

Research paper

User perspectives on long-term remote active electronic self-monitoring of mood symptoms in bipolar spectrum disorders

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ABSTRACT

Background: User feedback is crucial in the development of electronic self-monitoring tools for bipolar spectrum disorders (BSD). Previous studies have examined user experiences in small samples self-monitoring over relatively short time periods. We aimed to explore the experiences of a large sample of individuals with BSD engaged in long-term remote active electronic self-monitoring.

Methods: An online survey, containing closed and open questions, was sent to participants with BSD enrolled on the Bipolar Disorder Research Network (BDRN) True Colours mood-monitoring system. Questions related to experiences of using True Colours, including viewing mood graphs, and sharing data with healthcare professionals (HCPs) and/or family/friends.

Results: Response rate was 62.7 % (n = 362). 88.4 % reported finding using True Colours helpful. Commonly reported benefits were having a visual record of mood changes, patterns/triggers and identifying early warning signs. Limitations included questions not being comprehensive or revealing anything new. One third had shared their graphs, with 89.9 % finding it helpful to share with HCPs and 78.7 % helpful to share with family/friends. Perceived benefits included aiding communication and limitations included lack of interest/understanding from others.

Limitations: Responder bias may be present. Findings may not be generalisable to all research cohorts.

Conclusions: The majority of participants valued long-term self-monitoring. Personalisation and ease of use were important. A potential challenge is continued use when mood is long-term stable, highlighting the need for measures to be sensitive to small changes. Sharing self-monitoring data with HCPs may enhance communication of the lived experience of those with BSD. Future research should examine HCPs' perspectives.

1. Introduction

The importance of individuals with bipolar spectrum disorders (BSD) self-monitoring their mood is well established. It forms a key component of helping individuals understand and manage their mood symptoms more effectively (Colom and Lam, 2005; Suto et al., 2010). Advancing digital technology has led to the emergence of an increasing number of electronic mood monitoring tools designed for individuals with BSD. These fall into two main types: i) active monitoring, requiring users to actively input data via surveys and questionnaires and ii) automatically

generated passive data via sensors such as those embedded in smartphones and wearable devices.

As technology develops further, these tools will continue to shape and change the ways in which individuals with BSD monitor their mood and self-manage their disorder. A crucial element in the ongoing development of digital mood monitoring tools is to incorporate feedback from the user experience. The perspectives and preferences of individuals must be continually considered to ensure the tools meet the needs of those they are intended for. However, to date, studies examining the use of mood monitoring tools from the user perspective have

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been limited by cross-sectional/short follow-up research designs, and/or small sample sizes.

A cross-sectional online survey of self-monitoring practices, attitudes and needs of 552 individuals with BSD observed an increasing trend towards the use of digital technology (Murnane et al., 2016). Respondents reported the benefits of self-monitoring as enhanced self-reflection, increased self-awareness of BSD patterns and relationships, and assisting self-management. Difficulties using technology-based monitoring were reported, including tools not being intuitive, challenges in interpreting aggregated digital reports, and difficulties remembering or adhering to monitoring routines. A need for digital technologies to be more specifically orientated towards BSD, accessible across different devices and user-friendly was highlighted. Using an alternative approach, a cross-sectional qualitative exploration of the content of publicly available consumer reviews of 48 apps for BSD, most of which were for symptom monitoring, revealed that the majority (74 %, 1608 out of 2173 reviews) included positive feedback (Nicholas et al., 2017). Content that was supportive, helpful and easy to use was valued. Just over one quarter of reviews contained unfavourable feedback which included comments about the content or features not meeting user needs and technical issues. One in five reviews mentioned additional ‘wish-list’ features, including monitoring additions and reminders, highlighting the ways in which such apps might not be adequately addressing user needs.

As this type of technology becomes integrated into routine clinical care and research programmes, digital mood monitoring tools are likely to be increasingly accessed and used by more individuals with BSD including those who are less digitally confident. Individuals’ perspectives of using online mood monitoring systems in these settings may differ from those actively seeking out commercial smartphone-based apps and available online tools.

In a smaller study (N = 47, 6-week follow-up) involving participants with BSD self-monitoring symptoms using both a smartphone app and Fitbit activity tracker, the components that increased engagement and adherence with these technologies were investigated (Van Til et al., 2020). The main perceived barriers were forgetfulness, not knowing which devices and apps to use, and requiring too much effort. The primary reasons for self-monitoring were reported as increasing self-awareness and improving symptoms. The authors also noted that some participants provided feedback that they wanted to give context to their mood ratings to help them reflect on what was happening in their lives.

Another smaller qualitative study (N = 21, 12-week follow-up) of individuals with BSD explored the experiences of engaging in remote mood and activity monitoring as part of the Automated Monitoring of Symptom Severity (AMoSS) study (Saunders et al., 2017). Participants interviewed had monitored their mood on a daily basis using a study-specific smartphone app in addition to completing weekly mood measures using the online True Colours mood monitoring system (Goodday et al., 2020) and wearing movement sensing devices. Personal benefits were reported as increased insight and behavioural change. A small number of participants raised the issue of the potential for preoccupation with monitoring and paranoia when unwell. However, the majority (86 %) felt prospective mood monitoring would enhance decision making in routine clinical care, for example, by assisting recall of mood states between appointments. The importance of being able to add context was highlighted to ensure scores were not misinterpreted, and also flexibility and personalisation.

The studies reported above have been limited by cross-sectional/short follow-up research designs, and/or small samples sizes. We have previously reported the large-scale roll out of the Bipolar Disorder Research Network (BDRN) True Colours online mood-monitoring tool for research in the United Kingdom (UK) (Gordon-Smith et al., 2019), with 577 current participants enrolled for a median of more than 2 years (28 months). In the current study, we assessed what aspects of remote mood-monitoring were particularly helpful for the individuals with BSD in a subset of the BDRN True Colours cohort (N = 362). In addition, we

explored participants’ experiences of sharing their mood monitoring records with others, including healthcare professionals (HCPs; incorporating general practitioners [GP]/primary care physicians [PCP], and/or clinical/medical professionals in a psychiatric team), and family/friends.

2. Method

2.1. Participants

BDRN is an ongoing research programme into the genetic and environmental aetiology of BSD and related affective disorders. Participants are recruited throughout the UK via National Health Service (NHS) services and advertisements through patient support organisations, such as Bipolar UK (www.bipolaruk.org.uk). Inclusion criteria are: (i) aged 18 years or over at participation; (ii) able to provide written informed consent; (iii) meet Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV) criteria (American Psychiatric Association, 2000) for BSD; and (iv) onset of mood symptoms before the age of 65 years. Best-estimate main lifetime diagnosis is made according to DSM-IV criteria based on in-depth interview using the Schedules for Clinical Assessment in Neuropsychiatry (Wing et al., 1990), and review of psychiatric and GP/PCP case notes where available. As a principal focus of the BDRN research is to investigate genetic determinants of mood disorders, details were obtained on sex at birth and whether or not participants self-identified with this status. The research has approval from the West Midlands NHS Research Ethics Committee (MREC/97/7/01) and all participating NHS Trusts and Health Boards. Written informed consent is obtained from all participants.

Participants in the current study were a sub-set of BDRN participants enrolled on the BDRN True Colours system. The development and roll-out of BDRN True Colours, including uptake rates and length of engagement, has been described elsewhere (Gordon-Smith et al., 2019). In brief, the BDRN True Colours system sends participants weekly email prompts to complete two online self-report questionnaires: the Quick Inventory of Depressive Symptomatology patient-rated version (QIDS) (Rush et al., 2003) and the Altman Self-Rating Mania Scale (AMS) (Altman et al., 1997) which measure presence and severity of depressive and hypomanic/manic symptoms over the preceding week respectively. The total weekly scores and symptom scores are presented graphically and participants are able to login to view their mood graphs at any time and print them off if they wish. There is also an additional option for participants to create and complete personalised questions in addition to the QIDS and AMS questionnaires as described in (Gordon-Smith et al., 2021). Individuals can also add notes to record specific details such as a change in medication or other details to add context to their mood ratings.

2.2. True Colours user feedback survey

A bespoke online survey was sent to all current BDRN True Colours users (N = 577 - median time of enrolment; 28 months, range; 1–36 months.). The survey contained five-point Likert response questions (1 = “not helpful at all” to 5 = “extremely helpful”) relating to how helpful respondents found: i) using True Colours; ii) looking at their True Colours graphs; iii) sharing their True Colours data with HCPs; and iv) sharing their True Colours data with family and friends. For those who had shared their data, questions also asked whether HCPs and/or family and friends had commented on whether or not they found this helpful. Free text boxes after each question asked if individuals would be willing to provide further details.

2.3. Data analysis

Descriptive statistics were used to describe the sample and responses to the quantitative survey items. Demographic and clinical

characteristics were compared between survey responders and non-responders using non-parametric statistical tests as the majority of data were not normally distributed.

A qualitative content analysis approach (Elo and Kyngäs, 2008) was used to analyse the content of the free text survey boxes. For each of the free text boxes separately KGS read and re-read all comments as open-mindedly as possible and created an initial coding scheme of categories which acted as a guide. In an initial round of analysis KGS coded each comment individually, creating new categories where the content of a comment could not be categorised according to the initial coding scheme. To capture the interpreted meaning, comments could be coded into more than one category. The coding of each comment was checked for agreement by LJ. Different interpretations of the meaning of specific comments were subsequently discussed between KGS and LJ with consensus being reached, and the categories were refined further based on emerging understanding to create a final coding scheme. KGS re-read all the comments checking and updating the coding of categories against the final coding scheme which was then checked for agreement by LJ. Finally, the names of the categories were discussed and agreed between all authors. This process was repeated for the analysis of each of the free text boxes.

3. Results

3.1. Sample

Of the 577 individuals invited to complete the survey, 362 (62.7 %) responded. The sample of 362 individuals is described in Table 1. 67.4 % were female (in all cases sex at birth matched gender identity) with a median age of 54 years. 62.1 % had completed higher education. The majority had a DSM-IV diagnosis of bipolar I disorder (56.1 %) or bipolar II disorder (39.0 %), with the remaining minority having schizoaffective disorder bipolar type (1.4 %) or bipolar disorder not otherwise specified (3.6 %). Median age of onset of BSD was 19 years and the median lifetime number of episodes of depression and (hypo)mania was 9 and 6 respectively. 63.8 % had at least one past psychiatric admission and 50.8 % had a lifetime history of suicide attempt. The median length of time individuals had been using True Colours was 28 months (range

Table 1

Demographic and lifetime clinical characteristics of individuals enrolled on the True Colours remote self-mood monitoring system providing user perspective feedback (N = 362).

Sample	
<i>Demographic variables</i>	
Female n (%)	244 (67.4)
Current age, years: median (Iq R)	54.0 (17)
Completed higher education n (%)	195/314 ^a (62.1)
<i>Lifetime clinical characteristics</i>	
Bipolar I disorder n (%)	203 (56.1)
Bipolar II disorder n (%)	141 (39.0)
Schizoaffective disorder bipolar type n (%)	5 (1.4)
Bipolar disorder not otherwise specified n (%)	13 (3.6)
Age at onset of BSD, years: median (Iq R)	19.0 (10)
Number of episodes of depression: median (Iq R)	9.0 (15.0)
Number of episodes of hypo(mania): median (Iq R)	6.0 (10)
Psychiatric admission n (%)	220/345 ^a (63.8)
Suicide attempt n (%)	167/329 ^a (50.8)
<i>True Colours</i>	
Length of time using True Colours, months: median (Iq R) range	28 (14) 1–36
Additional personalised questions asked n (%)	161 (44.5)
Adding notes feature used n (%)	70 (19.3)

Iq R = interquartile range, BSD = bipolar spectrum disorders.

^a Totals vary due to unknown information that could not be established at interview or from available case notes.

1–36 months). 44.5 % had chosen to add additional personalised questions in True Colours, and 19.3 % had used the notes feature to add further context to their ratings.

For the majority of demographic and clinical characteristics, there were no significant differences between individuals opting to complete the survey (n = 362) and those who did not (n = 215). The only significant difference was that individuals who completed the survey were older than those who did not (54 vs. 50 years, p = 0.002).

3.2. Personal experiences of using True Colours

88.4 % of survey respondents (320/362) reported that they found using True Colours extremely or moderately helpful (40.6 % and 47.8 % respectively) (Fig. 1A). 87.8 % (318/362) reported that they had looked at their True Colours mood graphs, and of these 86.4 % (275/318) reported finding looking at their graphs extremely or moderately helpful (44.3 % and 42.1 % respectively) (Fig. 1B).

3.2.1. Content analysis of personal experiences of using True Colours

239 individuals (66.0 %) provided further details in the free text boxes about their experiences of using True Colours. Comments from approximately half of respondents were coded into a single category (120/239 = 50.2 %), and a slightly smaller number of respondents' comments were coded into two categories (88/239 = 36.8 %). A minority were coded into three (29/239 = 12.1 %), four (1/239 = 0.4 %) and five categories (1/239 = 0.4 %).

The categories are shown in Table 2 organised into those relating to the perceived benefits (nine categories) and limitations (six categories) of using True Colours. For each category, the frequency and percentage of individuals whose feedback included comments relating to that category are reported. The most commonly reported perceived benefits included having a visual record of mood changes, patterns and/or triggers (50.6 %) and helping to identify early warning signs (13.0 %). 12.6 % commented that completing their True Colours questionnaires each week encouraged them to reflect on their mood on a regular basis which they found helpful. Some individuals also made additional generic broad positive comments about True Colours for example how they felt it would be helpful for others to use also (7.5 %) and 6.7 % specifically commented that a key motivation for using True Colours was helping with research. Less commonly reported perceived benefits included True Colours helping individuals recognise aspects of their mood symptoms they were previously less aware of (5.4 %), being reassuring by showing improvement in mood (4.2 %), confirming individual's own subjective impression of their mood (3.3 %) and individuals finding it reassuring to receive the True Colours emails every week (1.7 %).

The most commonly reported perceived limitation of True Colours was the questions not being finely-tuned or comprehensive enough (30.1 %). For example, individuals reported the questionnaires did not cover the full range of symptoms they experienced or did not allow the opportunity to indicate where other factors such as longstanding comorbid health conditions were affecting their responses on specific items. Individuals also reported a limitation as being that their True Colours graphs did not reveal anything new (13.0 %), in a number of cases this was because individuals reported their mood had been stable over the duration of time they had been using True Colours. 8.4 % reported experiencing technical/usage problems and 4.6 % mentioned the presentation of the True Colours graphs was not immediately clear and/or that they had experienced difficulties understanding the graphs. A very small proportion of individuals reported that completing weekly mood ratings reminded them of being unwell (1.7 %) and 1.3 % reported that they would not complete True Colours when they were unwell.

3.3. Sharing True Colours graphs: HCPs

Of the 318 individuals who had looked at their True Colours graphs,

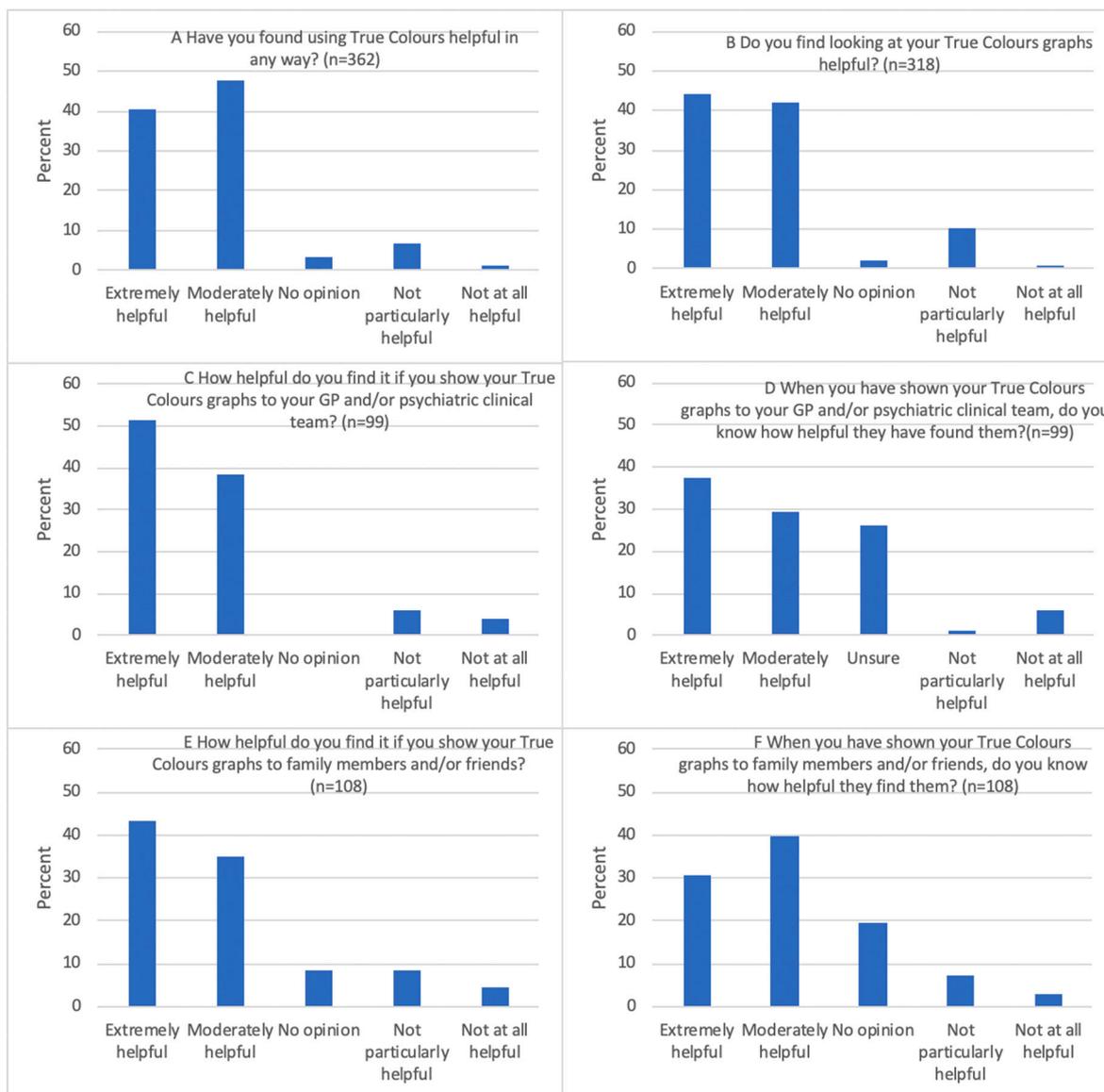


Fig. 1. Helpfulness of using True Colours remote self-mood monitoring and sharing data reported i) by participants and ii) to participants by their healthcare professionals and family/friends.

Healthcare professionals (HCP) = incorporating general practitioners (GP)/primary care physicians (PCP), and/or clinical/medical professionals in a psychiatric team.

99 (31.1 %) had chosen to share their graphs with their (HCPs). 89.9 % (89/99) reported that they had found it helpful (either moderately or extremely) to share their graphs with their HCPs (Fig. 1C) and 66.7 % (66/99) reported that HCPs told them they had found the graphs helpful (Fig. 1D).

3.3.1. Content analysis of experiences of sharing True Colours graphs with HCPs

Of the 99 individuals who had shown their True Colours graphs to their HCPs, 38 (38.4 %) and 51 (51.5 %) individuals respectively provided additional details relating to their and the HCPs' reported experiences (see Table 3).

Feedback from individuals on their experiences of sharing their True Colours graphs with their HCPs was coded into five categories which all related to helpful aspects. Comments from approximately three quarters of participants were coded into a single category (28/38 = 73.7 %), and 26.3 % (10/38) were coded into two categories. 50.0 % of individuals who provided feedback reported the graphs provided additional

evidence to support their description of their mood, to their HCP allowing a more objective accurate account than from memory and not affected by current mood. Another commonly reported benefit was that the graphs facilitated individual's ability to provide their HCP with a quick and easy overview of their mood (44.7 %). Participants also specifically mentioned the graphs aided discussions about medication and treatment (15.8 %), relationships between mood and other factors, for example comorbid conditions, (10.5 %), and specific mood patterns (5.3 %).

Feedback True Colours participants reported they had received spontaneously from their HCPs are organised into those relating to perceived benefits (five categories) and limitations (three categories). 78.4 % of reported comments were coded into a single category (40/51), and 21.6 % (11/51) were coded into two categories. Participants commented that their HCP had reported to them that it was helpful to see patterns in their patient's mood over time and identify times of concern (43.1 %). A smaller number of participants reported that their HCPs had told them that the True Colours graphs had helped them to make clinical

Table 2
Perceived benefits and limitations of using True Colours remote self-mood monitoring: categories according to frequency of individuals providing feedback.

	Example	N	% of respondents providing feedback (n = 239)
<i>Perceived benefits</i>			
Visual record of mood changes and visually spot specific patterns and/or triggers	<i>I'm finding it useful looking if there are patterns in how my mood shifts. I've always believed my illness to be seasonal, and I have had that confirmed by the graphs, which is helpful. The graphs help me to understand the patterns of my moods and how often they come around/ change. It has aided the tracking of stressful events and their impact on my mood.</i>	121	50.6
Identifying early warning signs	<i>They help me to see any early warning signs I may be missing. I find looking at the graphs really helpful in recognising when my mood in particular is repeatedly sinking more than it usually does, and it really helps me to be more objective about this.</i>	31	13.0
Regular reflection on moods is helpful	<i>It makes me stop and consider how I am feeling.</i>	30	12.6
Generic positive	<i>Please, please roll this out to all bipolar people it's a life saver and picks up slight changes in the condition that might not otherwise be apparent. I just wish it had been available a few decades ago! I think it would be incredibly useful in adolescents.</i>	18	7.5
Helping with research	<i>Not only a tool but being used for research too. It works for me!</i>	16	6.7
Recognise aspects of mood previously less aware of	<i>There's also a seasonal element that I hadn't recognised previously. It has helped me to recognise and to accept variations even when 'well'.</i>	13	5.4
Reassuring showing past and or current improvement in mood	<i>I only have to review the entire graph to see that the current feeling is not new or unique, it is part of my ongoing journey and that reassuringly, there are also periods of improvement.</i>	10	4.2
Confirms subjective impression of mood	<i>I often feel that I have been high or low and when I take the survey I have been right.</i>	8	3.3
Reassuring to receive emails every week	<i>I feel it's like having a third party to keep an eye on me!</i>	4	1.7
<i>Perceived limitations</i>			
		72	30.1

Table 2 (continued)

	Example	N	% of respondents providing feedback (n = 239)
Questions not fine-tuned/comprehensive enough	<i>I find the mania section too short and it doesn't cover the full range of my symptoms. Just being weekly, and only an average over that time, does not allow for the blips in moods on odd days.</i>		
No obvious trends/does not reveal anything helpful or new	<i>I have been stable for almost three years which may be why my answers are the same each week.</i>	31	13.0
Software/usage/technical problems	<i>I have had difficulty (and still am) in accessing the True Colours site via the email reminder link.</i>	20	8.4
Do not understand graphs/presentation could be clearer	<i>The graph with circles I don't understand and cannot read well. Never seen a graph like it.</i>	11	4.6
Reminded of being unwell	<i>I don't want to be reminded of being down.</i>	4	1.7
Would not complete when unwell	<i>I'm aware I don't do it when I am at my most unwell e.g. in hospital.</i>	3	1.3

Some examples have been edited slightly to protect privacy.

and treatment decisions (15.7 %). Other reported benefits included HCPs finding the graphs generically helpful (13.7 %), helping to see the effects of medication (11.8 %) and helpful to add to medical records (5.9 %). Conversely, a proportion of participants reported that their HCPs had not found participants sharing their graphs helpful and in the majority of cases this was described in general terms of HCPs not expressing interest rather than for specific reasons (23.5 %). Small proportions of individuals reported their HCP expressed a specific view on the limitations of True Colours (3.9 %) and that their HCP said they could not understand the graphs (3.9 %).

Although not specifically asked about in the survey, some participants voluntarily explained why they had not shared their graphs with HCPs. Some reported they had not considered doing so “*That sounds like it could be a good idea.*”, and others indicated they had actively chosen not to “*GP hasn't got the time*”.

3.4. Sharing True Colours graphs: family and friends

108 individuals (33.9 % of those who had looked at their own True Colours graphs) had chosen to share their graphs with their friends and/or family. 78.7 % (85/108) reported that they found it helpful (either extremely or moderately) to share their graphs in this way (Fig. 1E) and 70.4 % (76/108) reported that their friends and family had told them they found it helpful (Fig. 1F).

3.4.1. Content analysis of experiences of sharing True Colours graphs with family and friends

Of the 108 individuals who had shown their True Colours graphs to their family and friends, 33 (30.6 %) and 42 (38.9 %) individuals respectively provided additional details relating to their and their family/friends' reported experiences (see Table 4).

Feedback from individuals on their experiences of sharing their True Colours graphs with their family and friends was coded into six categories (three benefits and three limitations) with all comments being each coded into a single category. The most commonly reported benefits for individuals sharing their graphs was that they helped to explain to family/friends how they were currently feeling (33.3 %) and also aided

Table 3
Experiences of sharing True Colours remote self-mood monitoring graphs with healthcare professionals: categories according to frequency of individuals providing feedback.

	Example	N	% of respondents providing feedback (n = 38)
<i>Perceived benefits to True Colours users</i>			
Additional evidence to support description of mood	<i>I find it helpful evidence to back up what I am trying to describe. It gives a more accurate response to "how have you been?". Previously I couldn't really remember. Showing the graph is better than me trying to describe how I have been as my viewpoint is usually affected by how I feel on the day of the appointment, thus giving a false picture.</i>	19	50.0
Generic aid to give overview of mood	<i>To provide a quick overview of mood changes and sleep patterns. It is an easy way to convey a lot of information on one page.</i>	17	44.7
Aid discussion of medication and treatment	<i>I show my GP on every visit, helps to look at how my medication is working against my mood swings.</i>	6	15.8
Aid discussion of relationships with other factors	<i>I have used these to discuss my migraines.</i>	4	10.5
Aid discussion of mood patterns	<i>We have both found them helpful particularly in identifying a moderately severe mixed mood state last year.</i>	2	5.3

	Example	N	% of respondents providing feedback (n = 51)
<i>Reported benefits perceived by HCPs (reported to True Colours users)</i>			
See patterns and times of concern	<i>My GP was interested in seeing the graphs and how they fitted in with how they would find my mood in person. My CPN has commented on how useful it is for them to understand my situation or condition and that they would recommend that others use it.</i>	22	43.1
Help to make clinical and treatment decisions	<i>With this they said they're able to get an overview of how the conditions are doing, the potential triggers and also if medication needs to be adjusted or if talking therapy refreshers would be useful. This winter they helped to have the psychiatrist prescribe to help with depression.</i>	8	15.7
Generically helpful/interesting	<i>My GP thought it was a great idea.</i>	7	13.7
Can see effect of medication	<i>GP found it a useful addition to discussing the effect of medication, tracking medication related changes.</i>	6	11.8
Helpful to add to records	<i>My clinicians normally like to keep my graphs in order to scan and keep on file with my records.</i>	3	5.9

Sharing not helpful to HCPs (reported to True Colours users)

Table 3 (continued)

	Example	N	% of respondents providing feedback (n = 51)
Not expressed interest	<i>They were a bit interested but not enough to follow it up with looking at it further times.</i>	12	23.5
Specific limitations expressed	<i>They, the psychiatrist, thought the same as me it doesn't allow variations over the week and doesn't take meds into account.</i>	2	3.9
Could not understand graphs	<i>They said they don't understand what the scores represent, i.e. what score correlated with moderate depression.</i>	2	3.9

Some examples have been edited slightly to protect privacy.

HCPs = healthcare professionals, incorporating general practitioners (GP)/primary care physicians (PCP), and/or clinical/medical professionals in a psychiatric team.

family/friends' understanding of their mood symptoms (33.3 %). Participants also reported that sharing the graphs facilitated discussions with family/friends about their mood changes (24.2 %). A very small proportion of individuals reported it had not been beneficial sharing their True Colours graphs with family/friends as it did not provide them with any further information (3.0 %). Others reported they felt it made friends/family overreact (3.0 %) or that they had been dismissive when looking at the graphs (3.0 %).

The reported benefits and limitations that family/friends conveyed to participants were coded into eight categories (six benefits and two limitations). 95.2 % of reported comments were coded into a single category (40/42), and 4.8 % (2/42) were coded into two categories. It was reported by participants that family/friends said the graphs helped them to understand how the individual was currently feeling and explained their behaviours (28.6 %), and to see mood changes over time (26.2 %), for example, by observing particular patterns. Participants also reported that family members had said they found True Colours confirmed their own observations of the participant's mood (11.9 %), helped them gain a greater understanding of bipolar disorder (11.9 %), acted as a helpful objective measurement (7.1 %) and was helpful in understanding their own mood changes (7.1 %). A smaller number of participants reported that although family/friends expressed an interest in the graphs, they had mentioned the helpfulness was limited (9.5 %) and that others reported they found the graphs difficult to interpret (2.4 %).

Although not specifically asked about, a number of participants added comments to explain why they had decided not to share their graphs with family and friends. These included individuals commenting that they felt their records were personal and private, for example, "Wouldn't feel right, I don't think. Bit personal", "It is personal to me and I therefore don't wish to share it". Other comments mentioned that they thought family/friends would not be interested or that they could not see the benefit of doing so, for example, "My husband wouldn't be interested, my family and friends in general are not very into stats and graphs etc. I would never think of showing them".

4. Discussion

Technology is becoming an increasingly important aspect of mood monitoring for longitudinal research, self-management and clinical management in BSD. Feedback from users with BSD is vital to the ongoing development and success of digital mood monitoring tools. Our study explored the experiences of 362 individuals with BSD engaged in online remote mood monitoring in a research setting over a median duration of 2 years.

The majority of individuals completing the survey reported that they found their overall experience of using True Colours and looking at their

Table 4
Experiences of sharing True Colours remote self-mood monitoring graphs with family and friends: categories according to frequency of individuals providing feedback.

	Example	N	% of respondents providing feedback (n = 33)
<i>Perceived benefits to True Colours users</i>			
Show others how currently feeling	<i>Sometimes it's just easier to show the graph to my family rather than trying to explain how I feel.</i>	11	33.3
Explain mood symptoms to others so they have better understanding	<i>They appreciated the association of pattern with behaviour. Made me feel more understood.</i>	11	33.3
Facilitates discussions with others	<i>My partner and I use the graphs to look back at the prior week and attempt to identify any reasons for the changes in my mood.</i>	8	24.2
<i>Perceived limitations to True Colours users</i>			
Does not provide others with any further information	<i>The people closest to me know anyway how up and down I am. The graph was no surprise to them.</i>	1	3.0
Others overreact	<i>I find my partner worries too much about me and over reacts.</i>	1	3.0
Dismissive comments from others looking at graphs	<i>The friend I showed them to said 'we all have ups and downs. You could get a similar result from anyone'.</i>	1	3.0
	Example	N	% of respondents providing feedback (n = 42)
<i>Reported benefits perceived by family and friends (reported to True Colours users)</i>			
Helpful to understand how participant is currently feeling or explain current behaviours	<i>They could see that my behaviour was reflected the mood graph.</i>	12	28.6
Helpful for themselves to spot early signs, patterns and triggers over time	<i>My partner is very aware of day to day changes, and the graph gives a more long-term perspective.</i>	11	26.2
Objective confirmation their observations	<i>Often confirms their opinion of how my mood is.</i>	5	11.9
Gain greater understanding in general of bipolar disorder	<i>Just very helpful as to understanding the illness.</i>	5	11.9
Useful objective measurement	<i>My partner finds it gives him an objective measure of how I'm doing.</i>	3	7.1
Helpful to understand their own mood	<i>A family member suffers from occasional mood swings and I have shared my graphs with them.</i>	3	7.1
<i>Sharing not helpful to family and friends (reported to True Colours users)</i>			
Interested but limited helpfulness	<i>They look at the graph, understand what the graph means but find it hard to relate the graph to me personally.</i>	4	9.5
Others found hard to interpret	<i>Some of my friends find the graphs difficult to understand.</i>	1	2.4

Some examples have been edited slightly to protect privacy.

mood graphs helpful. These findings are consistent with previous literature which has found largely positive views from individuals with BSD about using, or potentially using, online tools to monitor their mood (Daus et al., 2018; Nicholas et al., 2017; Saunders et al., 2017). Benefits reported by our participants related to gaining an increased understanding and self-awareness of their BSD, particularly by helping to spot specific triggers and/or patterns of mood disruption and identifying early signs of a mood episode. The regular self-reflection on mood as a result of completing the weekly questionnaires was also reported as being beneficial. These findings align with previous studies that have found mood monitoring assists with self-management and increased insight among individuals with BSD (Murnane et al., 2016; Saunders et al., 2017).

Our participants valued having a visual record of their mood changes. Within True Colours, graphs can be adjusted to view mood changes over various time periods (3 months, 1 year, all time). A recent qualitative study identifying opinions about preferences on design and technical features of online mood monitoring among individuals with bipolar I disorder and professionals reported an adjustable graphic report was an agreed key element (Geerling et al., 2021). A small proportion of participants in our study reported that they did not understand aspects of the True Colours graphs or that their presentation could be clearer, with some individuals specifically mentioning the individual symptom graphs were difficult to understand. Within True Colours there is the option to view graphs of both total weekly mood scores and individual symptom scores, and participants can choose to switch off the view of either type of graph. This flexibility in both the timeframe for viewing mood changes, and the mode of graphical representation, according to user preference may be particularly helpful in engaging participants with mood monitoring over extended periods of time.

Just over one quarter of our respondents reported that the questions asked in the weekly mood measures were not fine-tuned and/or comprehensive enough. This finding is in keeping with previous research where participants have indicated the importance of personalisation and context when participating in longitudinal mood monitoring (Geerling et al., 2021; Saunders et al., 2017; Van Til et al., 2020). Despite the fact that True Colours has the option for participants to include notes to add context and/or additional details such as medication changes, some specific comments from our respondents included the suggestion of automatic prompts being included to remind individuals to add this information at the end of each questionnaire. Similarly some individuals suggested more frequent mood measurements or the addition of specific questions, which are both already possible with the personalised questions function within True Colours (Gordon-Smith et al., 2021). Both of these additional features currently involve an additional step to set up within True Colours, and our findings indicate that some participants may have struggled with this aspect. Therefore, ensuring ease of use for individuals, particularly for those who are digitally less confident, should be a priority for future developments of digital tools for remote mood monitoring. This finding is consistent with a recent international web-based survey about the perceived importance of various features of smartphone apps among people with BSD which suggested one of the main priorities for individuals was ease of use (Morton et al., 2021). In an attempt to improve the user experience, participants in our research programme are now routinely offered help with a member of the research team to set up personalised questions in True Colours. Similarly, ongoing and rapid help is available to assist with technical problems experienced by participants, such as password problems. Sustained use of True Colours by participants over time may have been aided by this additional 'personalised' input and help, which also likely explains the relatively small proportion of survey respondents reporting technical difficulties.

A small proportion of our respondents reported that completing the True Colours questionnaires did not reveal anything new to them, with a number of individuals reporting this was because their mood had been stable for a long period of time. In research settings this may represent a

challenge, particularly for engaging participants in longer term longitudinal studies. In clinical settings this is likely to reduce the incentive for individuals to continue mood monitoring and also share this information with their HCPs. One explanation for participants continuing with True Colours despite their mood remaining stable could be that individuals were motivated by helping with research. This is supported by a proportion of respondents spontaneously commenting that this was a key motivation for engaging with True Colours. BDRN True Colours participants receive biannual newsletters specifically with news and information about how the True Colours data are currently being used in research, which also may help with sustaining use over time. Reassuringly only a small number of participants ($n = 4$) reported that completing weekly ratings about their mood reminded them of being unwell. However, the experiences of participants who did not complete the survey may have differed. When we previously examined BDRN participants' reasons for declining to join True Colours, almost 20 % reported that they were concerned that longitudinal monitoring may adversely affect their mood (Gordon-Smith et al., 2019).

Approximately one third of respondents had chosen to share their True Colours graphs with their HCPs, with the majority reporting that both they themselves and their HCP had found it helpful. Many of the additional comments made related to improved communication about current mood and past mood changes and patterns, and, to a lesser degree, aiding discussions and decisions about treatment. Specifically some participants said they felt their True Colours graphs gave a more accurate objective picture of their mood between consultations rather than relying on memory alone, which is in keeping with previous research. Analysis of the content of publicly available consumer reviews of apps for bipolar disorder revealed that 1 in 10 reviews mentioned using apps in partnership with clinical services reporting improved recall and feeling better understood during clinical appointments (Nicholas et al., 2017). Similarly, in an online survey of self-monitoring practices of individuals with BSD, two-thirds reported that self-monitoring provided ways to open and maintain lines of communication with HCPs regardless of whether their HCP had introduced them to self-monitoring or they had initiated monitoring themselves (Murnane et al., 2016).

Within our survey other participants reported that their HCPs had not expressed an interest when participants had attempted to show them their True Colours graphs, with a smaller number mentioning their HCPs highlighted specific limitations or that they did not understand the graphs. True Colours has a participant guide with a section on how to interpret the graphs which individuals are encouraged to show to HCPs if they do decide to share their information. We did not however ask individuals whether or not they had shown the guide alongside their graphs. Other participants commented that although they had not shared their graphs they had told their HCPs about using True Colours and their clinical team had been encouraging and supportive. On the other hand, some participants specifically commented that they had not considered sharing their data with HCPs and others reported they felt the clinical team was too busy to be interested. Experiences are likely to be different where mood-monitoring tools are introduced in clinical settings, for example, True Colours has been successfully implemented clinically in a specialist care centre for bipolar disorder where graphs are accessible for both individuals with bipolar disorders and their HCPs (Simon et al., 2017). With an increasing number of mood-monitoring and self-managing apps for bipolar disorder being commercially available and used more commonly in research settings the decision about whether or not to share these data with HCPs will be relevant for an increasing number of individuals with BSD. Interestingly, in a recent survey of preferences for a range of potential bipolar disorder app features fewer than half of respondents indicated that they perceived the ability of sharing information with healthcare providers as important (Morton et al., 2021). It is possible that making a personal decision and having the choice on whether or not to share electronic self-monitoring information with their HCPs may be empowering for individuals.

Perceptions about this issue are also likely to depend on the mode by which information is shared, for example, whether HCPs are given permission to access individuals' information electronically or, as in the case of BDRN True Colours, sharing relies on individuals actively showing the record of their mood ratings at clinical appointments. Further research into HCPs' perceptions of the potential benefits and limitations of individuals with BSD sharing digital mood monitoring data and integrating this information into clinical care is needed. It would be helpful to explore the perceptions and experiences of the sharing of personalised data versus objective mood measures and whether certain groups of individuals may particularly benefit from sharing mood monitoring with their HCP, for example those who are newly diagnosed or more clinically unstable, and any role this may play in the therapeutic alliance.

A similar proportion (one third) of participants in our study had decided to share their True Colours graphs with their family/friends, with more individuals reporting that they found this helpful than their friends/family had reported it to be. Sharing information with family and friends was the least endorsed preferred app feature in the recent survey of preferences for potential bipolar disorder app features by (Morton et al., 2021), with 21 % of respondents perceiving the feature as important. A number of participants in our study spontaneously commented that they decided not to share their True Colours graphs. Reasons given were that the information was personal to them and/or they did not think family members would be interested or that it would be helpful. Of those participants who had decided to share their graphs with family/friends, the main reported benefits on both sides were aiding communication in how participants were currently feeling, aiding discussion and helping others to understand their mood symptoms more including the occurrence of patterns and triggers over time. Only a small number of comments related to limitations of sharing True Colours graphs with family and friends, including that it did not provide any helpful information. Reassuringly only one participant reported a potentially detrimental consequence of sharing their True Colours graphs in that they felt it caused others to overreact. In the current study we did not collect specific information on the relationship between participants and those they chose to share their True Colours graphs with, for example, if they were family members, a partner or friends. Further exploration of the views of both participants and family/friends on sharing mood monitoring data according to these specific relationships would be helpful and may be relevant to other fields, for example, family-focused psychotherapy and stigma research.

4.1. Limitations and future directions

Our study has a number of limitations. First, participants were a subsample of the larger adult BDRN cohort in the UK, and findings may thus diverge from studies of younger people with BSD, other research samples/clinical populations, and studies based in different countries. Second, while the only statistically significant difference between participants who did and not complete the survey was that respondents were older, non-responders may have had different experiences (which could have influenced their decision to not complete the survey). Third, the majority of participants were female (67.4 %), had completed higher education (62.1 %), had a DSM-IV diagnosis of bipolar I disorder (56.1 %), had at least one past psychiatric admission (63.8 %), and had a lifetime history of suicide attempt (50.8 %), which may limit the generalisability of the results. Fourth, the relatively smaller number of participants with bipolar disorder not otherwise specified (3.6 %) and schizoaffective disorder bipolar type (1.4 %) did not enable comparisons by subgroups. Fifth, only 31.1 % of participants chose to share their True Colours graphs with HCPs and/or family/friends, and feedback from these groups was conveyed indirectly via our participants meaning there are likely to be reporting biases. Some feedback from participants indicated that they felt that their HCP would not have the time or their family/friends would not be interested in viewing the graphs. Further

studies could aim to evaluate the perceptions of HCPs and family/friends directly. Finally, the range of length of participation in the True Colours study was from 1 to 36 months (median = 28 months). Although not the focus of this paper, exploring the experiences of individuals who engaged with digital mood monitoring for a short vs. a longer period of time would perhaps give different insight into the characteristics of the participants and their related experiences.

Our findings have implications for the use of digital mood monitoring tools for BSD in both research and clinical settings particularly among individuals who may be less digitally confident. Overall we have shown high levels of satisfaction and a number of benefits among a large group of individuals with BSD using remote online mood monitoring. Personalisation and ease of use in particular are important features. From our experience, a high level of ongoing support is required to help with technical problems in the form of email correspondence and phone calls which will be relevant in both research and clinical settings. A particular challenge can arise when mood scores are stable over a prolonged period of time which may prompt individuals to stop. The implications of this will vary depending on the setting, and, within research, the particular study design. Using validated questionnaires that are sensitive to small changes in mood over time are recommended. Our findings also suggest that it may be helpful for HCPs to ask individuals who have BSD if they are involved in any forms of mood monitoring outside of the clinical setting as this may potentially open up further lines of communication.

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CRedit authorship contribution statement

KGS, KAES, NC, IJ, JG, MS & LJ designed the study, wrote the protocol and collected the data. KAES, NC, IJ, JG & LJ obtained funding. KGS, TM and LJ conducted the analysis. KGS, TM, LJ, KAES and JS were involved in interpretation of the data analysis. LJ and KGS wrote the first draft of the manuscript. All authors contributed to and approved the final manuscript.

Conflict of interest

None.

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