

# **“Have I argued with my family this week?”: What questions do those with lived experience choose to monitor their bipolar disorder?**

[Running title: Personalised self-monitoring in bipolar disorder]

Katherine Gordon-Smith<sup>1</sup>, Kate EA Saunders<sup>2,3</sup>, Julia Savage, Nick Craddock<sup>4</sup>, Ian Jones<sup>4</sup>, Lisa Jones<sup>1\*</sup>

<sup>1</sup>Psychological Medicine, University of Worcester, Henwick Grove, Worcester, WR2 6AJ, UK.

<sup>2</sup>University of Oxford Department of Psychiatry, Warneford Hospital, Oxford, OX3 7JX, UK.

<sup>3</sup>Oxford Health NHS Foundation Trust, Warneford Hospital, Oxford, OX3 7JX, UK.

<sup>4</sup>Division of Psychiatry and Clinical Neurosciences, School of Medicine, Cardiff University, Cardiff, CF24 4HQ, UK.

\* Corresponding author

Professor Lisa Jones  
University of Worcester  
Henwick Grove  
Worcester  
WR2 6AJ

Email: [lisa.jones@worc.ac.uk](mailto:lisa.jones@worc.ac.uk)  
Telephone: +44 (0)1905 54 2801

## **Highlights**

Individuals chose to monitor many aspects of bipolar disorder extending beyond mood.

The most common categories were physical activity, anxiety, sleep and coping.

The sole use of mood scales to monitor mood may lack personal meaning for patients.

Additional individualised measures may help capture changes from the patient perspective.

## Abstract

**Background** Electronic self-report mood monitoring tools for individuals with bipolar disorder (BD) are rapidly emerging and predominately employ predefined symptom-based questions. Allowing individuals to additionally choose what they monitor in relation to their BD offers the unique opportunity to capture and gain a deeper insight into patient priorities in this context.

**Methods** In addition to monitoring mood symptoms with two standardised self-rated questionnaires, 308 individuals with BD participating in the Bipolar Disorder Research Network True Colours electronic mood-monitoring tool for research chose to create and complete additional personalised questions. A content analysis approach was used to analyse the content of these questions.

**Results** 35 categories were created based on the personalised questions with the most common being physical activity and exercise, anxiety and panic, sleep and coping/stress levels. The categories were grouped into six overarching themes 1) mental health; 2) behaviour and level of functioning; 3) physical wellbeing; 4) health behaviours; 5) active self-management; and, 6) interpersonal.

**Limitations** The average age of the sample was around 50 years meaning our findings may not be generalisable to younger individuals with BD.

**Conclusions** Aspects of BD important to patients in relation to longitudinal monitoring extend well beyond mood symptoms, highlighting the limitations of solely relying on standardised questions/mood rating scales based on symptoms primarily used for diagnosis. Additional symptoms and aspects of life not necessarily useful diagnostically for BD may be more important for individuals themselves to monitor and have more meaning in capturing their own experience of changes in BD severity.

## **1. Introduction**

In recent years with advancing technologies there has been an emergence of an increasing number of electronic mood monitoring tools designed for individuals with bipolar disorder (BD). These tools include a range of different self-rated mood questionnaires and scales and predefined generic questions relating other items including medication and alcohol consumption. In BD there has been increasing recognition of the value of gaining insights from the patient perspective both clinically and in research. To date studies have used patient-centred approaches to examine the challenges of both living with and managing BD (Jönsson et al., 2008; Maassen et al., 2018; Nestsiarovich et al., 2017) as well as to further define patient-important outcomes, including quality of life (Eiring et al., 2016; Michalak et al., 2006; Morton et al., 2018). However, the scope for electronic mood monitoring to capture the patient priorities for longitudinal BD monitoring from their own perspective has not been previously explored.

We have recently reported the large-scale UK roll out of the Bipolar Disorder Research Network (BDRN) True Colours electronic mood-monitoring tool for research (Gordon-Smith et al., 2019). In response to feedback from participants in the early stages of development, BDRN participants using True Colours have the option, in addition to monitoring mood symptoms with two specific and mandatory questionnaires, to monitor self-selected aspects of BD that they perceive as important. In this context individuals are experts on their own disorder by experience. Insights from the viewpoint of a large group of individuals living with the illness into important aspects of the course of BD, over and above changes in the presence and severity of the usually monitored symptoms, can provide new knowledge and understanding and aid the tailoring of psychoeducation and self-management interventions.

The aim of the current study was therefore to explore what aspects of BD those living with the disorder choose to monitor whilst participating in ongoing mood monitoring.

## **2. Method**

### **2.1. Participants**

BDRN is an ongoing research programme into the genetic and environmental aetiology of bipolar disorder and related affective disorders. Participants are recruited throughout the UK via NHS services and advertisements through patient support organisations, such as Bipolar UK ([www.bipolaruk.org.uk](http://www.bipolaruk.org.uk)). Inclusion criteria are: (i) aged 18 years or over at participation; (ii) able to provide written informed consent; (iii) meet DSM-IV criteria (American Psychiatric Association, 2000) for BD; and (iv) onset of mood symptoms before the age of 65 years. Best-estimate lifetime diagnoses are 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 general practice (primary care) case-notes where available. The research was approved by the West Midlands NHS Research Ethics Committee (MREC/97/7/01) and all participating NHS Trusts and Health Boards. Written informed consent was obtained from all participants.

### **2.2. Mood monitoring system - True Colours**

True Colours is an online mood monitoring system developed at the University of Oxford for clinical use in BD as well as other conditions (Goodday et al., 2020). A standalone BDRN version of True Colours was later developed for the primary purpose of research with remote participants. 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.

Over 1000 BDRN participants have now joined True Colours. For further details about the roll out of BDRN True Colours including uptake rates and length of engagement see Gordon-Smith et al. (2019).

### **2.3. True Colours personalised questions**

An option for participants to create and complete personalised questions in addition to the QIDS and AMS questions was introduced into BDRN True Colours following feedback from early participants that the mood questionnaires alone were not capturing fully their experiences of living with BD. Participants can choose up to 10 questions to answer daily, and up to 10 to answer weekly. They decide exactly what time, and which day for weekly questions, they will receive the email prompt to answer the question(s). Participants can select questions from a list of optional pre-set questions and/or they can create their own bespoke question(s).

BDRN True Colours contains 19 optional pre-set questions, arranged into 11 categories: i) anxiety & panic, ii) physical activity & exercise, iii) sleep, iv) coping, v) mood instability, vi) alcohol and drug use, vii) menstrual cycle, viii) medications, ix) migraine, x) smoking, and xi) gambling. The pre-set questions were created based on feedback from participants

regarding what they felt was important and not captured by the weekly mood questionnaires in addition to those addressing the specific research interests of the BDRN research group.

Bespoke questions that individuals create themselves can use one of six response types: i) a 'yes/no' response, ii) a time of day response (e.g., 'what time did I get out of bed this morning?'), iii) agreement on a scale of 0 to 4, iv) agreement on a scale of 0 to 10, v) agreement on a scale of 0 to 100, or vi) any number.

Participants add pre-set and bespoke personalised questions by means of a user-friendly interface with an online help guide, and assistance is available from the research group by telephone and email if required. Each participant's responses to their personalised questions are plotted on separate graphs below their mood graphs, with the facility for participants to directly match up dates across graphs and view their responses to all questions across any particular time period (see Figure 1).

FIGURE 1 HERE

## **2.4 Data analysis**

A qualitative content analysis approach (Elo and Kyngäs, 2008) was used as follows:

### *i) Analysis of the content of bespoke personalised questions*

KGS read and re-read all bespoke questions as open-mindedly as possible and created an initial coding scheme of categories which acted as a guide. This initial coding scheme incorporated the 11 categories relating to the pre-set optional questions. In an initial round of analysis KGS coded each question individually, creating new categories where the content of

a question could not be categorised according to the initial coding scheme. A category was also created for uncodeable questions where the meaning of the content could not be interpreted. To capture the interpreted meaning, questions could be coded into more than one category. The coding of each question was checked for agreement by LJ. Different interpretations of the meaning of specific questions 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 of 35 categories, 11 relating to the pre-set question categories and 24 developed from the bespoke questions. KGS re-read all the questions again 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, which included an expert by experience of BD.

*ii) Frequencies of individuals asking pre-set and/or bespoke questions according to category type*

For each of the 35 categories the number of participants asking a question (pre-set or bespoke) with content coded in that category was counted. Participants were only counted once in each category, for example, if a participant had selected a pre-set question about sleep and created an additional bespoke question about their sleep they were only counted in the sleep category once. Similarly, if a participant had created two or more bespoke questions that were coded in the same category, the participant was only counted in that category once.

*iii) Overarching themes*

Categories were grouped into six overarching themes initially by KGS. These overarching themes were refined and developed following discussion with all authors. The total number



of individuals asking themselves questions in each overarching theme was counted with individuals being counted in each overarching theme no more than once.

### **3 Results**

#### **3.1 Sample**

308 of 1080 BDRN True Colours participants (29%) selected at least one pre-set optional question (n=247) and/or created at least one bespoke personalised question (n=189) between July 2015 and May 2018. The sample of 308 individuals is described in Table 1. 71% were female with a mean age of 50 years (SD, 11.5; range, 21-81). The majority had a best-estimate main lifetime DSM-IV diagnosis of bipolar I disorder (BDI; 54.5%) or bipolar II disorder (BDII; 40.6%), with the remaining minority having schizoaffective disorder bipolar type (1.3%) or BD not otherwise specified (3.6%). Mean age of onset of BD was 21 years and the mean lifetime number of episodes of depression and (hypo)mania were 18 and 15 respectively. 61% had at least one past psychiatric admission and 50% had experienced psychotic symptoms. For the majority of lifetime demographic and clinical characteristics, individuals opting to select personalised questions did not significantly differ from those who did not. The only significant differences were that those selecting personalised questions were younger both at the time of using True Colours (50 vs. 52 years,  $p=0.010$ ) and at age of onset of bipolar disorder (21 vs. 22 years,  $p=0.037$ ).

TABLE 1 HERE

#### **3.2 Categories of questions - examples and frequencies**

927 bespoke personalised questions were created by 189 participants. 30 bespoke questions created by 22 participants were uncodeable. For the remaining questions, in most cases a

single question was coded in one category ( $781/897=87\%$ ), a smaller number of questions were coded into two ( $106/897=12\%$ ) and three categories ( $10/897=1\%$ ) as shown in Table 2.

The frequencies and percentages of individuals asking at least one pre-set or bespoke question with content coded into each of the 35 categories are presented in Table 2, along with an example of a pre-set and bespoke question exemplifying each category (note that bespoke question examples may be an amalgamation of two or more questions to protect privacy and avoid participants' questions being quoted verbatim). An example of a question that could not be coded, due to the meaning of the content being unclear, was "did something happen this week?".

The most common categories that participants chose to ask themselves about were: 1) physical activity and exercise ( $n=147, 48\%$ ); 2) anxiety and panic ( $n=147, 48\%$ ); 3) sleep ( $n=139, 45\%$ ); 4) coping/stress levels ( $n=112, 36\%$ ); and, 5) mood instability ( $n=82, 27\%$ ). These were all categories that contained pre-set questions, and the majority of participants chose to use a pre-set question with a smaller number creating their own bespoke question. For example, of the 147 participants choosing to ask themselves about physical activity, 118 used the pre-set questions and an additional 29 created a bespoke question (see Table 2).

Of the categories that emerged from the bespoke questions alone, the most common were: 1) anger/irritability ( $n=38, 12\%$ ); 2) cognitions ( $n=37, 12\%$ ); 3) physical symptoms/physical health ( $n=34, 11\%$ ); and, 4) mood monitoring ( $n=33, 11\%$ ). Bespoke questions relating to mood monitoring used a range of different general terms including depression, low mood, feeling flat, very down, manic, high, hyper.

TABLE 2 HERE

### **3.3 Overarching themes emerging from categories**

34 of the 35 categories were grouped into the following six overarching themes (one category relating to a single question asked by one participant about a comorbid developmental condition was not included in any of the overarching themes): 1) mental health; 2) behaviour and level of functioning; 3) physical wellbeing; 4) health behaviours; 5) active self-management; and, 6) interpersonal. These are represented, along with the categories included in each overarching theme, in Figure 2. The category sleep was included under and counted in three overarching themes (active self-management, health behaviours, and mental health) and libido and energy levels were both included and counted in two categories (physical wellbeing and mental health).

FIGURE 2 HERE

#### *Mental health (n=261)*

This theme related to questions about mood and mood instability in addition to mental health symptoms more widely including anxiety and panic, psychosis and psychotic like experiences, suicidal thoughts and self-harm. Included in this theme were categories about mental health more broadly in terms of levels of stress, ability to cope, tearfulness, levels of anger/irritability, impulsivity, specific thoughts and feelings (such as obsessive or negative thoughts, feelings of optimism and confidence), and memory and concentration.

#### *Behaviour and level of functioning (n=67)*

This theme related to individuals monitoring behaviours and functioning including questions about whether or not they left the house, were able to work, spending/finances, gambling and

other behaviours including listening to music and sending text and/or other messages.

Questions related to spending were frequently in the context of impulsive spending.

Questions in this theme also related to creative activities such as art and writing, and daily functions/motivations including completing housework and other tasks and personal care.

#### *Active self-management (n=169)*

This theme included questions about monitoring aspects of daily living relating to how individuals manage their BD including medication use and contact with healthcare professionals, in addition to specifically asking about the presence of particular triggers and participation in well-being activities for the purpose of BD management/coping such as gardening and meditation.

#### *Physical wellbeing (n=114)*

This theme included aspects of physical wellbeing including energy levels and libido (which overlapped with the theme related to mental health monitoring), as well as more specific physical health questions relating to, for example, the menstrual cycle, physical pain levels, and migraine/headaches and other physical health conditions.

#### *Health behaviours (n=229)*

This theme included questions about physical activity and exercise, tobacco smoking, and use of alcohol, non-prescription drugs and caffeine. Also included in this theme were questions relating to weight and eating habits in terms of types of foods eaten, regularity of meals and over/comfort eating.

#### *Interpersonal (n=43)*

Included in this theme were questions about social contact or isolation including about the occurrence of recent social contacts with friends and family, feelings of isolation/loneliness, and specific interactions with other people such as disagreements.

## **4 Discussion**

BDRN True Colours has offered a unique opportunity to explore what aspects of BD a large group of individuals living with BD perceive as important to monitor longitudinally over and above the core BD symptoms assessed in standardised high and low mood scales. We are not aware of any previous published research in BD or any other illness that is directly comparable to ours in analysing the content of personalised self-monitoring questions used outside of a clinical setting.

A strength of this study is that each individual's personalised questions were selected by them based on their own personal context and real time experiences. Importantly our findings reveal that aspects of the disorder important to patients extend well beyond mood symptoms. Participants chose to monitor much broader aspects of mental health, active self-management techniques (identifying personal triggers and developing coping strategies), various behaviours and level of general functioning, quality of interpersonal relationships, social contact with others, health behaviours and physical well-being. This highlights the limitations of the use of self-rated mood rating scales to monitor ongoing changes in BD. Rating scales are based on diagnostic symptoms and as a result may be impersonal and have the potential to lack clinical meaning to individuals themselves. Other non-specific symptoms and aspects of life, not necessarily useful diagnostically for BD, may be more important for individuals themselves to monitor and have more meaning in capturing their own experience of changes in BD severity. Even if rating scales include symptoms and aspects of life that individuals

find helpful to measure, the questions/items may not use terms/language that individuals themselves would use. The items in mood rating scales are often negatively worded to elicit the presence of specific negative aspects of mood whereas in our sample participants' bespoke questions included those measuring the occurrence of positive aspects such as engaging in creative and enjoyable activities.

Our findings are in agreement with a prospective study in patients with depression in primary care in the UK which compared changes in scores on self-administered depression questionnaires with patients' perceptions of changes in their mood (Hobbs et al., 2020). The study found evidence that changes in scores on these measures often differ from patients' own views of changes in their mood highlighting the limitations of mood scales to assess clinical change and the need for additional assessments that take into account the perspective of the patient.

Gaining a greater understanding about monitoring BD from the perspective of the patient can also help clinicians to become more aware of the challenges and issues that patients may wish to discuss in relation to their BD that may otherwise not be raised in routine clinical interactions and thus enhance lines of communication. Such discussions and a shift from the traditional focus on the management of mood symptoms to broader discussions about lifestyle, interpersonal relationships, and functioning levels may help align the expectations and goals of clinicians and patients in the clinical setting. Furthermore, symptom monitoring is a central component of many BD self-management programmes and our findings highlight the benefit of ensuring these tools offer the facility for individuals to personalise what is monitored in addition to the standard questions about mood symptoms which may also help with engagement. Two of the most common categories of questions that participants in our

sample chose to ask themselves about, sleep and physical activity, also have the scope to be remotely objectively monitored via wearable technologies. The incorporation of wearables into self-management programmes has become rapidly more feasible (Gillett and Saunders, 2019) and shown to be well accepted and tolerated by individuals with BD (Saunders et al., 2017).

Interestingly, whilst actively taking part in weekly mood symptom monitoring, over a quarter of individuals in our sample selected to ask themselves additional questions about more rapid changes in mood. Mood instability (or affective lability) is a prominent feature of BD with euthymic individuals reporting a higher affective lability than healthy controls (Henry et al., 2008). In a recent study of individuals using a smartphone-based self-monitoring system, mood instability in BD was associated with increased perceived stress and decreased quality of life and functioning even during full or partial remission (Faurholt-Jepsen et al., 2019). Previous work has also shown mood instability to be associated with long term functional recovery (Strejilevich et al., 2013). Thus our findings add to the existing literature and highlight the importance of clinicians exploring this aspect of BD, its impact on daily living with patients and potential use as an indicator of functioning and the efficacy of ongoing treatments.

Our findings are also in agreement with an online survey of self-monitoring strategies used by individuals with BD, which found that in addition to mood, sleep, finances, exercise and social interactions, individuals reported tracking various other areas relevant to their BD including, medication, personal triggers, caffeine and alcohol intake, pain levels and the structure of daily behaviours such as leisure time (Murnane et al., 2016). These reports were based on a single open-ended survey question, which formed part of a wider survey about

self-monitoring practices in BD. Our analyses provide more fine-grained examples of what individuals with BD actually choose to monitor in relation to their mood. The advantage of analysing personalised self-monitoring questions created in real-time by individuals with BD is the reduction of potential biases such as recall and social desirability inherent in retrospective surveys. For example, over a fifth of individuals in our sample created additional questions to monitor their anger/irritability. Another uniquely designed study, which reviewed the content of publicly available consumer reviews of apps for BD, revealed one of the five major themes was additional ‘wishlist’ features including the request for tracking options including sleep, medication, diet, mood triggers, exercise, anxiety and substance use (Nicholas et al., 2017).

A number of aspects of BD chosen to be monitored by individuals in our sample relate to domains of quality of life (QoL). In BD the broad construct of QoL represents aspects of functioning and satisfaction in occupational, environmental, psychological, physical and social aspects of life (Morton et al., 2017). The findings of a recent qualitative study exploring the experience of engaging with a QoL self-monitoring tool in BD among 43 individuals found a predominant experience was the value of tracking the breadth of life domains assessed by the tool (Morton et al., 2018). This is complemented by our finding that questions created by participants in our sample fell into 35 separate categories. The authors highlighted that some participants expressed a need for additional features to the QoL tool suggesting a need for lived experience in the development in future developments of online QoL monitoring (Morton et al., 2018). Our findings based on the questions created in a naturalistic setting by a large sample of individuals actively taking part in mood monitoring could therefore help inform further QoL measures.



## **Limitations and future directions**

Our sample comprised of a large number of individuals with BD with the opportunity to choose to measure any aspects of living with BD that were important to them whilst participating in ongoing online mood monitoring. Individuals were aware that their questions and responses were not being monitored clinically which may have shaped the content of the personalised questions. However, this could mean that individuals felt less restricted in what they choose to monitor in terms of their own personal experiences. As anticipated, participants more frequently chose pre-set optional questions than created their own bespoke questions. This may be because the pre-set questions were based on feedback from early participants about what was not being captured by the mood questionnaires alone, and that participants found it more convenient and simple to select pre-set questions than create their own. Interestingly two thirds of the True Colours participants chose not to select additional personalised questions. These individuals did not significantly differ from individuals opting to ask themselves personalised questions on the majority of demographic and lifetime clinical characteristics, though were slightly but significantly older (52 v 50 years old), suggesting other factors are likely to have played a role. For example, individuals may have different degrees of digital confidence, particularly in navigating around the True Colours system over and above completing their weekly mood ratings, which may be reflected in the age difference. It may also indicate differences in motivations for using True Colours, with a proportion of participants' main motivation being to provide data for research rather than using True Colours as a self-monitoring tool. Future research will examine participants' motivations for using True Colours. The average age of the sample was around 50 years, the benefit of which is that individuals had a number of years lived experience of BD on which to base their personalised questions but does mean that our findings may not be generalisable to younger individuals with BD.

The breadth and number of bespoke questions created by individuals in our sample to monitor various domains of living with BD highlights the limitations of solely relying on standardised questions/mood rating scales in measuring changes in mood overtime in BD. Such items and scales are based on symptoms primarily used for diagnosis and other additional symptoms aspects are important. To be the most clinically meaningful for individuals with BD there is the need for the introduction of individualised measures alongside the use of standardised rating scales to capture changes over time from the perspective of individuals themselves. Future research into the relationships between longitudinally measured patient priority aspects of BD, mood symptoms and long-term outcomes are warranted. These findings may aid the development of clinically effective real-time online personalised self-management tools.

### **Contributors**

KGS, KAES, NC, IJ & LJ designed the study, wrote the protocol and collected the data. KGS and LJ conducted the analysis. All authors 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.

### **Role of the funding source**

This research was funded by a Wellcome Trust strategic award (102616/Z). True Colours and KEAS received support from the National Institute for Health Research (NIHR) Oxford Health Biomedical Research Centre. The views expressed are those of the authors and not those of the NHS or NIHR. The funders had no role in study design; in the collection,

analysis and interpretation of data; in the writing of the manuscript; or in the decision to submit the manuscript for publication.

### **Acknowledgements**

We would like to thank all our BDRN True Colours participants for their ongoing support.

### **Declarations of Interest**

Conflicts of interest: none

## References

- Altman, E.G., Hedeker, D., Peterson, J.L., Davis, J.M., 1997. The altman self-rating Mania scale. *Biol. Psychiatry* 42, 948–955. [https://doi.org/10.1016/S0006-3223\(96\)00548-3](https://doi.org/10.1016/S0006-3223(96)00548-3)
- American Psychiatric Association, 2000. *Diagnostic and Statistical Manual of Mental Disorders*, 4th Edition, Text Revision (DSM-IV-TR).
- Eiring, Ø., Nylenna, M., Nytrøen, K., 2016. Patient-Important Outcomes in the Long-Term Treatment of Bipolar Disorder: A Mixed-Methods Approach Investigating Relative Preferences and a Proposed Taxonomy. *Patient* 9, 91–102. <https://doi.org/10.1007/s40271-015-0128-x>
- Elo, S., Kyngäs, H., 2008. The qualitative content analysis process. *J. Adv. Nurs.* 62, 107–115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- Faurholt-Jepsen, M., Frost, M., Busk, J., Christensen, E.M., Bardram, J.E., Vinberg, M., Kessing, L.V., 2019. Is smartphone-based mood instability associated with stress, quality of life, and functioning in bipolar disorder? *Bipolar Disord.* 21, 611–620. <https://doi.org/10.1111/bdi.12796>
- Gillett, G., Saunders, K.E.A., 2019. Remote Monitoring for Understanding Mechanisms and Prediction in Psychiatry. *Curr. Behav. Neurosci. Reports* 6, 51–56. <https://doi.org/10.1007/s40473-019-00176-3>
- Goodday, S.M., Atkinson, L., Goodwin, G., Saunders, K., South, M., Mackay, C., Denis, M., Hinds, C., Attenburrow, M.J., Davies, J., Welch, J., Stevens, W., Mansfield, K., Suvilehto, J., Geddes, J., 2020. The True Colours Remote Symptom Monitoring System: A Decade of Evolution. *J. Med. Internet Res.* 22, e15188. <https://doi.org/10.2196/15188>
- Gordon-Smith, K., Saunders, K., Geddes, J.R., Harrison, P.J., Hinds, C., Craddock, N., Jones, I., Jones, L., 2019. Large-scale roll out of electronic longitudinal mood-monitoring for research in affective disorders: Report from the UK bipolar disorder research network. *J.*

- Affect. Disord. 246, 789–793. <https://doi.org/10.1016/j.jad.2018.12.099>
- Henry, C., Van den Bulke, D., Bellivier, F., Roy, I., Swendsen, J., M'Baïlara, K., Siever, L.J., Leboyer, M., 2008. Affective lability and affect intensity as core dimensions of bipolar disorders during euthymic period. *Psychiatry Res.* 159, 1–6. <https://doi.org/10.1016/j.psychres.2005.11.016>
- Hobbs, C., Lewis, Gemma, Dowrick, C., Kounali, D., Peters, T.J., Lewis, Glyn, 2020. Comparison between self-administered depression questionnaires and patients' own views of changes in their mood: A prospective cohort study in primary care. *Psychol. Med.* 1–8. <https://doi.org/10.1017/S0033291719003878>
- Jönsson, P.D., Wijk, H., Skärsäter, I., Danielson, E., 2008. Persons Living With Bipolar Disorder—Their View Of The Illness And The Future. *Issues Ment. Health Nurs.* 29, 1217–1236. <https://doi.org/10.1080/01612840802370764>
- Maassen, E.F., Regeer, B.J., Regeer, E.J., Bunders, J.F.G., Kupka, R.W., 2018. The challenges of living with bipolar disorder: a qualitative study of the implications for health care and research. *Int. J. Bipolar Disord.* 6, 23. <https://doi.org/10.1186/s40345-018-0131-y>
- Michalak, E.E., Yatham, L.N., Kolesar, S., Lam, R.W., 2006. Bipolar disorder and quality of life: A patient-centered perspective. *Qual. Life Res.* <https://doi.org/10.1007/s11136-005-0376-7>
- Morton, E., Michalak, E., Hole, R., Buzwell, S., Murray, G., 2018. The 'new normal': relativity of quality of life judgments in individuals with bipolar disorder—a qualitative study. *Qual. Life Res.* 27, 1493–1500. <https://doi.org/10.1007/s11136-018-1811-x>
- Morton, E., Michalak, E.E., Murray, G., 2017. What does quality of life refer to in bipolar disorders research? A systematic review of the construct's definition, usage and measurement. *J. Affect. Disord.* <https://doi.org/10.1016/j.jad.2017.01.026>

- Murnane, E.L., Cosley, D., Chang, P., Guha, S., Frank, E., Gay, G., Matthews, M., 2016. Self-monitoring practices, attitudes, and needs of individuals with bipolar disorder: Implications for the design of technologies to manage mental health. *J. Am. Med. Informatics Assoc.* 23, 477–484. <https://doi.org/10.1093/jamia/ocv165>
- Nestsiarovich, A., Hurwitz, N.G., Nelson, S.J., Crisanti, A.S., Kerner, B., Kuntz, M.J., Smith, A.N., Volesky, E., Schroeter, Q.L., DeShaw, J.L., Young, S.S., Obenchain, R.L., Krall, R.L., Jordan, K., Fawcett, J., Tohen, M., Perkins, D.J., Lambert, C.G., 2017. Systemic challenges in bipolar disorder management: A patient-centered approach. *Bipolar Disord.* 19, 676–688. <https://doi.org/10.1111/bdi.12547>
- Nicholas, J., Fogarty, A.S., Boydell, K., Christensen, H., 2017. The reviews are in: A qualitative content analysis of consumer perspectives on apps for bipolar disorder. *J. Med. Internet Res.* <https://doi.org/10.2196/jmir.7273>
- Rush, A.J., Trivedi, M.H., Ibrahim, H.M., Carmody, T.J., Arnow, B., Klein, D.N., Markowitz, J.C., Ninan, P.T., Kornstein, S., Manber, R., Thase, M.E., Kocsis, J.H., Keller, M.B., 2003. The 16-Item quick inventory of depressive symptomatology (QIDS), clinician rating (QIDS-C), and self-report (QIDS-SR): a psychometric evaluation in patients with chronic major depression. *Biol. Psychiatry* 54, 573–583. [https://doi.org/10.1016/S0006-3223\(02\)01866-8](https://doi.org/10.1016/S0006-3223(02)01866-8)
- Saunders, K.E.A., Bilderbeck, A.C., Panchal, P., Atkinson, L.Z., Geddes, J.R., Goodwin, G.M., 2017. Experiences of remote mood and activity monitoring in bipolar disorder: A qualitative study. *Eur. Psychiatry* 41, 115–121. <https://doi.org/10.1016/j.eurpsy.2016.11.005>
- Strejilevich, S.A., Martino, D.J., Murru, A., Teitelbaum, J., Fassi, G., Marengo, E., Igoa, A., Colom, F., 2013. Mood instability and functional recovery in bipolar disorders. *Acta Psychiatr. Scand.* 128, 194–202. <https://doi.org/10.1111/acps.12065>

Wing, J.K., Babor, T., Brugha, T., Burke, J., Cooper, J.E., Giel, R., Jablenski, A., Regier, D., Sartorius, N., 1990. SCAN. Schedules for Clinical Assessment in Neuropsychiatry. Arch. Gen. Psychiatry 47, 589–93.

**Table 1 Demographic and lifetime clinical characteristics of sample (n=308)**

<i>Demographic variables</i>	
Female <i>n</i> (%)	220 (71.4)
Current age, years: mean (SD)	49.9 (11.5)
Completed higher education <i>n</i> (%)	153/274* (55.8)
<i>Lifetime clinical characteristics</i>	
Bipolar I disorder <i>n</i> (%)	168 (54.5)
Bipolar II disorder <i>n</i> (%)	125 (40.6)
Schizoaffective disorder bipolar type <i>n</i> (%)	4 (1.3)
Bipolar disorder not otherwise specified <i>n</i> (%)	11 (3.6)
Age at illness onset, years: mean (SD)	20.8 (8.5)
Number of episodes of depression mean (SD)	18 (23.2)
Number of episodes of hypo(mania) mean (SD)	15.3 (29.2)
Psychiatric admission <i>n</i> (%)	178/293* (60.8)
Psychotic symptoms present <i>n</i> (%)	127/253* (50.2)
*Totals vary due to unknown information.	



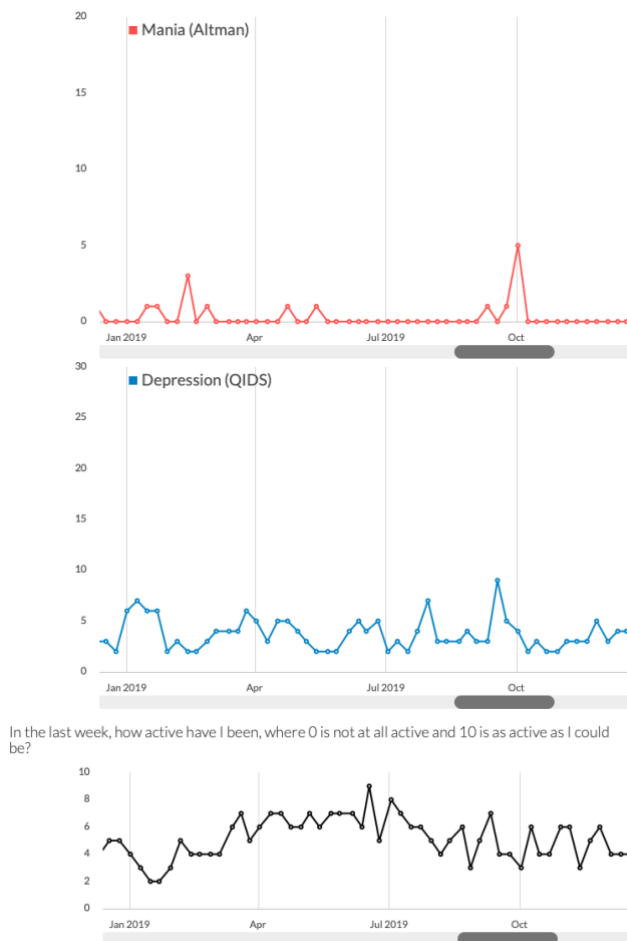
**Table 2 Frequencies of individuals asking personalised questions within BDRN True Colours according to category type**

Category	Example pre-set question	Example bespoke question*	<i>n</i> <sup>†</sup> (pre-set+bespoke <sup>‡</sup> )	% of total sample (n=308)
<i>Categories which include pre-set questions</i>				
Physical activity & exercise	In the last week, how active have I been, where 0 is not at all active and 10 is as active as I could be?	On how many days during the past week did I do a minimum of 30 minutes exercise?	147 (118+29)	47.7
Anxiety & panic	In the last week how many panic attacks did I have?	Did I get palpitations and feel anxious this week?	147 (130+17)	47.7
Sleep	During the past week, at what time did I typically go to bed?	How many times this week did I have a daytime nap?	139 (114+25)	45.1
Coping/stress levels	To what extent do I agree or disagree with the statement 'In the last week, I felt overwhelmed by life'	How many days this week did I overall feel relaxed and calm?	112 (94+18)	36.4
Mood instability	In the last week on how many days did I have rapid and intense changes in my mood that I had difficulty controlling?	On how many days this week did I have severe mood swings	82 (71+11)	26.6
Alcohol/drugs/caffeine	During the past week, how many alcoholic drinks did I have on a typical day?	How many joints did I have during the week?	64 (52+12)	20.8
Medication	During the past week, how much of the time have I taken my mood disorder medications as prescribed?	What dosage of Olanzapine have I been taking in the past week?	60 (38+22)	19.5
Menstrual cycle	In the last week how many days was I on my period (menstrual cycle)?	Over the last week have I experienced PMT symptoms?	58 (52+6)	18.8 (25% of women)

Category	Example pre-set question	Example bespoke question*	<i>n</i> <sup>†</sup> (pre-set+bespoke <sup>‡</sup> )	% of total sample (n=308)
Migraine/headache	During the past week, how many migraines did I have?	How frequent have my headaches been this week from a scale of 0 (none) to 10 (all the time)?	32 (25+7)	10.4
Smoking	During the past week, how many cigarettes did I smoke on a typical day?	No example as <i>n</i> =1	22 (21+1)	7.1
Gambling	In the last week how many pounds did I spend on gambling (not taking into account winnings)?	No example as <i>n</i> =1	2 (1+1)	0.6
<i>Categories which do not include pre-set questions</i>				
Anger/irritability		This week how many anger outbursts have I had?	38	12.3
Cognitions		On a scale of 0-4 how easy was it making decisions over the past week?	37	12.0
Physical symptoms/physical health		How severe has my pain been on a scale of 1-10?	34	11.0
Mood monitoring		This week has my mood generally felt dark? (yes/no)	33	10.7
Diet and weight		On how many days did I eat a proper meal last week?	29	9.4
Interactions with others		How many times have I had a significant disagreement with my wife this week?	28	9.1
Daily functioning and motivation		Have I had a shower on 4 or more days this week?	27	8.8
Behaviour monitoring		Have I not been answering texts?	24	7.8
Social contact or isolation		How many times have I seen a friend this week?	23	7.5
Finances		How many £ have I spent this week? <sup>§</sup>	20	6.5
Coping strategies/wellbeing activities		Did I do any activities that I enjoy this week	18	5.8
Impulsivity		Have I bought something over £10 that I didn't need on every day this week? <sup>¶</sup>	17	5.5
Tearfulness		How many times have I cried this week?	14	4.5
Leaving the house		How many days last week did I go out of the house?	13	4.2
Work		Did I go to work every day this week?	13	4.2

Category	Example pre-set question	Example bespoke question*	<i>n</i> <sup>†</sup> (pre-set+bespoke <sup>‡</sup> )	% of total sample ( <i>n</i> =308)
Creativity		How much time have I spent playing my guitar this week?	11	3.6
Psychosis/psychotic like experiences		During the past week, how often did I feel paranoid?	11	3.6
Suicidal thoughts and/or self-harm		How many days did I think about self-harm this week?	11	3.6
Energy levels		How were my energy levels this week on a scale of 0-10?	9	2.9
Libido		On how many days have I felt sexual this week?	9	2.9
Contact with healthcare professionals		Did I see my psychologist last week?	5	1.6
Response to external triggers		Were there any work related triggers this week?	5	1.6
Mixed mood		Did I have a mixed mood episode this week?	3	1.0
Comorbid conditions		No example as <i>n</i> =1	1	0.3
<p>*Example may be an amalgamation of two or more questions to protect privacy; †Participants are only counted in each category type once; ‡if an individual selected a pre-set and bespoke question in the same category they are counted in the pre-set; § question content also coded in category <i>behaviour monitoring</i>; ¶ question content also coded in category <i>finance</i>.</p>				

**Figure 1. Example of a participant's True Colours mood graphs (Altman Self-Rating Mania Scale (Altman) and Quick Inventory of Depressive Symptomatology (QIDS)) with responses to their personalised question about activity levels plotted below.**



**Figure 2. Representation of categories and overarching themes of the content of personalised questions by participants using BDRN True Colours**

\*Category incorporates optional pre-set questions. Thicker lines represent a higher frequency of participants asking questions with content relating to the category. The category Sleep contributed to three overarching themes (active self-management, health behaviours, and mental health), and the categories Libido and Energy Levels contributed to two overarching themes (physical wellbeing and mental health).

