

Manuscript Number:

Title: What do service users with Bipolar Disorder want from a web-based self-management intervention: a qualitative focus group study

Article Type: Research Paper

Keywords: Bipolar Disorder, web based, self-management.

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**Abstract:** **Background:** Bipolar Disorder (BD) is a chronic and recurrent severe mental health problem. A web-based self-management intervention provides the opportunity to widen access to psychological interventions. This qualitative study aimed to identify what an ideal web-based intervention would look like for service users with BD. **Methods:** 12 service users with BD were recruited in the UK and took part in 5 focus groups to inform and refine development of a web-based self-management intervention. Reported is a sub-set analysis of data gathered as part of a series of focus groups conducted with the primary aim of identifying the needs and desires of service users for a web-based self-management intervention for BD. We analysed service users' responses to questions about content, outcomes, format, barriers and support. Focus groups were transcribed verbatim and thematic analysis (Braun & Clarke, 2006) was employed. **Results:** The data was ordered into four key themes: (1) Gaining an awareness of and managing mood swings; (2) Not just about managing mood swings: the importance of practical and interpersonal issues; (3) Managing living within mood swings without losing the experience; (4) Internet is the only format: freely accessible, instant and interactive; (5) Professional and peer support to overcome low motivation and procrastination difficulties. **Limitations:** The small group of participants are not representative of those living with BD. **Conclusions:** These findings have significantly enhanced our understanding of what service users with BD want from a web-based self-management intervention and have clear implications for the development of such approaches.

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**Acknowledgements**

The authors wish to thank Kay Hampshire and Laura Wainwright for their assistance in the running of the focus groups.

An earlier version of this paper was presented at the Division of Clinical Psychology conference in Manchester 2010.

**\*Conflict of Interest**

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None.

**Contributors**

Author NT designed the study, wrote the protocol, conducted the focus groups and was part of the analysis team. Author FL & SJ were part of the analysis team used to discuss emerging themes and provided comments on the initial drafts of this manuscript. All authors have contributed to and have approved the final manuscript.

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**Word Count: 6,473 (excluding references)**

## What do service users with Bipolar Disorder want from a web-based self-management intervention: a qualitative focus group study

### Abstract

*Background:* Bipolar Disorder (BD) is a chronic and recurrent severe mental health problem. A web-based self-management intervention provides the opportunity to widen access to psychological interventions. This qualitative study aimed to identify what an ideal web-based intervention would look like for service users with BD. *Methods:* 12 service users with BD were recruited in the UK and took part in 5 focus groups to inform and refine development of a web-based self-management intervention. Reported is a sub-set analysis of data gathered as part of a series of focus groups conducted with the primary aim of identifying the needs and desires of service users for a web-based self-management intervention for BD. We analysed service users' responses to questions about content, outcomes, format, barriers and support. Focus groups were transcribed verbatim and thematic analysis (Braun & Clarke, 2006) was employed. *Results:* The data was ordered into four key themes: (1) Gaining an awareness of and managing mood swings; (2) Not just about managing mood swings: the importance of practical and interpersonal issues; (3) Managing living within mood swings without losing the experience; (4) Internet is the only format: freely accessible, instant and interactive; (5) Professional and peer support to overcome low motivation and procrastination difficulties. *Limitations:* The small group of participants are not representative of those living with BD. *Conclusions:* These findings have significantly enhanced our understanding of what service users with BD want from a web-based self-management intervention and have clear implications for the development of such approaches.

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**Declaration of Interest:** None.

## Introduction

Bipolar Disorder (BD) is a highly recurrent affective disorder characterised by periods of extreme mood including depression and mania or hypomania (Goodwin & Jamison, 1990). The effective management of BD is extremely important due to being identified by 2% of the population and ranked by the World Health Organisation as one of the sixth most debilitating conditions (Merikangas et al., 2007). Although people can experience severe and enduring symptoms throughout their lifetime they can also experience long periods of stability (Michalak et al., 2006).

Pharmacotherapy is the main treatment currently offered, but has only limited effectiveness. For instance, service users on the best course of medication may still relapse and experience substantial psychosocial difficulties between episodes (e.g. Geddes et al., 2004; Judd et al., 2002). In addition, many people are reluctant to take medication due to the side effects and restrictions they feel it places on their life (e.g. Adams & Scott, 2000). There is increasing evidence that people with BD respond well to structured psychological interventions evidenced by fewer relapses, improvements in social functioning and reduced hospital admissions (e.g. Morriss et al., 2007). This is consistent with treatment guidelines from the National Institute of Clinical Excellence which recommend people with BD have access to psychological interventions (Nice, 2006a). Service users also show a preference for psychological intervention over medication alone (e.g. Lish et al., 1994). Despite this few service users actually receive psychological intervention within routine clinical services (Mind, 2010). The cost of psychological intervention and lack of specially trained therapists (Bird, 2006) limits the treatment options to medication only for the majority and medication with case management for the most severely affected.

Trying to address this problem of accessibility will require the development of new treatment approaches. One potential new treatment modality is computerised or internet based therapies. Computerised interventions are one example of a range of self-help interventions which all have the advantage of being highly accessible, available 24 hours a day, entirely self-directed, and do not require people to engage with mental health services which they can perceive to be stigmatising.

Computerised interventions have additional advantages in that they can be designed to be highly engaging through an interactive interface. These approaches have been used extensively to solve the accessibility problem in 'mild to moderate' depression with numerous studies indicating the effectiveness of this platform (Proudfoot et al., 2004; Kaltenthaler et al., 2008). Furthermore, this platform has been recommended as part of the stepped care approach to the treatment of 'mild to moderate' depression as part of the National Improving Access to psychological Therapies (IAPT) Strategy (Nice, 2006b)

There is currently no empirical evidence for the effectiveness of this approach in BD and the self-management approach remains largely untested. There are however a number of trials currently assessing this platform in BD (Simpson et al., 2009; Proudfoot et al., 2007; Barnes et al., 2007). If the internet has been used to provide information and support for depression (Christensen et al., 2002) we argue there is no reason why interventions for BD cannot be provided on this platform. Firstly, there is a false dichotomy between 'mild to moderate' and 'severe and enduring' mental illness, we argue that someone with a 'severe and enduring' mental illness is not necessarily any less able or any less deserving of the opportunity to learn self-management techniques and take responsibility for at least part of their wellness. In fact, according to Mueser et al., 2002 the recovery movement in mental health, advocating personal responsibility has brought the focus on self-management into severe mental illnesses from the preserve of severe chronic physical illnesses. There is now the recognition that even the most severely affected service users can learn to self-manage and take control of their lives (Doh, 2001). Secondly, there is evidence that self-management such as maintaining stable routine, staying adherent to medication, the detection and management of early warning signs is effective in BD (Russell & Browne, 2005). Computerised interventions therefore clearly have their place as an adjunctive treatment. They provide service users with access to psychological intervention from the point of diagnosis, can be provided as easily as medication, and can direct people to seek more intensive support if required. Such interventions have the potential to work in harmony with routine case management having the potential to cover key information

and skills training that can free up Care Coordinator time. Thirdly, there is substantial evidence that effective components of self-help and face to face psychological therapy can be translated into computerised therapy with a robust treatment effect (e.g. Cavanagh & Shapiro, 2004; Marks et al., 2003). Lastly, a recent systematic review (Todd et al., In Preparation-b) draws tentatively on evidence that suggests the treatment effect in a number of computerised interventions for mild to moderate depression can also be seen in severely depressed sample subgroups (e.g. Proudfoot et al, 2003; Purves et al, 2009; De Graff et al, 2009). These reasons pave the way for the further development of computerised approaches in BD.

The aim of the current study was to involve service users in the development of a web-based intervention for BD. This paper reports specifically on a series of focus groups conducted with the aim of finding out what an ideal web-based intervention would look like for service users with BD.

## **Design**

Qualitative methodology was chosen as we were interested in gathering service user views and experiences to inform the development of an intervention. Focus groups were considered the ideal way of gathering this kind of data, as they facilitate the development of shared ideas, shared thoughts, feelings and attitudes and benefiting from everyone's experiences, and facilitating a problem solving approach (Stewart et al., 2006).

## **Procedure**

### **Sampling and Recruitment**

Service users with a diagnosis of BD were opportunistically recruited from service user groups in the North West of England and on the World Wide Web between November 2009 and February 2010. Participants responded to an advertisement presented at self-help groups and posted on internet discussion forums asking participants to take part in a number of focus groups to inform the development of a web-based intervention for BD.

The recruited participants were aged between 18 and 65 and had a clinical diagnosis of BD. Self-reported health professional diagnosis was confirmed using the Mood Disorders Questionnaire (MDQ) (Hirschfeld et al., 2000); a reliable and valid screening tool indicating the likelihood of meeting the DSM-IV criteria for BD (Twiss et al., 2008). The sample was further described through the completion of a socio-demographic information sheet.

Ethical approval was granted by the Division of Health Research Committee at Lancaster University and informed consent was obtained before each focus group.

### **The Focus Groups**

The focus groups were part of an iterative intervention development process (Figure 1). In total five focus groups were conducted to inform the development of a web-based self-management intervention 'Living with Bipolar' each with their own specific aims. All focus groups were conducted at Lancaster University face-to-face and lasted between 90 and 120 minutes, were facilitated by two members of the research team, digitally recorded and transcribed verbatim.

Focus group one aimed to guide the initial development of the intervention content. A set of loosely structured questions were used to guide the discussion, covering: (1) The needs of service users in terms of content, format, support, barriers and ideal outcomes which formed the sub-set analysis presented here; and, (2) The personal experiences of recovery and self-management presented elsewhere (Todd et al., In Preparation-a).

The first half of focus groups two and three aimed to ensure validity by presenting provisional themes from focus group one back to participants and encouraging discussion. The focus of this paper is on the data gained from focus group one and the first half of focus groups two and three. The second half of focus groups two and three and the entirety of focus groups four and five aimed to gather feedback on therapeutic content and the web based interface. This data will be reported elsewhere.

<Figure 1>

## Analysis

The qualitative data was analysed by one academic researcher (NT) and two academic clinical psychologists (FL & SJ). Thematic analysis was employed following the procedure detailed by Braun & Clarke, 2006. The procedure involves the coding of the transcripts and then organising of codes into emergent themes. The data was interpreted with the research question in mind and focussed on the identification of the needs and desires service users have for a web-based self-management intervention.

To ensure reliability a team approach was used to analyse the focus groups. All transcripts were initially coded by NT and refined and reviewed by FL and SJ to ensure coding was structured and consistent with the research question. The analysis team are primarily influenced by the cognitive behavioural model and the usefulness of approaches informed by the recovery movement. Different team members had various levels of expertise in the psychological management of BD, from clinical training and practice including treatment development work (FL & SJ) to experience limited to the research setting (NT).

## Results

### Participants Characteristics

12 service users with a diagnosis of BD took part in focus group one. The participants were then split for focus groups two and three with 6 participants in each. The average age of participants was 42 years. All bar one of the participants were of white British decent. The average number of days since last episode was 280 days and two participants were in current episode at the time of the focus groups.

< Table 1 >

## Key Themes

The data from the focus groups was ordered into five key themes: (1) Gaining an awareness of and managing mood swings; (2) Not just about managing mood swings: the importance of practical and interpersonal issues; (3) Live within mood swings avoiding the damage as the primary outcome; (4) Internet is the only format: freely accessible, instant and interactive; (5) Professional and peer support to overcome motivation and procrastination difficulties.

### Theme 1: Gaining an awareness of and managing mood swings

Participants recognised self-awareness as being crucial for self-management (**P5: “...it is really is about self-awareness. Talking the time to look at yourself”**) and desired support to better understand and manage their mood swings. Less experienced participants discussed the usefulness of mood charting especially when newly diagnosed to gain an awareness of their mood swings and to know when to commence self-management (**P6: “...recognising when I am going from one level of depression or mania to another more serious level where more intervention is needed on my own behalf or from outside help.”**). More experienced participants discussed the potential for mood charting to gain a prognosis and planning appropriate activities (**P1: “I use a chart and was able not only to chart the changes in my mood but also chart the effects that it would have on...a prognosis, so I can plan what I am going to do or not going to do over the next couple of days...”**). In addition to mood monitoring participants discussed a variety of other mood management techniques they wanted to implement including recognising and triggers, recognising and managing symptoms and using early warning signs to ultimately prevent relapse and plan for crises. For instance, one participant discussed the importance of using self-management to prevent relapse and plan for crises (**P3: “I was also thinking as well as recognising triggers, recognising warning signs because often you need to catch those before...you know in order to self-manage... it’s that relapse prevention and knowing what to do, and having a plan in place so if things are to go really pear shaped really quickly you can sort of stop that from happening.”**)

## **Theme 2: Not just about managing mood swings: the importance of practical and interpersonal issues**

Participants were not content with the sole focus of a self-management intervention being on symptom management. Participants described the abundance of symptom management information on the internet but noticed the lack of information on dealing with living with the condition (**P9: “...but there is so many (websites) out there they all resolve around the management of the illness...i’d like to see something that would deal with ‘how to live your life as somebody who suffers from Bipolar’.”**) Participants viewed quality of life and symptom management as intertwined (**P4: Unless I managed the symptom of trying to getting a bit more consistency in my life I don’t feel I can have a great quality of life because you are looking forward to something and then it is gone.**) For these reasons some participants even went as far as suggesting that a self-management intervention focussing entirely on symptom management would not be useful (**P2: You wouldn’t bother would you. You would be depressed just looking at it. I wouldn’t bother.**) Participants described non symptom related advice as both coping with the practical interpersonal issues related to living with BD. In terms of practical issues participants described wanting support understanding their legal rights, managing debt, managing pregnancy and coping with seasons and time zones (**P11: “...there is the whole medical factors as such, you know what I mean, but the whole practicalities of it...”**). A practical issue of particular importance to participants was getting back into or maintaining employment (**P10: “...so just things that can help you get back into employment and how to manage going to work everyday.”**). In terms of interpersonal issues, participants desired support in a number of areas. Firstly, participants desired greater control over their encounters with services, to be able to know how to access, navigate and talk to services to get the help they need (**P11: “...often people don’t know that there are things out there available to them...when you are going to the medical services, the things that you need to say to them to actually get the right help...”**). Secondly, participants desired to know how to tell people around them including family, friends, prospective partners and employers about their

condition and how to involve them in their self-management (**P2: “What do you do? I mean if you have got a diagnosis do you tell them (partners) at the beginning, do you not tell them and then blow the whole thing out of the water. What do you do?”**). Of particular importance to participants was being able to tell people in a positive way (**P5: “They don’t actually tell you how to deal with it in a nice way and actually accept the person for who they are.”**) Thirdly, participants desired support in dealing with broken relationships and maintaining relationships alongside their condition. (**P2: “...so he met me liked me, right, and I had a complete breakdown, came out of it and at some point I have told him I have Bipolar and he is still there and that is, I don’t know how long that is going to last for.”**)

### **Theme 3: Managing living within mood swings without losing the experience**

When participants were asked to think about what they would ultimately want to get out of a self-management intervention they desired to be able to live a fulfilling life within their mood swings. This was not about getting rid of the mood swings altogether, like some participants were concerned some medication can do. Instead, participants valued their mood swings as they made life interesting (**P1: “I value my mood swing, I rather like it...we don’t want it absolutely flat. We don’t want it absolutely perfect. We want an interesting life..., we want to maintain our relationships, quality of life and we want to be darn useful to someone.”**). Participants therefore wanted to be able to manage their mood swings so that they can stay within some limitations and avoid the damaging aspects including hyper-sexuality, overspending and pleasure seeking behaviours (**P5: I think it is, it is about getting along with yourself and just accepting yourself but being able to sort of keep it within some limitations as such, not going through the bloody roof so you end up causing so much damage to your life so that it does then send you into a downward spiral.**) Participants described a number of challenges to living within their mood swings and desired coping strategies to use when well to make it easier to live within mood swings. The first challenge participants faced was the anxiety about having future episodes (**P4: Fear, fear of another one**

*coming. I always fear that the one I had 3 and a half years ago is going to come back which probably talking to myself why I am trying to resist accepting the label.*). The second challenge participants faced was being able to make the most of stability when they have it and walking the fine line of not getting into a false sense of security (*P5: It is about enjoying that time whilst you have got it instead of rather constantly living in fear I suppose...*).

#### **Theme 4: Internet is the only format: freely accessible, instant and interactive**

When participants were asked to think about whether the internet was the best format for a self-management intervention participants suggested the internet as being 'the only format' (*P1: "It's the only format...the internet format allows people to freely access it rather than having to wait for interventions though the NHS therapies erm and what not."*). Participants described a number of disadvantages of self-help books including the engagability, lack of interaction, being hard to read, over facing and often forgotten about (*P5: "Something you can sort of interact with is much better. Reading a book for a start off, if you are manic or depressive ready is really difficult, really difficult..."*). Other disadvantages surrounded around accessibility of self-help books, including there being too much choice, the lack of instantaneous support and the cost attached (*P1: "Again though, a book, I mean there are loads of self-help books and different therapy books..."*). Participants described an ideal intervention as being varied, attention grabbing and not boring. Participants viewed potential participants as possibly having a disrupted state of mind and low concentration (*P1: "Because people will be in a very disrupted state of mind and people. They might only have a concentration span of 45 seconds and then they lose it."*). Participants therefore suggested a number of ways to improve concentration including the use of different media and technological additions such as a reward logo or a way to bookmark the text (*P1: "Could you actually have a reward logo? So you go read a page and a logo would flash up and say 'well done' you've won an award...or a bookmark that they could move up and down the text, so they could remember if they come back to it after a cup of tea which part they had already read..."*). In addition, participants

suggested the need for people to identify with the information (**P5: “...being able to look at things and think that other people are just the same as you and realising you’re not alone, you are not a freak....”**). A number of ways of doing this were suggested including the inclusion of case stories, worked examples and success stories (**P1: *Success stories. I believe a lot of people think they will never get well and no one has ever got well, you have to counteract that.***).

Participants suggested a number of ways to avoid potential barriers of a web-based intervention. Firstly, participants suggested people should not need to have high computer literacy to be able to use the intervention (**P3: “...if you get the design of the website right it should be pretty much intuitive”**). Secondly, participants discussed being put off using an intervention if there are delays, broken links and additional software requirements (**P1: “Using the intervention...connection probably would be the only thing that would stop me using it, like...the website being slow or the server or whatever...or you go on things and the page isn’t available or buttons don’t work and stuff that would...”**). However, it was recognised by participants that the intervention is not going to suit everyone and it is about getting “the best fit” (**P2: “...whatever you do you won’t...you can get the best fit can’t you?”**).

#### **Theme 5: Professional and peer support to overcome low motivation and procrastination**

When participants were asked to think about the barriers to using a self-management intervention they described the challenge of being continually involved in self-management due to mood changes. In particular participants described feeling unmotivated even though they desperately want to be doing it and it had worked in the past (**P4: *It’s really hard for me to sustain being involved in something for a long time depending on where my mood changes...there has been times when I really need to do that again and I know it works but for some reason I just couldn’t motivate myself to do it...***). Participants related to this feeling even when it is not to do with getting better, procrastinating on the very essential parts of life (**P2: “But that happens to me with things not just to do with getting better, the most ridiculous small things in all different bits of my life.”**).

Participants struggled to understand why they feel this way and desired to know why lack of motivation happens and how to overcome it so can work with self-management more effectively **(P4: “What would help is a paragraph on the website that explaining why people have that dynamic because I wish I could work out why.”)**.

These issues are something that support could overcome. In fact, when participants were asked to think about whether support would be required, they described desiring professional support not only for the technical aspects of the intervention but for more motivational aspects as well i.e. when they are well don't need to use it anymore **(P2: “Do you mean also as a prompt because you are the sort of person that thinks they are perfectly alright all the time and don't use it. I am really good at thinking I am perfectly alright and everything's fine.”)**. The various methods of support were discussed and email support from the research team was desired over other means of support such as telephone or home visits from a clinician. Emails were seen as less intrusive and as having the potential to stimulate significant engagement. Participants had a preference for this professional support to be separate from services to avoid exclusion of those not in services **(P1: “...I think people should be able to access that maybe haven't been diagnosed but feel you know...or have been diagnosed and have been well or a long time and not supported by services, because there are a lot of people out there that aren't under any services at all.”)**. In addition to professional support participants wanted to be able to talk about the intervention with their peers, and finding out about what helps them. Participants mentioned linking to social media websites but concerns were raised surrounding people who are not open about their condition **(P1: “People who are fairly similar may want to talk to someone else on Facebook or something to compare notes.”)**. As an alternative a dedicated discussion forum was the desired solution over a live chat room.

## Discussion

The aim of the study was to find out what service users with a diagnosis of BD want from a web-based self-management intervention. The participant accounts analysed from three focus groups

have yielded five detailed themes which are discussed in relation to the development of a new intervention.

The first theme, gaining an awareness of and managing mood swings. Participants described the importance of a self-management intervention that includes techniques to learn more about their mood swings and how to manage them. Participants described using and even specifically named a number of psychological techniques including mood charting, self-monitoring and self-regulation, trigger and early warning sign recognition and crisis / relapse prevention planning. These techniques form the foundation of the cognitive behavioural approaches for BD, for example, Lam et al., 2010 which has strong evidence base as an adjunctive treatment for BD (e.g. Morriss, et al., 2007; Scott et al., 2006). It is therefore crucial for the intervention to be evidence based and informed by the principles of CBT. The current web-based interventions under development are all informed by CBT principles focussing on the management of symptoms and prevention of relapse (Simpson, et al., 2009; Barnes, et al., 2007; Proudfoot, et al., 2007).

The second theme, not just about managing mood swings: the importance of practical and interpersonal issues. Participants were not content with an intervention that focuses solely on symptoms and discussed the relationship between symptoms and quality of life being intertwined. Participants desired additional support around managing daily life alongside BD. In contrast to self-management techniques, advice around practical and interpersonal issues is not something that is a prominent part of current web-based self-management approaches for BD. However it is clearly something of substantial importance to service users and deserves a central role due to the interconnected nature of symptom and the management of life. All the current web-based self-management interventions focus on average one interpersonal issue, for instance, managing relationships (Barnes, et al., 2007), support for supporters (Proudfoot, et al., 2007; Simpson, et al., 2009) and managing stigma (Simpson, et al., 2009). Consistent with the current interventions participants desired support around coping with their diagnosis which included avoiding the

negative effects of stigma. Stigma is clearly an important treatment target as it has been linked to poorer social adjustment and acting as a substantial barrier for full recovery (Perlick et al., 2001). Participants wanted to avoid the trap of stigmatisation by knowing how to talk to people about their diagnosis. Consistently, the literature suggests that stigma is maintained by service users avoiding social contact to avoid rejection and become socially isolated (Link & Phelan, 2001). Participants desired to be able to speak up for themselves and know how to get the best out of services. This desire could be interpreted as fighting the “us and them” relationship sometimes encountered by service users in services. The desire to have more control over their encounters with services is consistent with recent changes in Department of Health policy including the introduction of the expert patient initiative (Doh, 2001). In fact, self-advocacy under which this interaction can be described has been suggested as an essential part of fighting stigma (Byrne, 2000). Consistent with the current interventions participants desired support around managing relationships but romantic as well as platonic relationships and desired to involve peers in the self-management of the condition. There is evidence that people with BD struggle with relationships especially romantic relationships mainly due to mood instability (Keller et al., 1993). However, maintaining good relationships is important due to the evidence that peer support from family and other contacts can significantly enhance therapeutic outcome in mental health service users (Davidson et al., 1999). In addition to what is provided by current interventions, practical advice around living with the condition; for instance, legal rights, managing debt, managing pregnancy and coping with seasons and time zones was discussed by participants. The management of work in particular was of importance to participants. Participants desired support around getting back into or maintaining work. The literature focuses on the bleak employment prospects for service users with BD including the lower than average employment rate (Dean et al., 2004). However, Michalak et al., 2007 suggests a number of ways BD can interact with work function which can be targeted by a self-management intervention. For example, problems lack of continuity, loss, illness management, stigma and disclosure and interpersonal problems. These interpersonal and practical issues

described in this theme are not specific to BD and could in fact be relevant to any severe condition in mental and physical health. For instance, relatives of service users with Psychosis desired support around talking to mental health services, talking to others about diagnosis, finding out legal rights and getting back into employment (Lobban et al., In Submission). The desire for support around interpersonal and practical issues is consistent with the literature suggesting service users with BD can experience cognitive impairment affecting all areas of psychosocial functioning (Coryell et al, 1993), with work and interpersonal relationships being significantly affected (Goldberg et al., 1995).

The third theme, managing living within mood swings without losing the experience. Participants didn't describe the absence of symptoms as the desired outcome but instead they desired more control to be able to live a fulfilling life within their mood swings. This finding could be interpreted as participants describing the process of recovery; living a fulfilling life despite experiencing mental health symptoms (Jones et al., In submission; Anthony, 1993). For this reason it is crucial that the intervention focuses on supporting recovery and quality of life outcomes as well as symptom management. Although supporting recovery is contentious due to being an individual process (Deegan, 1988) participants desire support to living a fulfilling life alongside their mood swings. For instance, walking the fine line between stability and illness, being able to make the most of their stability and not worry too much about future relapses, but at the same time not getting into a false sense of security. There is evidence that self-management can in fact exacerbate these symptoms causing 'over vigilance' to relapse, leading to rumination, catastrophising and limiting of social life (Mansell et al., 2010). Therefore self-management techniques presented within a recovery approach focussing on more than just symptoms may provide an effective solution to this. There is evidence that service users are able to make the most of their stability and manage the fear once they have accepted there is no cure, gained more control and minimised the impact of the illness on their lives (Russell & Browne, 2005). Illness perceptions, self-management of symptoms and coping with symptoms alongside daily life are all areas that a recovery informed approach would aim to address. Participants desire to have support to live alongside mental health symptoms provides support for

the idea supporting recovery is the iterative relationship between the persons experience the conditions that may facilitate recovery (Roberts & Wolfson, 2004). In addition, participants desire to retain their symptoms was related to the view that Bipolar experiences can be positive despite the recognition that damaging aspects of the condition need to be avoided. Previous research confirms the importance of the positive aspects of BD in peoples' lives and the emotional blunting affect people can experience on long term medication (Lobban et al., In preparation). The literature is filled with examples of creative individuals who almost rely on the positive aspects of their condition to succeed (Galvez et al., 2011).

The fifth theme, professional and peer support to overcome low motivation and procrastination. Participants described motivation and procrastination as potential barriers to using a self-management intervention, participants discussed finding it hard to stay continually involved in something even if really want to do it and it has worked in the past. A recent study suggested the reduction of symptoms and positive experience with an intervention can increase motivation (Gerhards et al., 2011), however, in this study participants reported not having the motivation and procrastinated even though they wanted to take part. For some participants this was due to mood changes and for others even when stable. Consistent with this a qualitative study exploring reasons for drop out in a web-based intervention for BD found the most common reason being acute symptoms but participants were also plagued by more personal motivation issues (Nicholas et al., 2010). Although recognised symptoms of a depressive episode, motivation and procrastination are also affecting service users outside of episode and the knowledge of therapeutic benefit is not motivating them. It could be hypothesised that some service users are experiencing inter-episode symptoms (Morriss, 2002) or side effects of prophylactic medication which are well documented to cause impaired executive functioning (Aydemir, 2009). This barrier is crucial to overcome due to psychological intervention being most effective between episodes (Nice, 2006a) and because a number of service users accessing self-management are in need of coping strategies for mild to moderate symptoms which according to service users in this study can both be affected by

motivational difficulties. Motivation in self-management is much more of an issue than in face to face therapies due to the lack of the therapeutic relationship as an external motivator (Bados et al., 2007). Participants desired support around these difficulties especially to keep them involved in a therapeutic intervention that they want to do. Participant's motivation can be increased in two ways. Firstly, through psychological techniques; there is an abundance of self-help literature suggesting ways of improving motivation and overcoming procrastination through goal setting (e.g. Dryden, 2000). Secondly, adding support to self-management interventions can improve significantly enhance motivation. This has been demonstrated in an online intervention for depression with the lack of support to adhere to the program or gain a deeper understanding being seen as a barrier by participants (Gerhards, et al., 2011). In fact, when participants in this study were asked about support they described needing it particularly to stay involved when they are stable. Consistent with participant accounts a number of reviews of internet interventions for mood and anxiety disorders have suggested interventions with support have larger effect sizes than those that don't (e.g. Spek et al., 2007). Furthermore, research suggests without support web-based interventions can suffer a dropout rate of more than 50% (Todd, et al., In Preparation-b). The delivery, level and person delivering the support were all given a preference by participants. Interestingly participants did want substantial autonomy and the level of support requested was minimal. Participants desired email support in the form of prompts from the research team as opposed to full telephone or face to face support from a clinician which was seen as intrusive. In addition to research team prompts, participants wanted to be able to talk about the intervention. Consistent with previous research, minimal support such as contact from the research team in CCBT interventions for anxiety, depression and bulimia (Waller & Gilbody, 2009; Murray et al., 2007; Macgregor et al., 2009) is sufficient to improve therapeutic adherence meaning face to face support is not necessarily essential. The majority of the current web-based self-management approaches for BD take the minimal approach. For instance, one has no support at all (Proudfoot, et al., 2007) and one has an online forum moderated by a member of the research team (Simpson, et al., 2009). However, one

bucks the trend and links the intervention to a treating clinician (Barnes, et al., 2007 [ENREF 5](#)). We do however recognise that self-management interventions are not the answer to everyone problems, and even with the best support they do require the person to have the initial motivation to want to help themselves.

### Limitations

This study has a number of limitations. The qualitative nature of this study means valid generalisations cannot be made based on the results. The small group of participants are not representative of the population of those living with BD. Firstly, service users were recruited to take part in a number of focus groups about the development of a web-based intervention and therefore would be likely to be those were most interested in web-based based therapeutic approaches. Secondly, the study was not geographically representative as recruitment was limited to the North West of England for practical reasons. Thirdly, all participants bar one were of white British ethnic origin which limits the generalisability to other cultures. Although formal diagnosis was an inclusion criterion for this study no formal assessment of diagnosis was conducted and symptomatology at time of entry was not assessed. This means current symptomatology and co-morbid psychological disorders could have affected the results. Furthermore, participants were not asked what other psychological interventions they had been involved in prior to this study and therefore participants had varying levels of knowledge about the psychological management of BD.

### Conclusion

This study has significantly enhanced our understanding of what service users with BD want from a web-based self-management intervention in terms of content, outcomes, format, overcoming barriers and support. In regards to content, service users for the first time have described wanting a web-based self-management approach that not only gives them the techniques they need to manage their moods but also the techniques to manage their life alongside the disorder including

interpersonal and practical issues. In regards to outcomes, consistent with the recovery agenda service users have described their primary outcome not as a cure or reduction in their symptoms but instead being able to live a fulfilling life alongside condition. With regards to format, for the first time service users have suggested the internet as the preferred for a self-management intervention for a variety of pragmatic reasons. In terms of support and barriers, for the first time service users have described motivation and procrastination difficulties inside and outside mood episode and described the need for limited professional support in terms of email prompts to increasing motivation and emotional support through a peer support mechanism. This data has been used to inform the development of 'Living with Bipolar': an evidence-based, recovery informed web-based self-management intervention that aims to significantly improve quality of life for service users with BD (Todd et al., In Preparation-c).

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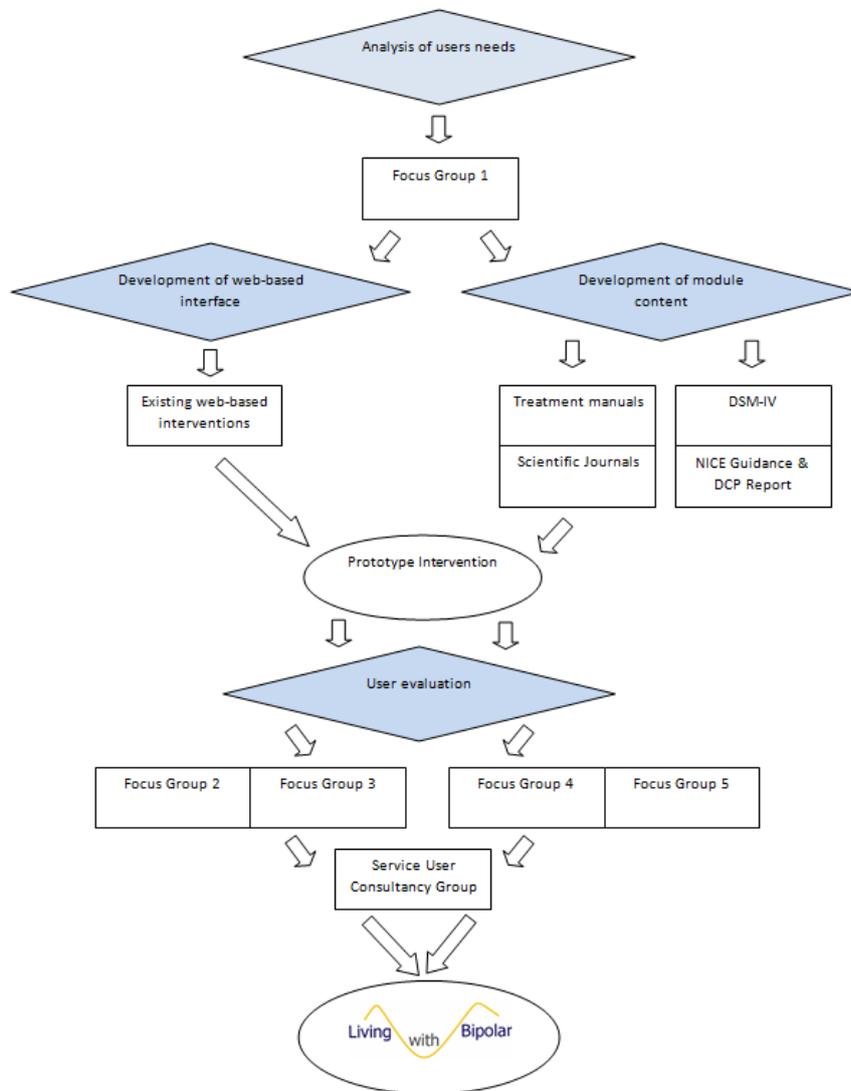


**Role of Funding Source**

The project was funded by a Mersey Care NHS Trust Research and Development Grant. Mersey Care NHS Trust had no further role in study design; the collection, analysis and interpretation of the data; in the writing of the report; and in the decision to submit the paper for publication.

Figure 1

*'Living with Bipolar' Developmental Pathway*



**Table 1***Socio-demographic characteristics of participants (n=12)*

ID	Gender	Age	MDQ Score	Problem	Formal Diagnoses	Employed	Medication
1	Male	56	11	Moderate	Bipolar 1 Disorder	Part Time	Yes
2	Male	45	11	Moderate	Bipolar 1 Disorder	Full Time	Yes
3	Male	43	11	Serious	Bipolar 1 Disorder	Full Time	Yes
4	Female	30	12	Moderate	Bipolar 2 Disorder	Part Time	Yes
5	Female	29	12	Serious	Bipolar 1 Disorder	Unemployed	Yes
6	Female	52	12	Serious	Bipolar 1 Disorder	Voluntary	Yes
7	Male	47	13	Moderate	Bipolar 2 Disorder	Full Time	Yes
8	Male	31	13	Moderate	Bipolar 1 Disorder	Full Time	Yes
9	Female	49	11	Serious	Bipolar 2 Disorder	Full Time	Yes
10	Female	37	13	Serious	Bipolar 1 Disorder (Rapid Cycling)	Unemployed	Yes
11	Male	37	11	Moderate	Bipolar 2 Disorder	Full Time	Yes
12	Male	42	13	Serious	Bipolar 1 Disorder	Voluntary	Yes



Nick Todd  
Spectrum  
Division of Health Research  
Lancaster University

8<sup>th</sup> December 2009

Dear Nick,

**Re: Web based self management intervention for Bipolar Spectrum Disorders  
Phase 1 – Focus Groups to Inform Development of Intervention**

Many thanks for your email of 8<sup>th</sup> December with accompanying attachments, detailing the revisions you have made to meet the requirements of the ethics committee. Your changes ensure that the proposed project meets all the requirements of the ethics committee, and we wish you well in the progress of the study.

Yours sincerely

Anna Daiches  
Chair  
DHR Ethics Committee