	18	39.5 (27.75-50.25)	38 (27-49.5)	39 (26.75-54.25)	p = 0.796
FAST sub-score "autonomy" **	23	4 (3-6)	5 (2-7)	4 (1-8)	p = 0.409
FAST sub-score "occupational functioning" **	18	12.5 (8.75-14)	14 (7.5-15)	12.5 (6.75-14)	p = 0.191
FAST sub-score "cognitive functioning" **	24	9 (5.25-11)	9 (6.25-11)	9 (7-11.75)	p = 0.564
FAST sub-score "financial" **	24	2.5 (1-4.75)	3 (1.25-4)	2 (1-4)	p = 0.773
FAST sub-score "relationships" **	23	8 (5-12)	8 (4-11)	9 (3-13)	p = 0.140
FAST sub-score "leisure" **	24	3 (2-5)	3 (1-4)	2 (2-4)	p = 0.947

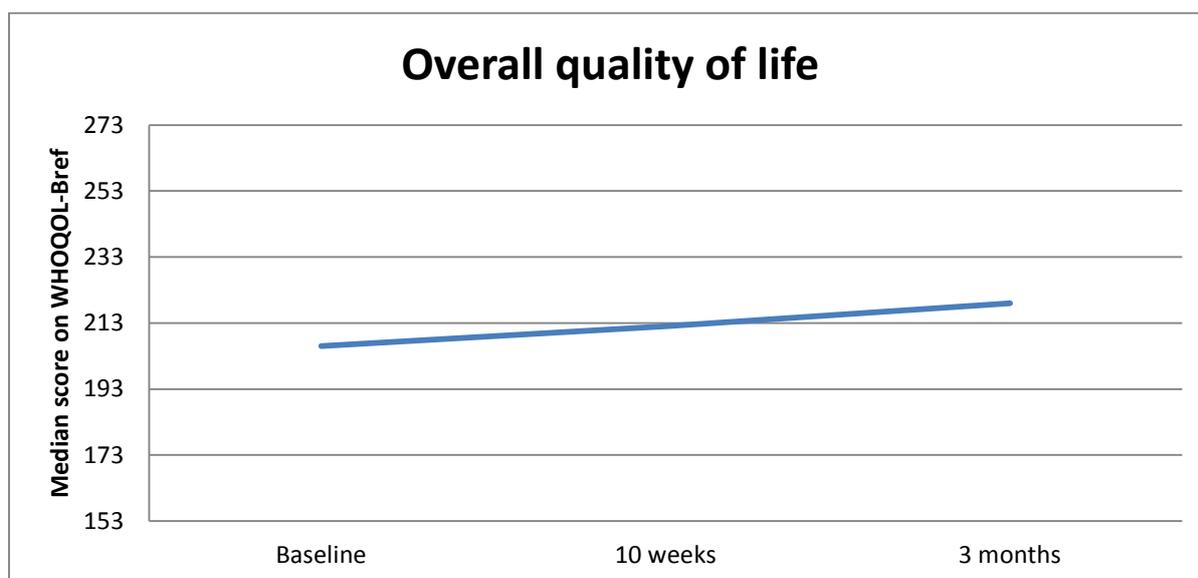
* The higher the score the better the outcome

** The higher the score the greater the difficulty in functioning

Table 14. Quality of life and functioning: outcomes for analyses conducted using the Friedman Test

Overall quality of life, which was assessed using the WHOQOL-BREF, did not significantly differ between the three time points; however, scores did increase slightly across the three time points (see Figure 6 below), although not clinically significant. Analyses of the four domain scores of the WHOQOL-BREF ("physical health", "psychological", "social relationships" and "environment") also revealed no significant differences between three time points.

Figure 6. Line chart to show medians of quality of life scores at baseline, 10 weeks and three months



Overall functioning, which was assessed using the FAST measure, did not significantly differ between the three time points. Furthermore, analyses of the six domains of the FAST (“autonomy”, “occupational functioning”, “cognitive functioning”, “financial”, “relationships” and “leisure”) also revealed no significant differences between three time points.

6.3.2.5 Insight, self-regulation and perceived health competence

Outcome	N	Percentiles: 50 th (25 th - 75 th) at baseline	Percentiles: 50 th (25 th - 75 th) at 10 weeks	Percentiles: 50 th (25 th - 75 th) at 3 months	Sig.
Overall SAI score for insight into mental illness *	22	5 (4-6.5)	5 (4-7)	4 (4-6.25)	p = 0.569
SSRQ score for self-regulation**	10	84.5 (73.75- 103.5)	90.5 (79.75- 99)	92.5 (76- 115.25)	p = 0.301
Perceived Health Competence score**	21	26 (22-30)	24 (21.5- 26.5)	24 (22-29)	p = 0.626

* The higher the score the poorer the insight

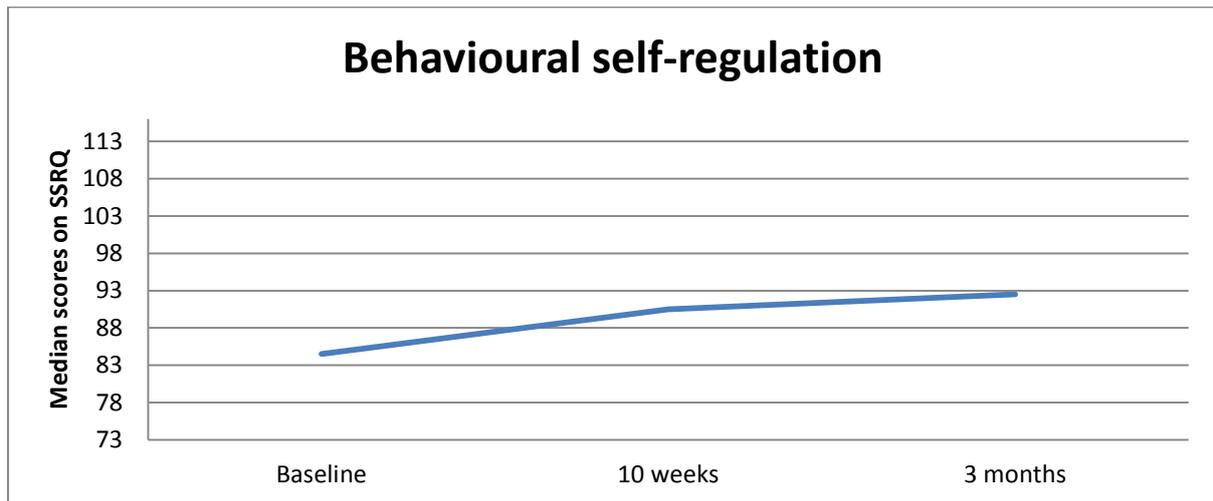
** The higher the score the better the outcome

Table 15. Insight, self-regulation and health competence: outcomes for analyses conducted using the Friedman Test

No significant differences between the three time points were found for scores on the modified schedule for the assessment of insight (SAI score). Participants’ abilities to self-regulate their behaviour to achieved desired outcomes, measured by the SSRQ, did not differ significantly between

the three time points, and neither did their perceptions of self-efficacy in managing their health. Participants' scores for the self-regulation questionnaire did improve slightly, however, as Figure 7 depicts.

Figure 7. Line chart to show medians of self-regulation scores at baseline, 10 weeks and three months



6.3.2.6 Perceived social support

Outcome	N	Percentiles: 50 th (25 th - 75 th) at baseline	Percentiles: 50 th (25 th - 75 th) at 10 weeks	Percentiles: 50 th (25 th - 75 th) at 3 months	Sig.
Rating on 5-point Likert scale of how easily help may be obtained from neighbours if needed*	23	4 (3-5)	3 (3-5)	3 (2-4)	p = 0.563
Rating on 4-point Likert scale of how many people one may rely on if one has serious problems**	23	3 (2-3)	2 (2-3)	2 (2-3)	p = 0.509
Rating on 5-point Likert scale of the extent others show concern in what one is doing***	23	2 (2-3)	2 (1-4)	2 (2-3)	p = 0.785

* 1=Very easy 2=Easy 3=Possible 4=Difficult 5=Very difficult

** 1=None 2=One to Two 3=Three to Five 4=Five plus

*** 1=A lot 2=Some 3=Uncertain 4=Little 5=No

Table 16. Social support: outcomes for analyses conducted using the Friedman Test

The three items within the Oslo social support scale were assessed individually for differences between the three time points. No significant differences between participants' ratings were found.

6.3.2.7 10-week feasibility and acceptability survey

Medians and ranges were calculated for the ratings of each question within the 10-week survey; ratings were on a 10-point Likert scale from “1” being the most negative response rating to “10” being the most positive response rating (please refer to the questionnaire in Appendix 6). Results are summarised in Table 17 below.

Question	N	Median rating	Range
To what extent did the facilitators appear to be prepared?	35	10	6-10
To what extent was the venue suitable for delivery?	35	10	1-10
Overall, to what extent could you understand the content of the sessions?	35	10	6-10
Overall, to what extent were the sessions relevant to you?	35	10	5-10
Overall, to what extent did you understand how to do the exercises?	35	10	5-10
Overall, to what extent were the exercises useful to you?	35	9	1-10
Overall, to what extent could you understand the content of the handouts?	35	10	6-10
Overall, to what extent have you found the handouts to be useful?	35	10	6-10
Overall, to what extent did the programme meet your expectations?	35	10	6-10
To what extent are you satisfied with the programme in general?	35	10	6-10
To what extent do you feel you have gained insights into your bipolar disorder and how to manage it?	35	9	6-10
To what extent would you like to see people with bipolar disorder as facilitators of BEP-Cymru sessions?	35	8	1-10
To what extent do you feel that people with bipolar disorder would be good facilitators of BEP-Cymru sessions?	33	8	1-10
To what extent would you recommend BEP-Cymru to others with bipolar disorder?	35	10	7-10

Table 17. Results of the 10-week BEP-Cymru participant survey

Overall, findings of the 10-week survey appear to be very positive, with all median ratings being eight or above on the 10-point Likert scale. The most variation between scores on items occurred for questions relating to venue suitability, usefulness of BEP-Cymru exercises and the preference for people with bipolar disorder as group facilitators.

6.3.2.8 Correlation matrix of relationships between potential independent and dependent variables

Table 18 shows the correlation matrix of relationships between potential independent and dependent variables.

Spearman's rho: ** Correlation is significant at the 0.01 level (2-tailed) / * Correlation is significant at the 0.05 level (2-tailed).		Age at baseline	length of diagnosis	baseline knowledge of BD	baseline social support	baseline self regulation	baseline self efficacy	3 month knowledge of BD	3 month self regulation	3 month self efficacy	3 month social support	3 month BDI score	3 month ASRM score	3 month FAST score
length of diagnosis in yrs at baseline	Correlation Coefficient	.638**	1.000											
	Sig. (2-tailed)	.000												
	N	49	50											
baseline knowledge of bipolar disorder	Correlation Coefficient	.003	.275	1.000										
	Sig. (2-tailed)	.983	.068											
	N	44	45	45										
baseline social support	Correlation Coefficient	.153	.179	.201	1.000									
	Sig. (2-tailed)	.289	.215	.185										
	N	50	50	45	51									
baseline self regulation	Correlation Coefficient	.419*	.403*	.407*	.199	1.000								
	Sig. (2-tailed)	.012	.017	.023	.244									
	N	35	35	31	36	36								
baseline self efficacy	Correlation Coefficient	.510**	.555**	.330*	.148	.829**	1.000							
	Sig. (2-tailed)	.000	.000	.030	.311	.000								
	N	49	48	43	49	35	49							
3 month knowledge of bipolar disorder	Correlation Coefficient	.155	.224	.423*	-.099	.468*	.253	1.000						
	Sig. (2-tailed)	.414	.235	.028	.597	.028	.178							
	N	30	30	27	31	22	30	31						
3 month self regulation	Correlation Coefficient	.392	.574**	.153	.151	.502*	.624**	.062	1.000					
	Sig. (2-tailed)	.071	.005	.509	.492	.034	.002	.779						
	N	22	22	21	23	18	22	23	23					
3 month self efficacy	Correlation Coefficient	.024	.091	-.218	.167	.213	.216	-.032	.606**	1.000				
	Sig. (2-tailed)	.900	.640	.284	.378	.354	.260	.867	.003					
	N	29	29	26	30	21	29	30	22	30				
3 month social support	Correlation Coefficient	.099	.252	.238	.682**	.116	.125	.025	.143	.251	1.000			
	Sig. (2-tailed)	.617	.196	.252	.000	.615	.526	.899	.538	.188				
	N	28	28	25	29	21	28	29	21	29	29			
3 month BDI score	Correlation Coefficient	-.241	-.294	.078	-.236	-.346	-.454*	.094	-.815**	-.608**	-.144	1.000		
	Sig. (2-tailed)	.199	.115	.699	.201	.115	.012	.616	.000	.000	.457			
	N	30	30	27	31	22	30	31	23	30	29	31		
3 month ASRM score	Correlation Coefficient	-.315	-.322	-.196	-.205	-.397	-.558**	.043	-.257	.113	.037	.169	1.000	
	Sig. (2-tailed)	.090	.083	.328	.268	.067	.001	.817	.237	.552	.850	.363		
	N	30	30	27	31	22	30	31	23	30	29	31	31	
3 month FAST score	Correlation Coefficient	.016	.040	-.167	-.248	-.532*	-.330	-.265	-.514*	-.551**	-.368	.656**	-.024	1.000
	Sig. (2-tailed)	.937	.843	.436	.203	.016	.093	.172	.017	.003	.065	.000	.902	
	N	27	27	24	28	20	27	28	21	27	26	28	28	28
3 month WHOQOL-Bref score	Correlation Coefficient	.125	.089	-.019	.222	.315	.183	.117	.717**	.696**	.259	-.814**	.161	-.809**
	Sig. (2-tailed)	.510	.639	.927	.229	.153	.332	.532	.000	.000	.175	.000	.388	.000
	N	30	30	27	31	22	30	31	23	30	29	31	31	28

Table 18. Correlation matrix of potential independent and dependent variables

6.4 Discussion of quantitative findings

6.4.1 *Main findings*

The data for characteristics of the sample at baseline show that the majority of participants: were female, Caucasian, educated post age 16 (and therefore of a higher socio-economic status), unemployed or retired, took medication for bipolar disorder, had previously learned techniques to manage their bipolar disorder, and had experienced an episode of mania or depression in the preceding six months.

The main statistically significant findings were the following:

- Median self-ratings of participants' knowledge of managing their bipolar disorder significantly increased from knowing "very little" at baseline to knowing "a moderate amount" at 10 weeks
- Median ratings of the extent participants' perceived group healthcare programmes, such as BEP-Cymru, to be helpful significantly increased from "very helpful" at baseline to "extremely helpful" at 10 weeks
- Median preferences for learning about bipolar disorder in a group context or on a one-to-one basis significantly differed from "no preference" at baseline to "favour group learning" at 10 weeks

No significant differences were found between time points for any other outcome; however, there were slight trends towards improvement on mania, self-regulation and quality of life scores and a notable decrease in median depression scores that is clinically significant – from moderate to mild depression.

Regarding participants' ratings of their mood during the course, many seemed to experience a mood episode, although they also reported that this was not a change in how they usually are. Given how frequently our sample seemed to experience mood episodes it appears that this was quite an impaired group of people with bipolar disorder, and may be representative of the level of impairment commonly seen in clinical practice.

Participants gave very high ratings overall within the survey to assess the feasibility and acceptability of the programme. The most variable ratings within the survey related to the usefulness of the exercises and the extent to which participants would like to see people with bipolar disorder as facilitators of BEP-Cymru groups.

6.4.1.1 Interpretation of relationships between potential explanatory and independent variables

There were strong positive correlations between participants' length of diagnosis in years and participants' age ($\rho = 0.638$, $n = 49$, $p < 0.001$), baseline self-efficacy scores ($\rho = 0.555$, $n = 48$, $p < 0.001$) and self-regulation scores at 3 months ($\rho = 0.574$, $n = 22$, $p < 0.01$). Participants with a longer diagnosis may be more likely to be older, have greater self-efficacy regarding health-related behaviour prior to the intervention, and be more able to regulate their behaviour at 3 months following the intervention, than those participants more recently diagnosed.

A strong positive correlation was found between baseline self-efficacy and baseline self-regulation ($\rho = 0.829$, $n = 35$, $p < 0.001$) and also between self-efficacy at 3 months and self-regulation at 3 months ($\rho = 0.606$, $n = 22$, $p < 0.001$). This finding suggests that a high self-efficacy score may indicate a high self-regulation score, and a low self-efficacy score may indicate a low self-regulation score.

There were medium-sized, positive correlations between participants' baseline self-regulation scores and participants' age ($\rho = 0.41$, $n = 35$, $p < 0.05$), length of diagnosis ($\rho = 0.403$, $n = 35$, $p < 0.05$), baseline knowledge of bipolar disorder ($\rho = 0.407$, $n = 31$, $p < 0.05$), knowledge of bipolar disorder at 3 months ($\rho = 0.468$, $n = 22$, $p < 0.05$) and self-regulation scores at 3 months ($\rho = 0.502$, $n = 18$, $p < 0.05$).

Outcome measures such as the BDI, ASRM and FAST, for which higher scores indicate a greater impairment, were negatively correlated with outcomes measures for which higher scores indicate greater functioning, such as the WHOQOL-BREF, PHCS and SSRQ. There were strong negative correlations between functioning scores at 3 months and self-efficacy and quality of life scores at 3 months ($\rho = -0.551$, $n = 27$, $p < 0.01$ and $\rho = -0.808$, $n = 28$, $p < 0.001$, respectively). There were also medium-sized, negative correlations between functioning scores at 3 months and baseline self-regulation ($\rho = -0.532$, $n = 20$, $p < 0.05$) and self-regulation scores at 3 months ($\rho = -0.514$, $n = 21$, $p < 0.05$). It may be that self-regulation scores on the SSRQ prior to the intervention may predict

functioning scores on the FAST at 3 months following the intervention, so that those with a high SSRQ score may have a low FAST score at 3 months and vice versa.

Baseline self-efficacy was strongly correlated with mania scores at 3 months ($\rho = -0.558$, $n = 30$, $p < 0.001$) and moderately correlated with depression scores at 3 months ($\rho = -0.454$, $n = 30$, $p < 0.05$), which may indicate that those with low self-efficacy scores at baseline may have a greater presence and degree of mania or depression 3 months following the intervention, relative to those with high self-efficacy scores at baseline.

Depression scores at 3 months were also strongly, negatively correlated with scores at 3 months for self-regulation ($\rho = -0.815$, $n = 23$, $p < 0.001$), self-efficacy ($\rho = -0.608$, $n = 30$, $p < 0.001$) and quality of life ($\rho = -0.814$, $n = 31$, $p < 0.001$), indicating that those with relatively high depression scores at 3 months were likely to have relatively low self-efficacy, self-regulation and quality of life scores at 3 months, and those with relatively low depression scores at 3 months were likely to have relatively high self-efficacy, self-regulation and quality of life scores at 3 months.

Functioning scores at 3 months were strongly, positively correlated with depression scores at 3 months ($\rho = 0.656$, $n = 28$, $p < 0.001$), which may demonstrate that a poor degree of functioning at 3 months may be linked to a notable degree of depression at 3 months.

There were strong positive correlations between quality of life scores at 3 months and self-regulation scores at 3 months ($\rho = 0.717$, $n = 23$, $p < 0.001$) and self-efficacy scores at 3 months ($\rho = 0.696$, $n = 30$, $p < 0.001$). Participants who reported high quality of life at 3 months were likely to have high self-efficacy and self-regulation at 3 months, and those who reported low quality of life at 3 months were likely to have low self-efficacy and self-regulation at 3 months.

Baseline perceived social support was found to positively correlate with perceived social support at 3 months with a strong effect ($\rho = 0.682$, $n = 29$, $p < 0.001$), and there was also a strong positive correlation between baseline self-efficacy and self-regulation at 3 months ($\rho = 0.624$, $n = 22$, $p < 0.01$). Therefore, participants' self-reported self-efficacy regarding their health related behaviour at baseline may predict their ability to self-regulate their behaviour at 3 months following the intervention, and perceived social support at baseline may predict perceived social support at 3 months.

Length of diagnosis at baseline was found to be moderately, positively correlated with baseline self-efficacy ($\rho = 0.330$, $n = 43$, $p < 0.5$) and moderately, positively correlated with knowledge of bipolar disorder at 3 months ($\rho = 0.423$, $n = 27$, $p < 0.05$). This finding may indicate that the longer a participant has had a diagnosis of bipolar disorder the greater the self-efficacy scores prior to the intervention and the greater the self-reported knowledge of bipolar disorder at 3 months following the intervention.

6.4.1.2 Suitability of outcome measures

A rigorous examination of the psychometric properties of potential outcome measures should have been conducted prior to being accepted for use within the BEP-Cymru programme evaluation. Although I did not select these outcome measures (they were selected by the BEP-Cymru team) I am able to comment on the suitability of these measures for use in this study.

Ideally, these outcome assessments would have been conducted via clinician-led face-to-face interviews, which may have minimised participants' bias, due to the potential lack of insight associated with bipolar disorder, and improved accuracy and questionnaire completion rates.

Table 8 summarises the psychometric properties of each of the outcome measures included in the analysis. Where a measure has been evaluated in a psychiatric sample, a summary of the psychometric analysis of that measure has been included. Where a measure has not been evaluated in a psychiatric sample, then I have included a summary of the psychometric analysis of that measure which has been evaluated in other samples.

I examined the validity and reliability of the measures, which are the most important considerations of psychometric properties [122], and also the samples in which the measures were evaluated. Regarding the validity of measures: "content validity" refers to the extent to which a measure includes all the items necessary to represent the concept being examined [123]; "construct validity" is the ability of the test to measure the concept (for example, test scores should differ between two groups who are hypothesised to differ on the construct of interest); "concurrent validity" is a type of criterion validity in that the measure is compared with a "gold standard" test measuring similar criteria and both measures are administered at the same time; and, "face validity" is the extent to which a test appears to measure what was intended [123]. I considered the test-retest reliability of measures, noting the intraclass correlation coefficients (ICC) which are regarded as good if above

0.75, adequate if between 0.50 and 0.75, and poor if below 0.5 [123]. Inter-rater reliability was not reported because these measures were selected for self-completion. Internal consistency was examined for each measure, or for each domain within a measure, to assess the extent to which all items within a domain reflect the domain's concept. This was assessed using Cronbach's alpha, for which the accepted standard of a measure should exceed 0.70 [124, 125].

Test-retest reliability was reported for the WHOQOL-BREF [118], FAST [110], ASRM [112] and SSRQ [117], for which Pearson's *r* coefficients exceeded 0.8, and for the BDI [121] and PHCS [33], for which Pearson's *r* coefficients were poor and adequate respectively.

The WHOQOL-BREF is an all-encompassing measure of health which, in addition to measuring an individual's health, measures standard of living, quality of housing, neighbourhood and job satisfaction. Ware (1987) criticised the WHOQOL-BREF for being too comprehensive a measure, and therefore confusing [126]; however, in recent evaluations sampling adult psychiatric patients it has been shown to demonstrate good internal consistency [81, 118] and good test-retest reliability [118] within each domain. Its lower test-retest reliability score for the environment domain may be accounted for by participants' struggling with the wording of some items, such as: "How healthy is your physical environment?" which may have been exacerbated by the translation of the measure into Italian. This particular item was excluded from further analysis when the WHOQOL-BREF was assessed in the Netherlands for content validity [81]. Findings from the studies in Italy and the Netherlands indicate that the WHOQOL-BREF is a valid and reliable measure for evaluating quality of life in psychiatric outpatients. For use within the present study this validated questionnaire was appropriate to use to measure quality of life to cover all four domains of interest, although shorter questionnaires would have been preferable to relieve the burden of the amount of questions for participants within the questionnaire packs.

The FAST was developed in Spain as a brief instrument to assess the main functioning problems of psychiatric patients, particularly for those with bipolar disorder [110]. Its authors state that the FAST is intended to be administered by a clinically trained interviewer; however, they do not assess the measure's inter-rater reliability. The FAST shows strong internal consistency on each of the domains and also demonstrates good concurrent validity with the GAF. The GAF was used in the BIPED trial when participants were being interviewed for the outcome assessments; however, the GAF is not suitable for self-completion, so would have been inappropriate to use within the BEP-Cymru study.

Although the BDI had poor test-retest reliability, it had high internal consistency and moderate concurrent validity with clinicians' ratings of patients [121]. However, the measure's low test-retest correlation in a sample of psychiatric patients may not necessarily reflect inadequate reliability, rather psychiatric patients' fluctuating mood – especially for those with mood disorders.

The ASRM demonstrated strong concurrent validity when compared with the CARS-M and MRS, moderate concurrent validity when compared with the YMRS, and strong internal consistency on the mania dimension [112, 127]. It showed only moderate internal consistency for the “psychosis” dimension and the “irritability/labile mood/racing thoughts/distractibility” dimension, perhaps because the ASRM covers fewer symptoms than other mania scales [127]. A recent review of assessment tools for bipolar disorder concluded that the ASRM has good psychometric properties and an optimal combination of sensitivity (85%) and specificity (86%); however, the review recognises that self-report ratings of symptom severity may not be accurate if patients have impaired insight [127].

Carey's psychometric analysis of the SSRQ, tested with a sample of 377 undergraduate students, showed high internal consistency, high test-retest reliability and strong correlations with the SRQ [117]. The SSRQ has not been validated within an adult psychiatric sample, and BEP-Cymru participants found the questionnaire difficult to read and complete because of its layout with very little spacing between questions. BEP-Cymru participants would have benefitted from a clearer presentation of this questionnaire.

Various studies have examined the psychometric properties of the PHCS, although not within a psychiatric sample [33, 113]. In a review of the development and validation of the PHCS, assessments of construct validity revealed that mean values were significantly lower in the patient sample (238 rheumatoid arthritis patients) than in the other four samples combined [33]. The PHCS is a reliable measure of self-efficacy for general health-related behaviour, with moderate to strong test-retest reliability [33], high internal consistency [33, 113] and significant correlations with each of the scales of the SF-36 [113]. Regarding the suitability of its use with BEP-Cymru participants, the PHCS is a brief measure which is useful for assessing self-efficacy. A UK-based study of the validity of the PHCS in a primary care setting found that those with higher PHCS scores are less likely to seek assistance with their health-related behaviours than those with lower scores [113], so PHCS scores may be associated with scores on the SSRQ.

The Oslo 3-item social support scale has not been evaluated in a UK sample or a psychiatric sample, although it was designed to be used as a measure of mental health and psychosocial variables [114]. Although it only comprises three questions which use different response formats, each question may be used individually [114]. Test-retest reliability of the measure has not been reported; however, the measure does show high internal consistency for both domains (“neighbourhood” and “family/friends”) and is highly correlated with the HSCL-25 and the BDI [114]. Validated and reliable self-report measures of social support which have been used with patients with bipolar disorder include the Interview Schedule for Social Interaction (ISSI), the Interpersonal Support Evaluation List (ISEL) and the Social Support Network Inventory (SSNI) [128]. The ISSI may have been more suitable for use with BEP-Cymru participants as it is a relatively short scale which measures both the availability and the adequacy of attachment (close emotional ties) and the availability and adequacy of social integration [128].

The knowledge and attitudes questionnaire was designed for use with BEP-Cymru participants because a single, brief measure to assess self-perceived knowledge of managing bipolar disorder, attitudes towards group healthcare interventions and medication did not exist. However, because this measure was not validated, other validated measures may have been more suitable for application. The Treatment Attitudes Questionnaire (TAQ) was developed for patients with bipolar disorder, but is long and shows poor internal consistency [129]; 9 of its 62 items correlated poorly with subscales, mostly because they were vaguely written, containing multiple clauses and ambiguities [129]. The Brief Medication Questionnaire (BMQ) was designed as a self-report measure for assessing medication adherence and barriers to medication adherence [130]. Psychometric analyses have shown that the BMQ has been shown to have moderate to high internal consistency in each of its domains and a positive predictive value of 100% [130]. Therefore, the BMQ may have been a more appropriate measure to use with BEP-Cymru participants.

The modified SAI has not been validated, although it was used for participants of the BIPED trial [23]. The SAI [116], designed for patients with psychosis, was adapted for use with patients with bipolar disorder, although it may not have worked for this diagnostic group. A comparative study of the Beck Cognitive Insight Scale (BCIS) for measuring cognitive insight in patients with schizophrenia and bipolar disorder found that its two subscales (self-reflectiveness and self-certainty) were applicable to both patient groups [131]. With a group of 92 patients with bipolar disorder, the BCIS was found to have adequate internal consistency on the self-reflectiveness domain (Cronbach’s alpha = 0.73) but inadequate internal consistency on the self-certainty domain (Cronbach’s alpha = 0.61); this

variance was also found for the control group and the schizophrenia group [131]. The BCIS may have performed better than the modified SAI for the BEP-Cymru outcome assessments.

6.4.2 Strengths

This study has a number of strengths including both psychological and social assessments, as well as measurement of potential mechanisms of the effect of the intervention. To date no studies have sought to understand the mechanism of group-based psychoeducation for bipolar disorder via analyses of potential mechanisms on the pathway to effect. Potential therapeutic mechanisms such as behavioural self-regulation, social support and perceived health competence have not been explored in the context of evaluating group psychoeducation, so this study contributes to the evidence base in a new way.

Exploratory analysis has yielded some significant findings and non-significant trends, some of which will be explored further in relation to the qualitative interviews (see Chapter 9). The qualitative interviews may offer further insights into the trends for increased quality of life scores, improved mania and depression scores and increased behavioural self-regulation scores. The interviews may also contribute evidence for the significant findings for participants' preferences for learning about bipolar disorder in a group context, the extent to which participants perceive programmes like BEP-Cymru to be helpful and how the programme has impacted on their knowledge of managing bipolar disorder.

6.4.3 Weaknesses

This was an exploratory study with a small sample size which was not powered to detect differences on any of the quantitative outcomes. Therefore, it would not necessarily have been expected that significant differences between time points would be detected unless the differences were large. We explored trends within the data using non-parametric tests. Because there was no sample size calculation p values are only indicative of real change between time points. It is also possible that the measures used may have not been sufficiently sensitive to detect differences between the time points. However, the trends are potentially interesting, particularly for the depression and mania scores. A larger randomised study powered on these outcomes could find these differences to be statistically significant.

This study was not randomised, had no comparison group, and used quite a lot of outcome measures on a relatively small sample. For these reasons any changes between time points may have occurred by chance, rather than as a result of the intervention.

Baseline data describes the characteristics of the sample, which informs us about the reach of the programme. For example, it is apparent that BEP-Cymru is not reaching many men, people of non-Caucasian ethnicity or people who are new to learning how to manage their bipolar disorder. The lack of representation within our cohort of people of non-Caucasian ethnicity is in concordance with population statistics in that according to the 2011 census 2.2 m (73%) of usual residents of Wales were born there [132]. The under-representation of men in our sample may be due to cultural and social norms in that men may feel less inclined to seek to share their personal experiences with unknown others in a group setting. Furthermore, participants were mostly signposted to BEP-Cymru through their mental health providers, the charity Bipolar UK, or through affiliation with previous involvement in research on bipolar disorder, and this may explain why few participants were new to learning how to manage their illness. As many participants were educated post age 16, it is likely that few were of lower socio-economic status and therefore less likely to access health care services [133].

The only significant findings were from non-validated questionnaires. It may be that the questions were not measuring what I intended them to, as they were not validated.

Another weakness is that the follow-up period was relatively short. Ideally we would have conducted follow-up assessments after a year or two, rather than just at three months. This was not possible due to the time constraints of my PhD.

Time spent undertaking the questionnaires was felt to be a burden to participants as it took them up to 40 minutes to complete and some complained that it was too time consuming. This could have resulted in poor completion and therefore poor data (such as the poor completion of questions within the SSRQ). Some participants found it difficult to concentrate on the task, particularly if their mood was high or they had a learning disability. For this reason, some participants took the baseline questionnaire pack home with them and returned it at the following week's group session or by post. If participants took the questionnaire pack home to complete, they may have delayed

answering the questions, which in turn would have shortened the time frame between their baseline questionnaire and 10 week questionnaire by up to a week.

There were some issues with the questionnaires regarding data completeness – the main issues being the difficulty many experienced with completing questions within the SSRQ and the non-relevance of questions relating to occupational functioning in the FAST for those retired or not in employment, which meant that for these participants total FAST scores could not be computed. The SSRQ has now been removed from the questionnaire packs for future BEP-Cymru groups.

Most participants completed the 10-week survey regarding the feasibility and acceptability of the intervention in the presence of the course facilitators. Participants were asked to hand in their questionnaires at the front desk before they left, which is where the facilitators were standing. Such factors may have resulted in these scores being biased in favour of the intervention.

6.4.4 Findings in relation to other studies

Other studies of group-based psychoeducation for bipolar disorder found that severity of depression and mania may be reduced [38, 39], in addition to reducing the frequency and duration of subsequent bipolar episodes [40, 48, 49, 51]. Although we didn't examine the frequency and duration of bipolar episodes across the time points we assessed participants mood immediately following the intervention and found that most participants rated their mood as not fluctuating more or less than usual during the programme (71.4%). Furthermore, we captured data on the presence and degree of depression and mania at the 3 time points and found a trend for decline in both. This trend was more prominent for median depression scores where the median score at baseline indicated moderate depression and at 10 weeks and three months indicated mild depression.

Our study also explored participants' ratings of the usefulness and acceptability of the programme. After participating in the programme participants' median ratings changed from baseline in that they felt their knowledge of bipolar disorder had increased, and their view of the extent to which they felt group health education programmes to be helpful increased. Similarly, qualitative studies of psychoeducation for bipolar disorder found that patients reported learning coping skills and strategies [42, 64] and felt empowered from the knowledge gained through psychoeducation [42, 43].

A randomised controlled trial of group psychoeducation for bipolar disorder found that after 6 months participants had significantly improved social functioning and improved mental quality of life [51]. We did not observe clinically or statistically relevant improvements on quality of life or social functioning measures after 3 months, although our study was not randomised or powered to detect significant differences.

6.4.5 Conclusion

This exploratory study found that group psychoeducation within the BEP-Cymru programme was acceptable to participants, who mostly rated their experiences of the intervention positively, and reported that their knowledge of bipolar disorder increased as a result. A key trend was identified in that participants' presence of depression at baseline, 10 weeks and three months reduced in clinical significance from an indication of moderate depression at baseline to an indication of mild depression at 10 weeks and three months.

A larger sample powered to detect significant differences between scores on dependent variables across time points would be needed to explore trends further. Additionally, a randomised design would be needed to minimise bias and properly assess whether the intervention works or not.

Future studies would benefit from a longer follow-up period to assess whether potential effects are sustained over time. Future studies which are conducted in the UK should also aim to recruit a sample which is more representative of the ethnic and social diversity present in the UK, and should also recruit participants from a more diverse range of sources to include those who are newly diagnosed and who may not necessarily begin a psychoeducation programme with knowledge of the disorder. The intervention may be more helpful and have a larger impact for this group than for participants of our sample, who were mostly of Caucasian ethnicity and not newly diagnosed.

A key strength of this study is that it explored a number of key psychological and social variables upon which the intervention could have impacted, including potential mediators of the efficacy of psychoeducation, and therefore our findings provide a worthwhile contribution to the literature on group-based psychoeducation for bipolar disorder. Further exploration of these findings in relation to the themes of the qualitative interviews with patient participants and facilitators of BEP-Cymru will provide more in-depth insights into the feasibility, acceptability and impact of the intervention.

Chapter 7: Feasibility, acceptability and impact of a group-based psychoeducation programme for bipolar disorder: a qualitative analysis

7.1 Introduction

I wished to explore the feasibility, acceptability and impact of a group-based psychoeducation programme for bipolar disorder (BEP-Cymru) from the perspectives of group participants and facilitators. Details of the content and delivery of BEP-Cymru have been described in Chapter 1.

I have previously published qualitative data from the Beating Bipolar trial [105]. Since I wished to compare results from this trial and the BEP-Cymru study, the qualitative interviews were loosely based on the topic guide designed for the Beating Bipolar interviews. However, based on my experiences with the Beating Bipolar qualitative study, I felt that it would be more fruitful to allow participants the flexibility to describe their experiences of the programme much more freely and to their own agenda by using a more in-depth phenomenological approach, thereby generating richer data. As with my qualitative interviews of Beating Bipolar participants I employed rigorous thematic analysis; however, my style of questioning was more loosely based on a semi-structured interview schedule to enable participants' narratives to develop.

My primary aim for this chapter was to explore the group participants' experiences of BEP-Cymru. I sought to explore their personal experiences and issues which were relevant for them which they disclosed during the interviews, especially those which related to the feasibility, acceptability and impact of the intervention, their self-perception, insights and relationships with others. In-depth interviews with BEP-Cymru facilitators aimed to explore their experiences of the programme; including their perceptions of participants' engagement and interaction with the sessions, the content of the modules and suggestions for improving the programme (see Chapter 8).

7.2 Methods

7.2.1 Procedure for qualitative interviews with group participants

I obtained attendance records for participants of BEP-Cymru from the facilitators so that I could invite those who had attended the majority of the group sessions and also those who had dropped out, in order to understand their reasons for opting out of the programme. I purposively sampled participants on the basis of their level of engagement with the programme (identified by attendance records), their location (either North or South Wales, to minimise clustering effects) and the length of their diagnosis of bipolar disorder – to include participants recently diagnosed as well as those with a longer-standing diagnosis. I conducted these interviews over the telephone at three months following their participation in the programme and audio recorded and transcribed the interviews verbatim. Interviews with patient participants were conducted until thematic saturation was achieved.

Qualitative interviews with participants explored their experiences of the programme, particularly in relation to its feasibility, acceptability and impact, and also complex processes and issues, such as motivations, decisions and outcomes, in depth and detail. Please refer to Appendix 8 for the topic guide. It was anticipated that these personal accounts would provide insights into the acceptability and usefulness of the various aspects of programme, contextual factors, how the programme is received and its meaning for participants. Furthermore, the interviews aimed to capture any problems encountered with the implementation of the programme, the potential impact of the programme on participants and recommendations for improvement.

7.2.2 Theoretical framework and analysis

The interviews were conducted flexibly and responsively to enable participants' narratives to develop. Consistent with phenomenological theory, the primary focus of these interviews was on the nature and meaning of participants' individual lived experiences, which were explored in relation to their personal contexts [134]. To explore the therapeutic mechanisms of BEP-Cymru I sought to examine the impact of the programme from participants' perspectives and whether their experiences of the programme changed their perception of themselves and the disorder. Thematic analysis [82] therefore incorporated personal contextualisation, such as identity change and

empowerment, amongst other emerging concepts relating to the feasibility and acceptability of the programme and its impact. Justification for not adopting a Grounded Theory or IPA approach is the same as provided in Chapter 4.

These interviews were designed to be less structured and more responsive than the interviews I conducted for the Beating Bipolar trial. Rather than closely adhering to a semi-structured interview schedule as I had done for Beating Bipolar, these interviews either began with an open-ended question about what BEP-Cymru was like for the participant or participants initiated discussion of their experiences of BEP-Cymru after introductions. This format was to enable participants to feel more freely able to discuss their experiences and to their own agenda, as well as to my agenda. They could discuss that which they felt most relevant or mattered most to them at the outset rather than waiting for the next question to come from me. I ensured that interviews covered the feasibility, acceptability of the intervention, as well as how it may have impacted upon participants, so in this sense the data captured would be comparable to the Beating Bipolar qualitative interviews.

I recorded my impressions of the interviews immediately following them, and developed these initial impressions when transcribing and familiarising myself with the data by mapping potential themes and categories. I inputted the data into NVivo 8 qualitative analysis software to code the data within an emerging thematic framework for themes which were developed and refined as analysis proceeded. The data were coded into categories, themes and sub-themes. I decided upon data saturation at the point at which no new perspectives were being offered. Due to resource constraints, it was not possible for any of the data to be double-coded by a second researcher. Results are presented as key themes. Any interactions between the themes which emerged from interviews with facilitators and the themes which emerged from interviews with patient participants are explored.

This change in my approach to interviewing meant that the conduct of the BEP-Cymru interviews and analyses were less focussed on the topics within the interview schedule than were the conduct and analysis of the Beating Bipolar qualitative interviews. Through employing open-ended and general questions I led participants towards topics without asking for their specific opinions about them. Analyses of BEP-Cymru interviews therefore presented a broader range of themes than the analysis of the Beating Bipolar interviews – so many themes that in order to summarise them in a meaningful way many of them had to be grouped by overarching domains which provide little

indication of thematic content when viewed in isolation (for example, “Perceptions of the facilitators”). Within the more relaxed structure of the BEP-Cymru interviews participants felt they had more time to respond and so could give more detailed answers and also reflect on comments they had made earlier in the interview.

Kvale and Brinkman’s account of the power asymmetry in qualitative research interviews describes a scenario where an interview is a one-way dialogue: “An interview is a one-directional questioning – the role of the interviewer is to ask, and the role of the interviewee is to answer” [78]. This one-way dialogue was unwittingly facilitated in the Beating Bipolar interviews at times when I adhered to the interview schedule, and therefore the power asymmetry between me as the questioner and the participant as respondent became apparent. As a result of this, within the analysis of the Beating Bipolar interviews I faced some data which were particularly closed to interpretation – some participants were responding very briefly in anticipation of my next question. This power asymmetry was avoided in the BEP-Cymru interviews as I had become more skilled at eliciting participants’ narratives and rich descriptions of their experiences and perspectives. The BEP-Cymru analyses therefore were more detailed and in-depth than the Beating Bipolar analysis, and also took into account participants’ perceptions of themselves and others within the group intervention. Please refer to Appendix 10 for annotated extracts from my analysis; included to demonstrate my application of coding.

7.3 Results

7.3.1 *Sample characteristics*

Thirteen BEP-Cymru patient participants were invited to be interviewed and all took part. Of the 13 participants:

- 10 were female and three were male
- 7 attended a group in South Wales and 6 attended a group in North Wales
- 3 attended 1-2 group sessions; 3 attended 6-7 group sessions; 7 attended 8-10 group sessions
- 6 had been diagnosed for 2 years or less and 7 had been diagnosed for longer than 2 years

Participants cited their reasons for deciding to participate in the group, which included: an interest in self-management, knowing nothing about bipolar disorder, being recently diagnosed with bipolar disorder, wishing to understand the condition better, seeking advice on how to live as normally as possible, to confirm or deny a diagnosis of bipolar disorder, to meet others with bipolar disorder, recommendation by their health care professional, and respecting the research at Cardiff University.

7.3.2 Feasibility of BEP-Cymru

7.3.2.1 Mood affecting engagement with the course

Some participants reported that their mood during the programme affected their ability to engage with it. Some participants who reported feeling low during the programme felt apathetic, less sociable and struggled to concentrate. Others who reported feeling high became angry, upset and found it difficult to sit still and focus. One participant reported that her mindfulness practice helped her overcome her low mood, and another participant reported being able to concentrate better when feeling high.

7.3.2.2 Timing of sessions

Some participants commented that mornings were difficult for them if they were feeling low and they would have preferred to attend afternoon sessions. Participants felt that evening sessions were preferable for those with day jobs, but some did not feel encouraged to leave the house on cold winter evenings.

"[...] it's dark at half past four and, you know, as I live alone as well, um the thought of going out and I don't drive, can make you feel quite vulnerable, you know, so I am definitely affected by the weather."

P2, female, South Wales

7.3.2.3 Community venues preferred to hospital settings

Many participants commented that they did not wish to attend the group in a hospital or university venue. It was important to them that the setting was neutral, sociable and central. Some

participants remarked that hospital premises had negative connotations for them and brought back memories of their bad experiences. Others felt that the Heath hospital was too far out of town to access.

RP: *“Have you any comments about the venue?”*

P13: *“I wouldn’t have it in the hospital.”*

RP: *“Right.”*

P13: *“Because of the different experiences that we’ve had, the bad experiences that most of us have had with the hospital. I think being attached to the hospital brings back bad memories for people [...] being made to sleep in a [...] blood spattered, food spattered wall, cell, like a prison cell was not conducive for improving one’s depression or bipolar or anything else quite frankly”*

P13, female, South Wales

All participants who were interviewed in North Wales highly praised the venues, which were both centrally-based community galleries. Participants commented that they were excellent, provided a lovely room and great refreshments, and were airy and light.

“[...] the organisers made a conscious choice to find a space that was very airy and light and it was part of an Oriel and gallery here, in the middle of Anglesey, um so these kind of, I felt like they really made a conscious decision about all these things, which everybody in the group appreciated it because bipolar people are very sensitive to their surroundings”

P5, female, NW

7.3.2.4 Attendance at sessions

Participants provided a variety of reasons as to why they missed sessions. Some participants who felt low during the programme missed sessions because they were disinterested in the topic, felt unsociable, struggled to get out of bed or leave the house, lacked energy and felt fatigued. Others missed sessions because of personal crises, hospital appointments or lacking the transport to attend. One participant reported missing sessions because the sessions were far from home and she didn’t feel motivated to make the journey on cold and dark winter evenings.

Participants gave many reasons for their attrition. Some participants in South Wales dropped out because of poor facilitation of the group. They complained that participants were allowed to rant

off-topic. They also felt that the facilitators were patronising and lectured them and they felt pressure to contribute when facilitators asked questions around the room. Some participants did not feel at ease within the group as a group member, or felt that the course was going over things they had already learned elsewhere.

Some participants dropped out because of their low mood and lack of energy. Others reported that they could not make that time of day because it clashed with their work schedule or because they felt that 10 weeks was too much of a personal commitment.

7.3.3 Acceptability of BEP-Cymru

7.3.3.1 Content

Participants regarded the quality of the information presented within the course to be at an expert level, reliable and informative. They felt that the information was easy to understand, well-structured and sessions flowed well.

One participant remarked that the letter and supporting information which he received prior to starting the course was too formal in tone and he felt it was intimidating. He also commented that the information given was too vague and lacked an explanation about the format of the course.

"I wasn't sure if I was going to go or not you know, and I think perhaps the literature that arrived beforehand was a bit too formal (.) the letter that arrived first to say that you've been accepted on the programme (.) So perhaps it could've explained a bit more you know that there would be other people there, you know with the same sort of condition"

P6, male, North Wales

Many participants commented that they found the handouts to be concise and useful for remembering the course material or for catching up if a session had been missed. Some participants found the handout on debt and mental health to be particularly useful, and one participant commented that to receive a personal certificate and folder at the end of the course gave her a sense of achievement.

Some participants reported that learning how to keep a mood diary was helpful, as was creating their lists of triggers and their action plan for becoming unwell. One participant said that creating his contacts sheet gave him a greater sense of security because he knew who to call in a crisis.

Participants enjoyed some of the exercises because they were fun and lightened the mood of the group.

Others commented that they particularly appreciated the visual representations within the exercises and presentations, particularly if they had literacy problems.

“It was visual and it was mental as well, so it was a little bit of both, which was helped me because I can’t um, (.) I can’t write or anything properly, so the visual things, the visual work as well was better for me (.) the visuals on the laptop and things, you could see the life-chart and things on the laptop and then look at it as a group on a white board.”

P11, female, North Wales

Participants found the session on medication to be really helpful and appreciated the facilitators’ expert knowledge.

“[...] the medication session was very important because too often medication is given, especially by GPs and it isn’t explained, you know, for the actual side effects of these drugs and how important it is to take them regularly”

P6, male, North Wales

Some participants said that they particularly appreciated the session on mood mapping, learning what was happening in a manic phase and learning to recognise their personal triggers for a bipolar episode. They found it helpful to inform their family members so that they could also recognise when their mood was becoming high or low.

Others appreciated the information within the session on lifestyle and took recommendations from the course. One participant also appreciated the exploration of the link between bipolar disorder and alcohol problems.

One participant found the session on women with bipolar disorder, family planning and birth to be particularly useful, and she shared the information with her friends with bipolar disorder who did not attend the course.

"[...] in particular I was quite pleased with the session on women with bipolar and family planning and child birth and things (.) because I think that gets neglected quite a lot and that was like the first course I'd been to that covers that because it's quite a complicated topic [...] I shared the handouts that I had, um because I think it isn't something that gets discussed that much, so I think that had, that was probably the biggest impact like for me and people I'm in contact with"

P12, female, South Wales

Some participants acknowledged that doing the life chart exercise had a psychological and emotional impact for themselves and others. Remembering upsetting times and losses as a result of the illness were hard for them to cope with and they felt depressed afterwards. Despite this, two participants commented that the constructing their life chart was helpful in that it confirmed when their illness began and enabled them to recognise former periods of mania or depression.

"[...] it just brought up all the sadness really, what I was dealt, just a bad hand really, in what I was born into [...] I went back the next week and the girl that was really depressed, I was worried about, she went back as well, she said she was really down and I said 'I was that week, but it gives you stuff to think about, you know and you should use that time to discuss it with people who are close to you, people who are helpful and work through it.' You don't want to relive it all the time but it needs to be, if it's that powerful, it needs to be faced head on and deal with it and just disempower it"

P9, female, South Wales

7.3.3.2 Perceptions of the facilitators

7.3.3.2.1 Positive comments

Participants said the facilitators created a relaxed environment, involved everyone and balanced the formal with the informal aspects of the programme. They appreciated facilitators' expert knowledge and said they answered their questions well.

“I thought it was always good to have a psychiatrist in the room. Um, I think he researches bipolar so it was very good to have him there”

P1, male, North Wales

Participants said that the facilitators “treated them like human beings”, were down-to-earth and participants felt accepted by them. Participants observed that the facilitators were keen to listen to them and learn from them. They appreciated the personal touch facilitators demonstrated in that they expressed an interest in them, were caring and looked after them.

“Accepted, that’s one of the main things, [F5] was very good to just accept us the way we were and [F6] was really, really keen, he’s the psychiatrist, he works in Bangor I don’t know if you’ve met him, he’s recently started doing research as well and they were very keen to listen to us and learn from what we had to tell them, so to feel looked after and to feel like you matter, like you are relevant in this world, like you are important, that’s the sort of main thing they gave all of us”

P5, female, North Wales

7.3.3.2.2 Negative comments

Some participants criticised or complained about some of the facilitators because of their style of facilitation and poor group management skills. Some facilitators did not stick to time or address some participants’ offensive remarks.

“I felt they just weren’t very good at managing the group really [...] it got very boring to be honest, so I was kind of switching off and thinking about other things, um, there were people I know who, friends of mine who were going to the group who dropped out, that’s what they found, um that it was getting to the stage of being really unbearable and also I think when some people made remarks that were either a bit discriminatory or quite biased or even slightly offensive and they weren’t very good, they didn’t often, um kind of redress that or balance it out “

P12, female, South Wales

Participants felt frustrated when people were allowed to talk about things that were not relevant to the day’s topic for too long. They felt that facilitators needed to summarise people’s points when they went off-topic because the rest of the group felt that they were not benefitting from the

digressions. They also said that the facilitators did not ensure that everyone was given an equal opportunity to contribute to discussions and that some people were allowed to dominate the group.

A couple of participants felt that the facilitators were being patronising towards them which they found to be disrespectful and disempowering. Some described feeling talked “at” rather than being talked “with”. They felt that their style was too didactic, lecturing or like classroom teaching.

“My overwhelming memories and feelings of this course was ‘it’s them and us’ [...] I didn’t feel very sort of ownership of ‘I’m finding out information for me to improve my health or my own management of my condition’ it felt more like ‘we’re telling you what you should do and if you don’t do it then you know on your own head be it’ [...] just because we have bipolar it doesn’t mean we’re stupid or need lecturing at”

P10, female, South Wales

A few reported feeling bored by facilitators’ dry and disengaging style of communication and did not feel engaged during the PowerPoint presentations. Some facilitators were also described to put pressure on people when asking questions around the room and some participants felt “put on the spot” or “trapped” with having to engage with uncomfortable topics. These participants felt that the facilitators did not appreciate the emotional impact of the course from participants’ perspectives.

Some participants suggested ways in which group facilitation could be improved. They suggested that they be given time to be asked how they felt, to enable people to talk more and build group rapport and trust. One participant suggested that a more natural ice-breaker exercise where participants had more options regarding their responses, rather than answers to close-ended questions, would have felt more empowering. More time in the first sessions was needed for participants to get to know one another and gain an insight into why everyone was there. Participants felt this was important to feel safe, trusting and at ease with the group to facilitate openness and self-disclosure.

To prevent participants from going off-topic and also to enable them to discuss unrelated topics at an appropriate time, one participant suggested that facilitators operate a “parking zone” to make a note of topics participants wish to discuss in order to address them later.

Some participants said that facilitators could be more sensitive and flexible to the needs of the group and they would have appreciated hearing their points of view more than simply talking from the PowerPoint slides. They also recommended that the rules of the group should be negotiated with the group rather than just stated by the facilitators. They felt that this was important for the group to take ownership of the rules and personalise them, and also for developing trust within the group based on the understanding that others have engaged with the rules and have voiced that they would be respecting them.

7.3.3.3 Participants perceptions of the group experience

7.3.3.3.1 Positive comments

All participants appreciated the opportunity to share their experiences with other group members. They exchanged their experiences of their lives in general, their bipolar disorder, their health care, their health care professionals and their hospital treatment. They found this aspect of the course to be therapeutic, and learned from others' insights and ways of coping.

"It's very difficult when you have bipolar to notice that you are going on a manic or on a depressive side, you don't notice it yourself and to see other people talking about it about the behaviour that you have, you know, you start noticing things then during the day that you're doing and you know, you can intervene then"

P6, male, North Wales

Others commented that they particularly appreciated being in a diverse group of people, some of whom were from different backgrounds, and reported feeling less lonely and isolated with the condition through meeting others with bipolar disorder. For some, the course provided their first encounter of meeting others who also had the condition.

"Cos it is such a, it can be a very lonely a very isolating um condition. [...] now I know what it is and I know other people in the same boat and I know how people are coping with it and stuff, whereas before I had no idea at all and I just felt so alone with it all, so yeah I've learnt a lot and it's been a great help"

P4, female, North Wales

Some participants reported sharing knowledge with each other and offering advice. Some also said that other members of the group were sensitive, concerned and respectful to how they were feeling.

Being a member of the group empowered participants who felt part of something important. Some also commented that being with others with bipolar disorder and discussing experiences reduced the stigma they felt in day-to-day life.

RP: *“So, tell me your experiences of the BEP Cymru group psychoeducation programme”*

P5: *“Oh it was really, really good, it was, well the best thing that’s happened since I’ve been diagnosed with bipolar, um, yeah it’s just so good to be together with like-minded people and feel like you’re normal because the rest of society makes you feel like you’re not normal, including most of our partners, who think we’re crazy [...] we all felt stronger because we were in a group”*

P5, female, North Wales

“[...] before I thought I was a bit mad in the past but now because I knew what it was and people had gone through the same experiences I realised that no, I wasn’t mad it was just part of the illness.”

P4, female, North Wales

Participants commented on the importance of humour within the groups. Humour was used as a way of coping.

P9: *“[...] it was just nice to be in a room full of people who all had the same thread running through, but we’re so different, funny and warm and just to be able to discuss openly how this bloody awful illness had affected us. It’s priceless [...] I’m terrible for making fun of myself and for making fun of my illness and psychiatry and the whole because I worked in psychiatry for a while and then I got ill and left [...] Terrible, my sense of humour is just, lets me down really.”*

RP: *“Well does it or is it helpful in some ways?”*

P9: *“It’s my way of coping and that’s the way I am and I won’t change”*

P9, female, South Wales

For some, humour was used to “normalise” bipolar disorder.

P5: *"[...] I think the course really helped them to accept this is just who I am and we made lots of jokes about being bipolar and oh yeah all the stupid things we've done and (laughs)"*

RP: *"And did the jokes help?"*

P5: *"Yeah, loads, they give just a bit of light to the because you are treated as a problem like you said as well, with an illness and you're not normal, all these things they are just really silly because we're just human beings"*

P5, female, North Wales

Joking and talking in a light-hearted way was cited as being important for communicating within the group and increasing participants' confidence.

Many said that they really looked forward to the weekly meetings and were disappointed when they came to an end. They looked forward to seeing others in the group with whom they had developed camaraderie, trust and friendship. For some, attending the group on a weekly basis provided support when they were having difficulties and they described looking forward to the meetings as a way of "getting through the week". One participant revealed that she missed the security of the group because it gave her an opportunity to meet with others with bipolar disorder, without which she lacked confidence to contact them.

"I wouldn't know how if I called somebody, I wouldn't know how to talk to them, I haven't got the confidence to text or to pick up the phone and say, 'how you are, how are you or?' I just keep myself to myself [...] we have exchanged numbers but I haven't used them and nobody's called me either"

P11, female, North Wales

For some participants the groups enabled them to compare themselves with others who were "in the same boat" in having bipolar disorder. They found meeting with others to be helpful for gaining a perspective on the extent of their illness.

"[...] when you're in a group like that and you see some that are better than you, they're doing much better than you, they're in a better place and some are in a worse place and I don't know it's just like a measure really of how ill you are"

P9, female, South Wales

A couple of participants said they were surprised and interested to hear that others had similar traumatic experiences to them.

7.3.3.3.2 Negative comments

It was the first time some participants had met with others with bipolar disorder, and they found the first meeting to be intimidating. Some were dissatisfied by group members who were too dominant within the meetings and too focussed on their own agendas, and reported feeling “put on the spot” with being asked to construct their life chart within the context of the group.

“I’ve got friends I know who are doing it with their [Community Psychiatric Nurses] and stuff, um like over a period of months because you know it can take a lot of time to be ready to look at what has happened throughout your life [...] [the facilitators] did put a lot of pressure on people and then they kind of went round one by one and were kind of going, ‘oh, show us your life line and explain it’, and I thought that wasn’t very helpful because obviously some people were fine with it but apart from, if you hadn’t wanted to do it or you wanted to kind of start on your own but you didn’t really want to share it with the rest of the group, you didn’t really feel like you had an option. Um, so I think yeah that kind of being put on the spot I found quite pressurising.”

P12, female, South Wales

One participant reported that she did not feel as though she connected within the group because it lacked others of a similar age to her.

7.3.3.4 Contrast with other self-management courses for bipolar disorder

Participants who had previously attended other self-management courses for bipolar disorder compared their experiences of these courses with their experiences of attending BEP-Cymru.

Some felt that the self-management course which was held over three days and offered by the Manic Depression Fellowship (MDF) was too intense. They felt that it was too introspective and did not adequately support vulnerable people who may have become traumatised by a distressing topic. One participant was particularly angered and upset by her impression that the MDF course focussed

on certain problems and assumed that everyone within the group had the same experiences. She felt that they did not allow for divergent experiences or viewpoints within the group.

One participant felt that the MDF course had given her a better opportunity for sharing her personal experiences and learning from others' experiences.

7.3.3.5 Key recommendations for improving the course

Some participants commented that they would have appreciated more information on certain topics and shared examples for further reading from self-help books. They felt that the course could have covered more on legal issues, psychological therapies, such as mindfulness and Dialectical Behavioural Therapy, and provided more up-to-date information on smartphone "apps" and mood diaries.

Some also felt that the course was too medical in its focus. They commented that the focus on diagnosis and diagnostic categories was not helpful for practical self-management. They suggested that the course lacked the concept of self-management as a process which takes time, and would benefit from focussing on more practical and experiential considerations.

"I think that was one of the things that was missing from the course was that idea of self-management as a process, um that it can take a lot of time for some people, or you can be good at one bit of it and it might take you time to develop other bits of it and I think that kind of time constraint on, you know, 'we do this session, we do that next session, you know, are you much better at self-managing now?' [...] I didn't really realise that until afterwards and I was kind of like, 'hmm, hang on, you can't do it all', you know some people might but it's a lot of stuff to go through"

P12, female, South Wales

One participant suggested inviting someone with bipolar disorder to one of the sessions to relate their personal experiences and how they had managed their illness throughout their life.

Four participants suggested that they would benefit from the opportunity to involve their partners or relatives with the group. They suggested that family and friends who were concerned should be invited to a couple of sessions or that a session could be provided specifically for them. They felt that this may help them to understand and accept the illness more and gain an insight into it.

“Strongly would recommend that partners, families were involved in at least two or three sessions, so that they have that understanding of what was going on because there’s nothing, no information for them at all [...] To understand the moods because you are very, very hard to live with, so the partner does tend to back off and then you feel like you’re not getting any support when it’s not because you’re in a mood it’s because [...] of the illness that makes you in that particular way but partners and family don’t have an understanding of it”

P4, female, North Wales

Some suggested that BEP-Cymru should arrange either a couple of recap sessions informally or a couple of casual meetings with or without facilitators after the course finishes. They stipulated that this should be organised by BEP-Cymru for participants even if a facilitator would not be present.

“[...] perhaps something [...] some months down the line that we came back to see how we are doing. [...] I think it’s worthwhile, it’s such a good programme for it to end like that it needs something I think (.) it wouldn’t cost much would it to bring a group of people together every couple of months”

P6, male, North Wales

Some participants made recommendations for improving the life chart exercise. They suggested that it would be better to give participants the tools necessary for undertaking the task and provide examples of how to complete it. Participants needed to be better prepared for, and better supported with, the life chart exercise. Participants also recommended that the exercise should have a health warning and people should have the option not to do it if they don’t feel ready or they don’t want to do it.

7.3.3.6 Reasons participants would recommend BEP-Cymru to others

Some participants recommended the information they received on the course because it helped them to understand the illness better and was accurate and reliable.

“[...] bipolar is like a foreign word really isn’t it? But when you get the information from you, you know what the disease is and what it involves you know”

P3, male, South Wales

Some participants would recommend the programme because it enabled them to meet others with bipolar disorder, discuss their experiences and make new friends from the group. They felt like they were no longer “the only one” with the illness and it had reduced their feeling of isolation. The course reduced the stigma they felt from having bipolar disorder.

RP: “So how did you find the group experience?”

P4: “Recommend it to anybody [...] because I’ve made friends, I’ve made friends from the group, um we meet on a Monday, we go for coffee or we go for lunch, we go swimming, it’s nice, yeah. Whereas before I didn’t have anybody, you know, I’ve lost lots of friends and stuff due to this illness and because they obviously don’t understand it and they couldn’t cope with my mood swings and things, so but at least you know with this group now, we’re all in the same boat, we all know how we feel and yeah it’s good”

P4, female, North Wales

7.3.3.7 Group versus computer-based formats

A few participants reflected that an online course would be better if they were feeling low and were finding socialising difficult. Some found it hard to leave the house when they felt low and, therefore, would have preferred an online course at that time.

Many remarked upon the usefulness of being able to share experiences within a group setting, and some expressed reservations regarding online forums. Some chose not to use forums and one participant said she lacked sufficient computing skills to use a forum. Concerns surrounded the permanency of forum posts, a fear of feeling attacked or upsetting others.

[...] because it’s open to a larger number of people, but at least in a group there’s like, you know ten people or whatever, but if you’re on a forum and you can have I don’t know how many people connected to it and they comment on something that you’ve said, it’s just kind of, I [...] wouldn’t necessarily be asking or saying the things that I really wanted to say because I would be worrying that I might you know upset someone or get attacked by someone or something

P12, female, South Wales

Some participants opined that a computer-based course may be more accessible, especially for those who cannot attend a 10-week course due to other commitments or for those who cannot

leave their home. They also commented that the forum would enable discussion and interaction with others.

Others valued the opportunity to ask in-depth questions and receive an answer instantly within the group setting, which they felt a computer-based course would lack.

7.3.4 Impact of BEP-Cymru

7.3.4.1 Impact on knowledge

Many participants commented that they had a better understanding of bipolar disorder, the causes of bipolar disorder and its treatment. Some discovered that the illness was more complex than they had previously realised.

"[...] it was nice to know what the cause of it was, yeah. Whereas before I didn't have a clue, you know? I'd just like do crazy stuff and end up in hospital and not know why, um and just being diagnosed with is something and being able to learn about it was a huge help"

P4, female, North Wales

Some appreciated attending the course even though they were already familiar with the information presented because the course confirmed what they already know and revisiting topics was helpful for them. Others reported their ability to explain their bipolar disorder in a concise way to others, without feelings of shame or stigma.

"I can explain it quite concisely now and I know the points that people want to hear and need to hear, whereas before you'd be explaining something that sounds so bizarre, you know all these mood swings and things [...] without feeling you have to hide anything"

P6, male, North Wales

7.3.4.2 Impact on social support

The main reason participants cited for appreciating the course despite not learning anything new was the group experience. Participants particularly welcomed feeling part of a group with others

who also have bipolar disorder and the opportunity to share their experiences, listen to others and offer support. They said that the openness of the group negated any shame or stigma associated with bipolar disorder, and the course enabled them to feel less isolated with the illness and become aware that others also suffered from bipolar disorder in similar ways to them. This realisation stemmed from others sharing their experiences of living with bipolar disorder and relating how they cope.

“I didn’t feel so isolated, you know. I thought that there are other people who suffer in the same way that I do [...] I benefitted a lot from talking about my illness with these people and finding that they shared aspects of the illness [...] there were other people like me”

P7, female, South Wales

The course did not impact on some participants’ personal relationships. This was because they felt that either their family did not need to be informed about their bipolar disorder or others were not interested or able to respond to them when they were unwell.

Some said that their families wouldn’t be interested in reading hand-outs, although they would be interested in learning about bipolar disorder within a group session specifically for them. Others described their partners to be more accepting and trusting of them and supported their involvement on the course.

Many befriended other participants on the course, and one group continued to meet as a bipolar support group beyond their involvement in BEP-Cymru.

“Just there for support you know, if someone’s not feeling well, somewhere where they can go where they’ve got support, because when you’re not feeling well it’s hard to actually get out of the house, whereas if you know there’s a group there who are going to support you, the group could actually pick you up and take you out, you know?”

P4, female, North Wales

7.3.4.3 Impact on confidence, stability and acceptance

Some participants commented that their confidence had improved as a result of attending the course and they were better able to cope with challenging situations. Some reported that as a result

of attending the course they felt calmer and their moods had become more stable. They said that they felt “normal” as a result of learning about the illness and feeling well.

“I’m a normal person, I think normal thoughts, I don’t want to do anything too outrageous [...] I’m calmer, I’m interested in reading books and things you know, things I wouldn’t have been bothered to do and I like watching certain programmes on television [...] I’m interested in things that I wouldn’t bother with before, all I was interested in before is how I felt all the time, very miserable or very happy, such a change in my feelings that it was unusual, I didn’t understand it you see but if you have a long session with people who have got the disease, you can understand it, you can leave the room knowing a little bit about it”

P3, male, South Wales

A few reflected upon how the course had impacted on their acceptance of bipolar disorder. For some, the acceptance and respect they felt from the facilitators reduced the stigma associated with bipolar disorder.

P5: “I think the fact that they are, were there as persons as human beings, as themselves and made us feel like we were human beings and could be ourselves”

RP: “So, I’m thinking did it reduce stigma for you then, is there a stigma around it?”

P5: “Yeah, massively, massively, yeah, yeah, I don’t know you should, you can’t experience it but you should have a go at telling people you are bipolar, wow! Just for a joke. You’ll get a feel of what it is like”

P5, female, North Wales

7.3.4.4 Impact on access to services

Some participants particularly benefitted from the contacts sheet which was created during the course and comprised numbers of services and individuals to contact in an emergency. For some this enabled them to access help when they needed emergency assistance.

“[F5] had given us this [...] leaflet where you can put all the numbers of the emergency in the home treatment and stuff and that’s, well that turned out to be like a life saver today because I managed to get through these numbers that [F5] gave me, I managed to get through to people who could help us”

P5, female, North Wales

7.3.4.5 Impact on diet

One participant commented that as a result of the lifestyle module he became aware of the importance of a healthy diet and not drinking alcohol.

“[...] in terms of my lifestyle issues, I’ve taken that on board in terms of healthy eating and no alcohol [...] because that was a very good module, lifestyle factors [...] I used to uh, try and control my condition by [...] drinking alcohol and eating comfort foods and you know, the module just made it quite clear that you’ve really got to live a healthy lifestyle as possible um, to try and gain control so the medications can work”

P1, male, North Wales

7.3.4.6 Impact on insight

Many participants reflected that as a result of attending the course they could understand what bipolar disorder is and gain an insight into themselves. One participant commented that she is now able to recognise when she is experiencing a high or low episode.

“I understand now when I am on a high and when I’m on a low, as before I didn’t”

P11, female, North Wales

Some participants commented that they were now able to accept their diagnosis, and realised that it was their personal responsibility to manage the illness and “keep on top of it”. They were aware of how to control their symptoms and maintain their wellbeing.

“It’s made me realise that I do have bipolar (laughs), for a year I was thinking, ‘oh I don’t have this thing you know, it’s not me, sort of thing’, once you see or you meet other people you see you think ‘I do that’ or ‘I behave in that way, so, so it really makes you think you know, yes I do have this condition, I have to deal with it’, yeah”

P6, male, North Wales

For some, a greater acceptance of themselves and their diagnosis resulted in less self-blame and more compassion towards themselves.

For one participant, however, attending the course had confirmed her belief that she has been misdiagnosed with having bipolar disorder. She describes herself as being naturally exuberant, which some health professionals have mistaken for mania, and believes she has only suffered from depression in the past.

RP: “So how do you feel about your diagnosis of bipolar disorder now?”

P13: “Absolutely up your arse! Excuse my language”

RP: “So you don’t think you have bipolar disorder?”

P13: “I believe I don’t, no [...] it’s not just me [...] I mean the thing is I exhibit and that’s what my partner says [...] a highly sensitive, highly principled, articulate, eloquent, whatever you want to call it, person, who is very, very motivated, very driven and very active. I mean I’ve done ballet, dancing, every day and I’m very, very busy, I always have been, except when I’ve been depressed and looking back I’ve done a mood chart, I’ve done a mood chart through my life and when I was on the course and I realised that I was only low when certain circumstances and people came into my life”

P13, female, South Wales

Some said that they could recognise what triggered their moods now.

“I recognise my triggers, whereas before I wouldn’t, I’d get panic attacks and hyperventilate and get confused and run around dizzy and getting angry and not knowing what was going on but now I know what’s going on and why it’s going on”

P4, female, North Wales

Others realised that certain people or circumstances would trigger their low mood. They said that the course gave them an insight into previous failed relationships and one participant cut ties with certain family members who were not considerate to her mental health.

P9: *"[...] at the time there was a lot going on and there was a lot of trauma around my family and it wasn't getting any better and I [...] couldn't take it anymore and I made a decision after the course and cut off from them and I'm better, I'm more well now, I should have done it years ago"*

RP: *"To cut off from your family who...?"*

P9: *"Well just a couple of them, not all of them, the ones that were making me ill really, year after year, the same things, just not being very considerate to my mental health"*

P9, female, South Wales

7.3.4.7 Impact on attitude to taking medication

Some participants said that they had become less resistant to taking medication for bipolar disorder because they acknowledged that it enabled them to feel well. Some participants accepted that they would be taking medication for the rest of their lives to control the illness.

"I could not accept I had to take tablets for the rest of my life, I just could not accept because the dosages that I was taking, they were so high and it was just accepting I had an illness, um I couldn't cope with that at first but then after talking it through, you know, what basically what they were saying these tablets and stuff they help you manage it, they don't stop it, they just help you manage it, control it better, so I've come to terms with the fact that yeah, I will have to take them for life, whereas before I couldn't and (laughs) it was mixed emotions it was"

P4, female, North Wales

Some participants re-evaluated their medication as a result of the session on medication. One participant remarked that because the facilitators had provided him with informed reassurance about his medication, now he takes his medication regularly as prescribed.

"I was concerned that I was on Lithium, Quetiapine and an anti-depressant you know but they, [P6] said no this is normal and these drugs go together well, yeah it puts your mind at ease really these drugs aren't as scary as you think. So I think I was going, I went for about two years without medication, um because I was concerned about taking, which I wouldn't be now having gone to these

sessions [...] and I make sure that I take them regularly because they can, some of them can have an effect if you take them two or three hours late, you know on the next day for example”

P6, male, North Wales

7.3.5 Definitions of bipolar disorder and identity talk

7.3.5.1 Bipolar is a “condition”, not an illness or a disorder

Some participants stipulated that bipolar disorder should not be labelled as a mental illness, dysfunction or disorder, but rather a “condition”. One participant preferred to refer to bipolar disorder as a condition, but later in the interview referred to it as an illness.

RP: “[...] it’s interesting for me to know what else has impacted upon your self-management of the illness”

P5: “Yeah, OK, I call it actually my condition (laughs)”

RP: “Ok, your condition, sure”

P5: “I don’t mind illness that much but it sounds a bit silly to me (laughs) because it’s just a condition”

[...]

P5: “I am very interested in the disease, illness maybe we should call it then”

P5, female, North Wales

7.3.5.2 Bipolar disorder is a privilege

One participant said that she felt special and appreciated having bipolar disorder.

P5: “I feel special having it, I’m not complaining”

RP: “Did you ever complain or did you feel...”

P5: “No, no I loved it, the whole bit, the whole journey”

RP: “Right, so you appreciate having bipolar disorder?”

P5: “Yeah, massively, massively, I couldn’t have done it without it”

RP: “So why do you appreciate having bipolar disorder?”

P5: *“Just because it makes me feel delightful (laughs)”*

RP: *“It’s how you feel when you go manic?”*

P5: *“Yeah, no it makes me also grounded, so I think the both sides are so extreme”*

P5, female, North Wales

7.3.5.3 Depending on medication to be “normal”

One participant repeatedly stated his dependence on medication to feel “normal” and stay well and happy.

“I was mad, typically mad you know, I just, I’d get nasty with people, or I was too nice to people, I’d stand out in a crowd, I couldn’t make many friends you know because I was a vicious person or I was a nice person and ah and since I went on to these tablets, which the psychiatrist knew all about, he knew I was bipolar, well in fact, he knew I was really manic depressive before I went to the meetings but now the meetings have told me what I’ve got, now I know the tablets he’s given me have cured me and I’m literally a normal person, I never feel unhappy, I never feel too happy, I’m just quite a normal person now, I like it, I like the feeling”

P3, male, South Wales

7.3.5.4 Sensitivity to difficult life events

Some participants remarked that they felt particularly sensitive to difficult life events. One participant reflected that difficult personal circumstances affected him a lot and that no course could protect him from the psychological impact of such circumstances. He said that the more socially isolated a person is the worse the outcome.

“[...] my mood fluctuates quite a lot you know, um, I think, I mean my nurse describes me like a ship lost at sea in a storm with a lot of storm waves coming around me all the time, which is family events and this kind of thing you know, yeah, I get impacted a lot by circumstances, I’m afraid. I try and do my best to stay afloat, but um, but circumstances affect me really. For example, my dad having cancer, you know? [...] I think the problem with the condition is it doesn’t matter how much, the courses, the materials, the handouts, the books that you can read, there is still such a great stigma towards people with bipolar, I mean, I haven’t been working for 12 years and it can be quite difficult

to get some kind of meaningful occupation going you see, and so you're left stuck at home, isolated, on benefits, that's enough to depress anybody you know, so that's a circumstantial issue. [...] and I think the circumstantial factors can be the most difficult of all to deal with really. I mean I lived in a council flat for eight years on a very tough council estate, it was a complete nightmare you know (laughs) it made me very very ill, very very ill. I'm afraid no course can seek to address that situation, you know. [...] I mean if you've got a supportive partner, family, career, job, healthy living environment, healthy social environment, it all gives you that boost so that you can sort of fight the ups and downs of the disorder really. I think the more isolated you are as a person the more cut-off you are from mainstream society, the worse it's going to get for you really"

P1, male, North Wales

7.4 Discussion

7.4.1 Main findings

7.4.1.1 Overview of key themes

The following table highlights the key themes in relation to the feasibility acceptability and impact of the programme from the participants' perspectives.

<p>7.3.2 Feasibility of BEP-Cymru</p> <ul style="list-style-type: none">7.3.2.1 Mood affecting engagement with the course7.3.2.2 Timing of sessions7.3.2.3 Community venues preferred to hospital settings7.3.2.4 Attendance at sessions
<p>7.3.3 Acceptability of BEP-Cymru</p> <ul style="list-style-type: none">7.3.3.1 Content7.3.3.2 Perceptions of the facilitators7.3.3.3 Participants perceptions of the group experience7.3.3.4 Contrast with other self-management courses for bipolar disorder7.3.3.5 Key recommendations for improving the course7.3.3.6 Reasons participants would recommend BEP-Cymru to others7.3.3.7 Group versus computer-based formats
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Table 19. Main areas of discussion arising from the qualitative interviews with BEP-Cymru participants

7.4.1.2 Feasibility of BEP-Cymru

Most participants were able to attend the course; however, venues which were located more centrally were easier for participants to access. Afternoon or evening sessions were preferable for some participants, especially for those with day jobs; however, courses held on dark winter evenings may inhibit participants who may feel vulnerable with using public transport at that time or reluctant to leave their homes. The type of venue was important for some participants who did not wish to attend courses in hospital or university venues and preferred light and attractive community-based venues.

Reasons for dropping out of the groups included: dominating group members, feeling patronised by some facilitators' lecturing style, feeling pressure to contribute to group activities, feeling they were not learning anything new or because of a lack of proper facilitation of the group. Other participants dropped out because they were depressed, they were unable to commit to a 10 week course or because the course clashed with their work schedules. Participants needed to feel well enough to be able to engage with the course, and those who were experiencing depression or manic symptoms were either unmotivated to participate or unable to concentrate on the sessions. Relapse was also found to be a barrier to engagement in internet-based psychoeducation programmes for bipolar disorder [45, 105].

7.4.1.3 Acceptability of BEP-Cymru

The course materials and handouts were commended for their expert and reliable information. Participants of a Spanish psychoeducation group for bipolar disorder felt that reliable information from specialised professionals instilled their confidence in the material and enabled them to feel understood, respected and able to ask questions in the group setting [135]. BEP-Cymru participants particularly appreciated topics regarding medication, mood mapping, recognising triggers, lifestyle, and women with bipolar disorder. Medication was also a popular topic for discussion within a Polish psychoeducation group for bipolar disorder, as some participants requested an additional session on medication for bipolar disorder [136].

The life chart exercise was a concern for many participants because they felt unprepared for the psychological and emotional impact of the exercise, they felt pressurised to do the exercise, or they consequently felt depressed. Despite experiencing low mood after creating their life charts, some

participants appreciated the opportunity the exercise had given them to review their history of the illness and in doing so they confirmed when their illness began. Participants recommended that future participants should be advised about the psychological impact of undertaking the life chart exercise and given the option not to do it. They said it was important for others to be appropriately supported when constructing their life chart in case they felt very depressed as a result.

Recommendations for improving the course content included the following suggestions: to provide more in-depth information, to provide information on mindfulness and different cognitive behavioural therapies, to provide examples from self-help literature and more up-to-date information on mood charts. Some participants suggested that the course could have less of a medical and diagnostic focus and more of an experiential focus; for example, focussing on the concept of self-management as an ongoing process and inviting someone with bipolar disorder to a session to relate their experiences of the illness and how they cope. Hatfield's research on psychoeducation in mental health settings emphasises that psychoeducation is an ongoing process which extends beyond participation in a programme and requires further input from a variety of sources [137]; a concept which may enable participants to understand that a long-term process of learning and ongoing support is required beyond the scope of a psychoeducation programme.

It was also recommended that concerned relatives should be involved with the psychoeducation groups and it would be useful to provide sessions specifically for them to enable them to better understand the condition. Regarding continuation of the groups after the course, some participants suggested that occasional follow-up sessions be arranged to see how participants are getting on, either with or without facilitators and arranged by BEP-Cymru.

Participants' perceptions of the facilitators varied depending on whether they were based in North or South Wales. Facilitators were praised primarily for their accepting, caring and down-to-earth approach and for balancing the formal and informal aspects of the course, and were also commended for being informative and professional. Some facilitators were also criticised for not managing dominant group members, poor time management, a "lecturing" style and putting the spotlight on people when asking questions around the room. Some recommended that facilitators should: ask people how they are feeling and provide more opportunities for them to talk, allow more time for group members to get to know each other in the first session, present open-ended rather than close-ended questions for the ice-breaker exercise, ask participants to suggest and negotiate

the rules of the group, talk more personally and conversationally rather than from lecture slides, and prevent dominant people from digressing off-topic by taking note and address their points later.

Participants stated the importance of sharing personal experiences, supporting others in the group and offering advice. They felt that being part of the group was empowering and reduced the sense of stigma surrounding bipolar disorder. Other psychoeducation programmes for bipolar disorder found that participants learned coping strategies from sharing experiences with others in the group [135] and they also welcomed the opportunity to advise others and learn more about the illness through doing so [135, 138].

Facilitators' accepting attitude towards them and the humour within the groups was important for "normalising" the illness, and participants reported feeling less isolated and lonely through meeting others perceived to be "in the same boat". Some participants compared themselves to others within the group to assess how well they were coping, and felt that it was important to have some people of a similar age in a group together; social comparison was also noted to be important for participants of an internet-based psychoeducation programme for bipolar disorder [138]. A few also reported that attending the first group meeting felt intimidating as it was the first time they had met others with bipolar disorder. These findings support outcomes of previous research on psychoeducation for bipolar disorder; in particular, improved self-confidence in participants' ability to communicate with others regarding the illness [139], enhanced self-acceptance [139] and a reduced sense of stigma, shame and feeling "worse" than others [135, 136].

When asked whether they would have preferred group or computer-based psychoeducation for bipolar disorder, participants commented that a computer-based course may have been easier for some to access and would have been better if they were feeling low or reluctant to socialise, although online forums may be problematic for those with low computer literacy or for those who feel intimidated by online forums. Many felt that it was useful to share experiences within a face-to-face group and receive immediate and in-depth answers to questions from group facilitators. Participants of another psychoeducation programme for bipolar disorder similarly reported that the group facilitators' explanations were particularly valued, as they did not receive such clarification within their clinical consultations [135].

7.4.1.3 Impact of BEP-Cymru

Although some participants reported that they did not benefit from the groups because they had not attended many sessions, some participants appreciated the course despite already knowing much of the information presented because the course confirmed their previous knowledge and gave them an opportunity to meet and share experiences with others. A number of participants reported making new friends on the course, no longer felt alone with having the disorder, accepted their diagnosis and their responsibility to self-manage their condition, and understood themselves more. Some participants gained insights into the illness, recognised their personal triggers, and felt more confident and stable as a result of the course. Others reported becoming less resistant to taking medication and felt better able to explain their condition. Enhanced commitment to treatment and improved illness awareness following group psychoeducation has also been found in a Spanish study of psychoeducation for bipolar disorder [135].

7.4.1.4 Definitions of bipolar disorder and identity talk

Participants defined bipolar disorder during the interviews both explicitly, when clarify bipolar disorder to be a “condition” rather than an illness, and implicitly, through identity talk. One participant regarded herself to be special in having bipolar disorder and another repeatedly stressed his dependence on medication to be “normal”. Similarly, a study of patients’ experiences of group psychoeducation for bipolar disorder in Spain found that some patients reported starting to lead a “normal” life following the intervention, in that they returned to work or re-engaged with household responsibilities [135]. Additionally, social support within the context of an internet-based psychoeducation programme for bipolar disorder has been found to contribute to “normalising” the illness, through the process of social comparison and receiving advice offered by informed patients which may be grounded in their experiential knowledge [138].

7.4.2 Strengths and weaknesses

The rich qualitative data from this study has provided insights into how patients experienced a new, group-based psychoeducation programme in Wales. The findings relate to the feasibility, acceptability and impact of the programme from participants’ perspectives and present their recommendations for improvement. Male and female participants from South and North Wales

were interviewed to explore perceptions of groups in different locations and with different group facilitators; and I was able to interview those who had only attended a small number of sessions to find out why they had dropped out. The flexible and responsive interviewing style enabled participants to discuss aspects of their experiences which were relevant to them, and minimised the risk of biasing participants' responses.

This study may have benefitted from having a portion of the data double-coded for reliability. I also did not interview participants who failed to attend a single session, despite signing up to participate; if I had then this may have aided understanding of barriers to attending. The number of interviewees was relatively small, although the sample was carefully selected and interviews were in-depth. Furthermore, additional follow-up interviews at one year may have provided insight into how participants' perceptions of bipolar disorder change over time and the longer-term impact of the intervention.

In Chapter 9, findings from this study are compared with the qualitative findings from the interviews with BEP-Cymru group facilitators (Chapter 8), interviews with participants of the Beating Bipolar trial (Chapter 4) and the analysis of the Beating Bipolar online forum (Chapter 5), and assessed in relation to the quantitative outcome data from BEP-Cymru participants (Chapter 6).

7.4.3 Conclusions

This is the first in-depth qualitative study of patients' perspectives and experiences of a UK-based group psychoeducation programme for people with bipolar disorder. This research demonstrates that group psychoeducation may impact on participants' perceived social support, knowledge and acceptance of bipolar disorder, personal insights, attitude towards medication and access to services. The key recommendations presented for improving the content and delivery of group psychoeducation for bipolar disorder may enhance engagement and widen access to such programmes. Future research into psychoeducation for bipolar disorder may explore how to target and engage people of diverse ethnic backgrounds, men and those in lower socioeconomic groups who are less likely to access healthcare services.

Chapter 8: Facilitators' perceptions of a group-based psychoeducation programme for bipolar disorder: a qualitative analysis

8.1 Introduction

I conducted in-depth qualitative interviews with facilitators of BEP-Cymru to explore their perceptions of the programme and assess the fidelity of programme delivery. My main aims were:

- To assess how BEP-Cymru was delivered by facilitators in North and South Wales
- To assess the extent to which the programme was delivered according to the manual
- To explore facilitators' experiences and perceptions of the programme and group participants
- To explore the feasibility and acceptability of the programme from facilitators' perspectives
- To identify areas for improvement and regional differences for future roll out of the programme

8.2 Methods

The theoretic approach, conduct of the interviews and method of analysis was the same as for the BEP-Cymru patient interviews (see Chapter 7 for details). All six group facilitators were invited to take part in this study via letter along with the patient information sheet and consent form. Consent was obtained face-to-face. I drafted a topic guide for the semi-structured interviews with BEP-Cymru group facilitators (see Appendix 9). The topic guide was designed to explore facilitators' experiences and impressions of the programme, contextual factors, what they found to be useful, what could be improved upon and their perceptions of participant engagement with the programme. I obtained informed consent from all BEP-Cymru group facilitators to take part in the interviews. Four facilitators who were based in South Wales were interviewed face-to-face, and two facilitators who were based in North Wales were interviewed by telephone. All interviews were audio-recorded, transcribed verbatim and analysed by hand using thematic analysis [82].

8.3 Results

Key emerging themes were grouped within the following categories:

- Structure, content and delivery
- Perceptions of the groups
- Differences between sites
- Personal insights and roles
- Challenges faced by facilitators
- Issues surrounding recruitment
- Areas for improvement

8.3.1 Sample characteristics

Of the 6 group facilitators:

- 5 were male and 1 was female
- 4 led groups in South Wales and 2 led groups in North Wales
- 3 were Psychiatrists and 3 were Community Psychiatric Nurses

8.3.2 Structure, content and delivery

8.3.2.1 Format

The course manual recommended a formal presentation delivered by the facilitators followed by a group exercise and a group discussion. In practice, this format differed depending on the facilitators' styles of delivery. In South Wales the didactic element of the presentation was preserved, although facilitators in South Wales also reported rushing to get through the material in time.

"[...] there's a kind of more didactic element to each session (.) which is for about 20 to 30 minutes of telling them about the topic of the day in a more formal presentation and then after that the next job of a facilitator really is to um get people to conduct an exercise and help them think about the topic of the day in a bit more detail (.) and to process it a bit (.) deeper (.) then (.) after coffee break your job as a facilitator really is to let people (.) to guide a discussion really and to keep the discussion as

free-flowing as possible but also to try to keep it on the topic of the day and try to ensure that everyone has an opportunity to speak and that no one person dominates too much and that you know that it's done in a constructive way that people interact in a constructive way"

F1, South Wales

Facilitators in North Wales adopted a more fluid approach in that they combined the group discussions with the presentations and exercises, and they did not report feeling pressed for time.

"Well ours actually ran slightly different (laughs) [...] because it was meant to be divided up into the presentation that bit always happened, the presentation, but the exercise and the discussion were often entwined. [...] because what we found was people were, when people were actually going with it and getting involved in the exercise they wanted to discuss things at the same time"

F5, North Wales

Facilitators found that having a second facilitator present was helpful as they were able to support each other, and give each other a break from the spotlight when needed.

"[...] we've done sessions with one person but it's quite good for two people to do it because the other person can jump in if somebody's having a difficult time or back somebody up"

F4, South Wales

They recognised that different groups had different needs and it was important to respond to those needs flexibly. Some groups would be more vocal and wish to discuss topics more than other groups which were more reserved.

Facilitators stressed the importance of tea and coffee breaks for participants to take a break from the structure of the course and get to know each other informally and have a cigarette. Having tea and coffee facilities in a different room from where the course was held gave participants an opportunity to talk without the presence of the facilitators.

"I don't think it's a good idea having tea and coffee in the room because I think you should get, let people get out, go and have a cup of coffee and talk outside the room, rather than talking in the room because A: you're stuck in the room for two, over two hours and B: it gives you a chance to talk

quietly, away from the facilitators, away from other people. Or go for a fag if you want to. Um, the one in Newport was lovely because there was a cafe right next door to it"

F3, South Wales

8.3.2.2 Timing of sessions

Facilitators in South Wales felt rushed in order to cover the material in the sessions, although they reported that two hours was a sufficient amount of time and longer sessions wouldn't be feasible to sustain participants' attention. Other facilitators felt that two hours offered plenty of time to cover the material.

As with the group participants, facilitators found that evening sessions were preferable to accommodate participants with day jobs, although many participants were also able to attend daytime sessions.

8.3.2.3 Course materials

Facilitators found the structure, pace and content of the modules to be helpful and pitched at an appropriate level for delivery and participants' understanding.

"So I must admit we were sort of expecting it to be a bit of a shambles, the first group, if I'm honest but actually we were really surprised how, the actual material does actually guide you through very well actually [...] the material that's there is a very good framework to go in from scratch and run the groups and actually, maybe do a pretty good job, I feel we managed to do a pretty good job of that [...] we had the sort of manual itself and I think that was really pitched at about the right level of detail and pitched at the right level of structure and so I think [...] if you're making the assumption that they're going to be delivered by clinicians that have got reasonable experience of the disorder itself then actually the materials you've got are pitched just right in terms of leading someone through the presentations"

F6, North Wales

They commented that participants were particularly engaged with the session on medication and found information on side effects to be particularly useful. Some participants were reported to

discuss their medication options with their psychiatrists as a result of feeling more informed from the course.

“But the medication sessions were quite (laughs) lively. [...] there were lots and lots of questions. [...] we did a lot on the side effects of the medication et cetera for them, what they could actually do to reduce those effects [...] and some of them had actually gone off and discussed it with their psychiatrists after their medication [...] I think they felt that they were, they were more able to say ‘look I’ve done this, I’m now doing this and I don’t think this medication is working for me’, they feel more empowered to be able to say to them, ‘look OK fine, it’s OK for you to say keep all the side effects but I’ve got all the side effects from my medication and I’m still not well’ [...] Because I think sometimes I think some people are quite frightened of psychiatrists”

F5, North Wales

Although the majority of participants were observed to have appreciated the information regarding medication options and side effects, facilitators in South Wales noted some participants’ resistance to the medical orientation of the course.

8.3.2.4 Community venues preferable to hospital settings

In line with what the group participants said, most facilitators stressed the importance of holding the groups at community-based venues, away from medical and social services settings. Facilitators appreciated that participants may attach a lot of stigma to medical settings, which would negatively influence their perception of, and involvement with, the course. It was important for venues to be accessible in terms of being located centrally within a town and with parking facilities.

“I think it’s important to have somewhere that is non-medical, non-social services, um, somewhere which is, where people can actually feel they’re relaxed, they don’t feel stigmatised by going there and I think we were very lucky here with the two venues we had. They were both art centres [...] and it was something that you know I said from day one really, I wasn’t going to look for, you know, a social services building or a health building because I think people don’t want to go there for things like groups, they’ve got enough of that if [...] they’re seeing their GP or if they’re going to see a psychiatrist, they’ve had enough of that and they all said they really enjoyed the venues (.) um and that it was so pleasant, because in Llangefni some of them had been in the past been involved in an anxiety group in the voluntary place, [names venue] and they said, ‘oh it was awful there, I went

once, I never went back.’ Because they said it was dark a dreary and it was associated with people having mental health problems”

F5, North Wales

Facilitators in North Wales made a conscious effort to select venues which were hubs of the local communities. They chose community centres which are referred to as art galleries which house cinemas, function rooms and cafes. Participants of the North Wales groups were said to have really appreciated the venues and felt at ease there, and this was reflected in the interviews with participants in North Wales.

“[...]the gallery in Caernarfon has a sort of cinema and they all have cafes there as well, so they are, these are quite small communities and actually these galleries are actually impressively well used, the one in Llangefni is really buzzing actually, I’ve never been there during the week days but I was staggered by how busy it was actually, um, so they are real hubs actually within the local communities [...] so people know these galleries and there’s easy parking there and people really appreciated being able to have these groups within that setting”

F6, North Wales

In South Wales, however, one facilitator felt that an NHS venue would add a sense of authenticity and credibility to the programme from participants’ perspectives. Facilitators of both groups recognised the importance of a private setting.

“[...] it was a very nice room [...] but it did have a big glass window by the door and you know if you’re having slides with bipolar education, you know that’s opening onto a sort of public area [...] it was [...] perhaps not what we wanted”

F2, South Wales

As with the group participants, some facilitators stressed the importance of light and spacious rooms.

8.3.3 Perceptions of the groups

8.3.3.1 Participants' knowledge and insights

Facilitators commented that participants seemed to have learned a lot from attending the course, and for some the course made a big difference to their lives. Facilitators found this observation to be very rewarding and encouraging.

“And the final exercise, you know the one on week ten, when they go on the holiday to Australia (.) That in the Caernarfon group, because that was where we finished first, that was just amazing because it just proved how much they had actually learnt in the ten weeks because they came out with so many things of the precautions they'd have to take and how'd they'd sort everything out, how they'd sort all their medication out, it was fantastic, it was so lovely to see how much they had actually learnt in the ten weeks”

F5, North Wales

They commented that the course had enabled some participants to come to terms with their bipolar disorder so that they could accept their diagnosis and feel empowered to manage their condition.

Some facilitators stressed the importance of the group exercises to give participants the opportunity to gain personal insights into their bipolar disorder. Facilitators observed that participants were learning a lot about their triggers from sharing their work in the groups with their close families and friends.

“[...] particularly in the Llangefni group it was quite evident that a lot of the families were totally unaware of what people's triggers were and even looking for them and it was quite interesting because after we'd done the week on looking at their triggers and what they could do about it, we asked them to share that with whoever they were living with and to bring back if there was anything different and they said 'oh no they won't see anything different', we said 'no you need to ask them because they may actually be seeing something other than (.) that you may not notice as being your first signs.' It was quite interesting because a majority came back saying that their partners had told them 'well actually that's not your first sign, this is what I see first.'”

F5, North Wales

One facilitator commented that the ideal time to offer the course would be when someone is newly diagnosed, because an early intervention may lead to a better outcome and reduce fear of the diagnosis.

Facilitators from both groups observed that the course was filling a gap in routine care. Participants were not getting basic information on bipolar disorder and self-management from the NHS services, and many were asking the facilitators why they had not been informed about certain things by their health care worker.

“[...] by the end I came to realise that a lot of the stuff which I thought was relatively basic psychoeducational material and thinking hadn’t actually been delivered within the NHS really for the vast majority of participants within the group and I was quite surprised by that (.) so that even very basic information about what causes bipolar (.) how treatments work (.) how you can do relapse prevention work (.) [...] seem for most people to be quite novel [...] I think that’s where this programme definitely is filling a gap in routine care where it’s often easy to assume that people get these interventions at this level but actually day-to-day it doesn’t really happen”

F1, South Wales

8.3.3.2 Group dynamics

Facilitators felt that it was helpful to have people from different backgrounds, of different ages and with different lengths of diagnoses in a group. This enabled participants to learn from each other’s different experiences. Some noted that groups where there was a big age gap between participants groups bonded less well than if participants were of similar ages and had similar lifestyles. Whether participants were employed or not may also have been a contributing factor to how well they bonded with each other.

They observed that initially participants were reserved and felt awkward communicating with each other, but this initial shyness dissipated as the weeks progressed.

“I’ve seen dominant characters begin to be challenged I guess as other people get confident as well”

F4, South Wales

As with the group participants, facilitators in North and South Wales commented on the existence and function of humour within the groups. One facilitator in South Wales felt that participants' use of humour with each other was a sign that they had gelled as a group and enjoyed each other's company.

"[...] the humour as well is the other thing, the fact they're able to joke with each other or mock in a friendly way, you know have a laugh with each other, as I say, you know some, often, very often characters in the group who might be very outspoken, people feel comfortable to make a comment or tell them to be quiet or to shut up or laugh at them, you know without it being unpleasant you know. So I think those sort of things are the indicators that they've gelled as a group. (.)it's again a kind of revelation that sort of humour crops in, that I didn't expect it to be quite, people having fun I suppose in the group that was going to be a very serious learning about your illness but actually it has, it is quite a lot of fun I think for them"

F2, South Wales

Facilitators in North Wales joked with each other and had a light-hearted approach to delivering the course to participants. One facilitator in North Wales felt that participants responded very well to the co-facilitator's conversational, down-to-earth and whimsical approach.

"[...] we would tend to play a little bit of a double act I guess and that's partly because we've worked together for a long, long time anyway and we know each other's styles as it were and [F5] has a very conversational style and has a sort of Irish blarney really that enables her to deliver things in a very down to earth way, sticking, really sticking to the script but she has a very easy going style about her which I think people respond very well to actually, um. I think at the same time you do get a clear sense that she knows what she's talking about, which is important [...]"

F6, North Wales

Facilitators of both areas were surprised by the intimate nature of some of the personal experiences participants' disclosed within the groups in the first few meetings. Occurrences such as child abuse, rape and violence were disclosed and some participants became very upset. Other group members were supportive of each other and were mostly non-judgemental.

Both facilitators in North Wales remarked on the stark contrast between the two groups they facilitated. The group in Caernarfon was characterised as being rowdy and boisterous, whereas the

group in Llangefni was more sedate. The nature of the two groups was observed to reflect the socio-cultural differences of communities within the areas.

F5: (.) but the difference (F6) and I found was, the Caernarfon group could be quite boisterous is we'd say, whereas the Llangefni group were more sedate. (.) But that is quite, I know this is going to sound judgemental, it's quite typical of the two areas [...] some of the people in the group I would say in Llangefni would be more reserved [...] but they, Llangefni group they definitely gelled as well [...]

RP: So what is it about the areas then that's different?

F5: Well Caernarfon [...] people there will take no nonsense from anyone, if they don't like you you'll know it [...] They have no qualms about telling you. [...] There's some big housing estates there, there's a lot of crime there and people aren't afraid to tell you what they think, so if they didn't like the group they would have told us straight, there'd been no qualms (laughs). [...] We'd have known very quickly that they didn't like the group because they would've said.

F5, North Wales

Facilitators in South Wales reported having participants who had strongly opposing views on some issues which may have caused tension if they were grouped together for the group exercises. For this reason, facilitators in South Wales mindfully avoided mixing certain participants for group exercises.

8.3.3.3 Social support

Facilitators remarked that they felt that the therapeutic element of peer support made the most difference to participants. Learning from others' experiences, making friends with others with bipolar disorder for the first time and having the opportunity to talk openly about their illness with their peers gave participants a sense of mutual support and contributed to their self-acceptance.

RP: "What do you think made the most difference to participants from the programme?"

F1: "Um, well I think that peer support is the most (.) I mean I'd like to think the information was very useful to them and I think that's true but I think the experience of speaking to other people with the same diagnosis and hearing how they've overcome obstacles I'm sure that that's a key therapeutic element of this [...] anecdotal evidence to support that would be that you know people arrived early for sessions, they engaged with each other before the sessions started, they were very keen to talk to each other during the coffee break and then they often stayed behind afterwards

speaking to each other, not necessarily speaking to the facilitators and they've expressed an interest to continue seeing each other as a group after the sessions finished, so I'm sure there's a very strong kind of therapeutic element to do with peer support really"

F1, South Wales

One facilitator commented that participants felt less lonely and isolated with having bipolar disorder when they met others with the diagnosis living in close proximity to them; a sentiment which group participants also expressed in the interviews.

"Because also they said you know, you get this diagnosis and you feel really alone [...] and it was interesting because two of the group lived quite near each other and they didn't actually know each other and they said 'oh well that's quite nice now, at least I know that you actually also have the same illness as me, I thought I was the only person in the place who had it' because it can be very lonely, can't it?"

F5, North Wales

The routine regularity of the weekly group meeting offered stability for some participants, particularly for those whose lives lacked structure. Facilitators commented that some participants appreciated and depended on the weekly meetings to the extent that they missed the meetings when the course ended.

8.3.4 Differences between sites

8.3.4.1 Facilitators in North Wales emphasised lifestyle changes

Facilitators in North Wales repeatedly emphasised the importance of a healthy lifestyle throughout the course, beyond the single session on lifestyle within the manual. Their key messages were to exercise, cut-down on one's alcohol intake, have a healthy diet and quit smoking. They observed that some of their participants had given up smoking, had changed their diets and were doing more exercise.

"[...] during the ten weeks there were some people who gave up smoking and people were reporting changing their diets and some people were taking up more exercise [...] There was a lot of discussions

around that actually and we pushed that heavily and again, partly because we've been involved with other local initiatives here [...] with the lifestyle change, it's just something that's really, really high on our agenda because of other work that we've been doing over the years and being very, very aware [...] that this is a patient group that is particularly disadvantaged in terms of physical health care outcomes and access to services, it's a big thing for us [...] so it's something that is really important to us, the exercise and the healthy diet, cutting the alcohol down, stopping smoking, those are the four key messages that have always been important to us really"

F6, North Wales

8.3.4.2 Caernarfon group met up outside the group setting

All members of the Caernarfon group made friends with each other and met up socially on a weekly basis outside of the group meetings. The group comprised six women of a similar age who were all unemployed.

"[...] they actually started meeting up even outside of the group. (.) Which was something most of them hadn't done previously, quite a few of them in the Caernarfon group had described themselves as actually not having any friends and actually became very supportive of each other [...] and they started meeting up for lunch [...] they didn't even do it on the same day, they did it on a different day [...] and they're looking at setting up a Bipolar UK group in Caernarfon. But they were a very different group in Llangefni, they did not socialise outside of the group"

F5, North Wales

8.3.4.3 Facilitators in South Wales were challenged by group dynamics

Only facilitators in South Wales struggled to keep participants focussed on the material without discussions digressing too far. They were concerned about offending people by quietening them and were less assertive in dealing with participants than facilitators in North Wales, who commented that it was easy to halt wayward discussions.

" [...] occasionally there's issues where the discussion, trying to get them back on track or where the you know, getting people when it sort of goes off tangent, trying to keep people on target, um, trying to sort of control that, so I suppose more difficult sometimes because you do feel, although we say at

the start, you know these are the rules of the group and you know and we may need to interrupt you [...] telling them to be quiet [...] trying to maintain order I suppose is difficult without trying to offend people”

F2, South Wales

Facilitators in South Wales found it challenging to give everyone an equal opportunity to contribute to discussions, through silencing more vocal and forthcoming participants and inviting quieter participants to speak.

“The majority of participants did actually contribute um to the discussions really and you know it was actually a bit of a challenge to make space for everyone to be able to say something and a challenge to get one or two people to perhaps say a bit less and to give other people a chance to speak”

F1, South Wales

In contrast, facilitators in North Wales had no problem with assertively dealing with more dominating group participants. They referred to the rules set out at the beginning which stated that facilitators may ask participants to stop speaking in order to keep to time and to enable everyone to have a fair opportunity to contribute to discussions.

“[...] because we had the rules at the beginning, you know ‘don’t get upset or insulted basically if we have to stop and move on from you’, what we tended to do was to say, ‘hold on just a moment, right OK fine, you’ve said that, can we now just listen to what [names participant] has to say?’ (.) Who was trying to speak [...] and I found that quite easy to do (.) And must say it is quite easy to be able to do normally, to be able to somebody, ‘well you know, OK great, can you hold onto that for that just a minute while we have a listen to what’s going to be said here?’”

F5, North Wales

8.3.4.4 North Wales enabled an inpatient to attend the group

Facilitators in South Wales reported not allowing people to attend the group sessions if they were experiencing a severe relapse; however, facilitators in North Wales encouraged one participant to continue to attend the group when she was admitted to hospital for becoming manic. The facilitators reported that having her attend the group as an inpatient worked really well and the other participants were supportive towards her and visited her in hospital.

“[...] there was a core six of them in the end, um one became unwell during the group and was actually admitted but even came from the inpatient unit to the group. (.) And ah, it worked really well [...] it was obvious to [F6] and I that she was a bit high [...] [F6] and I felt really that she was having an episode and that’s why she wasn’t sleeping. (.) But she still came to the group [...] they were just really supportive of her and some of them actually went to see her whilst she was an inpatient”

F5, North Wales

8.3.4.5 Facilitators in North Wales presented others’ coping strategies

Group participants’ personal experiences and ways of coping were anonymously shared by facilitators in North Wales to other groups alongside anecdotes from their clinical work with patients with bipolar disorder. These anecdotes were used to highlight useful coping strategies and enable participants to relate to real-life experiences.

8.3.5 Personal insights and roles

8.3.5.1 Role to inform and support participants

Facilitators felt responsible for conveying up-to-date information and being fully informed about bipolar disorder. They referred to their role as being that of “expert”, “teacher” and “presenter” to fully impart all relevant information about bipolar disorder to participants.

“I see the role as ensuring that the information that’s provided is legitimate, yeah, so that there’s a bit of quality control on what people are told, yeah. (.) so that hopefully why being a professional is useful is [...] you can make sure that myths and half- truths aren’t perpetuated as they could otherwise be”

F4, South Wales

Some facilitators felt that it was their role to ensure that participants were informed about the routine care and check-ups they should be receiving. When participants realised that they were not

receiving certain important medical checks they promptly booked the necessary appointments with their GPs.

Facilitators adopted a pastoral role in the sense that they looked out for participants' wellbeing and took action if their mental health was becoming a cause for concern. Facilitators phoned participants between sessions to ask how they'd been getting on and to offer support.

Facilitators in North Wales spent additional time liaising closely with participants' mental health teams and key workers to ensure that participants were getting support and accessing services as effectively as possible.

"[...] there was quite a bit of [...] both within the group and after the group, spending time with individuals and then spending some time liaising with treatment teams for instance and key workers to make sure people were getting support and, um, so being careful you know not to stick out or interfere with the management plans that people had in place but just to make sure that we were communicating back to the relevant teams how people were in the groups and just making sure and helping to facilitate that they were accessing services as effectively as possible"

F6, North Wales

In contrast to their experiences of working in busy clinical settings, facilitators appreciated the time to interact with patients more informally and the opportunity to get to know them on a more personal level. Facilitators appreciated learning more about patients' experiences of the illness and getting to know them over the 10 week course.

8.3.5.2 Role to motivate and empower participants

Some facilitators reported that their role was to motivate and empower participants to take responsibility for their medication, lifestyles and managing their bipolar disorder. They felt it was important for participants to realise that the efforts they make to look after themselves make a difference to their health-related outcomes.

Others were reluctant to adopt a dictatorial approach with participants when conveying the health-related information. Rather, they focussed on valuing everyone's opinions and sensitively informing participants about potential risks. They contrasted their reflective approach with the more

prescriptive approach presented by Colom and Vieta's psychoeducation programme in Barcelona, which BEP-Cymru was based on.

"[...] it wasn't telling people what the appropriate response was, it was just helping people themselves to sort of make a decision to how they were going to sort of deal with that [...] just to really allow people to discuss that and try and reach some views themselves [...]"

F6, North Wales

8.3.5.3 Facilitators' knowledge, awareness and attitudes

Many facilitators remarked that facilitating groups improved their knowledge and awareness of bipolar disorder and challenged their professional attitudes. It also helped some facilitators to reassess how they convey health information to patients.

"Because each time you do it, it does challenge you as a professional, in what you feel and what you think, what your knowledge and attitudes are [...] I think it makes you assess or reassess what you know about bipolar disorder. It really helps you think about how to communicate what your understanding is, so I think it really helps you think about the best way in order to get concepts across"

F4, South Wales

"[...] it would be ignorant to say that you know all about bipolar, when you do the groups, because you always learn new stuff from every group"

F3, South Wales

Some facilitators learned new things from hearing participants' experiences of the illness; for example, idiosyncratic relapse signatures such as a flickering eyelid or lots of static electricity when about to become high.

"I think it's made me a better clinician because you can think you know about a disorder and you can do research on disorders but there are lots of nuances to this that you don't [...] even pick up over many years of clinical experience [...] as I've learnt through the sessions, people have idiosyncratic relapse signatures [...] like one person said that their eyelid begins to flicker in a sort of anxious way"

and that that's a really strong sign that they might be going to relapse which obviously isn't something you read about in text books"

F1, South Wales

8.3.6 Challenges faced by facilitators

8.3.6.1 Managing group discussions

Facilitators in South Wales found managing participants' discussions of their negative experiences of healthcare. In such instances they tried to steer participants' discussions in a more positive direction and prevent negative comments about healthcare professionals.

One facilitator was concerned about gauging the right intellectual pitch for the group, and commented that some participants may require more detailed information and others may require more simplistic information depending on their intellect.

The importance of having a mental health professional present to answer participants' questions was noted by some participants. Some facilitators were challenged to seek answers to some questions posed by participants from academics who study bipolar disorder.

F3: "I think as long as there's somebody in there who has some sort of professional qualification because there are questions people ask in groups and we're not sure so we just go off and ask somebody else. Like um, if you're high are you more likely to get static energy, static electricity (laughs) because one person said it and then two other people said, 'yeah I get that as well'. And we couldn't work out why, apart from them moving faster (Laughs) so perhaps they pick up a static charge"

RP: "And you found an answer for that?"

F3: "No, everyone laughed at me (laughs) all the academics did anyway (.) Yeah, static yeah, buzz, too much electric, perhaps that's what it is when you're high you've got too much electricity buzz"

F3, South Wales

Some facilitators found it difficult to judge when to challenge others and when to accept their viewpoints as having stemmed from their personal experiences.

Facilitators in South Wales described their need to manage participants' expectations or false hopes early on in the course. They dispelled the notion that attending the course would be a "cure" for the illness, that the groups are educational rather than group therapy, and explained that not everyone works well with group work.

"[...] we try to dispel [...] at the start, this idea that it's going to be a cure for their bipolar, saying that it's going to be helpful and has been shown to be helpful but it doesn't, it's not going to say that that you come on this course you'll never going to have an episode of mania or depression again"

F2, South Wales

8.3.6.2 When participants became unwell

Facilitators in South Wales emphasised that participants should not participate in sessions if they were experiencing severe bipolar episodes. Otherwise their involvement may interfere with the group dynamic, it may remind other participants of their vulnerabilities, and make controlling the group a more difficult task. In contrast to this perspective, facilitators in North Wales allowed some participants who were experiencing severe bipolar episodes to continue to attend the sessions if they were able to do so because they felt that the group support and information would benefit them.

Some struggled to know how best to intervene when participants became noticeably unwell. They were reluctant to notify participants' health care providers, especially without their prior consent.

"I've had to have that, a discussion with somebody to say, 'look I want to, I'm concerned enough to contact your CMHT [Community Mental Health Team]' but that person said, 'I think I'm going to do that myself, I'll do that myself' [...] but I can't contact him at the moment so, it does cause anxiety, you think 'did I play that right?' Should I have just said 'look, I'm concerned, I'm going to contact your CMHT?'"

F2, South Wales

8.3.6.3 Feeling nervous or insecure

One facilitator described feeling of nervousness and insecurity, particularly when starting a new group and when evaluating why participants dropped out.

RP: "What's been most challenging for you about running the programs?"

F3: "Um, I think it's just getting the first few weeks, getting to know people, you feel a bit nervous talking to them [...] there's a lot of things that weren't great, I mean one of the things (.) is, you know obviously, people don't turn up all the time (.) and it's a shame (.) And then you think, you start thinking was it because the course wasn't very good or was it because they couldn't come and then you speak to them afterwards and they said it's because they couldn't come [...] I felt like they were missing out and then you start thinking 'gosh is it uh, was it me making it not very good?'"

F3, South Wales

8.3.7 Issues surrounding recruitment

8.3.7.1 Refusing potential participants

One facilitator in South Wales described having to refuse potential participants from enrolling on the course. One potential participant was refused on the basis of a conflicting diagnosis and advice from his consultant regarding his vulnerability and the possibility that he may pose a risk to other participants. Another potential participant was refused on the ground of a recent conviction for sexual offences, which may have concerned other group members if the information was disclosed.

8.3.7.2 Persuading mental health teams to refer their patients

The main issue surrounding recruitment from all sites concerned persuading reluctant mental health teams to refer their patients to the course. Some healthcare professionals felt that their patients were unprepared to attend the course and felt protective of their patients. Other healthcare professionals were concerned that the course may cause problems for patients or upset them.

"If you have a team with poor morale they don't seem to be very proactive in referring people on. Some health professionals have mentioned that they think 'yes I have got people who are bipolar but

I don't want to refer them because I don't think they're ready for a course like this.' My feeling on that is, well it's, that's not your decision to make, it's up to the person to decide that and they should have the knowledge but you know that still doesn't mean to say that they won't be protective"

F2, South Wales

Facilitators reported that some healthcare providers may feel that they were interfering with the care they were providing by offering the course and lacked confidence in the benefits of the course.

"[...] I suspect services potentially may feel that people are coming in and interfering or you know, will be producing patients that are more critical, yeah, less willing to accept that their management may be judged or people (yawns) may just not believe that it does any good, you know, that it's not, they're not convinced of the or they don't know about the evidence base suggesting that this sort of thing is important to do"

F4, South Wales

Facilitators in North Wales commented that they had been working very hard to push the course with the local community mental health teams and key workers in order to obtain referrals. They conducted follow-up visits with teams and key workers who were not referring their patients and questioned why this was the case with them and their managers. They felt that it was unacceptable for eligible patients not to be informed of the course and referred if they wished to take part. They also acknowledged that as participants feed back their positive experiences from the course to their key workers they would expect to see more referrals coming through.

"[...] we were fairly intensively badgering the teams, the community teams and that's the biggest barrier [...] the single biggest barrier to delivering stuff is the key workers. [...] we've done sort of visits to the teams as a whole and then followed that up with individual contacts to key workers and when we're not getting the referrals through and saying 'look we're expecting you, you know everybody you see with bipolar disorder should have the opportunity to have access to these groups and we haven't had any referrals from your team, why is that?' [...] and ultimately we've had to apply pressure at the senior managers to say, 'we're not getting the referrals through, why not? This is not acceptable.' So we've had to push it pretty hard and I'm sure we haven't made friends in the process [...] the funding will probably run out just at the time when people are latching on to this, much more willing to refer and stuff.

F6, North Wales

8.3.8 Areas for improvement

8.3.8.1 Less didactic teaching and more free discussions

Facilitators in South Wales suggested that sessions may benefit from less didactic teaching (meaning presentations) and more time for free discussions. Facilitators in North Wales incorporated discussions throughout the presentations and exercises and so didn't feel short of time for free discussions.

They noted that different facilitators have different styles of leading the groups: some lecture more whilst others enable more discussion around a topic.

"I think it's better to let the self-help element enter the group. As long as you're sharing the basics with them or giving them the basics then letting them develop it because I think they'll probably learn more from processing it themselves, rather than listening to someone going on for a long time"

F3, South Wales

8.3.8.2 Continuity of the groups

Facilitators recognised that continuity of the groups once the programme had finished may be an issue for some participants who appreciated the regular face-to-face peer support. They invited representatives from the Manic Depression Fellowship, now known as Bipolar UK, to attend a session to inform participants of their local self-help group meetings.

In accordance with group participants' comments, some facilitators reflected on the usefulness of a refresher session for participants to meet again and revise what they had learned.

"I think that to provide some refresher session or perhaps to recap on what they've learnt in the group might be useful"

F2, South Wales

One facilitator remarked that if the groups were to be continued for a longer period participants may become dependent on them for their wellbeing.

8.3.8.3 Improving content

Mirroring the group participants' feedback, some facilitators acknowledged that the life-chart exercise was distressing for some participants and recommended that it be improved in some way to make it less of a concern.

"[...] some people have found life charts quite challenging, so it's although it is part of the programme we do say to people 'you don't have to do it if you find it upsetting'. Perhaps it's kind of ways of looking at addressing that sort of concern for people"

F2, South Wales

Facilitators opined that participants may appreciate a psychiatrist or pharmacist to be present for the session on medication to answer their specific questions.

"[...] when we do this sort of session on medication, I don't know whether people might appreciate it if we had either a psychiatrist or a pharmacist even there, somebody who's perhaps more versed in medication"

F2, South Wales

Facilitators noted that participants struggled to complete the lengthy evaluation questionnaire packs which they were asked to complete during the first and final sessions of the course and did not wish to do them. Participants complained that they took too long to complete and those with lower levels of literacy had particular difficulty with getting through them.

One facilitator commented that participants needed more information on debt within the course because the topic arose frequently and was particularly relevant to those who overspend when experiencing a manic episode.

"I think one thing that does, maybe that needs covering more really is about debt people get into. (.) Because that came out quite a bit really, of the amount of debt people got into particularly when

they were manic. (.) We did have, I think session four we had something on debt in but I think we need more on it, really all they were given was a booklet about debt”

F5, North Wales

8.3.8.4 A separate group for family members or partners

Facilitators in North Wales stressed that feedback from participants of both groups highlighted their need for a separate psychoeducation group to be run for participants’ key family members or partners. Facilitators said that participants wanted their close family members and partners to understand more about themselves and the condition. They suggested that they run a separate group for significant others who would be suggested by the patient participants, with the modules just as they are.

“The one big thing [...] that’s come across really consistently from both groups [...] very strong feedback for us was you need to run this group with the family, you know the significant others, the family or the carers [...] You’d say ‘who is the one person who is most important for them to really understand about your condition, who would that be and would they be keen to come to the group?’ We both said we’d be really keen to explore that, um and potentially just running the modules as they are, not re-jigging them at all, just running those modules as they are but with a group made up of the important family members or partners of people who have gone through the programme themselves and there is a real demand for that”

F6, North Wales

8.4 Discussion

8.4.1 Main findings

8.4.1.1 Overview of key themes

The following paragraphs describe the main findings which arose from the interviews within each domain. Table 20 presents the key themes.

<p>8.3.2 Structure, content and delivery</p> <p>8.3.2.1 Format</p> <p>8.3.2.2 Timing of sessions</p> <p>8.3.2.3 Course materials</p> <p>8.3.2.4 Community venues preferable to hospital settings</p>
<p>8.3.3 Perceptions of the groups</p> <p>8.3.3.1 Participants' knowledge and insights</p> <p>8.3.3.2 Group dynamics</p> <p>8.3.3.3 Social support</p>
<p>8.3.4 Differences between sites</p> <p>8.3.4.1 Facilitators in North Wales emphasised lifestyle changes</p> <p>8.3.4.2 Caernarfon group met up outside the group setting</p> <p>8.3.4.3 Facilitators in South Wales were challenged by group dynamics</p> <p>8.3.4.4 North Wales enabled an inpatient to attend the group</p> <p>8.3.4.5 Facilitators in North Wales presented others' coping strategies</p>
<p>8.3.5 Personal insights and roles</p> <p>8.3.5.1 Role to inform and support participants</p> <p>8.3.5.2 Role to motivate and empower participants</p> <p>8.3.5.3 Facilitators' knowledge, awareness and attitudes</p>
<p>8.3.6 Challenges faced by facilitators</p> <p>8.3.6.1 Managing group discussions</p> <p>8.3.6.2 When participants became unwell</p> <p>8.3.6.3 Feeling nervous or insecure</p>
<p>8.3.7 Issues surrounding recruitment</p> <p>8.3.7.1 Refusing potential participants</p> <p>8.3.7.2 Persuading mental health teams to refer their patients</p>
<p>8.3.8 Areas for improvement</p> <p>8.3.8.1 Less didactic teaching and more free discussions</p> <p>8.3.8.2 Continuity of the groups</p> <p>8.3.8.3 Improving content</p> <p>8.3.8.4 A separate group for family members or partners</p>

Table 20. Key themes arising from the qualitative interviews with psychoeducation group facilitators

8.4.1.2 Structure, content and delivery

Facilitators in South Wales felt that the two-hour sessions occasionally felt rushed and would benefit from more time for free discussion and less time spent giving formal presentations, whereas

facilitators in North Wales allowed time for participants to discuss topics freely throughout the presentations and exercises and felt that the two hour sessions offered plenty of time as a result.

Key recommendations were that it was helpful to have two facilitators supporting each other in running the groups, it was important to be flexible and responsive to the needs of different groups, and evening groups were recommended for participants with day jobs.

Facilitators noted that participants found the information on medication and side effects to be particularly useful, and many consequently discussed their medication options with their psychiatrist or mental health worker following the session on medication. Most opined that groups should not be held on NHS premises, because of the stigma attached to hospitals and medical settings from participants' perspectives, rather groups should be held in community venues which are centrally-based and have parking facilities. It was important for venues to have tea and coffee facilities, be light and spacious and offer privacy to participants.

8.4.1.3 Perceptions of the groups

Facilitators felt that the aspect of peer support was most therapeutic element of the groups from participants' perspectives, and was important for participants to share their experiences and offer support to each other to reduce any feelings of isolation and learn from the group. This finding resonates with findings of other studies of psychoeducation for bipolar disorder, as meeting others with bipolar disorder reduces participants' self-stigmatisation [135, 136, 138]. Participants were able to make friends on the course, and those of a similar age gelled better with each other than those of different age groups. Some facilitators felt that it was helpful to have a mix of different ages, backgrounds, occupations and lengths of diagnoses within a group for participants to learn from different experiences.

Facilitators witnessed humour emerging within the groups as participants' initial shyness towards each other dissipated. Research on staff's experiences of delivering mental health patient education groups found that staff noted participants' confidence growing throughout the course as initially shy participants talked at length in later sessions [140]. Also as the present study shows, this research also found that staff were aware of the group potential to create a sense of security and enable participants to share their experiences and give each other positive feedback and advice [140]. BEP-Cymru participants disclosed personal information early on in the course, which indicated that they

trusted the group and felt supported. The groups were perceived to offer stability for participants in terms of their regularity and the benefit of meeting with the same facilitators each week, which offered an intensive continuity of care that they would be unlikely to receive through usual care services.

It was observed that participants learned a lot from attending the course, and facilitators felt encouraged by participants' demonstration of what they'd learned in the final exercise which revises all the key learning points from the previous sessions. Facilitators stressed the importance of the group exercises for participants to gain insights into their illness, their triggers and early warning signatures. Some facilitators viewed that the intervention should be offered to all those newly diagnosed with bipolar disorder to inform them, reduce their fear of the diagnosis or of psychiatrists and improve their outcomes. The course was viewed to fill a gap within routine care where participants were not receiving basic psychoeducation to understand and self-manage their condition.

8.4.1.4 Differences between sites

Differences between groups were noted by facilitators, some groups were more sociable and forthcoming whereas others were more reserved. Group facilitators of a mental health education programme also noted that some group members became friends and socialised with each other beyond the group sessions [140].

Facilitators in South Wales frequently reported struggling with keeping participants focussed on the material and giving everyone an equal opportunity to talk, whereas facilitators in North Wales had no problem with instructing people to stop talking so they could move on to a different topic or let a quieter person contribute. This may have been because the groups in North Wales were smaller, and facilitators in North Wales were more experienced with facilitating patient groups and had better assertiveness skills than facilitators in South Wales. Facilitators in South Wales reported feeling uncomfortable with silencing participants who were digressing off-topic and felt that in doing so they were being rude, in spite of the rules they presented at the beginning of each course which advised participants not to feel offended if facilitators needed to stop them in their tracks if it's time to move on with the session or allow another person to speak.

Facilitators in South Wales took precautions not to mix people with strongly opposing views for group exercises in case this created tension. They also only allowed outpatients to attend the groups, whereas a participant who became hospitalised for a potential manic episode when attending a group in North Wales continued to attend the group as an inpatient. Other participants showed their support and visited the patient in hospital and the facilitator commented that the arrangement worked very well. It may be that because the groups in North Wales were typically smaller than the groups in South Wales the facilitators in North Wales were better able to manage the group dynamic when some participants became notably unwell.

The importance of a healthy lifestyle and making necessary changes to accomplish this was repeatedly emphasised by facilitators in North Wales throughout the course. They also presented anonymous examples of others' coping strategies from their clinical experiences and personal experiences which were shared within the groups, which they felt highlighted good practice, alternative ways of coping and to highlight the practical application of the course material.

8.4.1.5 Personal insights and roles

Facilitators described their role to be that of an expert, a teacher, a presenter, and to motivate and empower participants to take responsibility for their health and wellbeing. They adopted a pastoral role in looking out for participants and supported participants who they were concerned were becoming unwell. Many facilitators phoned participants between sessions to check how they'd been getting on that week, and in some instances they intervened with participants healthcare workers to ensure they were being adequately supported.

In contrast with their experiences of working in busy clinical practices, facilitators appreciated their time spent with participants to get to know them on an informal level and to learn more about bipolar disorder from them. Facilitating the groups enhanced facilitators' knowledge, awareness and attitudes towards bipolar disorder and people with the diagnosis. Mental health education facilitators interviewed in another study also reported appreciating seeing patients "in a different light" through the group sessions, and consequently developed their professional attitudes and awareness [140].

8.4.1.6 Challenges faced by facilitators

The challenges which facilitators in North Wales described solely pertained to issues surrounding recruitment (see next section 5.4.1.7), whereas facilitators in South Wales found curtailing participants' discussions of their negative experiences of healthcare and discussions which were off-topic to be problematic because they were concerned about offending participants by interrupting them; and they were also unsure of how to intervene when participants became noticeably unwell because of a reluctance to interfere with their healthcare.

Facilitators were sometimes challenged by participants' questions which related to bipolar disorder and sought answers from academic members of staff. They also felt obliged to dispel any false hopes or expectations regarding the course early on, such as any expectations of group psychoanalysis or hopes for enhanced wellbeing from attending the course. One facilitator felt a key challenge concerned how to engage participants suffering from social anxiety, as they may benefit from the course but feel reluctant to participate; as with other health education group facilitators the importance of actively involving participants was acknowledged [140].

8.4.1.7 Issues surrounding recruitment

Both sites faced issues surrounding recruitment which centred on persuading reluctant mental health teams to refer their eligible patients. Mental health teams and key workers were described to be reluctant to refer their patients for the following reasons: if they felt protective of their patients, if they thought the course would upset their patients, if they thought the course would not be beneficial to patients, if they felt a patient was unprepared to attend the course, or if they felt information from the course interfered with the care they offered or if patients consequently challenged them. Facilitators in North Wales persisted in pushing the course to mental health teams despite resistance and even complained to managers if certain people were not referring their patients. Facilitators described non-referrals to be "unacceptable" because patients had a right to access the course which could make a positive difference to their health outcomes.

Another issue surrounding recruitment was flagged by a facilitator in South Wales who described instances of having to refuse potential participants because of recommendations from their mental health worker of their unsuitability or because of their criminal convictions which may have concerned other group members.

8.4.1.8 Areas for improvement

Regarding the content of the course, facilitators recommended that more information should be provided on managing debt and the life-chart exercise should be improved so that participants feel less distressed. An important recommendation from facilitators in North Wales on behalf of participants was that a separate psychoeducation group should be run for participants' key family members or partners so that they may access the same material and learn about bipolar disorder to be able to better support their loved ones.

Facilitators seemed uncertain as to how best to support participants beyond the programme. They observed that participants frequently said they would miss attending the sessions when the courses came to an end and suggested refresher sessions to recap on the course material. Representatives from the charity Bipolar UK (formerly known as Manic Depression Fellowship) were introduced within the introductory group session and at the final group session to present information on the local self-help support groups the charity organises. Facilitators felt that these groups may help with the issue of continuity, but perhaps not sufficiently. One BEP-Cymru group in North Wales set up their own support group and in that way continued to meet as a group, which may be the ideal model for continuation without requiring the input of facilitators.

8.4.2 Strengths and weaknesses

This is the first qualitative study to examine group facilitators' experiences of leading psychoeducation groups for people with bipolar disorder. Interviews were in-depth and yielded rich data regarding how facilitators delivered the groups in practice, their perceptions of the group experiences, personal insights and challenges, issues surrounding feasibility and acceptability, areas for improvement and regional differences. The study has provided clear descriptions of how the groups were facilitated, lessons learned by facilitators and ways in which the programme may be developed. These findings may inform future roll-out of the programme, which is part of the reason for conducting a process evaluation. Additionally, facilitators' insights into how participants may benefit from BEP-Cymru provide a counterpoint for interpreting patients' data relating to potential therapeutic mechanisms and impact. This consideration will be explored in Chapter 9.

For the purpose of assessing fidelity, the study may have benefitted from the use of complementary observational methods to systematically observe and record how the groups were delivered by facilitators at each of the sites. This would have been useful to compare what facilitators said they did with what they actually did, in terms of their styles of facilitation and adherence to the manual. Other weaknesses include the small number of intervention staff and that it was not possible to double code any data, which may have minimised interpretation bias.

Respondent bias may account for the fact that the facilitators may have been keen to present the psychoeducation groups favourably, two facilitators interviewed were also my PhD supervisors (and therefore have a vested interest in how psychoeducation is presented in my research). However, perspectives of all facilitators were sought, and negative aspects were explored in as much depth as positive aspects. The interviews and analysis were in-depth, and the emerging key themes do not map closely to the topic guide – an indication that the interviews allowed for detailed exploration of experiences and ideas.

8.4.3 Conclusions

These findings present a valuable insight into group facilitators' perspectives and experiences of a UK-based group psychoeducation programme for people with bipolar disorder, and highlight the barriers to recruiting patients, the importance of motivating, informing and empowering patients and effectively managing group dynamics. Mental health teams and key workers may be more likely to refer their patients to psychoeducation programmes if they believed that such interventions may make a positive difference to health outcomes. Furthermore, it may be helpful for participants of group psychoeducation to receive continuity of group support following a group psychoeducation programme, especially for those otherwise without peer support and a regular routine.

Psychoeducation group facilitators should consider signposting participants to established groups such as Bipolar UK or other self-help support networks which may offer continuity of group support, or alternatively offer occasional follow-up sessions to reassemble psychoeducation groups and recapitulate key content.

Chapter 9: Discussion and conclusion

9.1 Main findings

Facilitators and participants of BEP-Cymru felt that peer support was the key element of group-based psychoeducation for bipolar disorder. Participants of BEP-Cymru appreciated being able to share their experiences, learn from others and gain new friendships. They felt empowered by the group experience and through realising that they were “not alone” in having bipolar disorder, which increased their sense of self-efficacy. Participants also reported benefitting from the support and expert knowledge of the facilitators.

Facilitators and participants also recognised the need to offer group-based sessions for friends and relatives to learn about bipolar disorder. Those who shared aspects of Beating Bipolar or BEP-Cymru with others reported that it facilitated open communication, understanding and support.

The educational content of the internet-based programme was of primary benefit to participants who undertook Beating Bipolar. Beating Bipolar was particularly recommended for those newly diagnosed with bipolar disorder. Many appreciated the anonymity and flexibility it provided, as they could log in at any time. They also stressed the importance of accessing the programme in a private environment. The forum would have benefitted from more contributing members and more focussed direction and input from the moderator.

Participants’ mood did not change significantly as a result of either programme, as measured by the questionnaires, although many participants reported feeling better able to manage their bipolar disorder and a clinically significant decrease in depression scores was noted for BEP-Cymru participants.

Some participants of both courses made lifestyle changes, such as improving their diet and exercising regularly, in response to advice provided within the course. Many learned more about bipolar disorder and gained insights which facilitated acceptance and compassion towards themselves.

9.1.1 What can we learn from the literature on psychoeducation for bipolar disorder?

I conducted a systematic literature review of randomised controlled trials and qualitative studies of individual, group and internet-based psychoeducation interventions for bipolar disorder to assess whether psychoeducation may be beneficial for patients.

The quantitative evidence showed that there is a limited evidence base for the efficacy of psychoeducation for bipolar disorder; however, available evidence indicates that psychoeducation may reduce recurrences and severity of bipolar episodes and increase quality of life and social functioning.

Qualitative evidence suggests that some patients learned coping skills through psychoeducation which positively impacted on their relationships with others, medication adherence and acceptance of their diagnosis. Studies also highlighted that some patients felt distressed about discussing past episodes or felt overwhelmed when confronted by facts about their illness which they did not wish to engage with.

There was lack of good quality evidence regarding the efficacy of psychoeducation in different formats, so conclusions could not be drawn regarding the effectiveness of one mode of psychoeducation delivery over another. Further in-depth qualitative research was also needed to explore how these interventions are experienced by patients and those delivering the interventions.

9.1.2 How feasible and acceptable are internet-based and group-based face-to-face psychoeducation interventions for bipolar disorder?

- To find out whether the interventions are feasible and acceptable to participants
- To explore the barriers and motivators to participant engagement, what participants like and dislike about the interventions, and ways in which the interventions may be improved
- To identify why some participants engage more with a psychoeducation intervention than other participants

9.1.2.1 Feasibility and acceptability of internet-based psychoeducation for bipolar disorder

Internet-based psychoeducation for bipolar disorder is feasible to deliver to patients who are motivated and well enough to engage with the programme, have access to a computer in a private environment and are computer literate. In practice, internet-based psychoeducation for bipolar disorder should be offered to people with bipolar disorder within their routine health care consultations, particularly soon after diagnosis.

Beating Bipolar was attractive to patients, who appreciated its professional appearance and the quality of the information, which was viewed to be comprehensive and reliable. They particularly appreciated its content relating to triggers, medication, lifestyle and women with bipolar disorder, and the ability to share aspects of the programme with others.

Participants disliked the use of actors within the programme, the presentation of the life chart exercise and the presentation of information on medication. They also recommended that the online forum be improved to involve more people with bipolar disorder and receive greater input from the psychiatrist.

Participants appreciated the flexibility of engaging with the programme in their own time, the anonymity it offered, and the potential to share and revisit its content. Many suggested that it would be particularly beneficial for those with a recent diagnosis of bipolar disorder.

Reasons participants gave for non-engagement with the programme included feeling unwell, not wishing to access the programme in a public environment and not wishing to engage with the illness when well. Some participants were resistant to using a computer because they preferred face-to-face communication or reading materials.

9.1.2.2 Feasibility and acceptability of group-based psychoeducation for bipolar disorder

Group-based psychoeducation is feasible to deliver to groups of no more than 15 patients who are well enough to focus on the course and motivated to learn about how to manage their illness and meet others who also have bipolar disorder. Facilitators who have a professional background in mental health can deliver group-based psychoeducation, and participants appreciate the expert knowledge and experience they offer.

Regarding the context of group-based psychoeducation, facilitators reported that it was challenging to recruit participants through some mental health teams, especially if morale within teams was low or if they regarded the course to interfere with the care they were offering their patients.

Therefore, some mental health teams posed a barrier to reaching potential participants who may benefit from the intervention. To overcome this issue, facilitators suggested that much time and effort is required to effectively communicate the importance and potential benefits of the intervention to health care professionals to ensure that anyone eligible for BEP-Cymru is referred. They also surmised that over time healthcare professionals will receive positive feedback from their patients who participated in BEP-Cymru which may facilitate more referrals coming through.

Psychoeducation groups are acceptable to patients if they are held in a centrally located, light and airy venue with good refreshments and facilities, and may be more acceptable to participants if they are grouped with some others of a similar age. Medical or university premises are not acceptable to most patients due to negative connotations.

BEP-Cymru participants mostly regarded facilitators as being supportive, well-informed, caring and respectful. Participants also liked to be able to ask in-depth questions and receive answers from the facilitators. Some participants felt lectured to, however, as a result of some facilitators' style of presentation. They recommended that the facilitators better managed dominating members of the group to enable fair and equal contributions from all participants.

Facilitators felt that two hours offered sufficient time to cover the psychoeducational material and enable free discussion. The information provided and the handouts were perceived to be useful, informative and easy to understand, especially if visual representations were presented. Facilitators in North Wales had less of an issue with keeping to time compared with facilitators in South Wales, potentially because they adopted a more flexible approach to the format of the sessions and confidently handled participants prone to dominating discussions. Therefore, structuring sessions more flexibly to better facilitate and manage group discussions is recommended.

Many struggled with the emotional impact of the life chart exercise and felt pressurised to undertake it in the group setting. They recommended that the life chart be presented with caution as an optional task to complete with support from a health care professional.

Some participants who received Beating Bipolar said that a group-based intervention would not have been acceptable to them because they found groups of people with mental illness unappealing. They did not identify with others with bipolar disorder, did not perceive group work to be helpful, disliked dominating group members, and were fearful of seeing others very unwell or heavily medicated who had the same condition.

9.1.3 What is the impact of internet-based and group-based face-to-face psychoeducation interventions for bipolar disorder?

Psychoeducation for bipolar disorder may equip patients with the knowledge and skills to effectively self-manage their condition, prevent relapse, and maintain a healthier lifestyle. It may have positive impact on their cognitive, emotional and social wellbeing, and facilitate insight and self-acceptance. Remembering traumatic events or focussing on their bipolar disorder when well may trigger low mood for some participants.

Some participants of BEP-Cymru and Beating Bipolar changed their behaviour as a result of the course, by adopting a healthier diet, maintaining a regular routine or quitting smoking. Some also gained a more positive attitude to medication and felt confident to discuss options with their psychiatrists or take their medication regularly as prescribed. Those who shared aspects of the course with family, partners or colleagues reported that doing so facilitated open communication about bipolar disorder, enhanced understanding and support.

Participants and facilitators said that psychoeducation in any format may have a greater impact for those newly diagnosed with bipolar disorder, as well as for those who lacked a good understanding of bipolar disorder. For those who had a good prior knowledge of bipolar disorder and self-management techniques the internet-based intervention had very little or no impact; however, the group-based intervention was perceived to be beneficial to them because it provided peer support. Some Beating Bipolar participants shared their personal stories, sought and offered advice and expressed encouragement and empathy on the online forum, but this lacked the critical mass for worthwhile conversations.

The social support that the group-based intervention provided had a significant impact for participants. For some, it was the first time that they had met others with bipolar disorder and it enabled social comparison (e.g. “we’re all in the same boat”). Participants benefitted from sharing

experiences, learning from others and feeling inspired, supported, cared for and valued by others. They felt that they were no longer “alone” with having bipolar disorder, and that others had suffered similar traumatic experiences. They also felt empowered by the group, less stigmatised and more confident, and therefore their self-efficacy increased. Many gained new friendships from the group and continued to meet with other members on a regular basis after the course.

Group-based psychoeducation also provided continuity of care in that participants met with the same mental health care professionals who facilitated the course every week for 10 weeks. Many participants felt dependent on the social support and regularity of the group sessions, which they looked forward to each week, and were disappointed or upset when the course ended.

The groups impacted on facilitators’ knowledge and awareness of bipolar disorder and challenged their professional attitudes. Facilitators learned from the groups and reassessed their knowledge base and how they communicated health information to others. They felt that their experiences of psychoeducation group facilitation had made them better clinicians, as the insights they gained from the groups informed their approach to their clinical work.

9.1.4 When patients and facilitators describe their experiences of internet-based and group-based face-to-face psychoeducation interventions for bipolar disorder what is relevant to them?

From the qualitative interview data and the online forum data I explored what participants considered to be most relevant to them and the “take home messages” they stressed as being important.

Patients and facilitators stressed the importance of holding group psychoeducation at well-regarded community venues, which were preferable to hospital settings. They also strongly recommended that additional psychoeducation groups should be provided for patients’ concerned family members or carers, and recommended that occasional follow-up sessions should be organised centrally for the groups to reconvene.

Many Beating Bipolar participants said that they would have appreciated the course when they were newly diagnosed, because they did not have access to comprehensive and reliable information at that time. The most popular topics which were discussed on the Beating Bipolar online forum were:

medication, employment, social stigma, social support, coping strategies, insight, acceptance, the life chart exercise and negative experiences of health care.

Humour was observed on the forum and group participants also cited humour to be important. Humour was used as a way of coping to communicate within the group, increase participants' confidence and "normalise" bipolar disorder.

BEP-Cymru participants particularly appreciated the new friendships and confidence they had gained from the groups. Many also felt that the acceptance and respect they received from the facilitators reduced the stigma associated with bipolar disorder from their perspectives. Some participants regarded themselves to be "normal" and felt that bipolar disorder should not be labelled as a mental illness, but rather a "condition".

9.1.5 What are the similarities and differences between internet-based and group-based face-to-face psychoeducation for bipolar disorder?

Both internet-based and group-based psychoeducation may offer accurate, up-to-date and comprehensive information about bipolar disorder and activities to support learning. Both may be beneficial to patients and concerned others, and should be offered as soon as possible following diagnosis.

Internet-based psychoeducation is a more private experience, with less scope for enhancing social support. It may be most beneficial to those who lead busy lives, who are newly diagnosed or who are disinclined to socialise with others in the context of a group healthcare programme.

Group-based face-to-face psychoeducation is a more intensive experience as the learning material is interspersed with group discussions and activities. Participants may benefit from the enhanced social support the group provides; however, some may also feel dependent on it.

9.2 Main findings in context

“This class has meant so much to me. I spent the whole week waiting for it. I’m like a schoolkid about this class,” she confessed. “I do apologise for all this,” she said as he was leaving. “It’s just the pain that makes you so alone. It’s so shameful.”

“There’s nothing shameful about it.”

“There is, there is,” she wept. “The not being able to look after oneself, the pathetic need to be comforted, the dependence, the helplessness, the isolation, the dread – the utter otherness of it all is awful.”

Excerpt from the novel “Everyman” by Philip Roth [11]

9.2.1 Research

Many Beating Bipolar and BEP-Cymru participants reported feeling better able to manage their bipolar disorder, acceptance of themselves increased, and many also felt empowered as a result of their experience on the course. In other studies, psychoeducation facilitated some patients’ acceptance of their diagnosis, and patients learned new skills for managing their bipolar disorder [42, 64].

Those who shared aspects of Beating Bipolar and BEP-Cymru with their families, partners or colleagues related that it facilitated communication about bipolar disorder and others were able to recognise their triggers and early warning signs of bipolar disorder. A study by Peters et al (2011) similarly found that patients’ personal relationships were enhanced through increased understanding of bipolar disorder, and caregivers learned to recognise triggers and early warning signs which patients were unaware of [43]. The theme of empowerment is reflected by patients and carers perspectives of other psychoeducation interventions for bipolar disorder [42, 43], some of whom also felt distressed by recalling previous bipolar episodes [42] - as some Beating Bipolar and BEP-Cymru participants reported feeling distressed by recalling previous episodes when constructing their life charts.

Qualitative studies of psychoeducation interventions for bipolar disorder have also found that medication adherence increased for some patients as a result of their participation [42, 64], and that the group context provided friendship and respect for participants [64]. Likewise, BEP-Cymru

participants reported sharing humour, friendship and support with other group members, as did some Beating Bipolar forum users.

Quantitative studies of group-based psychoeducation found that it may reduce recurrences [48, 49] and duration [40, 49, 51] of bipolar episodes. The BEP-Cymru study did not find that participants' moods were more or less stable than usual following the programme; however, some participants reported feeling better able to manage their symptoms and recognise their triggers.

One study also found that severity of depression and mania may be reduced after one year [38]. The BEP-Cymru study found that severity of depression may be reduced at 10 weeks and after three months from a rating of "moderate" depression to a rating of "mild" depression on the BDI.

Other studies found that group psychoeducation may increase social functioning after six months [40, 51]. Qualitative data from the BEP-Cymru study supports this, as many participants reported the impact of the intervention on their relationships with others and some also continued to meet as a group on a regular basis after the course had ended; although the quantitative data showed no difference between social support ratings at baseline, 10 weeks or three months.

Although the present study has not presented strong statistical evidence that psychoeducation for bipolar disorder may reduce episode severity, number of relapses, and number and duration of hospitalisations, as have previous studies [38, 39, 48, 49, 141], it has produced qualitative evidence for the efficacy of psychoeducation for people with bipolar disorder – for example, as some participants reported they had improved their lifestyles, felt better equipped and more capable of effectively managing their mood or felt less isolated and stigmatised as a result of the intervention.

Authors of a qualitative study of family psychoeducation primarily for schizophrenia among Latinos in New York City conducted three focus groups with patients, family members and group facilitators [142]. They found that stigma surrounding mental illness was a key issue among all focus group participants, as mental illness was associated with ideas of shame and lack of respect, which may be a Latino culture-specific manifestation of stigma; one group facilitator explained that "We [Latinos] use that word for almost everything... You are either full of shame or you're shameless... So sometimes symptoms are presented as a lack of shame" [142]. It would have been interesting to understand more about the culture-specific underpinning of stigma from BEP-Cymru and Beating Bipolar participants' perspectives; potentially, the stigma surrounding mental health in a UK context

may be more associated with fear due to lack of understanding, but also similarly due to a lack of respect for the causes of mental illness. Furthermore, the present sample was predominantly of Caucasian ethnicity, which may reflect the demographic in Wales but may also reflect the issue that those of Black ethnicity are less likely to receive mental health treatment, due to stigma and negative views regarding treatment [143]. A study in the US sought the perspectives of Black consumers when developing a psychoeducational booklet about stigma for Black mental health clients, and consequently included within it experiences of stigma, coping strategies and issues relevant to the Black community [143]. The development of Beating Bipolar online materials involved local patient representatives and health care professionals; however, a more diverse sample may have provided greater insights into the culture-specific stigma surrounding mental health and how to address it within the programme.

From the information they received on the course and through developing positive relationships with the BEP-Cymru group facilitators some participants felt more confident with getting the support they needed from the NHS, in spite of their previous negative experiences of healthcare. The study of family psychoeducation for schizophrenia also found that many patients and carers described their former negative experiences of healthcare in the focus groups, which consequently led to mistrust of current and future providers and barriers in developing therapeutic relationships from providers' perspectives [142].

Key issues surrounding negative interactions with healthcare professionals for participants of the present study were: the length of time to be diagnosed with bipolar disorder, fear of hospitalization, being prescribed unsuitable medication or being uninformed about side effects from medication. Some participants of both BEP-Cymru and Beating Bipolar reported feeling more equipped to discuss medication options with their GP or psychiatrist following the session on medication. A study by Happell et al (2004) in Australia found that it was important for mental health patients to be informed about their medication and have an opportunity to participate in shared decision making with their healthcare professional; aspects of care which participants of their study felt dissatisfied with [144].

A qualitative study of service users' perspectives of mental health information in the UK also found a strong theme of lack of information for people with mental health issues, particularly with regard to a lack of explanation for diagnosis and presentation of treatment options [145]. The authors link this lack of information from healthcare providers with a lack of respect for the patient, as patients

reported having felt patronised by healthcare professionals and disliked by them when their own personal research was perceived to challenge the practitioner-patient relationship [145]. This threat of the “informed patient” for healthcare providers was perceived by BEP-Cymru facilitators to be one of the barriers to having patients referred to the programme.

Like Beating Bipolar participants, some participants of the mental health information study particularly appreciated the anonymity of the internet to learn about their illness – mostly due to stigma inhibiting them from seeking information from other sources [145]. Many participants of this study sought mental health-related information predominantly through others’ similar experiences of mental health issues; either through personal interactions or from reading materials [145]. This instilled hope, empathy, understanding and universality (knowing “one is not alone” because others have similar problems was described by many interviewees in a common way, as it was by participants of the present study) [145]. As with BEP-Cymru participants, studies of psychoeducation for people with schizophrenia also found that sharing experiences within the group was very important for reducing isolation, enabling social interaction and learning coping strategies [146, 147].

I searched for relevant research on psychoeducation for bipolar disorder which had been published since I conducted the systematic literature review on 28 March 2012. Five RCTs [148-152] and one non-randomised trial were identified [153], in addition to three qualitative studies relating to online support for people with bipolar disorder [96, 138, 154] and qualitative studies of patients’ experiences of bipolar disorder [13, 14, 155, 156]. This latest research is discussed below to contextualise my main findings.

Four trials examined group psychoeducation for bipolar disorder; either compared with CBT [148], functional remediation [152] or treatment as usual [151, 153]. A controlled trial in Italy compared 21 sessions of group psychoeducation according to Colom and Vieta’s model [22] with treatment as usual for 102 outpatients with bipolar disorder [153]. The primary outcome measure was number of hospitalizations at the 1-year follow up [153]. Results indicated that the number of patients hospitalised during the follow up period and the mean number of hospitalisations per patient were significantly lower for the psychoeducation group [153]. A weakness of this study is that participants were not randomised to each arm of the trial, which may have led to selection bias. Despite this, the hospitalization prevention effect this study shows supports the premise that psychoeducation may prevent recurrences of bipolar episodes as patients learn to recognise their early warning signs of

relapse and intervene effectively [153]. Qualitative findings from the present study indicate that patients who have received psychoeducation feel better able to self-manage their condition and recognise their early warning signs, which may in turn prevent relapse and hospitalisations.

Another controlled trial which compared group psychoeducation according to Colom and Vieta's model [22] with treatment as usual aimed to evaluate the effects of psychoeducation on symptomatic and functional recovery for patients with bipolar disorder who were in remission [151]. Fifty-five patients were randomised to receive 16 sessions of group psychoeducation, which were delivered twice weekly, or 16 sessions of relaxation [151]. The primary outcome measure and the method of randomisation was not described, however, and the intervention arm had nine (16%) more participants at baseline. The study found no significant differences between the groups on mood symptoms, quality of life or functioning, although group psychoeducation contributed to an improved global clinical impression from patients' and clinicians' perspectives (as assessed by the Clinical Global Impressions scale[157]) [151]. A drawback of this study is that it has a small sample size of 55 patients, no description of the randomisation process and no power calculation was conducted to ascertain the minimum sample size required to detect a statistically significant effect. Quantitative results from the BIPED trial and the evaluation of BEP-Cymru also found no significant differences on mood symptoms, functioning or quality of life; however, a marginal improvement in psychological quality of life was noted for participants of Beating Bipolar.

A novel group intervention (the Functional Remediation Program) was designed to improve functioning in functionally impaired euthymic patients with bipolar disorder and comprised 21 sessions of 90 minutes duration involving neurocognitive techniques, training, psychoeducation on cognition-related issues and psychoeducation [152]. Functional remediation was compared with 21 sessions of psychoeducation for bipolar disorder [22] and treatment as usual in a multi-centre RCT to assess improvement in global functioning (assessed by the Functioning Assessment Short Test [110]) at the end of the intervention (21 weeks) and at six months follow-up [152]. 239 outpatients were randomised to receive functional remediation, psychoeducation or treatment as usual, and 183 were followed up [152]. The trial demonstrated that euthymic patients had greater functional improvement with the functional remediation programme than with group psychoeducation, although the difference was not found to be statistically significant [152]. The study also found that functional remediation may improve patients' occupational functioning as 5.4% of patients were able to obtain paid employment in the functional remediation group compared with none in the control group [152]. The study does not report the percentage of patients able to obtain paid

employment in the psychoeducation group. In the present study, qualitative findings found that one participant who received Beating Bipolar intended to return to work after being a housewife for 13 years and another participants who received Beating Bipolar reported that work colleagues with became more aware of what triggers his bipolar disorder and identified when he was vulnerable to experiencing a depressive episode [105]. Therefore, psychoeducation may have a wider impact on occupational functioning than may be captured by quantitative outcome data alone, as we did not find improvements on occupational functioning using the FAST measure [110].

A recent RCT compared 20 individual sessions of CBT with six group sessions of psychoeducation for 204 euthymic participants with bipolar disorder across four sites in Canada [148]. This study primarily assessed mood burden over 72 weeks, according to scores on the Longitudinal Interval Follow-up Evaluation (LIFE) scores for mania and depression [148]. Results showed that both treatments had similar outcomes relating to symptom burden and likelihood of relapse; however, a weakness of this study is that it lacked a control group [148]. In conclusion, group-based psychoeducation intervention may be more cost-effective to deliver than 20 individual sessions of CBT, although health economic evaluations are needed.

Another recently published RCT which compared multi-family group psychoeducation (MFGP) with solution focussed group therapy (SFGT) and treatment as usual sought to assess carers' knowledge, burden, psychological distress, quality of life and global functioning at 1-year and 2-year follow up [150]. 47 carers were randomised within the trial [150]. At 1 and 2 year follow ups carer knowledge, carer burden, carer psychological distress and quality of life significantly improved for the MFGP group compared with treatment as usual [150]. No significant differences between the intervention groups were found [150]. This study demonstrates that carers in both intervention arms had greater knowledge and reduction in burden than those in the control arm [150]. This finding supports BEP-Cymru participants' and facilitators' recommendation to provide additional psychoeducation groups for concerned relatives, as doing so may not only enhance relatives' knowledge of bipolar disorder to enhance understanding and provide increased support, but it may also increase their quality of life and decrease their burden and psychological distress.

Since the publication of the BIPED trial [23, 105], another RCT has been published regarding the effectiveness of an online psychoeducation programme for people recently diagnosed with bipolar disorder by Proudfoot et al (2012) [149]. This RCT was conducted in Australia and examined whether online peer support provided during the programme affected participants' symptoms and

perceived control of their illness [149]. The authors developed an online psychoeducation programme (Bipolar Education Program) which consisted of 8 weekly modules of 30-40 minutes in duration encompassing the following topics: causes of bipolar disorder, diagnosis, medication, psychological treatments, omega-3, wellbeing plans and support networks [149]. 407 participants were allocated at random to receive either an 8-week online psychoeducation programme, an eight week online psychoeducation programme plus email support from expert patients, or weekly emails containing links to simple information about bipolar disorder [149]. The primary outcome measures were the Personal Control and Understanding subscales of the self-report Brief Illness Perception Questionnaire, for which no significant differences between groups were observed [149]. Despite this, participants of all groups reported increased control and understanding, decreased stigmatisation and improvements in their anxiety and depression from baseline to post intervention [149]. The authors speculated that the structure of the interventions, the rationale for the study and participants' expectations that they would improve as a result were factors which contributed to the observed therapeutic effects [149]. Furthermore, participants in the control group were also required to monitor their mood on a daily basis for the trial data, which may have influenced their symptoms [149] and their perceptions of self-control. Regarding the impact of peer support by email from expert patients, those who received online peer support had greater adherence to the programme than those who did not [149]. This finding reflects the importance of peer social support, as identified in the present study, and the recommendation from Beating Bipolar participants who said that more input from a psychiatrist to the online forum may generate more engagement from participants within the forum, which lacked sufficient and regular contributions, thereby providing a greater opportunity for peer support.

An embedded qualitative study within the aforementioned RCT by Proudfoot et al (2012) [149] explored the email correspondence between the expert patients who provided the online peer support and those undertaking the online intervention and interviews with the expert patients [138]. They found that the informed peer supporter offered social comparison and experiential knowledge to the supported person and the peer supporter also received a greater sense of their own competence in managing their health as well as reciprocated peer support. Similar to participants of the present study, those newly diagnosed felt less stigmatised and isolated with the condition, and realised that "I'm not the only one!" and "other people experience this too!" The expert patients in the Proudfoot trial offered empathy and practical advice which was grounded in their experiential knowledge, as well as enabling social comparisons to motivate and give hope to those newly diagnosed [138]. In the present study, BEP-Cymru participants also made social comparisons and

felt kinship and inspiration from their encounters with other group members. They also reported learning from others' experiences of the illness and their coping strategies. These elements of constructive peer support were also noted in the Beating Bipolar forum, as participants shared their experiences and offered advice and friendship.

A qualitative focus group study by Todd et al (2013) was designed to inform the design of an internet-based self-management intervention (Living with Bipolar) for bipolar disorder by identifying the needs and desires of its prospective service users [154]. Participants stated the importance of techniques to manage their mood and also their lives more generally and said that the internet is the only format which is freely accessible, instant and interactive [154] – a sentiment which participants of the present study also shared. They also suggested that professional and peer support may overcome low motivation [154], which echoes qualitative findings from the RCT by Proudfoot et al [138]. Similarly, BEP-Cymru participants reported that they looked forward to meeting others within the psychoeducation group each week; the prospect of social interaction with the group motivated them to attend the sessions.

9.2.2 Theory

In general terms, quantitative research is used to test theory whereas qualitative research is used to generate theory. Findings from this research contribute to theory regarding the ways in which psychoeducation in different formats may work for people with bipolar disorder. The therapeutic mechanisms by which psychoeducation may work include: improved knowledge and skills, peer support, improved self-efficacy, improved self-monitoring and regulation of behaviour, and self-disclosure.

9.2.2.1 Self-disclosure

Within a Canadian study of quality of life for people with bipolar disorder, qualitative interviews with patients and their caregivers revealed that many felt affected by the stigma of having bipolar disorder and the choice of disclosing the diagnosis to others, particularly within the workplace [13]. This finding echoes the themes explored within the Beating Bipolar forum, as many participants discussed social stigma and issues surrounding their employment. Within the BEP-Cymru groups many participants disclosed traumatic personal experiences to receive acceptance and empathy

from other group members. Participants and facilitators described the effects self-disclosure had on participants, as many bonded and gained confidence over the ten weeks. From a theoretical perspective we know that self-disclosure may help people to find meaning in their experiences and express their feelings [12]. Findings from the present research suggests that group and internet-based psychoeducation may facilitate self-acceptance and reduce social stigma through the process of self-disclosure, as others may provide empathy and social support in response.

9.2.2.2 Self-efficacy and self-regulation

A previous study found that many people with bipolar disorder reported a sense of dependency and being out of control of their lives [13]. The present study found that psychoeducation may impact on participants' perceptions of their ability to manage their health (self-efficacy), as many reported feeling confident with the skills and insights they had gained to effectively take control of their bipolar disorder by monitoring their cognitions and behaviour and looking for signs and symptoms of relapse (self-regulation).

Knowledge gained from the course materials, facilitators or other participants contributed to their enhanced self-efficacy and self-regulation. Participants who shared their experiences of having bipolar disorder and their coping strategies inspired other participants to develop strategies to improve the management of their condition. They regarded mood diaries to be particularly effective for monitoring mood and identifying early warning signs of relapse (self-regulation). Furthermore, feeling better informed regarding medication for bipolar disorder increased some participants' confidence to either take their medication regularly as prescribed (self-efficacy) or empowered them to discuss medication options with their psychiatrists. Elsewhere, self-efficacy has been found to benefit medication adherence for people with mood disorders; in particular, the confidence to communicate with prescribers and receive support [158].

9.2.2.3 Self-monitoring

Self-monitoring is becoming increasingly common in the digital age. Through "lifelogging" people routinely record their personal information using online social media (such as Facebook, Twitter and blogs) and online applications ("apps") via their computers or mobile devices. A randomised controlled trial showed that self-monitoring mood and stress levels using a mobile phone may

increase coping strategies and decrease depressive symptoms for adolescents with depression [159]. Recently, the BEP-Cymru project launched the “Bipol-App” – an app which may be downloaded to a smart phone to enable users to monitor their symptoms and triggers of relapse. Users rate their mood, energy, sleep and anxiety levels on a scale, and are able to view their ratings on a graph (depicting weekly, monthly or trimonthly trends) which they may then share with their family, friends or health care professionals via the online platform. Future research may examine the acceptability and efficacy of apps such as these for regular mood monitoring and refine them.

A further step for people with bipolar disorder with regard to self-monitoring may be mindfulness training, which involves grounded, non-judgemental awareness of the present moment. A review of mindfulness training for those with mood disorders found that this form of cognitive self-monitoring and control reduced negative self-evaluation, increased acceptance and improved self-compassion and empathy for people suffering from chronic depression [160]. The present study found that some participants of BEP-Cymru would have appreciated the inclusion of psychological therapies such as mindfulness within the course; hence, mindfulness training could be an effective adjunct to psychoeducation for people with bipolar disorder.

9.2.2.4 Social support

A study which investigated the impact of social support on symptomatic recovery and remission in people with bipolar disorder found significantly lower levels of perceived social support and a greater risk of relapse for patients who had partially recovered compared with those who had fully recovered from a major bipolar episode [161]. Social support emerges as one of the key elements within psychoeducation programmes which runs through the other potential mechanisms of effect described above. It was particularly important in the BEP-Cymru group setting; however, even with the internet-based programme some participants felt the peer interactions were helpful, although it was difficult to achieve through the online forum. A mixed methods study of online self-help forums for bipolar disorder analysed 2400 posts from two German forums and found that disclosure, friendship and group cohesion were the main self-help mechanisms [96]. The Beating Bipolar forum also exhibited disclosure through participants’ confessional posts and personal narratives, and also friendship and peer support as participants advised, encouraged and empathised with others.

Social support gave participants encouragement, motivation, feedback, empathy, improved self-efficacy and it provided the opportunity for role modelling or social comparison. It facilitated

participants' self-acceptance and compassion towards themselves and others. As participants learned more about bipolar disorder many also came to terms with their diagnosis and felt prepared to take responsibility for their health. Other research has found that people with bipolar disorder regarded relationships with others who were accepting of them and non-judgemental to be very important, and some realised that certain social groups were non-conducive to their mental health [13]. In the present study, some participants reported that as a result of receiving psychoeducation for their bipolar disorder they had reassessed some relationships and had consequently removed themselves from social situations or relationships which they felt compromised their wellbeing.

9.3 Strengths and limitations

This is the first study to evaluate the feasibility, acceptability and impact of internet-based psychoeducation for people with bipolar disorder. It is also the first study of a UK-based online forum for people with bipolar disorder, to examine the topics relevant to them and how an online forum may be effectively used alongside an internet-based psychoeducation intervention to offer peer support, and it was also the first UK-based qualitative study of a group-based psychoeducation intervention for bipolar disorder. The mixed methods study of the feasibility, acceptability and impact of BEP-Cymru provided an in-depth account of participants' and facilitators' experiences and perceptions of group-based psychoeducation for bipolar disorder, and contributed to the sparse literature on the subject as the first study to relate qualitative and quantitative data on the topic. In-depth comparisons of group and internet-based interventions have also been possible, which highlight participants' preferences and the benefits and drawback of each mode of delivery. Findings from these studies have enhanced our understanding of how such interventions are delivered and received and how they could be improved in the future.

This was an exploratory study with a small sample size which was not powered to detect differences on any of the quantitative outcomes; and, therefore, it would not necessarily have been expected that significant differences between time points would be detected unless the differences were large. Within a RCT, a sample size powered to detect significant differences between time points may quantitatively demonstrate that psychoeducation has a significant impact on aspects such as mood, self-efficacy and self-regulation, for example. Furthermore, a longer follow-up period for both the qualitative and quantitative research may show the endurance or change of effects and perceptions over time.

As with all studies, bias is inevitable and may occur at any stage of the research process. As a healthy-sounding young woman interviewing an older man with bipolar disorder, for example, my perceived identity may have affected interviewees' responses. Peer interviewing may have reduced this bias. The Hawthorne Effect (people changing their behaviour due to the presence of a researcher) was noted to be present on two occasions during qualitative interviews where participants began to divulge more personal and relevant information after I had announced that I was stopping the tape recording; hence, I interrupted them and asked for their permission to continue the recording. To prevent interpretation bias, it would have been useful to have at least two researchers double coding all the qualitative data. There may also have been a sampling bias as few people from ethnic minorities and few men participated in this research. This may have been because people who have immigrated to the UK access health services less, and therefore are less likely to have become aware of the interventions, and it may be possible that men are less attracted to the prospect of sharing their personal experiences with others within a group setting.

Given more time I would have updated the systematic literature review. However, I have searched for relevant studies published since conducting the literature review, and these studies have been discussed in relation to my findings, within this chapter.

Through mixed methods exploration of the data I assessed trends and interactions. Parallel mixed analysis involved mixing the qualitative and quantitative data at the interpretive stage of the research process, when combining data to construct enhanced meanings [29, 74]. In this case, the qualitative component (or "dominant paradigm" [29]) had priority and both types of data were analysed separately before being compared. Mixed methods exploration of the data at this interpretative stage served as a flexible approach to explore complementarity – to clarify the meaning of results from one method to another, to deepen understanding, and to investigate the connections between different strands of enquiry [73]. To synthesise findings, I mapped the findings from each of the results chapters by hand according to each domain, and then I summarised the key themes. Specifically, I looked for areas where the qualitative and quantitative findings complimented or contradicted each other. This parallel mixed analysis involved pulling together the main findings to construct a meaningful and coherent picture of the group-based and internet-based psychoeducation interventions for bipolar disorder. I synthesised the results of data collection and analysis of qualitative and quantitative methods effectively to assess the key trends and interactions between the qualitative and quantitative findings. Through exploring and clarifying the themes of

each strand of enquiry I gained a deeper understanding of the key themes and issues relating to psychoeducation for bipolar disorder in different formats. However, the quantitative data was not powered to detect differences on any of the quantitative outcomes; hence many qualitative observations could not be supported or refuted by comparison. To ensure reliability of this approach another researcher could have conducted this analysis in parallel, prior to comparing and discussing the main findings. As the only researcher to summarise the results, I minimised interpretation bias by maintaining focus on my research questions and reviewing my reflections log. I may have been able to explore potential interactions further with mixed methods analysis; however, due to time restrictions I could not do any more through mixing methods. On reflection, a narrower methodological focus of the thesis may have given me a greater opportunity to explore the data more extensively.

Over a longer period, further exploration of the data by mixing methods could have been undertaken. Rather than reading through the results chapters and cross-referencing by hand, I could have returned to the raw data to code it according to a new emerging thematic framework. Also, using NVivo would have enabled another researcher to double code the data and contribute to the framework to enhance rigour and consistency. This more rigorous approach to mixed methods analysis may have yielded different insights into how the findings from the studies may relate to each other.

It may also have been useful to compare individual participants' scores on the questionnaires (assessing: quality of life, general functioning, insight, self-regulation, self-efficacy, social support, knowledge and attitudes, and overall satisfaction with the programme) with their interview responses to see where there may have been consistency and divergence in their perspectives.

For deeper integration of mixed methods, an iterative approach to data collection and analysis may have been undertaken, as opposed to the parallel mixed analysis, where findings from each strand of enquiry may build on the next for sampling, data collection and analysis. Rather than having separate coding frameworks for each qualitative study, a single coding framework could have been developed, enhanced and refined as the analyses progressed. Additionally, quantitative findings could have been included within the analytic framework to be linked to relevant emerging qualitative themes.

A sequencing decision was made to enable the quantitative data to inform the purposive sampling of the qualitative studies. An additional quantitative follow-up survey with participants may have helped to evaluate and interpret the qualitative findings; for example, in relation to themes such as stigma, lifestyle changes, compassion and self-acceptance - aspects which the quantitative data did not address. Morgan (1998) suggests that qualitative or quantitative follow-up studies may facilitate cross-validation and complementarity between methods [162].

Data transformation may have been another way to usefully mix methods – by transforming qualitative data into quantitative data or vice versa. The Beating Bipolar forum data could have been analysed using content analysis to enable the frequency of topics and themes to be assessed. The number of forum posts per user could also have been noted, as well as the number of topics initiated per user and the length of topic threads. Creswell et al (2004) recommends data transformation models for adding rigour to mixed methods research [28].

Another way in which the value of combining methods may have been enhanced could have been through using the findings from the BEP-Cymru patient interviews to inform follow-up interviews with group facilitators. This may have provided insights into group facilitators' responses to patients' perspectives of the programme and the viability of patients' recommendations for improving the programme.

9.4 Implications for policy and clinical practice

Issued in January 2014, a key strategy document from the Department of Health entitled "Closing the Gap: Priorities for essential change in mental health" sets the agenda for local service planning and delivery over the next couple of years and highlights 25 areas for change [133]. It places importance on increasing access to mental health services, improving quality of life, mental health promotion and integrating physical and mental health care [133]. It describes an "information revolution" for mental health, where over 900,000 may access psychological therapies each year, and adults will be given choices regarding their mental health care [133]. The present research has also highlighted the importance of widening access to mental health information as many participants reported benefitting from psychoeducation for bipolar disorder and few were of non-Caucasian ethnicity. The Department of Health and the Race Equality Foundation are working together to find out why those of ethnic minority communities are less likely to use psychological

therapies [133]. Participants of the present study also suggested that psychoeducation groups should also be offered to patients' families and carers, which resonates with the government's promise that "carers will be better supported and more closely involved" with mental health services because their needs are often overlooked [133].

Psychoeducation delivered through the online medium may also contribute to the government agenda of widening access [133] as it may engage those unable or unwilling to attend group psychoeducation, or where group psychoeducation may be unavailable in their region. Internet-based psychoeducation may be more cost-effective than group-based or individual psychoeducation, so governments may favour the former approach; however, a full economic evaluation should be conducted and potential differences between the therapeutic mechanisms of each approach should be considered; for example, group psychoeducation may provide more effective social support than internet-based psychoeducation.

Stigma has been found affect quality of life and social functioning [155]. Some people with bipolar disorder internalise these prejudicial beliefs and emotions to the effect that stigma becomes a barrier to their effective treatment [155]. The present research found that stigma was a pervasive theme across all strands of enquiry, as many had concerns about meeting with others who had bipolar disorder, labelling bipolar disorder as a mental illness rather than a condition, being misunderstood by families or colleagues, or the representation of bipolar disorder in the media. At present, the "Time for Change" public relations programme, led by the charities Mind and Rethink Mental Illness, is launching several initiatives to prevent mental health discrimination and promote fair opportunities for those with mental illness. Various community-based projects have been launched to encourage discussion about people's experiences of mental health issues and to foster communication, respect and understanding. Cardiff University is one of many organisations which have signed the "Time for Change" pledge to end mental health discrimination. The "Time for Change" agenda places mental health at the forefront of health policy, and it is hoped that its focus on equality and reducing stigma may have a positive impact on individuals and society in general. Psychoeducation programmes such as Beating Bipolar and BEP-Cymru may benefit from increased public awareness of mental health issues and reduced stigma towards those with mental illness as people may feel more confident to participate.

The evidence base for psychoeducation interventions is not complete and there is a need for large scale well conducted trials. However, based on the current evidence base which indicates that

psychoeducation may be helpful, along with the fact that there seems to be no negative outcomes and the qualitative research findings are very positive, psychoeducation may be useful in managing this condition. There is a gap between the needs of bipolar patients and the availability of services and support, and psychoeducation could provide patients with extra support that is not otherwise available. With this in mind, patients should be routinely offered it within clinical practice; ideally soon after diagnosis. Patients should be offered internet-based and group-based psychoeducation so they have the choice of the format which suits them. It is anticipated that patients who are young, newly diagnosed, lead busy lives and have access to a private computer may particularly benefit from internet-based psychoeducation in particular. Those who suffer from social anxiety or feel depressed may also benefit from internet-based psychoeducation. Patients who prefer face-to-face interaction and who may feel isolated with the condition may benefit more from group-based psychoeducation.

9.5 Implications for future research

There is a need for well designed, large scale RCTs with longer-term follow up periods. Future psychoeducation programmes should also be developed and tested specifically for the caregivers of those with bipolar disorder, and further research may investigate the feasibility, acceptability and impact of caregiver psychoeducation on caregivers' understanding and perceptions of bipolar disorder, those they care for, their sense of burden, anxiety and quality of life, via a mixed methods approach.

Changing the health behaviours of participants was a specific goal of both Beating Bipolar and BEP-Cymru, as unhealthy behaviours are much higher in this group than in the general population and patients with bipolar disorder have an increased risk of cardiovascular disease and shorter life expectancy [163, 164]. The NICE guidelines for behaviour change which specifically covers alcohol, diet, physical activity, sexual behaviour and smoking recommend that behaviour change interventions should include "goals and planning", "feedback and monitoring" and social support [165]. Some of these elements were included in the psychoeducation programmes tested here, and some participants of Beating Bipolar reported undertaking regular exercise and quitting smoking as a result of the programme. Exercise has been found to assist with mood regulation for many people with bipolar disorder, although it has also been described as a "double-edged sword" as it may also exacerbate symptoms of mania [156]. The importance of mindful exercise and routine (diet, sleep,

activities) [13, 105, 156] for the wellbeing of people with bipolar should be promoted by those involved in their care. Psychoeducation programmes like BEP-Cymru or Beating Bipolar could assist with changing the health-related behaviours of those with bipolar disorder.

Future research into psychoeducation for bipolar disorder may explore how to target and engage people of diverse ethnic backgrounds, men and those in lower socioeconomic groups who are likely to access healthcare less. It may also explore the fidelity of group psychoeducation which is delivered in different geographical areas by different facilitators according to the manual, by using tape recordings, observations and a checklist approach. From the qualitative interviews with facilitators and participants, BEP-Cymru was identified to differ slightly between sites, particularly with regard to facilitators' presentation style, the format of the groups and their handling of dominant group members. Given more time, it may have been possible to conduct structured fidelity assessments.

Future work could also examine whether there are differences in response to psychoeducation according to the diagnostic subgroups (BP-I and BP-II) and whether there are related conditions which may benefit from this approach such as depression or anxiety. It would be useful to undertake a direct comparison of internet-based and group-based psychoeducation for bipolar disorder within a large multi-centre RCT, to include an economic evaluation and a qualitative study conducted in parallel.

9.6 A final word

Although some facilitators of BEP-Cymru were keen to stress to participants that the course was educational rather than “group therapy”, participants certainly felt that the support they received from the group was a very important therapeutic element for them. Therefore, in my opinion, there appears to be a crucial distinction for patients between internet-based psychoeducation, primarily perceived to be an educational tool for learning about bipolar disorder, and group-based psychoeducation, which some participants may perceive as group therapy coupled with useful educational content. In my view, the ways in which these two approaches may differ in how they work for should be made clear to patients and health care providers. Additionally, group and internet-based psychoeducation should be routinely offered within the NHS and people should be able to access internet-based psychoeducation freely online, regardless of whether or not they have

a diagnosis of bipolar disorder. The content of Beating Bipolar may help anyone who knows anyone with bipolar disorder, through raising awareness of the condition and health promotion, such as maintaining a healthy lifestyle, monitoring mood and identifying signs of relapse. Last year, two surveys conducted by the Royal College of Psychiatrists, Bipolar UK and Bipolar Scotland revealed that the average wait for a diagnosis of bipolar disorder was 13.2 years, with 50% reporting that their first indication of symptoms occurred between the ages of 11 and 20 years of age, 85% reporting difficulty in obtaining their diagnosis and 71% feeling that their condition had worsened as a result of being prescribed inappropriate medication, such as antidepressants [166]. As we know that many people are waiting years before they receive a correct diagnosis of bipolar disorder, it would be helpful for those who feel they may be yet to be formally diagnosed to gain a better understanding of the condition and the ways in which they can help themselves. The accessibility of online modules on the signs and symptoms of bipolar disorder and how it is diagnosed may help some people assess whether they may have the condition so that they can seek professional help accordingly.

APPENDICES

Appendix 1: Study selection, quality assessment and data extraction form for RCTs

Version 2.0, 8 May 2012

Title of the review:

The benefits of psychoeducation for bipolar disorder: a mixed-methods systematic review

Aim of the review:

To review the evidence from quantitative and qualitative studies that psychoeducational approaches in different modalities may or may not be beneficial for patients with bipolar disorder

Objectives of the review:

Review psychoeducation interventions (individual, online, and group-based face-to-face) for bipolar disorder to include randomised controlled trials and qualitative studies

NB: If completing this form electronically please save the form like this: your initials _ study ID number; e.g., "RP_04" / "DS_15" and also add this to page headers

Study ID number	
First author of study	
Date of publication	
Type of study (e.g. journal or conference paper)	
Initials of person completing form	
Is this linked to another paper or study? If so, provide details	

Notes:

--

Study eligibility

Criteria for assessing papers for inclusion in literature review

(Delete each option below as appropriate)

Must answer “yes” to each of the following:

- 1) Does the study have original data? Y / N / Unclear
- 2) Do all the patients studied have ICD-10 or DSM-IV bipolar disorder? Y / N / Not reported / Unclear
- 3) Is the intervention described within the study broadly psychoeducational? Y / N / Not reported / Unclear
- 4) Has the study been published in English? Y / N
- 5) Is the study a RCT or a qualitative study? Y / N / Not reported / Unclear
- 6) Does the study report patient focused outcomes? Y / N / Not reported / Unclear

Must answer “no” to the following:

- 1) Is the study sample predominantly paediatric (patients under 12 years of age)? Y / N / Not reported / Unclear
- 2) Are the studies of caregiver therapy only and do not comprise patient psychoeducation as a comparator? Y / N / Not reported / Unclear
- 3) Is the study predominantly of bipolar disorder patients with comorbid conditions (e.g., alcohol dependence, personality disorder)? Y / N / Not reported / Unclear

If any answer to the above is incongruent with the required answer, then record if/why the study should be excluded below:

Reason(s) for exclusion:

Details of study

Aim of study	
Trial design	
Single centre or multicentre	
Country / countries	
Time when study took place	

Characteristics of intervention(s) – delete intervention columns where not needed

	Intervention A	Intervention B	Intervention C	Control
Name of intervention				
Description of intervention				
Aim of intervention				
Delivery format				
Details of providers				
Duration of intervention				
Frequency of intervention				
Timing of intervention				

Participants

Inpatient / outpatient / community-based sample / caregivers / families / other: please	
---	--

specify	
Type(s) of bipolar disorder	
Average length of diagnosis / stage of bipolar disorder	
Other health problems	
Age range	
Age mean	
Gender (numbers or %)	
Other social/demographic details	
Method(s) of recruiting participants	
Incentive(s) to participate	Y / N / not reported / unclear
Sample size reported	
Inclusion criteria	
Exclusion criteria	
Number eligible	
Number excluded	
Number refused to take part	
Number randomised to intervention A	
Number randomised to intervention B	
Number randomised to intervention C	
Number randomised to control	
<i>For those excluded post-randomisation:</i>	
Number withdrawn	
Number lost to follow-up	
Number died	

Number included in analysis	
Number included for each outcome	

Assessment of study quality

Main outcomes clearly described in intro/method	Y / N / not reported / unclear
Intervention clearly described	Y / N / not reported / unclear
Randomisation	Y / N / not reported / unclear
Method of generating randomisation schedule	
Method of concealment of allocation (to prevent foreknowledge of group assignment)	
<i>Blinding:</i>	
Participants	Y / N / not reported / unclear
Providers	Y / N / not reported / unclear
Outcome assessor(s)	Y / N / not reported / unclear
Baseline comparability of intervention and control groups	Y / N / not reported / unclear
Statistical methods and their appropriateness	
Maintenance of comparable groups (including attrition, crossovers, adherence, contamination)	
Power calculation	Y / N / not reported / unclear
Were withdrawals described	Y / N / not reported / unclear
Were participants in all groups followed up in the same way	Y / N / not reported / unclear

Are estimates of variance reported for main results	Y / N / not reported / unclear
Do analyses adjust for different lengths of follow-up	Y / N / not reported / unclear
Were all participant data analysed regardless of adherence to protocol or continuation in trial (i.e., analysed according to intention-to-treat principle)	Y / N / not reported / unclear If appropriate, give details:
All important outcomes considered	Y / N / not reported / unclear If appropriate, give details:
Appropriate attention to confounders in analysis	Y / N / not reported / unclear If appropriate, give details:
Are the conclusions supported by the results	Y / N / not reported / unclear If appropriate, give details:
Advantages of study	
Disadvantages of study	
Overall quality rating of study	Good / Fair / Poor

Data extraction - outcomes

Principal outcome measures	
----------------------------	--

Secondary outcome measures	
Validated measurement tools for each outcome	
Length of follow-up	

Data extraction – results

Outcome data in format reported:

Other information relevant to the results:

Further considerations

Key conclusions of study authors	
How meaningful are results?	

How precise are these results?	
Can results be applied? How?	
Include any references to published reports of RCTs or qualitative studies not already identified for this review – if so, provide details	
Is the funding source clearly acknowledged?	
Is correspondence required?	

Appendix 2: Study selection, quality assessment and data extraction form for qualitative studies

Version 1.0, 4 May 2012

Title of the review:

The benefits of psychoeducation for bipolar disorder: a mixed-methods systematic review

Aim of the review:

To review the evidence from quantitative and qualitative studies that psychoeducational approaches in different modalities may or may not be beneficial for patients with bipolar disorder

Objectives of the review:

Review psychoeducation interventions (individual, online, and group-based face-to-face) for bipolar disorder to include randomised controlled trials and qualitative studies

NB: If completing this form electronically please save the form like this: your initials _ study ID number; e.g., "RP_04" / "DS_15" and also add this to page headers

Study ID number	
First author of study	
Date of publication	
Type of study (e.g. journal or conference paper)	
Initials of person completing form	
Is this linked to another paper or study? If so, provide details	

Notes:

Study eligibility

Criteria for assessing papers for inclusion in literature review

(Delete each option below as appropriate)

Must answer “yes” to each of the following:

- 1) Does the study have original data? Y / N / Unclear
- 2) Do all the patients studied have ICD-10 or DSM-IV bipolar disorder? Y / N / Not reported / Unclear
- 3) Is the intervention described within the study broadly psychoeducational? Y / N / Not reported / Unclear
- 4) Has the study been published in English? Y / N
- 5) Is the study a RCT or a qualitative study? Y / N / Not reported / Unclear
- 6) Does the study report patient focused outcomes? Y / N / Not reported / Unclear

Must answer “no” to the following:

- 1) Is the study sample predominantly paediatric (patients under 12 years of age)? Y / N / Not reported / Unclear
- 2) Are the studies of caregiver therapy only and do not comprise patient psychoeducation as a comparator? Y / N / Not reported / Unclear
- 3) Is the study predominantly of bipolar disorder patients with comorbid conditions (e.g., alcohol dependence, personality disorder)? Y / N / Not reported / Unclear

If any answer to the above is incongruent with the required answer, then record if/why the study should be excluded below:

Reason(s) for exclusion:

Details of study

Aim of study	
Study design	
Single centre or multicentre	
Country / countries	
Time when study took place	

Characteristics of intervention(s) – delete intervention columns where not needed

	Intervention A	Intervention B	Intervention C	Control
Name of intervention				
Description of intervention				
Aim of intervention				
Delivery format				
Details of providers				
Duration of intervention				
Frequency of intervention				
Timing of intervention				

Participants

Inpatient / outpatient / community-based sample / caregivers / families / other: please specify	
---	--

Type(s) of bipolar disorder	
Average length of diagnosis / stage of bipolar disorder	
Other health problems	
Age range	
Age mean	
Gender (numbers)	
Other social/demographic details	
Incentive(s) to participate	Y / N / not reported / unclear
Informed consent	Y / N / not reported / unclear
Ethical approval obtained	Y / N / not reported / unclear
Sample size reported	
Inclusion criteria	
Exclusion criteria	
Number eligible	
Number excluded	
Number refused to take part	
Number withdrawn	
Number lost to follow-up	
Number died	
Number included in analysis	

Assessment of study quality using CASP: Qualitative Research

The 10 questions have been developed by the national CASP collaboration for qualitative methodologies.

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1) Was there a clear statement of the aims of the research? <i>(Consider what the goal of the research was, why it is important, its relevance)</i>	Y / N
2) Is qualitative methodology appropriate? <i>(Consider if the research seeks to illuminate the actions and/or subjective experiences of research participants)</i>	Y / N

	PROVIDE DETAILS BELOW
3) Was the research design appropriate to address the aims of the research? <i>(Consider if the researcher has justified the research design – e.g., have they discussed which methods to use?)</i>	<u>Appropriate research design:</u>

<p>4) Was the recruitment strategy appropriate to the aims of the research?</p> <p><i>Consider:</i></p> <ul style="list-style-type: none"> - <i>if the researcher has explained how the participants were selected</i> - <i>if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study</i> - <i>if there are any discussions around recruitment (e.g. why some people chose not to take part)</i> 	<p><u>Sampling:</u></p>
<p>5) Were the data collected in a way that addressed the research issue?</p> <p><i>Consider:</i></p> <ul style="list-style-type: none"> - <i>if the setting for data collection was justified</i> - <i>if it is clear how data were collected</i> - <i>if the researcher has justified the methods chosen</i> - <i>if the researcher has made the methods explicit (e.g. is there an indication of how interviews were conducted, did they use a topic guide)</i> 	<p><u>Data collection:</u></p>
<p>6) Has the relationship between researcher and participants been accurately considered?</p> <p><i>Consider whether it is clear:</i></p> <ul style="list-style-type: none"> - <i>if the researcher critically examined their own role and background, potential bias and influence during:</i> <ul style="list-style-type: none"> o <i>formulation of research questions</i> o <i>data collection, including sample recruitment and choice of location</i> - <i>how the researcher responded to events during the study and</i> 	<p><u>Reflexivity (research partnership relations / recognition of researcher bias):</u></p>

<p><i>whether they considered the implications of any changes in the research design</i></p>	
<p>7) Have ethical issues been taken into consideration? <i>Consider: explanations to participants, issues around informed consent of confidentiality, how they have handled the effects of the study on participants</i></p>	<p><u>Ethical issues:</u></p>
<p>8) Was the data analysis sufficiently rigorous? <i>Consider:</i> – <i>if there is an in-depth description of the analysis process</i> – <i>if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?</i> – <i>whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process</i> – <i>if sufficient data are presented to support the findings</i> – <i>to what extent contradictory data are taken into account</i> – <i>whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation</i></p>	<p><u>Data analysis:</u></p>
<p>9) Is there a clear statement of findings? <i>Consider:</i> – <i>if the findings are explicit</i> – <i>if there is adequate discussion of the evidence both for and against the researcher’s arguments</i> – <i>if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)</i> – <i>if the findings are discussed in relation to the original research questions</i></p>	<p><u>Findings:</u></p>
<p>10) How valuable is the research?</p>	<p><u>Value of the research:</u></p>

Consider:

- if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)*
- if they identify new areas where research is necessary*
- if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*

Data extraction

Describe aims	
Describe outcomes sought	
Intervention clearly described	Y / N / not reported / unclear
Study nested within RCT (if so, provide brief details of main RCT or reference)	Y / N / not reported / unclear
Were withdrawals described	Y / N / not reported / unclear
What were the primary findings?	
What were the secondary findings?	
What were the authors' interpretations of the findings?	
Were the findings supported appropriately by quotations?	Y / N / not reported / unclear If appropriate, give details:
All important outcomes considered	Y / N / not reported / unclear If appropriate, give details:
Appropriate attention to outliers in analysis	Y / N / not reported / unclear If appropriate, give details:
Are the conclusions supported by the results	Y / N / not reported / unclear If appropriate, give details:
Advantages of study	
Disadvantages of study	

Overall quality rating of study	Good / Fair / Poor
---------------------------------	--------------------

Further considerations

Key conclusions of study authors	
How meaningful are results?	
Can results be applied? How?	
Include any references to published reports of RCTs or qualitative studies not already identified for this review – if so, provide details	
Funding source	
Is correspondence required?	

Appendix 3: Table 3. Design characteristics and main results of included RCTs

Author, year, country, (study ID) [reference]	Details of intervention(s), control arm, setting	Number in analysis	Diagnostic group, mood state at entry	Design, aim, methodological quality rating	Length of follow-up	Main outcome(s)	Main findings	Relevant and significant additional findings
Eker & Harkin, 2012, Turkey (1) [52]	Psychoeducation group programme consisting of 6 weekly sessions of 90-120 minutes. Content focused on the durability of medical treatment, detecting relapse, coping with symptoms or adverse effects, decreasing suicide risk and increasing quality of life. Groups were held in a hospital meeting room, led by a therapist with 7 years of psychiatric clinical experience. The control group received training on medication by a doctor for a maximum of 5-10 minutes	63 (intervention: 30 / control: 33)	Met the Bipolar Affective Disorder DSM-IV diagnosis criteria, in remission	Semi-experimental design (pre-test-post-test, randomised controlled groups); To evaluate the effects of a psychoeducation programme and patients' adherence to it; Fair quality	6 weeks	Patients' treatment adherence after psychoeducation	Patients' adherence to medication in the intervention group significantly increased (86.7%) after psychoeducation, which was significantly different from the control group's decreased treatment adherence after psychoeducation (chi-square=24.649, p<0.01)	
Smith et al, 2011, UK (4) [23]	Internet-based psychoeducation programme consisting of 8 online, interactive modules to be completed by patients on an individual basis, fortnightly, with peer discussion available via an online forum. Modules covered diagnosis, causes of bipolar disorder, medication, lifestyle, relapse prevention, psychological approaches and advice for families and carers. Waiting list control group. A	37 (intervention: 17 / control: 20)	Met the Bipolar Affective Disorder DSM-IV diagnosis criteria, in remission	Exploratory randomised controlled trial; To examine the efficacy, feasibility and acceptability of an internet-based psychoeducation programme for bipolar disorder; Fair quality	6 months	Patients' quality of life after psychoeducation	There was no significant difference between groups on the quality of life measure (total WHOQOL-BREF score)	The intervention group showed a marginally significant improvement in psychological quality of life: an increase from baseline to follow-up in the intervention group compared with a decrease

	psychiatrist debriefed participants on how to use the programme in an initial face-to-face consultation							from baseline to follow-up in the control group (p = 0.05; 95% CI 0.24 to 22.6)
Perlick et al, 2010, USA (13) [53]	Family-Focused Treatment – Health Promoting Intervention (FFT-HPI) was a manualised psychoeducation intervention for caregivers of patients with bipolar disorder, comprising 15 weekly group sessions of 45 minutes duration, led by two experienced clinicians trained in FFT and CBT. Sessions covered psychoeducation, goal setting and behavioural analysis of self-care barriers, with educational videos and reading materials. The control group received a Health Education intervention (HE), which comprised 8 20-25 minute DVDs on the most common health problems experienced by caregivers	43 caregiver participants (FFT-HPI: 24 / HE: 19) 40 patients (FFT-HPI: 22 / HE: 18)	Primary caregivers of patients with bipolar disorder (DSM-IV bipolar disorder types I and II) who have current physical and mental health problems	Randomised controlled trial; To evaluate the efficacy of FFT-HPI where family members received either FFT-HPI or brief education about bipolar disorder and common health problems; Fair quality	6 months	Primary outcome variables for caregivers were depressive symptoms and health behaviour. Primary outcome measures for patients were symptoms of depression and mania	Caregivers receiving FFT-HPI had significantly fewer depressive symptoms and reduced health risk behaviour. Patients associated with caregivers in the intervention arm also had fewer depressive symptoms	
Castle et al, 2010, Australia	The group-based psychosocial intervention for bipolar disorder comprised	72 (intervention: 32 / control: 40)	Met DSM-IV-TR criteria for	Randomised controlled trial; To evaluate a group-	9 months	Relapse of any type	The intervention group had a significantly reduced rate of relapse	The intervention group spent less time unwell

(14) [54]	12 weekly sessions of 90 minutes each and 3 additional monthly booster sessions, facilitated by clinicians experienced in mental health. Weekly telephone calls during the programme reminded participants of the next group session and offered support with homework. The programme was designed to enable participants to optimise their health and prevent relapse by developing and maintaining coping strategies. The control group received TAU plus brief weekly telephone calls in the 12-week intervention period. Outpatient setting		bipolar disorder	based intervention for bipolar disorder in a naturalistic setting; Fair quality				
Lobban et al, 2010, UK (15) [37]	Community Mental Health Team (CMHT) workers either received training in enhanced relapse prevention (ERP) to offer to patients with bipolar disorder or continued to provide TAU. Six 1-hour manual-based training sessions of ERP were provided by care-coordinators. Content included psychoeducation, early warning signs, coping strategies, action plans, how to respond with services to different stages of relapse, and involving a friend or relative	23 teams and 96 patients (intervention: 11 teams and 56 patients / control: 10 teams and 40 patients)	Bipolar disorder type I or II; no major episode in the previous 4 weeks	Cluster randomised controlled trial; To assess feasibility and effectiveness of training CMHTs to deliver enhanced relapse prevention; Good quality	1 year	Time to recurrence of an episode of mania, hypomania or depression	No significant difference between groups in terms of time to relapse, although treatment increased median time to the next bipolar episode by 8.5 weeks	

D'Souza et al, 2009, Australia (17) [58]	The Systematic Illness Management Skills Enhancement Programme-Bipolar Disorder (SIMSEP-BD) was a psychoeducation programme for companion-patient dyads. Four trained mental health clinicians led 12 weekly group sessions of 90 minutes. The control arm received TAU, which was a community based case management model involving a 45-minute weekly review with a clinician and a monthly medical review. Outpatient setting	53 (treatment: 26 / control: 27)	Met criteria for bipolar disorder according to the MINI assessment; recently remitted patients were recruited within 1 month following discharge from hospital for relapse of bipolar disorder	Pilot randomised controlled trial; To assess the effectiveness of group-based psychoeducation for recently remitted patients and their companions in reducing relapse; Poor quality	60 weeks or until relapse	Relapse requiring hospital or intensive community intervention	The intervention group were significantly less likely to relapse (Fisher's exact test p=0.013; OR=0.16; 95% CI 0.04-0.70) and had an 11 week longer time to relapse than the control group (chi-square (1)=8.48, p<0.01)	
Sajatovic et al, 2009, USA (27) [59]	The Life Goals Program (LGP) was a manual-based group psychotherapy programme for bipolar disorder. It focused on illness education, self-management and problem-solving. Mental health therapists provided 6 weekly sessions of LGP at a community mental health centre. The control group received TAU, which comprised medication management by a psychiatrist, psychosocial therapy and counselling by mental health clinicians	164 at baseline (treatment: 84 / control: 80); 128 participated in at least 1 follow-up rating; (treatment: 63 / control: 65)	Met criteria for bipolar disorder I or II according to the MINI assessment; outpatients	Randomised controlled study; To determine whether there were differences between groups receiving LGP or TAU in medication adherence attitudes and behaviours; Poor quality	3-, 6-, and 12-months	Attitudes to treatment and self-reported treatment adherence	There were no differences between two groups in treatment attitudes	
Zaretsky et al, 2008,	Cognitive behavioural therapy (CBT) plus	46 (treatment: 20 / control: 26)	Diagnosis of BD I or	Randomised pilot study; To assess the	1 year	Levels of affective symptoms and	Some difference between groups: the	

Canada (30) [60]	psychoeducation was compared with psychoeducation (PE) alone (control arm). PE and pharmacotherapy was provided to both groups by an outpatient psychiatrist. PE for bipolar disorder comprised 7 weekly audio-taped individual therapy sessions. CBT consisted of 13 weekly audio-taped sessions focused on goal-setting, cognitive restructuring, problem-solving, self-monitoring, behavioural activation and stimulus control strategies		BD II; in remission	efficacy and additional benefit of CBT combined with a standard course of brief psychoeducation; Poor quality		psychosocial functioning, antidepressant adjustment	intervention group had 50% fewer days of depressed mood and fewer antidepressant increases	
Reinares et al, 2008, Spain (32) [55]	Caregivers of the psychoeducation group received 12 weekly 90-minute group psychoeducation sessions in a hospital setting. Patients did not attend. It included structured information about the nature of the illness, skills training for its management, the role of the family and the importance of reducing feelings of guilt. Caregivers received written summaries of topics, and groups were conducted by a psychologist with relevant experience. Caregivers of patients in the control group did not receive any specific intervention	113 (intervention: 57 / control: 56)	Met DSM-IV criteria for bipolar disorder I or II; euthymic at the intervention onset	Randomised controlled trial; To assess the efficacy of group psychoeducation for caregivers of euthymic bipolar patients; Fair quality	1 year	Time to any mood recurrence	Significant between-group differences for time to recurrence of any mood episode, favouring the intervention group (chi-square = 6.53, p = 0.011)	The intervention group had fewer patients with mood recurrences and longer relapse-free intervals
Colom et al, 2003, Spain	Group psychoeducation consisted of 21 90-minute	120 (treatment: 60 / control: 60)	Met DSM-IV criteria for	Randomised controlled trial; To	2 years	Number of recurrences, time	The intervention group had significantly fewer	

(38) [48]	sessions delivered by 2 experienced psychologists. Content focused on illness awareness, adherence to treatment, early detection of prodromal symptoms and recurrences, and lifestyle regularity. The control arm received 20 weekly group meetings with the psychologists, with very minimal psychoeducational feedback		bipolar disorder type I or II; Euthymic for previous 6 months	assess the efficacy of group psychoeducation; Good quality		to recurrence and hospitalizations	relapsed patients, recurrences per patient and greater time to recurrences. The intervention group also had fewer and briefer hospitalisations	
Colom et al, 2003, Spain (41) [56]	Intervention as described above (38)	50 (treatment: 25 / control: 25)	Met DSM-IV criteria for bipolar disorder type I; in remission	Randomised prospective clinical trial; To assess the efficacy of group psychoeducation for euthymic patients who adhere well to treatment; Fair quality	Every month for 2 years	Number of recurrences and hospitalizations	The intervention group had significantly fewer recurrences ($p < 0.01$)	The intervention group had significantly fewer depressive episodes
Colom et al, 2005, Spain (72) [57]	Intervention as described above (38)	93 (treatment: 49 / control: 44)	Met DSM-IV criteria for bipolar disorder type I; in remission	Subanalysis of randomised controlled trial; To assess the effect of group psychoeducation on the lithium levels of euthymic patients; Fair quality	6, 12, 18 and 24 months	Changes in serum lithium level	The intervention group had significantly higher and more stable serum mean serum lithium levels ($p < 0.03$)	
Colom et al, 2009, Spain (53) [49]	Intervention as described above (38)	99 (treatment: 50 / control: 49)	Met DSM-IV criteria for bipolar disorder type I or II; Euthymic for previous 6 months	Randomised controlled trial; To assess the efficacy of group psychoeducation; Good quality	5 years	Time to any recurrence, number of recurrences, total number of days spent ill, frequency and length of	The intervention group had longer time to recurrence (log rank=9.953, $P < 0.002$), fewer recurrences, ($F=23.6$, $P < 0.0001$), spent less time acutely ill ($F=31.66$, $P=0.0001$),	

						hospitalisations	and had lower median number of days hospitalised (F=4.26, P=0.047)	
Colom et al, 2009, Spain (54) [61]	Intervention as described above (38)	20 (treatment: 8 / control: 12)	Met DSM-IV criteria for bipolar disorder type II; Euthymic for previous 6 months	Randomised controlled trial; To assess the efficacy psychoeducation for patients with bipolar disorder type II; Poor quality	5 years	Number of recurrences, time spent acutely ill, functional outcome	The treatment group had fewer recurrences (mean number of episodes $p<.02$), fewer hypomanic episodes ($p<.03$) and depressive episodes ($p<.03$), less time spent in mood episodes ($p=.004$) and higher levels of functioning ($p<.05$)	
Solomon, 2008, USA (58) [62]	Participants either received family therapy plus pharmacotherapy (a therapist working with a patient and family member/s), multifamily group therapy (2 therapists leading a group of 4-6 patients and their family members for manual-based psychoeducation), or pharmacotherapy alone in the control condition (medication management appointments with a psychiatrist). Outpatient setting	53 (family therapy: 16 / multifamily group therapy: 21 / control: 16)	Inpatients, partial hospital inpatients and outpatients receiving treatment for an active bipolar I mood episode	Randomised controlled trial; To compare the efficacy of three treatment conditions (individual family therapy, group family therapy, and TAU) in preventing recurrence of bipolar I mood episodes and hospitalization; Poor quality	Assessed monthly for up to 28 months	Number of recurrences, number of hospitalisations, time to recurrence, and time to hospitalisation	No differences between groups in number of recurrences, time to recurrence and time to hospitalisation. Patients who received multifamily group therapy had significantly fewer hospitalisations than patients who received individual family therapy or TAU (chi-square = 6.53, df = 2, $p< 0.04$)	
Perry et al, 1999, UK (77) [50]	7-12 individual treatment sessions with a research psychologist (teaching patients to identify early signs of relapse and obtain treatment) vs routine care in the control arm. Outpatient setting	69 (treatment: 34 / control: 35)	Diagnosis of bipolar disorder I and II; not stated	Randomised controlled trial; To determine the efficacy of teaching patients to identify early signs of relapse and seek prompt help; Good quality	Assessed every 6 months for 18 months	Time to first manic or depressive relapse, number of manic or depressive relapses, social functioning	Time to first manic relapse ($p=.008$) and number of manic episodes ($p=.013$) significantly differed between groups, favouring treatment. The treatment significantly improved	The treatment significantly improved rates of employment ($p=.030$)

							overall social functioning (p=.003)	
Clarkin et al, 1998, USA (78) [63]	Patients with their partners received medication management and 25 sessions of marital psychoeducation over 11 months from trained social workers. Patients with partners in the control arm only received medication management. Inpatient and outpatient sample	33 (treatment: 18 / control: 15)	Diagnosis of major affective disorder or bipolar disorder, manic, depressed, or mixed; not stated	Randomised controlled trial; To assess the benefit of adding psychoeducation to standard medication for married patients; Poor quality	After 11 months of treatment	Symptoms, functioning, adherence to medication	Medication adherence was better in the intervention group (mean level of medication adherence: 5.70 versus 5.17, t=2.84, df=38, p=.008). The intervention group also showed improved overall functioning	
Simon et al, 2005, USA (80) [38]	Patients received a multi-component group intervention programme over 2 years, involving group psychoeducation (adapted from Bauer and McBride's Life Goals Program: 5 weekly then twice-monthly sessions) and monthly telephone monitoring of mood and symptoms by trained nurse care managers, also trained in motivational interviewing techniques. The control group received TAU. Community setting	441 (treatment: 212 / control: 229)	Diagnosis of bipolar I and II; most patients had some bipolar symptoms at baseline	Randomised controlled trial; To evaluate a multi-component care package in a population-based sample; Good quality	Every 3 months for 12 months	Severity of manic and depressive symptoms	Psychoeducation group had significantly lower mean mania ratings in 12-month follow-up (Z=2.44, p=0.015) and a greater decline in depression ratings (Z=1.98, p=0.048)	
Simon et al, 2006, USA (83) [39]	Intervention as described above (same study, but with an additional follow-up year)	331 (treatment: 156 / control: 175)	Diagnosis of bipolar I and II; most patients had some bipolar symptoms at baseline	Randomised controlled trial; To evaluate a multi-component care package in a population-based sample; Good quality	Every 3 months for 2 years	Severity of manic and depressive symptoms	Psychoeducation group had significantly lower mean mania ratings (z=2.09, P=.04) and less time with significant mania symptoms (19.2 vs 24.7 weeks; F1=6.0, P=.01)	

Bauer et al, 2006, USA (81 & 82) [40, 51]	Bipolar Disorders Program intervention comprised group psychoeducation (Life Goals Program focused on personal symptom profiles, early warning symptoms and triggers for self-management), clinician support via simplified clinical practice guidelines, and improved information flow, access to and continuity of care from nurse care coordinators. The control arm received TAU. Outpatient setting	306 (treatment: 157 / control: 149)	DSM-IV diagnosis of bipolar disorder type I or II; sample identified at hospital for acute bipolar episode (acutely ill and highly comorbid sample)	Randomised controlled trial; To assess the outcome of a team-based intervention comprising group-based psychoeducation; Good quality	3 years	Clinical outcome, functional outcome, quality of life, social adjustment and service use	Treatment group had a significant reduction in weeks of a bipolar episode, significantly improved social functioning (specifically relating to work, parental and extended-family roles) and significantly improved mental quality of life from first 6-month assessment	Treatment group had significantly higher treatment satisfaction from first 6-month assessment
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Appendix 4: Table 4. Design characteristics and main results of included qualitative studies

Author, year, country, (study ID)	Details of intervention(s), setting	Aim, methodological quality rating	Diagnostic group, mood state at entry	Method of data collection, number in analysis	Details of data analysis	Main findings
O'Connor et al, 2008, Ireland (23) [64]	The intervention received was group psychoeducation for bipolar disorder delivered by a clinical psychologist and a mental health nurse, and comprised 8 weekly sessions of 90 minutes. Sessions included an overview of bipolar disorder and focussed on treatment, relapse prevention, coping with psychosocial stressors, and cognitive and behavioural strategies. Community outpatient setting	To explore service users' experiences of group psychoeducation for bipolar disorder; Poor quality	Met criteria for DSM-IV bipolar disorder, in remission	Semi-structured interviews; 11 participants	IPA (interpretative phenomenological analysis)	3 main themes emerged: 1) the treatment of bipolar disorder, 2) comparison with and perception of others, and 3) learning from the group. 1) Participants had differing views on the health service's approach to the illness, many expressed either reluctance or acceptance towards taking medication, and some described the trauma of hospitalisation. 2) Participants compared themselves to other group members, and recognised that others shared similar experiences and issues. They also acknowledged the friendship and respect of others and felt a heightened sense of self-esteem as a result. 3) The programme helped some participants accept their diagnosis of bipolar disorder and learn cognitive-behavioural coping strategies for managing depression and mania
Pontin et al, 2009, UK (49) [42]	The intervention was Enhanced Relapse Prevention (ERP) delivered by Care Coordinators (psychiatric nurses, social workers or occupational therapists) within their case management. It comprised 6 manual-based 60-minute sessions of psychoeducation for bipolar disorder to teach patients to recognise early warning signs to manic and depressive episodes	To explore the value to service users of enhanced relapse prevention (ERP) for bipolar disorder from service users' and mental healthcare professionals' perspectives;	Bipolar disorder type I or II; no major episode in the previous 4 weeks (see: Lobban, 2010, UK, study 15)	Semi-structured interviews; 21 Care Coordinators and 21 service users	A grounded theorizing approach to develop conceptual categories from the data by thematic analysis. 2 researchers identified and compared patterns within the data to develop an account. All interviews read by at least 2 researchers for reliability. Data triangulation and investigator triangulation to increase trustworthiness	Service users (SUs) and Care Coordinators (CCs) found that ERP improved their understanding of bipolar disorder, developed their ways of managing and working with bipolar disorder and enhanced working relationships. SUs: learned about early warning signs and coping strategies, acceptance of diagnosis and medication adherence increased, felt more empowered, felt distressed about discussing past illness episodes, had more contact with their CC, and trust in services increased. CCs: increased their knowledge of bipolar disorder, increased competence and confidence in working with patients, acquired new

		Good quality				skills and strategies, learned more about the SU perspective and experience of bipolar disorder, had greater sense of purpose, added burden to workload and time, more contact with SUs, creation of concise and individualised action plans, and increased SU dependency on CC rather than service as a whole.
Peters et al, 2011, UK (50) [43]	Community Mental Health Team (CMHT) workers either received training in enhanced relapse prevention (ERP) to offer to patients with bipolar disorder or continued to provide TAU. Six 1-hour manual-based training sessions of ERP were provided by care-coordinators. Content included psychoeducation, early warning signs, coping strategies, action plans, how to respond with services to different stages of relapse, and involving a friend or relative (as described in study 15: Lobban et al, 2010) The intervention was delivered to service users and their relative	To explore the values and barriers of involving relatives in relapse prevention for bipolar disorder from the perspectives of service users, their relatives and care-coordinators; Good quality	Bipolar disorder type I or II; no major episode in the previous 4 weeks (see: Lobban, 2010, UK, study 15)	Semi-structured interviews; 21 Care Coordinators (CCs), 21 service users (SUs) and 10 relatives	A grounded theorizing approach to develop conceptual categories from the data. Emerging themes were explored during data collection and developed in further interviews. The interviewer analysed all the data, which was separately analysed by at least one other researcher for reliability. Findings were discussed within a multidisciplinary team for trustworthiness. Data collection and analysis were conducted in parallel until thematic saturation was achieved	Values of involving relatives in relapse prevention (RP): RP increased relatives understanding of bipolar disorder, triggers and early warning signs. They recognised triggers and early warning signs that SUs were unaware of. They felt empowered, less anxious about a relapse and more equipped to intervene. Novel information was shared between SUs and relatives which led to increased understanding; although sometimes information was withheld because relatives were present. Barriers to involving relatives in RP: Some relatives lacked the time to be involved, some SUs didn't have an appropriate family member to involve, and some SUs wanted to keep their illness private, either due to stigma or not wanting to burden their relatives. Relatives felt uncomfortable about "intruding" on the established CC and SU relationship. CCs found maintain SU confidentiality difficult, and RP with relatives was viewed as a professional burden, increasing their caseload. Some found it difficult to manage family dynamics, and reported that keeping the focus on SUs was difficult at times
Nicholas et al, 2010, Australia (65) [41]	Participants were randomised to receive either an online bipolar education programme alone (BEP) or with email support from informed supporters (BEP + IS) or a control condition, which consisted of 8 online text-based modules about bipolar disorder, of no more than 2 pages in length, with a brief	To identify predictors of attrition and explore reasons for non-adherence to an online psychoeducation programme	Diagnosis of bipolar disorder by a general practitioner or psychiatrist within past 12 months; Mood state at	Qualitative study and regression of RCT results. Semi-structured interviews with 39 participants	Qualitative: Thematic analysis was used to identify patterns in participants' reasons for attrition. Interviews were analysed by two researchers. Discrepancies in theme identification were resolved through discussion.	Attrition patterns: 26.5% returned 3 or fewer module workbooks. Adherence was significantly higher in BEP + IS compared with BEP alone (P = .01). Predictors of attrition: Significant predictors of attrition were: young age, male gender and recruitment via a clinic Participants' reported reasons for non-adherence: The most common theme for discontinuation was

	<p>quiz and a mood chart to complete. BEP comprised 8 online modules delivered weekly with associated workbooks for participants to develop their “stay well plan”. Modules were approximately 30 minutes, presented via a lecture-style slide presentation with voice narration. Topics included: causes of bipolar disorder, medications and psychological treatments. Informed supporters were expert patients with bipolar disorder trained to provide email support under supervision from the research team</p>	<p>for bipolar disorder; Fair quality</p>	<p>entry not specified</p>	<p>(BEP: 16 / BEP + IS: 9 / control: 14) who met criteria for non-completion (i.e. they returned 3 or fewer completed workbooks). 358 participants included in the quantitative analysis to identify predictors of attrition</p>	<p>Quantitative: Standard multiple linear regression to explore predictors of attrition, with the number of workbooks completed as the outcome measure</p>	<p>being in an acute phase of the illness – those in a depressive phase lacked energy and motivation to complete, and those in a manic phase became distracted by their symptoms. Many didn’t want to think about their illness and found the weekly information confronting or overwhelming. A few regarded the information to be too basic or simplistic, and were aware of much of the content beforehand. Some expected more tailored information and were dissatisfied with its generality. Some didn’t feel the need to continue with it when well. Some said they would re-access the programme if depressed. Some didn’t view the programme as a priority or lacked motivation to complete it</p>
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Appendix 5: BIPED semi-structured interview schedule

INITIAL QUESTIONS

How are you doing at the moment?

Have you felt better or worse since April, or do you feel the same as you felt then?

If patient feels better or worse: To what extent?

A) ACCESS

Could you access the programme?

To what extent do you feel competent in using a computer?

Did you access the programme at home or in a public venue (such as a library or internet café)?

If patient accessed programme in public venue: Did you feel that your privacy was compromised as a result of accessing the programme a public venue?

How much of the programme did you do?

(Can you tell me which modules you did?)

(Did you finish the modules?)

(Did you skip any modules?)

If patient did not continue with programme: Why did you decide not to continue with the programme?

Did you need assistance from anyone with any aspect(s) of the programme?

If so: who; with what; why?

Did you use the forum?

(Did you contribute to the forum or just read it?)

What are your impressions of the forum?

How could the forum be improved?

Do you, or would you, still log in to the website? (*If so:* Why?)

B) REFLECTIONS ON MOOD

Did you experience a significant high or low before, during, or after the programme (such as depression or mania)?

Do you feel that this may have impacted on your ability to benefit from the programme?

C) GENERAL

Why did you want to undertake the programme?

What did you like about the programme?

What didn't you like about the programme?

Were there aspects you found to be particularly helpful?

Were there aspects you found to be frustrating?

Overall, would you say you have benefitted from undertaking the programme?

D) CONTENT

Could you understand the content of the modules? (*Ask for elaboration if necessary*)

Were some modules easier to grasp than others? (*If so: which were easier and why; which more difficult and why*)

Did you have any difficulty paying attention to the modules? (*If so: why?*)

Were any modules more interesting than other modules? (*If so: why?*)

Were any modules more relevant to you than other modules? (*If so: why; and why were other modules less relevant?*)

Have you any other comments or suggestions for improvement regarding the content of the modules?

Did you share the content of any of the modules with anyone? (*If so: which [aspects of] modules, why, and how?*)

Did the programme impact on your relationship with your family?

Since using the programme have you made any lifestyle changes? (*If so: What are they? and what triggered this?*)

E) PRESENTATION FORMAT

What are your impressions of the visual appearance of the programme? (*Probe: videos; tasks to do*)

Was the pace of each module okay, or too fast or too slow?

Did the programme run smoothly on your computer?

Did you find any aspect of the design of the programme particularly engaging? (*If so: which?*)

Did you find any aspect of the design of the programme particularly frustrating? (*If so: which?*)

Have you any other comments or suggestions about the presentation of the modules?

Was the gap between modules about right?

F) INSIGHT

Has the programme as a whole, or any module or modules in particular, impacted upon your understanding of bipolar disorder? (*Can you tell me more?*)

As a result of the programme are you more aware of how to manage your condition? (*Can you tell me more?*)

As a result of the programme have you modified aspects of your behaviour or your routine? (*Can you tell me more?*)

Has your attitude towards medication changed as a result of the programme? (*Can you tell me more?*)

G) SUGGESTIONS FOR IMPROVEMENT

Have you any other comments or suggestions for improvements?

H) RECOMMENDATIONS

Do you think the programme may help others with bipolar disorder?

Would you recommend the programme to others with bipolar disorder? (*Why?*)

In the future should the programme be accessible to patients with bipolar disorder via the NHS?

Can you think of characteristics of some patients which may prevent them from fully benefiting from this programme? (*Prompt for elaboration if necessary*)

I) ADDITIONAL SUPPORT

Aside from the programme, since July 2009 has anything or anyone else provided you with additional support to manage your bipolar disorder?

(If asked, give examples: a self-help book; support from a close friend, partner or relative; yoga; alternative therapies; face-to-face group meetings with peers with bipolar disorder)

If so: How did this help?

If you had been given the choice of either Beating Bipolar the online programme or a group-based programme (where you may have up to 15 people with bipolar disorder learning together under the direction of a clinician) which format would you have preferred?

Why?

Appendix 6: BEP-Cymru Questionnaire Packs



BEP-Cymru Pre-course questionnaires

NAME:.....

NAME:

DATE OF BIRTH:/...../.....

AGE

GENDER: (circle one) **Male** **Female**

TEL. NO: (home)

TEL. NO: (mobile)

EMAIL:

HOME ADDRESS:

.....

.....

GP (SURGERY NAME AND ADDRESS):

.....

.....

Name and contact details of consultant psychiatrist and/or community mental health team (if currently in contact):

.....

.....

.....

ETHNIC ORIGIN:

Which of these groups do you regard yourself as belonging to? (circle one):

White – British

White – Irish

Any other White background

Mixed - White and Black Caribbean

Mixed - White and Black African

Mixed - White and Asian

Any other mixed background

Asian/Asian British – Indian

Asian/Asian British – Pakistani

Asian/Asian British – Bangladeshi

Any other Asian background

Black/Black British – Caribbean

Black/Black British – African

Any other Black background

Chinese

Other (please specify).....

MARITAL HISTORY: (circle one)

0 Has married or lived as married

1 Has never married nor lived as married

HIGHEST EDUCATIONAL LEVEL: (circle one)

1 Up to age 16

2 Post age 16

EMPLOYMENT: (circle one)

1 Currently in paid employment

2 Currently unemployed or retired

DO YOU HAVE A DIAGNOSIS OF BIPOLAR DISORDER? (circle one) Yes No

CURRENT MEDICATION:

.....
.....
.....
.....

Knowledge and attitudes questionnaire

This questionnaire is designed for you to self-assess your knowledge of bipolar disorder and your attitudes to medication and to the group format of the programme.

Please answer all questions

How much do you think you know about managing your bipolar disorder?

Please circle one response option which accurately reflects your view:

Nothing Very little A moderate amount Quite a lot or: Not sure

How long have you been diagnosed with bipolar disorder?

..... (years) / (months)

Do you currently take medication for bipolar disorder?

Circle either: YES / NO

If YES to above question:

To what extent do you take medication for bipolar disorder on a regular basis?

Please circle one response option which accurately reflects your view:

Never Seldom Sometimes Most of the time Always

Even if you are not currently taking medication please answer all the following questions...

Describe your feelings towards taking medication for bipolar disorder by ticking all boxes where the corresponding statements apply to you:

1. Taking medication for my bipolar disorder has not been suggested to me
2. I do not take medication for bipolar disorder because it is not for me
3. Taking medication helps to keep my mood stable
4. I take my medication regularly as prescribed
5. I do not think that taking my medication helps to keep my mood stable
6. I do not like taking my medication
7. I suffer from the side effects of my medication
8. The side-effects I get from my medication are tolerable

To what extent do you feel that group healthcare programmes, such as this, may be helpful to you?

*Please **circle one** response option which accurately reflects your view:*

Not at all A little bit Quite Very Extremely

or: Not sure

To what extent would you prefer either learning about bipolar disorder in a group context or learning about bipolar disorder on a one-to-one basis?

*Please **tick one** response option which accurately reflects your view:*

Strongly favour one-to-one learning Favour one-to-one learning
No preference Favour group learning Strongly favour group learning

Have you learned any techniques to manage your bipolar disorder prior to this programme?

Circle either: YES / NO

If YES please provide brief details on the settings of your learning experiences and the techniques you used:

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

Have you learned techniques to manage your bipolar disorder in a face-to-face group-based setting prior to this programme?

Circle either: YES / NO

If YES: Did this experience help you to manage your bipolar disorder?

Circle either: YES / NO

Wellness Questionnaire

*These questions relate to how you have felt in the **past 6 months***

- In the past 6 months have you experienced period(s) of **significantly** high or irritable mood where you may have had racing thoughts, been more energetic than usual or felt especially efficient in your daily activities so that it **caused significant problems** at home, at work or socially, and lasted at least a week? (This is called **mania**)

Circle either: YES / NO

If YES to above question, then in the past 6 months:

- How many episodes of mania did you have?
- How many **days** was your longest episode of mania?
- How many **days** have you experienced mania in total?
- In the past 6 months were you hospitalised for mania?

Circle either: YES / NO

- In the past 6 months have you experienced period(s) of high or irritable mood, for at least 4 consecutive days, where you may have had racing thoughts, been more energetic than usual or felt especially efficient in your daily activities, but which **didn't cause significant problems** at home, at work or socially, and lasted at least 4 days? (This is called **hypomania**)

Circle either: YES / NO

If YES to above question, then in the past 6 months:

- How many episodes of hypomania did you have?

- How many **days** was your longest episode of hypomania?
 - How many **days** have you experienced hypomania in total?
-

- In the past 6 months have you experienced period(s) when you've felt consistently depressed or down, and felt much less interested in most things or less able to enjoy the things you used to enjoy, for at least two weeks (This is called a **depressive episode**)

Circle either: **YES / NO**

If YES to above question, then in the past 6 months:

- How many episodes of depression did you have?
- How many **months** was your longest episode of depression?
- How many **months** have you experienced depression in total?
- Have you had any suicidal thoughts or behaviours? *Circle either: YES / NO*
- In the past 6 months were you hospitalised for a depressive episode?

Circle either: YES / NO

Please answer some questions about your episodes of depression:

At what age did depression start to cause problems for you (e.g., time off work/school, problems at home, or you went to see your GP)?

Have you ever been admitted to hospital because of depression?

Circle either: YES / NO

Were you ever sectioned under the Mental Health Act for depression?

Circle either: YES / NO

Did you ever experience a psychotic symptom during an episode of depression?

Circle either: YES / NO

Please answer some questions about your episodes of hypomania or mania:

At what age did hypomania or mania start to cause problems for you (e.g., time off work/school, problems at home, you went to see your GP)?

Have you ever been admitted to hospital because of hypomania or mania?

Circle either: YES / NO

Were you ever sectioned under the Mental Health Act for hypomania or mania?

Circle either: YES / NO

Did you ever experience a psychotic symptom during an episode of hypomania or mania?

Circle either: YES / NO

If you have any additional comments regarding any of these questions in relation to your bipolar disorder please use the space on the following page.

WHOQOL-BREF

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

	Very poor	Poor	Neither poor nor good	Good	Very good
How would you rate your quality of life?	1	2	3	4	5

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two weeks.

	Not at all	A little	A moderate amount	Very much	An extreme amount
To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
How much do you enjoy life?	1	2	3	4	5
To what extent do you feel your life to be meaningful?	1	2	3	4	5
How well are you able to concentrate?	1	2	3	4	5
How safe do you feel in your daily life?	1	2	3	4	5
How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

	Not at all	A little	Moderately	Mostly	Completely
Do you have enough energy for everyday life?	1	2	3	4	5
Are you able to accept your bodily appearance?	1	2	3	4	5
Have you enough money to meet your needs?	1	2	3	4	5
How available to you is the information you need in your day-to-day life?	1	2	3	4	5
To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your sleep?	1	2	3	4	5
How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
How satisfied are you with your capacity for work?	1	2	3	4	5
How satisfied are you with your personal relationships?	1	2	3	4	5
How satisfied are you with your sex life?	1	2	3	4	5
How satisfied are you with the support you get from your friends?	1	2	3	4	5
How satisfied are you with the conditions of your living place?	1	2	3	4	5
How satisfied are you with your access to health services?	1	2	3	4	5
How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks.

	Never	Seldom	Quite often	Very often	Always
How often do you have negative feelings such as blue mood, despair anxiety, depression?	1	2	3	4	5

FUNCTIONING ASSESSMENT SHORT TEST (FAST)

To what extent are you experiencing **difficulties** in the following aspects?

Circle one score per statement using the following scale:

(0): no difficulty, (1): mild difficulty, (2): moderate difficulty, (3): severe difficulty

AUTONOMY	No dif'	Mild dif'	Moderate dif'	Severe dif'
1. Taking responsibility for a household	(0)	(1)	(2)	(3)
2. Living on your own	(0)	(1)	(2)	(3)
3. Doing the shopping	(0)	(1)	(2)	(3)
4. Taking care of yourself (physical aspects, hygiene)	(0)	(1)	(2)	(3)
OCCUPATIONAL FUNCTIONING	No dif'	Mild dif'	Moderate dif'	Severe dif'
5. Holding down a paid job	(0)	(1)	(2)	(3)
6. Accomplishing tasks as quickly as necessary	(0)	(1)	(2)	(3)
7. Working in the field in which you were educated	(0)	(1)	(2)	(3)
8. Occupational earnings	(0)	(1)	(2)	(3)
9. Managing the expected work load	(0)	(1)	(2)	(3)
COGNITIVE FUNCTIONING	No dif'	Mild dif'	Moderate dif'	Severe dif'
10. Ability to concentrate on a book, film	(0)	(1)	(2)	(3)
11. Ability to make mental calculations	(0)	(1)	(2)	(3)
12. Ability to solve a problem adequately	(0)	(1)	(2)	(3)
13. Ability to remember newly-learned names	(0)	(1)	(2)	(3)
14. Ability to learn new information	(0)	(1)	(2)	(3)
FINANCIAL ISSUES	No dif'	Mild dif'	Moderate dif'	Severe dif'
15. Managing your own money	(0)	(1)	(2)	(3)
16. Spending money in a balanced way	(0)	(1)	(2)	(3)
INTERPERSONAL RELATIONSHIPS	No dif'	Mild dif'	Moderate dif'	Severe dif'
17. Maintaining a friendship or friendships	(0)	(1)	(2)	(3)
18. Participating in social activities	(0)	(1)	(2)	(3)
19. Having good relationships with people close you	(0)	(1)	(2)	(3)
20. Living together with your family	(0)	(1)	(2)	(3)
21. Having satisfactory sexual relationships	(0)	(1)	(2)	(3)
22. Being able to defend your interests	(0)	(1)	(2)	(3)
LEISURE TIME	No dif'	Mild dif'	Moderate dif'	Severe dif'
23. Doing exercise or participating in sport	(0)	(1)	(2)	(3)
24. Having hobbies or personal interests	(0)	(1)	(2)	(3)

Modified SAI

The following questions are about your **attitudes to bipolar disorder**.

Please **circle one** response per question using the following scales.

1. During my life I have experienced emotional and/or psychological difficulties

Completely agree	Agree	Neither agree nor disagree	Disagree	Completely disagree
1	2	3	4	5

2. My condition amounts to a mental illness or mental disorder

Completely agree	Agree	Neither agree nor disagree	Disagree	Completely disagree
1	2	3	4	5

3. This condition has led to adverse consequences or problems in my life

Completely agree	Agree	Neither agree nor disagree	Disagree	Completely disagree
1	2	3	4	5

4. I think that this condition needs to be treated

Completely agree	Agree	Neither agree nor disagree	Disagree	Completely disagree
1	2	3	4	5

BDI

On this questionnaire are groups of statements. Please read each group of statements carefully, circle the number (0, 1, 2 or 3) next to the one statement in each group which **best** describes how you feel **today**. If several statements within a group seem to apply equally well, circle each one.

Be sure to read all the statements in each group before making your choice

1	0 I do not feel sad. 1 I feel sad. 2 I am sad all the time and I can't snap out of it. 3 I am so sad or unhappy that I can't stand it.	8	0 I don't feel I am worse than anyone else. 1 I am critical of myself for my weaknesses or mistakes. 2 I blame myself all the time for my faults. 3 I blame myself for everything bad that happens.
2	0 I am not particularly discouraged about the future. 1 I feel discouraged about the future. 2 I feel I have nothing to look forward to. 3 I feel that the future is hopeless and that things cannot improve.	9	0 I don't have any thoughts of killing myself. 1 I have thoughts of killing myself, but I would not carry them out. 2 I would like to kill myself. 3 I would kill myself if I had the chance.
3	0 I do not feel like a failure. 1 I feel I have failed more than the average person. 2 As I look back on my life, all I can see is a lot of failures. 3 I feel I am a complete failure as a person.	10	0 I don't cry any more than usual. 1 I cry more now than I used to. 2 I cry all the time now. 3 I used to be able to cry, but now I can't cry even though I want to.
4	0 I get as much satisfaction out of things as I used to. 1 I don't enjoy things the way I used to. 2 I don't get real satisfaction out of anything anymore. 3 I am dissatisfied or bored with everything.	11	0 I am no more irritated now than I ever am. 1 I get annoyed or irritated more easily than I used to. 2 I feel irritated all the time now. 3 I don't get irritated at all by the things that used to irritate me.
5	0 I don't feel particularly guilty. 1 I feel guilty a good part of the time. 2 I feel quite guilty most of the time. 3 I feel guilty all of the time.	12	0 I have not lost interest in other people. 1 I am less interested in other people than I used to be. 2 I have lost most of my interest in other people. 3 I have lost all of my interest in other people.
6	0 I don't feel I am being punished. 1 I feel I may be punished. 2 I expect to be punished. 3 I feel I am being punished.	13	0 I make decisions about as well as I ever could. 1 I put off making decisions more than I used to. 2 I have greater difficulty in making decisions than before. 3 I can't make decisions at all anymore.
7	0 I don't feel disappointed in myself. 1 I am disappointed in myself. 2 I am disgusted with myself. 3 I hate myself.		

- 14** 0 I don't feel I look any worse than I used to.
 1 I am worried that I am looking old or unattractive.
 2 I feel that there are permanent changes in my appearance that make me look unattractive.
 3 I believe that I look ugly.

- 15** 0 I can work about as well as before.
 1 It takes an extra effort to get started at doing something.
 2 I have to push myself very hard to do anything.
 3 I can't do any work at all.

- 16** 0 I can sleep as well as usual.
 1 I don't sleep as well as I used to.
 2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
 3 I wake up several hours earlier than I used to and cannot get back to sleep.

- 17** 0 I don't get more tired than usual.
 1 I get tired more easily than I used to.
 2 I get tired from doing almost anything.
 3 I am too tired to do anything.

- 18** 0 My appetite is no worse than usual.
 1 My appetite is not as good as it used to be.
 2 My appetite is much worse now.
 3 I have no appetite at all anymore.

- 19** 0 I haven't lost much weight, if any, lately.
 1 I have lost more than 5 pounds.
 2 I have lost more than 10 pounds.
 3 I have lost more than 15 pounds.

I am purposely trying to lose weight by eating less. Yes No (please circle)

- 20** 0 I am no more worried about my health than usual.
 1 I am worried about physical problems such as aches and pains; or upset stomach; or constipation.
 2 I am very worried about physical problems and it's hard to think of much else.
 3 I am so worried about my physical problems that I cannot think of anything else.

- 21** 0 I have not noticed any recent change in my interest in sex.
 1 I am less interested in sex than I used to be.
 2 I am much less interested in sex now.
 3 I have lost interest in sex completely.

ASRM scale

Please place a circle around the statement that best describes how you have been feeling in the last week.

1. I have been feeling happier or more cheerful...

No more than usual	0
Just occasionally	1
More often than usual	2
Most of the time	3
All of the time	4

2. I have been feeling more self-confident...

No more than usual	0
Just occasionally	1
More often than usual	2
Most of the time	3
All of the time (extremely self-confident)	4

3. I have needed less sleep...

No more than usual	0
Just occasionally	1
More often than usual	2
Frequently needed less sleep	3
Don't need sleep and don't feel tired	4

4. I have been talking...

No more than usual	0
Occasionally more than usual	1
Often talking more than usual	2
Frequently talking more than usual	3
Talking constantly and cannot be interrupted	4

5. In terms of my activity levels...

No more active than usual	0
Occasionally more active	1
Often more active than usual	2
Frequently more active than usual	3
Constantly active or on the go all the time	4

SSRQ:

Please answer the following questions by circling the response that best describes how you are today.
There are no right or wrong answers. Work quickly and don't think too long about your answers.

	Strongly Disagree	Disagree	Uncertain or Unsure	Agree	Strongly Agree
1. I have trouble making plans to help me reach goals	1	2	3	4	5
2. I have a hard time setting goals for myself	1	2	3	4	5
3. Once I have a goal, I can usually plan how to reach it	1	2	3	4	5
4. I give up quickly	1	2	3	4	5
5. I set goals for myself and keep track of my progress	1	2	3	4	5
6. When I'm trying to change something, I pay attention to how I'm doing	1	2	3	4	5
7. I don't notice the effects of my actions until it's too late	1	2	3	4	5
8. I tend to keep doing the same thing even when it doesn't work	1	2	3	4	5
9. I have personal standards and try to live up to them	1	2	3	4	5
10. I get easily distracted from my plans	1	2	3	4	5
11. I have trouble following through with things once I've made up my mind to do something	1	2	3	4	5
12. I have a lot of willpower	1	2	3	4	5
13. I'm able to accomplish goals I set for myself	1	2	3	4	5
14. If I make a resolution to change something, I pay a lot of attention to how I'm doing	1	2	3	4	5
15. I put off making decisions	1	2	3	4	5
16. Most of the time I don't pay attention to what I'm doing	1	2	3	4	5
17. I don't seem to learn from my mistakes	1	2	3	4	5
18. If I wanted to change I am confident that I could do it	1	2	3	4	5
19. I usually keep track of my progress towards my goals	1	2	3	4	5
20. I usually think before I act	1	2	3	4	5
21. As soon as I see a problem or challenge, I start looking for possible solutions	1	2	3	4	5
22. When it comes to deciding about a change, I feel overwhelmed by the choices	1	2	3	4	5
23. I learn from my mistakes	1	2	3	4	5
24. I am able to resist temptation	1	2	3	4	5
25. Often I don't notice what I'm doing until someone calls it to my attention	1	2	3	4	5
26. I have trouble making up my mind about things	1	2	3	4	5
27. I know how I want to be	1	2	3	4	5
28. I usually only have to make a mistake one time in order to learn from it	1	2	3	4	5
29. I can stick to a plan that is working well	1	2	3	4	5
30. I can usually find several different possibilities when I want to change something	1	2	3	4	5
31. It's hard for me to notice when I've had enough (alcohol, food, sweets)	1	2	3	4	5

Strongly Disagree Disagree Uncertain or Unsure Agree Strongly Agree

PHCS: Please rate the extent to which you agree or disagree with the following statements, by circling one number on the scale for each statement.

1. I handle myself well with respect to my health.

1 2 3 4 5
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

2. No matter how hard I try, my health just doesn't turn out the way I would like.

1 2 3 4 5
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

3. It is difficult for me to find effective solutions to the health problems that come my way.

1 2 3 4 5
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

4. I succeed in the projects I undertake to improve my health.

1 2 3 4 5
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

5. I'm generally able to accomplish my goals with respect to my health.

1 2 3 4 5
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

6. I find my efforts to change things I don't like about my health are ineffective.

1 2 3 4 5
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

7. Typically, my plans for my health don't work out well.

1 2 3 4 5
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

8. I am able to do things for my health as well as most other people.

1 2 3 4 5
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

Perceived social support

Please answer the following questions, by circling one answer per question.

How easy can you get help from neighbours if you should need it?

Very easy Easy Possible Difficult Very difficult

How many people are so close to you that you can count on them if you have serious problems?

None 1-2 3-5 5+

How much concern do people show in what you are doing?

A lot Some Uncertain Little No

THANK YOU FOR FILLING OUT THIS FORM



BEP-Cymru

Post-course questionnaires

(10 weeks)

NAME:.....

Please hand this form to the session leaders or post it to:

FREEPOST RSEK-HXKK-JRXH
Ms Helen Davies
University Hospital of Wales
Monmouth House
Heath Park
Cardiff
CF14 4XW

YOUR NAME:

DATE OF BIRTH:/...../.....

TODAY'S DATE:/...../.....

Now that you have finished BEP-Cymru we would like to keep you informed about the programme via an annual newsletter and send you other relevant information which might be of interest to you. Please could you indicate whether you are happy to join our mailing list? We will not pass your details on to anyone else:

I am / am not happy for my details to be added to the
BEP-Cymru mailing list

Knowledge and attitudes questionnaire

This questionnaire is designed for you to self-assess your knowledge of bipolar disorder and your attitudes to medication and to the group format of the programme.

Please answer all questions

How much do you think you know about managing your bipolar disorder?

Please circle one response option which accurately reflects your view:

Nothing Very little A moderate amount Quite a lot or: Not sure

How long have you been diagnosed with bipolar disorder?

..... (years) / (months)

Do you currently take medication for bipolar disorder?

Circle either: YES / NO

If YES to above question:

To what extent do you take medication for bipolar disorder on a regular basis?

Please circle one response option which accurately reflects your view:

Never Seldom Sometimes Most of the time Always

Even if you are not currently taking medication please answer all the following questions...

Describe your feelings towards taking medication for bipolar disorder by ticking all boxes where the corresponding statements apply to you:

9. Taking medication for my bipolar disorder has not been suggested to me
10. I do not take medication for bipolar disorder because it is not for me
11. Taking medication helps to keep my mood stable
12. I take my medication regularly as prescribed
13. I do not think that taking my medication helps to keep my mood stable
14. I do not like taking my medication
15. I suffer from the side effects of my medication
16. The side-effects I get from my medication are tolerable

To what extent do you feel that group healthcare programmes, such as this, are helpful to you?

*Please **circle one** response option which accurately reflects your view:*

Not at all A little bit Quite Very Extremely

or: Not sure

To what extent would you prefer either learning about bipolar disorder in a group context or learning about bipolar disorder on a one-to-one basis?

*Please **tick one** response option which accurately reflects your view:*

Strongly favour one-to-one learning Favour one-to-one learning

No preference Favour group learning Strongly favour group learning

Wellness Questionnaire

These questions relate to how you have felt in the past 10 weeks

- In the past 10 weeks have you experienced period(s) of **significantly** high or irritable mood where you may have had racing thoughts, been more energetic than usual or felt especially efficient in your daily activities so that it **caused significant problems** at home, at work or socially, and lasted at least a week? (This is called **mania**)

Circle either: YES / NO

If YES to above question, then in the past 10 weeks:

- How many episodes of mania did you have?
- How many **days** was your longest episode of mania?
- How many **days** have you experienced mania in total?
- In the past 6 months were you hospitalised for mania?

Circle either: YES / NO

- In the past 10 weeks have you experienced period(s) of high or irritable mood, for at least 4 consecutive days, where you may have had racing thoughts, been more energetic than usual or felt especially efficient in your daily activities, but which **didn't cause significant problems** at home, at work or socially, and lasted at least 4 days? (This is called **hypomania**)

Circle either: YES / NO

If YES to above question, then in the past 10 weeks:

- How many episodes of hypomania did you have?
 - How many **days** was your longest episode of hypomania?
 - How many **days** have you experienced hypomania in total?
-

- In the past 10 weeks have you experienced period(s) when you've felt consistently depressed or down, and felt much less interested in most things or less able to enjoy the things you used to enjoy, for at least two weeks (This is called a **depressive episode**)

Circle either: **YES / NO**

If YES to above question, then in the past 10 weeks:

- How many episodes of depression did you have?
- How many **months** was your longest episode of depression?
- How many **months** have you experienced depression in total?
- Have you had any suicidal thoughts or behaviours? *Circle either: YES / NO*
- In the past 6 months were you hospitalised for a depressive episode?

Circle either: **YES / NO**

Please **circle one** answer for each of the following questions:

Since the course began have you experienced an episode of depression?

Yes **No** **Not sure**

Since the course began, have you experienced an episode of mania?

Yes **No** **Not sure**

During the course, how has your mood been overall?

More stable **Less stable** **Same as usual**

If you have any additional comments regarding any of these questions in relation to your bipolar disorder please use the following space.

.....

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WHOQOL-BREF

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

	Very poor	Poor	Neither poor nor good	Good	Very good
How would you rate your quality of life?	1	2	3	4	5
	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two weeks.

	Not at all	A little	A moderate amount	Very much	An extreme amount
To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
How much do you enjoy life?	1	2	3	4	5
To what extent do you feel your life to be meaningful?	1	2	3	4	5
How well are you able to concentrate?	1	2	3	4	5
How safe do you feel in your daily life?	1	2	3	4	5
How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

	Not at all	A little	Moderately	Mostly	Completely
Do you have enough energy for everyday life?	1	2	3	4	5
Are you able to accept your bodily appearance?	1	2	3	4	5
Have you enough money to meet your needs?	1	2	3	4	5
How available to you is the information you need in your day-to-day life?	1	2	3	4	5
To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your sleep?	1	2	3	4	5
How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
How satisfied are you with your capacity for work?	1	2	3	4	5
How satisfied are you with your personal relationships?	1	2	3	4	5
How satisfied are you with your sex life?	1	2	3	4	5
How satisfied are you with the support you get from your friends?	1	2	3	4	5
How satisfied are you with the conditions of your living place?	1	2	3	4	5
How satisfied are you with your access to health services?	1	2	3	4	5
How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks.

	Never	Seldom	Quite often	Very often	Always
How often do you have negative feelings such as blue mood, despair anxiety, depression?	1	2	3	4	5

FUNCTIONING ASSESSMENT SHORT TEST (FAST)

To what extent are you experiencing **difficulties** in the following aspects?

Circle one score per statement using the following scale:

(0): no difficulty, (1): mild difficulty, (2): moderate difficulty, (3): severe difficulty

AUTONOMY	No dif'	Mild dif'	Moderate dif'	Severe dif'
1. Taking responsibility for a household	(0)	(1)	(2)	(3)
2. Living on your own	(0)	(1)	(2)	(3)
3. Doing the shopping	(0)	(1)	(2)	(3)
4. Taking care of yourself (physical aspects, hygiene)	(0)	(1)	(2)	(3)
OCCUPATIONAL FUNCTIONING	No dif'	Mild dif'	Moderate dif'	Severe dif'
5. Holding down a paid job	(0)	(1)	(2)	(3)
6. Accomplishing tasks as quickly as necessary	(0)	(1)	(2)	(3)
7. Working in the field in which you were educated	(0)	(1)	(2)	(3)
8. Occupational earnings	(0)	(1)	(2)	(3)
9. Managing the expected work load	(0)	(1)	(2)	(3)
COGNITIVE FUNCTIONING	No dif'	Mild dif'	Moderate dif'	Severe dif'
10. Ability to concentrate on a book, film	(0)	(1)	(2)	(3)
11. Ability to make mental calculations	(0)	(1)	(2)	(3)
12. Ability to solve a problem adequately	(0)	(1)	(2)	(3)
13. Ability to remember newly-learned names	(0)	(1)	(2)	(3)
14. Ability to learn new information	(0)	(1)	(2)	(3)
FINANCIAL ISSUES	No dif'	Mild dif'	Moderate dif'	Severe dif'
15. Managing your own money	(0)	(1)	(2)	(3)
16. Spending money in a balanced way	(0)	(1)	(2)	(3)
INTERPERSONAL RELATIONSHIPS	No dif'	Mild dif'	Moderate dif'	Severe dif'
17. Maintaining a friendship or friendships	(0)	(1)	(2)	(3)
18. Participating in social activities	(0)	(1)	(2)	(3)
19. Having good relationships with people close you	(0)	(1)	(2)	(3)
20. Living together with your family	(0)	(1)	(2)	(3)
21. Having satisfactory sexual relationships	(0)	(1)	(2)	(3)
22. Being able to defend your interests	(0)	(1)	(2)	(3)
LEISURE TIME	No dif'	Mild dif'	Moderate dif'	Severe dif'
23. Doing exercise or participating in sport	(0)	(1)	(2)	(3)
24. Having hobbies or personal interests	(0)	(1)	(2)	(3)

Modified SAI

The following questions are about your **attitudes to bipolar disorder**.

Please **circle one** response per question using the following scales.

1. During my life I have experienced emotional and/or psychological difficulties

Completely agree	Agree	Neither agree nor disagree	Disagree	Completely disagree
1	2	3	4	5

2. My condition amounts to a mental illness or mental disorder

Completely agree	Agree	Neither agree nor disagree	Disagree	Completely disagree
1	2	3	4	5

3. This condition has led to adverse consequences or problems in my life

Completely agree	Agree	Neither agree nor disagree	Disagree	Completely disagree
1	2	3	4	5

4. I think that this condition needs to be treated

Completely agree	Agree	Neither agree nor disagree	Disagree	Completely disagree
1	2	3	4	5

BDI

On this questionnaire are groups of statements. Please read each group of statements carefully, circle the number (0, 1, 2 or 3) next to the one statement in each group which **best** describes how you feel **today**. If several statements within a group seem to apply equally well, circle each one.

Be sure to read all the statements in each group before making your choice

1	0 I do not feel sad. 1 I feel sad. 2 I am sad all the time and I can't snap out of it. 3 I am so sad or unhappy that I can't stand it.	8	0 I don't feel I am worse than anyone else. 1 I am critical of myself for my weaknesses or mistakes. 2 I blame myself all the time for my faults. 3 I blame myself for everything bad that happens.
2	0 I am not particularly discouraged about the future. 1 I feel discouraged about the future. 2 I feel I have nothing to look forward to. 3 I feel that the future is hopeless and that things cannot improve.	9	0 I don't have any thoughts of killing myself. 1 I have thoughts of killing myself, but I would not carry them out. 2 I would like to kill myself. 3 I would kill myself if I had the chance.
3	0 I do not feel like a failure. 1 I feel I have failed more than the average person. 2 As I look back on my life, all I can see is a lot of failures. 3 I feel I am a complete failure as a person.	10	0 I don't cry any more than usual. 1 I cry more now than I used to. 2 I cry all the time now. 3 I used to be able to cry, but now I can't cry even though I want to.
4	0 I get as much satisfaction out of things as I used to. 1 I don't enjoy things the way I used to. 2 I don't get real satisfaction out of anything anymore. 3 I am dissatisfied or bored with everything.	11	0 I am no more irritated now than I ever am. 1 I get annoyed or irritated more easily than I used to. 2 I feel irritated all the time now. 3 I don't get irritated at all by the things that used to irritate me.
5	0 I don't feel particularly guilty. 1 I feel guilty a good part of the time. 2 I feel quite guilty most of the time. 3 I feel guilty all of the time.	12	0 I have not lost interest in other people. 1 I am less interested in other people than I used to be. 2 I have lost most of my interest in other people. 3 I have lost all of my interest in other people.
6	0 I don't feel I am being punished. 1 I feel I may be punished. 2 I expect to be punished. 3 I feel I am being punished.	13	0 I make decisions about as well as I ever could. 1 I put off making decisions more than I used to. 2 I have greater difficulty in making decisions than before. 3 I can't make decisions at all anymore.
7	0 I don't feel disappointed in myself. 1 I am disappointed in myself. 2 I am disgusted with myself. 3 I hate myself.		

- 14** 0 I don't feel I look any worse than I used to.
 1 I am worried that I am looking old or unattractive.
 2 I feel that there are permanent changes in my appearance that make me look unattractive.
 3 I believe that I look ugly.

- 15** 0 I can work about as well as before.
 1 It takes an extra effort to get started at doing something.
 2 I have to push myself very hard to do anything.
 3 I can't do any work at all.

- 16** 0 I can sleep as well as usual.
 1 I don't sleep as well as I used to.
 2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
 3 I wake up several hours earlier than I used to and cannot get back to sleep.

- 17** 0 I don't get more tired than usual.
 1 I get tired more easily than I used to.
 2 I get tired from doing almost anything.
 3 I am too tired to do anything.

- 18** 0 My appetite is no worse than usual.
 1 My appetite is not as good as it used to be.
 2 My appetite is much worse now.
 3 I have no appetite at all anymore.

- 19** 0 I haven't lost much weight, if any, lately.
 1 I have lost more than 5 pounds.
 2 I have lost more than 10 pounds.
 3 I have lost more than 15 pounds.

I am purposely trying to lose weight by eating less. Yes No (please circle)

- 20** 0 I am no more worried about my health than usual.
 1 I am worried about physical problems such as aches and pains; or upset stomach; or constipation.
 2 I am very worried about physical problems and it's hard to think of much else.
 3 I am so worried about my physical problems that I cannot think of anything else.

- 21** 0 I have not noticed any recent change in my interest in sex.
 1 I am less interested in sex than I used to be.
 2 I am much less interested in sex now.
 3 I have lost interest in sex completely.

ASRM scale

Please place a circle around the statement that best describes how you have been feeling in the last week.

1. I have been feeling happier or more cheerful...

No more than usual	0
Just occasionally	1
More often than usual	2
Most of the time	3
All of the time	4

2. I have been feeling more self-confident...

No more than usual	0
Just occasionally	1
More often than usual	2
Most of the time	3
All of the time (extremely self-confident)	4

3. I have needed less sleep...

No more than usual	0
Just occasionally	1
More often than usual	2
Frequently needed less sleep	3
Don't need sleep and don't feel tired	4

4. I have been talking...

No more than usual	0
Occasionally more than usual	1
Often talking more than usual	2
Frequently talking more than usual	3
Talking constantly and cannot be interrupted	4

5. In terms of my activity levels...

No more active than usual	0
Occasionally more active	1
Often more active than usual	2
Frequently more active than usual	3
Constantly active or on the go all the time	4

SSRQ:

Please answer the following questions by circling the response that best describes how you are today.
There are no right or wrong answers. Work quickly and don't think too long about your answers.

	Strongly Disagree	Disagree	Uncertain or Unsure	Agree	Strongly Agree
1. I have trouble making plans to help me reach goals	1	2	3	4	5
2. I have a hard time setting goals for myself	1	2	3	4	5
3. Once I have a goal, I can usually plan how to reach it	1	2	3	4	5
4. I give up quickly	1	2	3	4	5
5. I set goals for myself and keep track of my progress	1	2	3	4	5
6. When I'm trying to change something, I pay attention to how I'm doing	1	2	3	4	5
7. I don't notice the effects of my actions until it's too late	1	2	3	4	5
8. I tend to keep doing the same thing even when it doesn't work	1	2	3	4	5
9. I have personal standards and try to live up to them	1	2	3	4	5
10. I get easily distracted from my plans	1	2	3	4	5
11. I have trouble following through with things once I've made up my mind to do something	1	2	3	4	5
12. I have a lot of willpower	1	2	3	4	5
13. I'm able to accomplish goals I set for myself	1	2	3	4	5
14. If I make a resolution to change something, I pay a lot of attention to how I'm doing	1	2	3	4	5
15. I put off making decisions	1	2	3	4	5
16. Most of the time I don't pay attention to what I'm doing	1	2	3	4	5
17. I don't seem to learn from my mistakes	1	2	3	4	5
18. If I wanted to change I am confident that I could do it	1	2	3	4	5
19. I usually keep track of my progress towards my goals	1	2	3	4	5
20. I usually think before I act	1	2	3	4	5
21. As soon as I see a problem or challenge, I start looking for possible solutions	1	2	3	4	5
22. When it comes to deciding about a change, I feel overwhelmed by the choices	1	2	3	4	5
23. I learn from my mistakes	1	2	3	4	5
24. I am able to resist temptation	1	2	3	4	5
25. Often I don't notice what I'm doing until someone calls it to my attention	1	2	3	4	5
26. I have trouble making up my mind about things	1	2	3	4	5
27. I know how I want to be	1	2	3	4	5
28. I usually only have to make a mistake one time in order to learn from it	1	2	3	4	5
29. I can stick to a plan that is working well	1	2	3	4	5
30. I can usually find several different possibilities when I want to change something	1	2	3	4	5
31. It's hard for me to notice when I've had enough (alcohol, food, sweets)	1	2	3	4	5

Strongly Disagree Disagree Uncertain or Unsure Agree Strongly Agree

PHCS: Please rate the extent to which you agree or disagree with the following statements, by circling one number on the scale for each statement.

1. I handle myself well with respect to my health.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

2. No matter how hard I try, my health just doesn't turn out the way I would like.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

3. It is difficult for me to find effective solutions to the health problems that come my way.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

4. I succeed in the projects I undertake to improve my health.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

5. I'm generally able to accomplish my goals with respect to my health.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

6. I find my efforts to change things I don't like about my health are ineffective.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

7. Typically, my plans for my health don't work out well.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

8. I am able to do things for my health as well as most other people.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

Perceived social support

Please answer the following questions, by circling one answer per question.

How easy can you get help from neighbours if you should need it?

Very easy Easy Possible Difficult Very difficult

How many people are so close to you that you can count on them if you have serious problems?

None 1-2 3-5 5+

How much concern do people show in what you are doing?

A lot Some Uncertain Little No

BEP-Cymru participant survey

Please answer the following questions to enable us to evaluate and improve the service we offer

Please answer the following questions by *circling one* number per corresponding scale

Please include any specific comments you may have in the space below each answer scale

1. To what extent did the facilitators appear to be prepared?

Not at all prepared
1 2 3 4 5 6 7 8 9 10
Extremely prepared

.....

.....

2. To what extent was the venue suitable for the delivery of the programme?

Not at all suitable
1 2 3 4 5 6 7 8 9 10
Extremely suitable

.....

.....

3. Overall, to what extent could you understand the content of the sessions?

No understanding
1 2 3 4 5 6 7 8 9 10
Complete understanding

.....

.....

4. Overall, to what extent were the sessions relevant to you?

12. To what extent would you like to see people with bipolar disorder as facilitators of BEP-Cymru sessions?

Would not like
1 2 3 4 5 6 7 8 9 10
Would completely like

.....
.....

13. To what extent do you feel that people with bipolar disorder would be good facilitators of BEP-Cymru sessions?

Not good
1 2 3 4 5 6 7 8 9 10
Extremely good

.....
.....

14. To what extent would you recommend BEP-Cymru to others with bipolar disorder?

Would not recommend
1 2 3 4 5 6 7 8 9 10
Would definitely recommend

.....
.....

If you have any other comments please use the following page...



BEP-Cymru

Follow-up questionnaires

(3 months)

NAME:.....

Knowledge and attitudes questionnaire

This questionnaire is designed for you to self-assess your knowledge of bipolar disorder and your attitudes to medication and to the group format of the programme.

Please answer all questions

How much do you think you know about managing your bipolar disorder?

Please circle one response option which accurately reflects your view:

Nothing Very little A moderate amount Quite a lot or: Not sure

How long have you been diagnosed with bipolar disorder?

..... (years) / (months)

Do you currently take medication for bipolar disorder?

Circle either: YES / NO

If YES to above question:

To what extent do you take medication for bipolar disorder on a regular basis?

Please circle one response option which accurately reflects your view:

Never Seldom Sometimes Most of the time Always

Even if you are not currently taking medication please answer all the following questions...

Describe your feelings towards taking medication for bipolar disorder by ticking all boxes where the corresponding statements apply to you:

17. Taking medication for my bipolar disorder has not been suggested to me

18. I do not take medication for bipolar disorder because it is not for me

19. Taking medication helps to keep my mood stable

20. I take my medication regularly as prescribed

21. I do not think that taking my medication helps to keep my mood stable

22. I do not like taking my medication

23. I suffer from the side effects of my medication

24. The side-effects I get from my medication are tolerable

To what extent do you feel that group healthcare programmes, such as this, may be helpful to you?

Please circle one response option which accurately reflects your view:

Not at all A little bit Quite Very Extremely

or: Not sure

To what extent would you prefer either learning about bipolar disorder in a group context or learning about bipolar disorder on a one-to-one basis?

Please tick one response option which accurately reflects your view:

Strongly favour one-to-one learning Favour one-to-one learning

No preference Favour group learning Strongly favour group learning

Have you learned any techniques to manage your bipolar disorder prior to this programme?

Circle either: YES / NO

If YES please provide brief details on the settings of your learning experiences and the techniques you used:

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

Have you learned techniques to manage your bipolar disorder in a face-to-face group-based setting prior to this programme?

Circle either: **YES / NO**

If YES: Did this experience help you to manage your bipolar disorder?

Circle either: **YES / NO**

Wellness Questionnaire

These questions relate to how you have felt in the **past 6 months**

- In the past 6 months have you experienced period(s) of **significantly** high or irritable mood where you may have had racing thoughts, been more energetic than usual or felt especially efficient in your daily activities so that it **caused significant problems** at home, at work or socially, and lasted at least a week? (This is called **mania**)

Circle either: **YES / NO**

If YES to above question, then in the past 6 months:

- How many episodes of mania did you have?
- How many **days** was your longest episode of mania?
- How many **days** have you experienced mania in total?
- In the past 6 months were you hospitalised for mania?

Circle either: **YES / NO**

- In the past 6 months have you experienced period(s) of high or irritable mood, for at least 4 consecutive days, where you may have had racing thoughts, been more energetic than usual or felt especially efficient in your daily activities, but which **didn't cause significant problems** at home, at work or socially, and lasted at least 4 days? (This is called **hypomania**)

Circle either: **YES / NO**

If YES to above question, then in the past 6 months:

- How many episodes of hypomania did you have?

- How many **days** was your longest episode of hypomania?
 - How many **days** have you experienced hypomania in total?
-

- In the past 6 months have you experienced period(s) when you've felt consistently depressed or down, and felt much less interested in most things or less able to enjoy the things you used to enjoy, for at least two weeks (This is called a **depressive episode**)

Circle either: **YES / NO**

If YES to above question, then in the past 6 months:

- How many episodes of depression did you have?
- How many **months** was your longest episode of depression?
- How many **months** have you experienced depression in total?
- Have you had any suicidal thoughts or behaviours? Circle either: **YES / NO**
- In the past 6 months were you hospitalised for a depressive episode?

Circle either: **YES / NO**

Please answer some questions about your episodes of depression:

At what age did depression start to cause problems for you (e.g., time off work/school, problems at home, or you went to see your GP)?

Have you ever been admitted to hospital because of depression?

Circle either: **YES / NO**

Were you ever sectioned under the Mental Health Act for depression?

Circle either: **YES / NO**

Did you ever experience a psychotic symptom during an episode of depression?

Circle either: YES / NO

Please answer some questions about your episodes of hypomania or mania:

At what age did hypomania or mania start to cause problems for you (e.g., time off work/school, problems at home, you went to see your GP)?

Have you ever been admitted to hospital because of hypomania or mania?

Circle either: YES / NO

Were you ever sectioned under the Mental Health Act for hypomania or mania?

Circle either: YES / NO

Did you ever experience a psychotic symptom during an episode of hypomania or mania?

Circle either: YES / NO

If you have any additional comments regarding any of these questions in relation to your bipolar disorder please use the space on the following page.

WHOQOL-BREF

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

	Very poor	Poor	Neither poor nor good	Good	Very good
How would you rate your quality of life?	1	2	3	4	5
	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two weeks.

	Not at all	A little	A moderate amount	Very much	An extreme amount
To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
How much do you enjoy life?	1	2	3	4	5
To what extent do you feel your life to be meaningful?	1	2	3	4	5
How well are you able to concentrate?	1	2	3	4	5
How safe do you feel in your daily life?	1	2	3	4	5
How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

	Not at all	A little	Moderately	Mostly	Completely
Do you have enough energy for everyday life?	1	2	3	4	5
Are you able to accept your bodily appearance?	1	2	3	4	5
Have you enough money to meet your needs?	1	2	3	4	5
How available to you is the information you need in your day-to-day life?	1	2	3	4	5
To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your sleep?	1	2	3	4	5
How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
How satisfied are you with your capacity for work?	1	2	3	4	5
How satisfied are you with your personal relationships?	1	2	3	4	5
How satisfied are you with your sex life?	1	2	3	4	5
How satisfied are you with the support you get from your friends?	1	2	3	4	5
How satisfied are you with the conditions of your living place?	1	2	3	4	5
How satisfied are you with your access to health services?	1	2	3	4	5
How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks.

	Never	Seldom	Quite often	Very often	Always
How often do you have negative feelings such as blue mood, despair anxiety, depression?	1	2	3	4	5

FUNCTIONING ASSESSMENT SHORT TEST (FAST)

To what extent are you experiencing **difficulties** in the following aspects?

Circle one score per statement using the following scale:

(0): no difficulty, (1): mild difficulty, (2): moderate difficulty, (3): severe difficulty

AUTONOMY	No dif'	Mild dif'	Moderate dif'	Severe dif'
1. Taking responsibility for a household	(0)	(1)	(2)	(3)
2. Living on your own	(0)	(1)	(2)	(3)
3. Doing the shopping	(0)	(1)	(2)	(3)
4. Taking care of yourself (physical aspects, hygiene)	(0)	(1)	(2)	(3)
OCCUPATIONAL FUNCTIONING	No dif'	Mild dif'	Moderate dif'	Severe dif'
5. Holding down a paid job	(0)	(1)	(2)	(3)
6. Accomplishing tasks as quickly as necessary	(0)	(1)	(2)	(3)
7. Working in the field in which you were educated	(0)	(1)	(2)	(3)
8. Occupational earnings	(0)	(1)	(2)	(3)
9. Managing the expected work load	(0)	(1)	(2)	(3)
COGNITIVE FUNCTIONING	No dif'	Mild dif'	Moderate dif'	Severe dif'
10. Ability to concentrate on a book, film	(0)	(1)	(2)	(3)
11. Ability to make mental calculations	(0)	(1)	(2)	(3)
12. Ability to solve a problem adequately	(0)	(1)	(2)	(3)
13. Ability to remember newly-learned names	(0)	(1)	(2)	(3)
14. Ability to learn new information	(0)	(1)	(2)	(3)
FINANCIAL ISSUES	No dif'	Mild dif'	Moderate dif'	Severe dif'
15. Managing your own money	(0)	(1)	(2)	(3)
16. Spending money in a balanced way	(0)	(1)	(2)	(3)
INTERPERSONAL RELATIONSHIPS	No dif'	Mild dif'	Moderate dif'	Severe dif'
17. Maintaining a friendship or friendships	(0)	(1)	(2)	(3)
18. Participating in social activities	(0)	(1)	(2)	(3)
19. Having good relationships with people close you	(0)	(1)	(2)	(3)
20. Living together with your family	(0)	(1)	(2)	(3)
21. Having satisfactory sexual relationships	(0)	(1)	(2)	(3)
22. Being able to defend your interests	(0)	(1)	(2)	(3)
LEISURE TIME	No dif'	Mild dif'	Moderate dif'	Severe dif'
23. Doing exercise or participating in sport	(0)	(1)	(2)	(3)
24. Having hobbies or personal interests	(0)	(1)	(2)	(3)

Modified SAI

The following questions are about your **attitudes to bipolar disorder**.

Please **circle one** response per question using the following scales.

1. During my life I have experienced emotional and/or psychological difficulties

Completely agree	Agree	Neither agree nor disagree	Disagree	Completely disagree
1	2	3	4	5

2. My condition amounts to a mental illness or mental disorder

Completely agree	Agree	Neither agree nor disagree	Disagree	Completely disagree
1	2	3	4	5

3. This condition has led to adverse consequences or problems in my life

Completely agree	Agree	Neither agree nor disagree	Disagree	Completely disagree
1	2	3	4	5

4. I think that this condition needs to be treated

Completely agree	Agree	Neither agree nor disagree	Disagree	Completely disagree
1	2	3	4	5

BDI

On this questionnaire are groups of statements. Please read each group of statements carefully, circle the number (0, 1, 2 or 3) next to the one statement in each group which **best** describes how you feel **today**. If several statements within a group seem to apply equally well, circle each one.

Be sure to read all the statements in each group before making your choice

1	0 I do not feel sad. 1 I feel sad. 2 I am sad all the time and I can't snap out of it. 3 I am so sad or unhappy that I can't stand it.	8	0 I don't feel I am worse than anyone else. 1 I am critical of myself for my weaknesses or mistakes. 2 I blame myself all the time for my faults. 3 I blame myself for everything bad that happens.
2	0 I am not particularly discouraged about the future. 1 I feel discouraged about the future. 2 I feel I have nothing to look forward to. 3 I feel that the future is hopeless and that things cannot improve.	9	0 I don't have any thoughts of killing myself. 1 I have thoughts of killing myself, but I would not carry them out. 2 I would like to kill myself. 3 I would kill myself if I had the chance.
3	0 I do not feel like a failure. 1 I feel I have failed more than the average person. 2 As I look back on my life, all I can see is a lot of failures. 3 I feel I am a complete failure as a person.	10	0 I don't cry any more than usual. 1 I cry more now than I used to. 2 I cry all the time now. 3 I used to be able to cry, but now I can't cry even though I want to.
4	0 I get as much satisfaction out of things as I used to. 1 I don't enjoy things the way I used to. 2 I don't get real satisfaction out of anything anymore. 3 I am dissatisfied or bored with everything.	11	0 I am no more irritated now than I ever am. 1 I get annoyed or irritated more easily than I used to. 2 I feel irritated all the time now. 3 I don't get irritated at all by the things that used to irritate me.
5	0 I don't feel particularly guilty. 1 I feel guilty a good part of the time. 2 I feel quite guilty most of the time. 3 I feel guilty all of the time.	12	0 I have not lost interest in other people. 1 I am less interested in other people than I used to be. 2 I have lost most of my interest in other people. 3 I have lost all of my interest in other people.
6	0 I don't feel I am being punished. 1 I feel I may be punished. 2 I expect to be punished. 3 I feel I am being punished.	13	0 I make decisions about as well as I ever could. 1 I put off making decisions more than I used to. 2 I have greater difficulty in making decisions than before. 3 I can't make decisions at all anymore.
7	0 I don't feel disappointed in myself. 1 I am disappointed in myself. 2 I am disgusted with myself. 3 I hate myself.		

- 14** 0 I don't feel I look any worse than I used to.
1 I am worried that I am looking old or unattractive.
2 I feel that there are permanent changes in my appearance that make me look unattractive.
3 I believe that I look ugly.

- 15** 0 I can work about as well as before.
1 It takes an extra effort to get started at doing something.
2 I have to push myself very hard to do anything.
3 I can't do any work at all.

- 16** 0 I can sleep as well as usual.
1 I don't sleep as well as I used to.
2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
3 I wake up several hours earlier than I used to and cannot get back to sleep.

- 17** 0 I don't get more tired than usual.
1 I get tired more easily than I used to.
2 I get tired from doing almost anything.
3 I am too tired to do anything.

- 18** 0 My appetite is no worse than usual.
1 My appetite is not as good as it used to be.
2 My appetite is much worse now.
3 I have no appetite at all anymore.

- 19** 0 I haven't lost much weight, if any, lately.
1 I have lost more than 5 pounds.
2 I have lost more than 10 pounds.
3 I have lost more than 15 pounds.

I am purposely trying to lose weight by eating less. Yes No (please circle)

- 20** 0 I am no more worried about my health than usual.
1 I am worried about physical problems such as aches and pains; or upset stomach; or constipation.
2 I am very worried about physical problems and it's hard to think of much else.
3 I am so worried about my physical problems that I cannot think of anything else.

- 21** 0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.

ASRM scale

Please place a circle around the statement that best describes how you have been feeling in the last week.

1. I have been feeling happier or more cheerful...

No more than usual	0
Just occasionally	1
More often than usual	2
Most of the time	3
All of the time	4

2. I have been feeling more self-confident...

No more than usual	0
Just occasionally	1
More often than usual	2
Most of the time	3
All of the time (extremely self-confident)	4

3. I have needed less sleep...

No more than usual	0
Just occasionally	1
More often than usual	2
Frequently needed less sleep	3
Don't need sleep and don't feel tired	4

4. I have been talking...

No more than usual	0
Occasionally more than usual	1
Often talking more than usual	2
Frequently talking more than usual	3
Talking constantly and cannot be interrupted	4

5. In terms of my activity levels...

No more active than usual	0
Occasionally more active	1
Often more active than usual	2
Frequently more active than usual	3
Constantly active or on the go all the time	4

SSRQ:

Please answer the following questions by circling the response that best describes how you are today.
There are no right or wrong answers. Work quickly and don't think too long about your answers.

	Strongly Disagree	Disagree	Uncertain or Unsure	Agree	Strongly Agree
1. I have trouble making plans to help me reach goals	1	2	3	4	5
2. I have a hard time setting goals for myself	1	2	3	4	5
3. Once I have a goal, I can usually plan how to reach it	1	2	3	4	5
4. I give up quickly	1	2	3	4	5
5. I set goals for myself and keep track of my progress	1	2	3	4	5
6. When I'm trying to change something, I pay attention to how I'm doing	1	2	3	4	5
7. I don't notice the effects of my actions until it's too late	1	2	3	4	5
8. I tend to keep doing the same thing even when it doesn't work	1	2	3	4	5
9. I have personal standards and try to live up to them	1	2	3	4	5
10. I get easily distracted from my plans	1	2	3	4	5
11. I have trouble following through with things once I've made up my mind to do something	1	2	3	4	5
12. I have a lot of willpower	1	2	3	4	5
13. I'm able to accomplish goals I set for myself	1	2	3	4	5
14. If I make a resolution to change something, I pay a lot of attention to how I'm doing	1	2	3	4	5
15. I put off making decisions	1	2	3	4	5
16. Most of the time I don't pay attention to what I'm doing	1	2	3	4	5
17. I don't seem to learn from my mistakes	1	2	3	4	5
18. If I wanted to change I am confident that I could do it	1	2	3	4	5
19. I usually keep track of my progress towards my goals	1	2	3	4	5
20. I usually think before I act	1	2	3	4	5
21. As soon as I see a problem or challenge, I start looking for possible solutions	1	2	3	4	5
22. When it comes to deciding about a change, I feel overwhelmed by the choices	1	2	3	4	5
23. I learn from my mistakes	1	2	3	4	5
24. I am able to resist temptation	1	2	3	4	5
25. Often I don't notice what I'm doing until someone calls it to my attention	1	2	3	4	5
26. I have trouble making up my mind about things	1	2	3	4	5
27. I know how I want to be	1	2	3	4	5
28. I usually only have to make a mistake one time in order to learn from it	1	2	3	4	5
29. I can stick to a plan that is working well	1	2	3	4	5
30. I can usually find several different possibilities when I want to change something	1	2	3	4	5
31. It's hard for me to notice when I've had enough (alcohol, food, sweets)	1	2	3	4	5

Strongly Disagree Disagree Uncertain or Unsure Agree Strongly Agree

PHCS: Please rate the extent to which you agree or disagree with the following statements, by circling one number on the scale for each statement.

1. I handle myself well with respect to my health.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

2. No matter how hard I try, my health just doesn't turn out the way I would like.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

3. It is difficult for me to find effective solutions to the health problems that come my way.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

4. I succeed in the projects I undertake to improve my health.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

5. I'm generally able to accomplish my goals with respect to my health.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

6. I find my efforts to change things I don't like about my health are ineffective.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

7. Typically, my plans for my health don't work out well.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

8. I am able to do things for my health as well as most other people.

1	2	3	4	5
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

Perceived social support

Please answer the following questions, by circling one answer per question.

How easy can you get help from neighbours if you should need it?

Very easy Easy Possible Difficult Very difficult

How many people are so close to you that you can count on them if you have serious problems?

None 1-2 3-5 5+

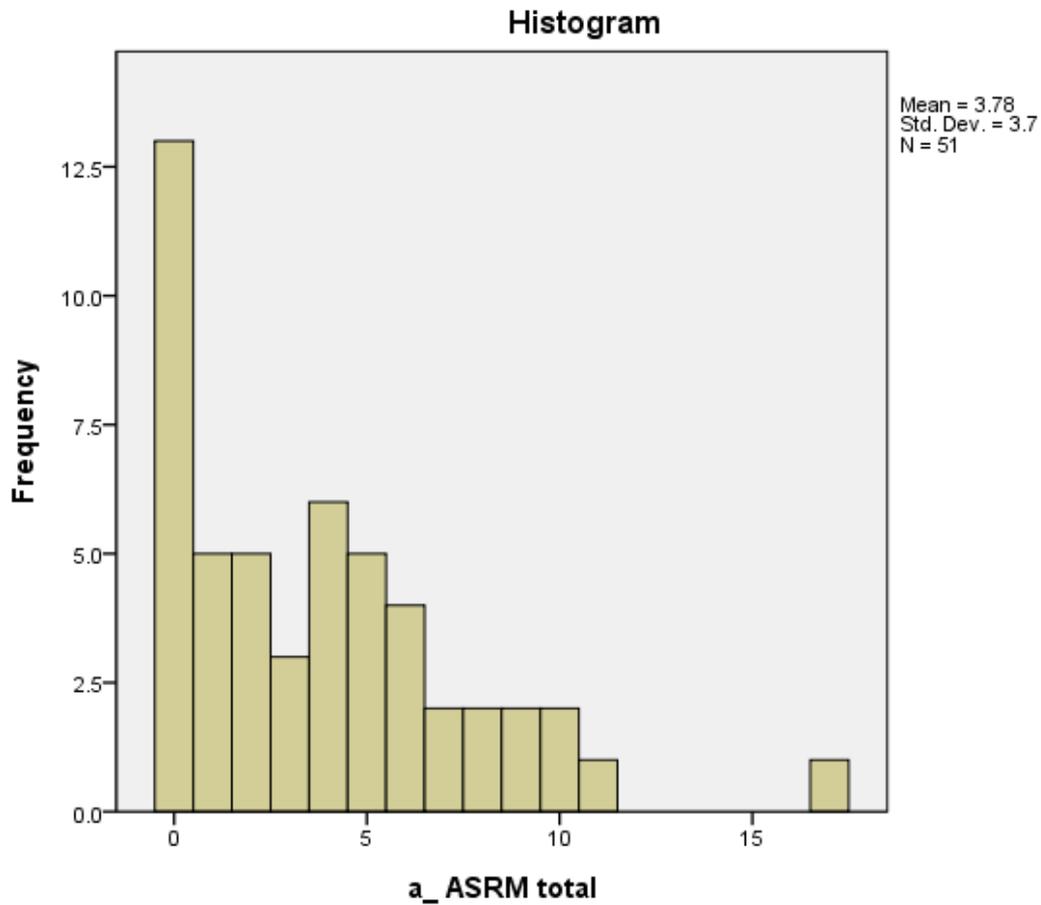
How much concern do people show in what you are doing?

A lot Some Uncertain Little No

THANK YOU FOR FILLING OUT THIS FORM

Appendix 7: Assessing normality within baseline data: examples to show non-normal distribution of scores on the dependent variable

Example 1 Distribution of baseline scores on the ASRM



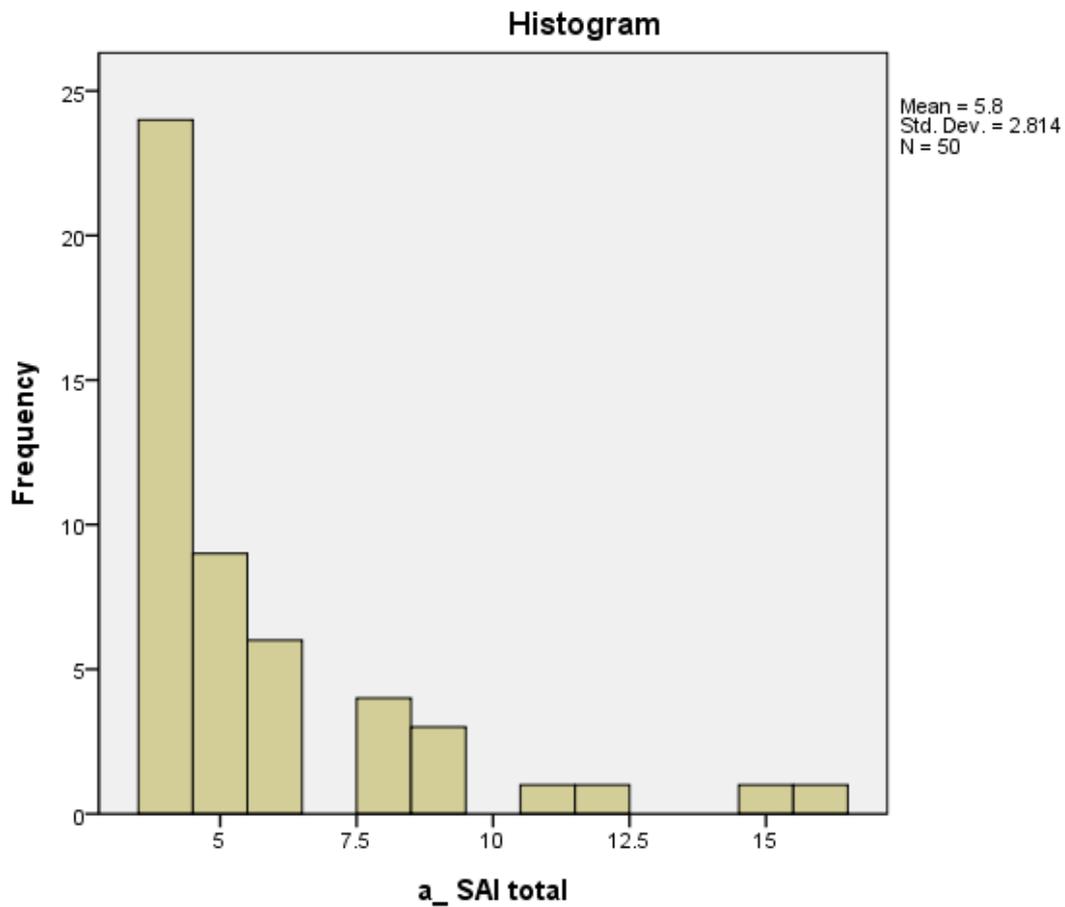
Tests of Normality

	Kolmogorov-Smirnov ^a			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
a_ ASRM total	.153	51	.004	.881	51	.000

a. Lilliefors Significance Correction

The significance value of .004 of the Kolmogorov-Smirnov statistic suggests violation of the assumption of normality, which is supported by inspection of the distribution of the histogram (see above).

Example 2 Distribution of baseline scores on the modified SAI



Tests of Normality

	Kolmogorov-Smirnov ^a			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
a_SAI total	.272	50	.000	.688	50	.000

a. Lilliefors Significance Correction

The significance value of .000 of the Kolmogorov-Smirnov statistic suggests violation of the assumption of normality, which is supported by inspection of the distribution of the histogram (see above).

Appendix 8: Topic guide for interviews with BEP-Cymru patient participants

INITIAL QUESTIONS:

How are you doing at the moment?

Please tell me your experiences of the BEP-Cymru group psychoeducation programme; what was it like for you?

How was the group experience for you?

Probes:

Why did you want to undertake the programme?

What did you like about the programme?

What didn't you like about the programme?

Were there aspects you found to be particularly helpful?

Were there aspects you found to be unhelpful?

Overall, would you say you have benefitted from undertaking the programme?

ACCESS

How many sessions of the programme did you attend?

If patient did not continue with programme: Why did you decide not to continue with the programme?

If patient did not continue with programme: Why did you miss sessions?

REFLECTIONS ON MOOD

Did you experience a significant high or low before, during, or after the programme (such as depression or mania)?

If so: Do you feel that this may have impacted on your ability to benefit from the programme?

CONTENT

Can you cast your mind back to the content of the sessions, and tell me your thoughts?

Probes:

Could you understand the content of the sessions? (*Ask for elaboration if necessary*)

Were some sessions easier to grasp than others? (*If so:* which were easier and why; which more difficult and why)

Did you have any difficulty paying attention to the sessions? (*If so:* why?)

Were any sessions more interesting than other sessions? (*If so:* why?)

Were any sessions more relevant to you than other sessions? (*If so:* why; and why were other modules less relevant?)

How did you find the group activities? (*Ask for elaboration if necessary*)

Have you any other comments or suggestions for improvement regarding the content of the sessions?

Did you share the content of any of the sessions with anyone outside the group? (*If so:* which [aspects of] sessions, why, and how?)

Did the programme impact on your relationship with your family or friends?

Since using the programme have you made any lifestyle changes? (*If so: What are they? and what triggered this?*)

PRESENTATION FORMAT

Was the pace of each module okay, or too fast or too slow?

Would you have preferred more or fewer sessions?

Did the time of day of the sessions suit you?

What are your views on the venue?

INSIGHT

Has the programme as a whole, or any module or modules in particular, impacted upon your understanding of bipolar disorder? (*Can you tell me more?*)

Has the programme impacted on your sense of who you are? (*Can you tell me more?*)

As a result of the programme are you more aware of how to manage your condition? (*Can you tell me more?*)

As a result of the programme have you modified aspects of your behaviour or your routine? (*Can you tell me more?*)

Has your attitude towards medication changed as a result of the programme? (*Can you tell me more?*)

Do you feel more able to change or modify your behaviour according to goals you set yourself?

Do you feel more capable of effectively managing your health?

Has your perception of the support you receive from others changed as a result of this programme?

SUGGESTIONS FOR IMPROVEMENT

Have you any other comments or suggestions for improvements?

RECOMMENDATIONS

Do you think the programme may help others with bipolar disorder?

Would you recommend the programme to others with bipolar disorder? (*Why?*)

In the future should the programme be accessible to patients with bipolar disorder via the NHS?

Can you think of characteristics of some patients which may prevent them from fully benefiting from this programme? (*Prompt for elaboration if necessary*)

ADDITIONAL SUPPORT

Aside from the programme, has anything or anyone else provided you with additional support to manage your bipolar disorder?

(*If asked, give examples: a self-help book; support from a close friend, partner or relative; yoga; alternative therapies; face-to-face group meetings with peers with bipolar disorder*)

If so: How did this help?

If you had been given the choice of either participating in group psychoeducation for bipolar disorder or an online course of psychoeducation for bipolar disorder with a user forum which format would you have preferred?

Why?

Appendix 9: Topic guide for interviews with group facilitators

INITIAL QUESTIONS:

I'm just going to ask a couple of questions about your experiences of the BEP-Cymru group psychoeducation programme. What is it like for you?

How is the group experience for you?

What is your role, as a facilitator? Can you describe it?

REACH

Can you tell me about how you recruit participants?

What are the barriers to recruitment?

To what extent do participants engage with the sessions?

To what extent do participants interact with each other?

Do their interactions with each other change over the course of the group sessions?

Are participants supportive of each other?

If so: How?

Can you think of what may prevent some patients from fully benefiting from this programme?

(Prompt for elaboration if necessary)

Are you aware of whether some participants have been newly diagnosed or whether they've lived with the diagnosis for a while, and do you think that the recency of their diagnosis would make a difference to their experience of the programme?

GENERAL

What do you like about the programme? What stands out for you?

Are there any problems with any aspects of the programme that you might have already addressed or be thinking to address?

What do you think has made the most difference to participants?

Have there been any aspects of the programme that you feel participants have been resistant to?

Have there been any logistical or contextual difficulties?

What has been most challenging about running the groups?

If response to above: How has this impacted on you personally?

What has been most rewarding?

If response to above: How has this impacted on you personally?

CONTENT

What are your views on the content of the sessions?

Have you comments or suggestions for improvement regarding the content of the sessions?

Would you add or eliminate any sessions?

PRESENTATION FORMAT

What are your views on the format of the sessions?

Probe: Should there be more or less didactic or group work, or is the balance about right?
Do you feel that the pace of each module is okay, or too fast or too slow?
What are your thoughts on the time of day of the sessions?
What are your thoughts on venues for the sessions?
What are your thoughts on continuity for participants once their group sessions have finished?

SUGGESTIONS FOR IMPROVEMENT

How might you improve the programme?

ONLINE VS GROUP

What advantages are there for the group setting of the psychoeducation programme as opposed to an online psychoeducation programme for bipolar disorder?

What may be the disadvantages of the group setting?

Is there anything else you wanted to add?

Appendix 10: NVivo samples of Beating Bipolar and BEP-Cymru interview analyses

Excerpt 1: Beating Bipolar analysis

diagnosed many years ago but I'd never really done anything about my conditions.

You've been...

I've been diagnosed a long time ago, sort of tentatively, and then I just didn't really pursue it, so I'd had a sort of rediagnosis and I was still struggling, well I think I probably still am, fully struggling to accept the condition and I just thought it would be, um, I thought it might be helpful to me in that regard and it would provide me with more information and I think just having more information, um, well, yeah, having more information is empowering for me anyway I suppose, some people might say they don't want to have a choice but I found it useful and I think it has contributed to a greater acceptance of where I'm at.

What did you like about the programme?

Um ... well um, I suppose I liked, I liked the programme itself and its delivery, and it worked, and it worked on all my computers which is a bit unusual because some of them, the older ones don't always run everything well. So I just thought it was well put together and it functioned, I don't know if you found this with every user but with my web browsers anyway it functioned really well, so I liked that aspect of it. It would drive me crackers if I had, if it had been a programme that kept ceasing up and things like that, so I liked that side of it. Um, I quite liked the talking heads, although I probably got more out of the professionals than the, of course that was one of their debates wasn't it, are they actors or are they real people, and somebody suggested we guess which was which, but I probably got more out of the professionals on the talking heads, but I liked all of that, you know that was quite, that was quite useful. Um, I liked the bit on the medication particularly, although firstly it doesn't seem to have worked quite as it should have done with me, but you know especially the ranking or the rating of the various mood stabilizers and options for that, so that I found quite good. And I suppose the other thing, I mean it's not really related directly to the site itself but I just quite like the idea of, you know, being part of a group of people, you know made me more aware of being part of a group of people who are all sort of managing with the same thing which is also sort of, well it is empowering really because you don't feel so marginalized, although I'm not sure I was all that fussed about



Excerpt 2: Beating Bipolar analysis

Yeah, my fitness obviously, going to the gym, and whereas before I would finish, say I would work an afternoon shift from 4pm til 2am, I would then, I need an hour or so, an hour and a half to unwind before I can go to bed, especially with the nature of my job, but I was getting home 2.30, 2.40, and I was staying up til 7, 7.30, but I had to be back in work by 3 in the afternoon.

So what do you do now?

I go home, I unwind

So you didn't unwind before

Yeah, I used to unwind, but I used to sit up, cos I just didn't feel like going to bed, I'd think no, I'll be fine, and when you do a run of 6 shifts like that by the time

Ah right, so your shift was 4pm to 2am, and you're next shift when would that be, from 6

From 3pm in the afternoon, but I would stay up til 7, 7.30 in the morning, and then I'd go to bed and I'd get up tired, and the next one I'd perhaps finish at 2 and stay up til 7 or 8 and I'd have to be back in at, the last shift I finished at 2 in the morning and I have to be back in by midday, so I was staying up til 6 or 7 o'clock, then going to bed so was only having 4 or 5 hours sleep, and as a result of that the 2 rest days I get, Monday and Tuesday, I'm absolutely exhausted.

OK, so that's kind of prevented exhaustion

Yeah. And again, when I'm tired, it's when I get more stressed in work than I would normally do, and of course stress and tiredness are triggers for my Bipolar, they're my triggers for Bipolar for a low.



Excerpt 3: Beating Bipolar analysis

What are your impressions of the forum?

Very quiet.

Quiet.

Yeah, really quiet. Um I think initially there was only 2 of us putting things back and forth and I think once we realized we were the only 2 we quickly retreated as well. Yeah, I think it was a bit busier it would have been, I mean we should have persisted really, um but all in, I found it really quiet to be honest, that's the best way to describe it.

Yeah, so if it had been more like lively you would have appreciated it?

Yes. But in itself, I actually met up with one of the people from the forum and we were chatting about this and we both felt that if other people were contributing we wouldn't have felt like we were taking over, so we tried to back off to let other people come in, but they still didn't do that, you know.

So more input from others

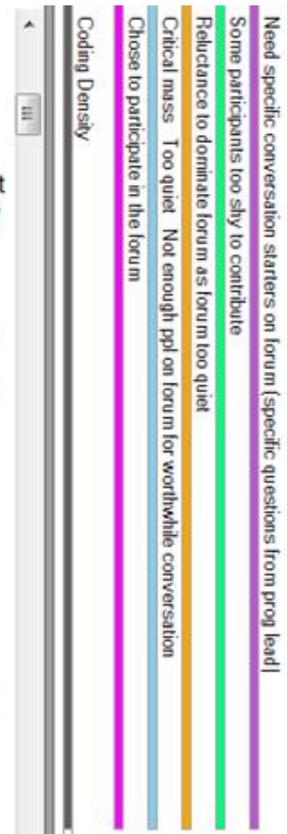
Yes, that's what, yes.

How could the forum be improved then?

Um, I would say conversation starters. Somebody needs to be the starter of topics because nobody wants to be the one to kick it all off. So if there could be some external, you know perhaps somebody running the programme, to kick the topics off, as opposed to just sort of saying please discuss, ask proper question where people go, oh I'm not having that, you know be specific, get somebody who's in charge there or involved in the project to be specific to get the conversations starting.

So specific questions

Yeah.



Excerpt 4: Beating Bipolar analysis

If you had been given the choice of either Beating Bipolar the online programme or a group-based programme (where you may have up to 15 people in a room with bipolar disorder learning together under the direction of a clinician) which format would you have preferred?

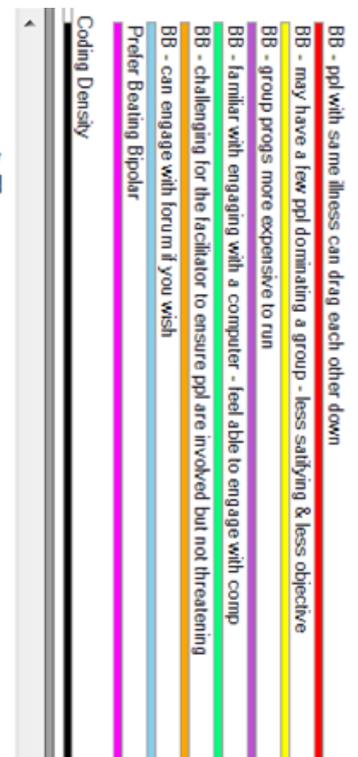
Whilst it sounds exciting, being in a room with 15 people, I'd have to say that from a practicality and um, um, I think what's the word, objective stance I'd think that Beating Bipolar online would be my favourite choice.

So what is it do you think about Beating Biopolar that would make you choose that do you think?

My concern I suppose is having a whole bunch of people is that we all get down into the dirt, you know, you will have, as I know from my own experience in teaching, you will have one or two vociferous ones in the group and um who will probably, who will even with the best facilitator in the world, will church out their experiences, etc, etc, etc, and it can be less satisfying and objective for the others whereas in an online version it's just you. It's you, and you can engage, and again with the forum you can engage if you so wish.

So you've got the choice of engaging

Yes you have and whereas you kind of, it's more of a challenge for the facilitator as well, you know if you've got a medical facilitator at the front it's more of a challenge for them to ensure people are involved but not threatenly so, you know. And I think that could be quite a challenge, and not to mention the economics. Not from the patients point of view but from the clinicians point of view if you're having to do these group sessions, you know. It doesn't suit everyone and I suppose you know online, packages like Beating Bipolar doesn't suit everyone, but it suited me because it was just my bread and butter. I don't think there's a day goes by when I'm not accessing a computer for one thing or another, so it's second nature to me.



Excerpt 5: BEP-Cymru analysis

P9: Because with your course there was a lot of information, a hell of a lot we had to get through and you go home and you look at it when you've got time but it was, they cut you short, so you didn't go too far into you know, you didn't get carried away with yourself and go off on a tangent which is what I did, I do and I was trying not to but they don't let you, they just say 'don't take it personally but we've got to cut it short' because their giving you vital information you know, stuff to work with, which, that's fine and then you can deal with that. It was only the history bits that I think shook people up. I think we made suggestions at the end of the course about how to tackle that but um it is a difficult one I think, and some of them they weren't ready for it and they said 'no, I'm not going to look at it now I'm going to do it with my CPN or my social worker or my therapist', so they were OK.

RP: Thinking about how it made you feel, it made you feel, I noticed you said you were a little bit depressed following the session on life history.

P9: Yeah it just brought up all the sadness really, what I was dealt, just a bad hand really, in what I was born into, um, but I you know, I'm OK about that today, it's just at the time there was a lot going on and there was a lot of trauma around my family and it wasn't getting any better and I made a decision then that I was going to, I lived quite a way from them, they're not very mobile and I just decided to that I couldn't take it any more and I made a decision after the course and cut off from them and I'm better, I'm more well now, I should have done it years ago.

RP: To cut off from your family who?

P9: Well just a couple of them, not all of them, the ones that were making me ill really, year after year, the same things, just not being very considerate to my mental health.

RP: Sure.

P9: Just needy and yeah.

The screenshot shows a text analysis interface. On the left, a vertical sidebar labeled 'Coding Density' contains a list of codes: 'cut you short so didn't go too deep into an experience', 'preferred to MDF self-ment', 'some ppl not ready to do this', 'traumatic', 'psych. and emotional impact of doing it', 'felt depressed afterwards', 'insight into previous failed relationships', 'certain circumstances or people trigger low mood', 'after course cut off from family who were inconsiderate to MH', and 'did not adequately support vulnerable ppl after traumatised by distressing topic'. The main text area on the right shows the transcript from Excerpt 5 with various words and phrases highlighted in colors corresponding to the codes in the sidebar.

Excerpt 6: BEP-Cymru analysis

P13: Gosh now then, I remember we were playing, we played games which was great fun because it sort of broke up the seriousness, the serious aspect of it so we could get down to the lecture part, so to speak, the learning process part of it and then we had the games which were good fun, which broke it up and unfortunately I mucked a couple of the games which was quite funny because I misunderstood the games, what was behind the games, the relevance of them, well not the relevance but the actual, what, I couldn't understand, anyway whatever but it wasn't important but it did create some humour at the time.

RP: So I'm getting from you that this sort of light-hearted this jokey atmosphere is very important actually.

P13: Well actually I'll tell you why, this is a personal thing. My mother was a teacher from the time I was born and I went into my first classroom at the age of five and she made me, she hated comics, I couldn't be allowed to have comics, and games I wasn't encouraged to do because she didn't have the time and my father was busy as an accountant, so I think that's why I love games now at this age (laughs).

RP: Right.

P13: Everybody else has had games and I haven't and I love games because it breaks it up.

RP: So what were these games then at the Bipolar Education Programme that you played?

P13: Well there was um, now hang on I can't remember now it was a few months ago now, um but there was one game, well no there were a couple of them, colour-coded and we had to, we split

The screenshot shows a text analysis interface. On the left, a vertical sidebar labeled 'Coding Density' contains a list of codes: 'fun and games not encouraged as a child so now indulges', 'Humour, its importance', 'able to joke and talk in light-hearted way, banter', 'played games, broke up seriousness, good fun, humour', and 'game for diagnosis and symptoms and how to deal with BD, coloured cards'. The main text area on the right shows the transcript from Excerpt 6 with various words and phrases highlighted in colors corresponding to the codes in the sidebar.

Excerpt 7: BEP-Cymru analysis

P12: Yes (laughs), yeah and however much I'm saying that you know we weren't getting that kind of personal perspective and that was frustrating, there's some people would always be able to recognise that OK, we're still in a learning environment and I can't go off on one (laughs) and other people won't and that's you know and that's levels of the frustrations and maybe more levels of self restraint but I think that's why it was happening and then after that it often leads, as you say it would be extended monologues and they weren't, sort of, they weren't tied back in, they would be, you know, understandably you're eventually cut-off, then I got back to what we were doing, it wasn't, it didn't appear to be handled particularly well and I don't know why that is but it's but it's, where similar things had happened on the previous course I'd been on, it happened less, because there was always an opportunity to sort of have a personal perspective in it and to kind of share some of those and I think that, you know, when you're looking at group-based learning that there's, that there needs to be that because otherwise why do it in a group, um, other than saving resources and money and time but you know, we might as well all sort of sat in lectures not round a table but in lecture sort of seating and just been lectured at and then all gone off and I don't think that's what people expected, I know it's not what I expected purely because I'd been on the course before, on the other course before, I kind of expected more of the same, that I'm going to be able to sort of share other people experiences, to learn from them and not just hear a load of stories but even though, obviously there's merit in that, um but I'm going to, there would be opportunities, there just didn't seem to be opportunity to do that, whereas in previous experiences of group-based learning, even if people are sort of cut over the top of the subject, their own personal agendas, that's been facilitated well enough so that people say 'well, not to cut you off but what we'll do is, we'll park that and we'll have a half an hour, an hour at the end of this session to look at those issues that you've brought up and share with other people', so then people didn't feel like they had to keep interrupting because they know there will be the opportunity later, um to kind of have their feedback on what had been said and I don't know whether it's just because of things getting out of, not out of control, it sounds like it was a riot but it wasn't (laughs) but it was, it never, I got more

Coding Density

need a parking zone for topics p's wish to discuss
not sticking to time
not good at managing the group
allowing people to talk off topic for too long
going over things already knew, no new info
feeling low and lacking energy
expected more sharing of personal experiences
extended monologues were frustrating, ppl not reigned in

Excerpt 8: BEP-Cymru analysis

P6: It has, yeah, it's very good, first to meet, to meet other sufferers you know? And to know that you had a weekly sort of meeting to look forward to.

RP: Right, OK.

P6: Yeah.

RP: So, it helped to have a weekly meeting.

P6: Yes and the information that was given was excellent but I think the main thing that we got out of meeting other people that were in the same boat, um.

RP: And that's the first time you'd met others with bipolar disorder?

P6: Yes.

RP: Right, so what was that like for you?

P6: Ah, intimidating the first meeting I think for everyone but as the weeks got on we sort of spoke to each other about, how it has affected their lives and we found things that we have in common really.

RP: Right OK.

P6: So you felt less isolated with the bipolar, yeah.

Coding Density

didn't know anyone with BD to talk with before
previously felt isolated in having BD
I'm not the only one, feel less isolated, others suffer like me
gaining confidence with others with BD
regarding BD, life in general
Exchanging experiences
First meeting was intimidating, meeting others with BD for first time
had looked forward to meetings

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