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Large-scale roll out of electronic longitudinal mood-monitoring for research in affective disorders: Report from the UK bipolar disorder research network

Katherine Gordon-Smith a, Kate Saunders b, John R Geddes b, Paul J Harrison b, Chris Hinds b, Nick Craddock c, Ian Jones c, Lisa Jones a,

a Psychological Medicine, University of Worcester, Henwick Grove, Worcester, WR2 6AJ, UK
b Department of Psychiatry, University of Oxford, UK and Oxford Health NHS Foundation Trust, Warneford Hospital, Oxford, UK
c National Centre for Mental Health, Cardiff University, UK

ABSTRACT

Background: Electronic longitudinal mood monitoring has been shown to be acceptable to patients with affective disorders within clinical settings, but its use in large-scale research has not yet been established.

Methods: Using both postal and email invitations, we invited 4080 past research participants with affective disorders who were recruited into the Bipolar Disorder Research Network (BDRN) over a 10 year period to participate in online weekly mood monitoring. In addition, since January 2015 we have invited all newly recruited BDRN research participants to participate in mood monitoring at the point they were recruited into BDRN.

Results: Online mood monitoring uptake among past participants was 20%, and among new participants to date was 46% with participants recruited over the last year most likely to register (61%). More than 90% mood monitoring participants engaged for at least one month, with mean engagement period greater than one year (58 weeks) and maximum engagement for longer than three years (165 weeks). There were no significant differences in the proportion of past and new BDRN participants providing data for at least 4 weeks (91%, 92% respectively), 3 months (78%, 82%), 6 months (65%, 54%) or one year (51%, 44%).

Limitations: Our experiences with recruiting participants for electronic prospective mood monitoring may not necessarily generalise fully to research situations that are very different from those we describe.

Conclusions: Large-scale electronic longitudinal mood monitoring in affective disorders for research purposes is feasible with uptake highest among newly recruited participants.

1. Introduction

Clinical assessment of the subjective experience of mood symptoms in individuals with affective disorders has traditionally relied on retrospective techniques, whereby patients are asked to recall their experience of the presence/absence, severity and fluctuation of mood symptoms often weeks or months later. For researchers

attempting to measure lifetime course of affective illness, semi structured interviews are mainly used which require participants to try to accurately remember mood episodes and symptoms that may have occurred many years previously. Such methods pose a significant risk of unreliable and biased recall and are thus limited in their ability to accurately identify long-term patterns of mood variability. The emergence of new technologies has led to vast improvements in the methods used for capturing real-time mood data and a number of studies have reported on the feasibility of technology-driven mood monitoring in clinical samples of individuals with affective disorders (Ortiz and Grof, 2016).

Initial evidence suggests high levels of acceptability and feasibility of ongoing mood monitoring of patients with affective disorders within clinical settings. For example, Bopp et al. (2010) demonstrated the utility of the University of Oxford's True Colours digital mood monitoring system within 62 adult outpatients with bipolar I and bipolar II disorder. They reported an overall compliance rate of 75% over an average of 36 weeks, suggesting that the system was readily adopted by the clinical population. However, it is currently unknown how effectively such electronic mood monitoring methods can be implemented within large research cohorts in which no clinical feedback is provided.

Here, we report on our experience of implementing online longitudinal mood monitoring within the UK Bipolar Disorder Research Network (BDRN; www.bdrn.org). We aimed to roll out mood monitoring to a large previously recruited sample of 4285 individuals with affective disorders recruited throughout the UK over a 10 year period between January 2005 and December 2014, and to newly recruited individuals from January 2015 onwards.

2. Methods

2.1. Participants

BDRN is an ongoing research programme into the genetic and environmental aetiology of bipolar disorder and related affective dis-orders. Participants are recruited throughout the UK via 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 DSM-IV criteria (American Psychiatric Association, 2000) for major affective disorder; 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 interview using the Schedules for Clinical Assessment in Neuropsychiatry (SCAN; Wing et al., 1990) and review of psychiatric and general practice (primary care) case-notes where available.

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 bipolar disorder (Bopp et al., 2010; McKnight et al., 2017). The True Colours system sends weekly email prompts to patients with an internet link to complete two validated and widely-used self-report questionnaires: the 16-item Quick Inventory of Depressive Symptomatology patient-rated version (QIDS-SR; Rush et al., 2003) and the 5-item Altman Self-Rating Mania Scale (ASRM; Altman et al., 1997), which measure presence and severity of depressive and hypomanic/manic symptoms compatible with DSM-IV criteria over the preceding week respectively. The total scores and symptom scores are presented graphically, and can be viewed by participants and the clinical team via the secure True Colours website. Patients choose when to receive the weekly email prompt, and a re-minder email is sent after 24 h if there is no response.

Some adaptations to True Colours were necessary for use as a standalone research tool within a non-clinical environment. This involved the development of a comprehensive research participant user and help guide (both printable and online versions) which explained not only how to use True Colours but also how to interpret the output data. It was of crucial importance that BDRN participants understood that True Colours is a research tool and responses are not clinically monitored. Signposting that any concerns regarding mood symptoms should be expressed to healthcare teams through normal routes was added throughout the system. These adaptations were piloted on a small sample of 34 BDRN participants to ensure clarity, acceptability and practicality before large-scale roll out. The BDRN version of True Colours was ready for use in January 2015.

2.3. Roll out of True Colours within BDRN

UK National Health Service (NHS) Research Ethics Committee approval was obtained to use True Colours within BDRN (MREC/97/7/ 01).

Past participants: BDRN participants who had been recruited over the previous 10 year period (January 2005 to December 2014), had consented to ongoing contact from the research group, and for whom we had current contact details were invited to join True Colours using the following approaches:

i) three postal invitations were sent over a period of 8 months.
ii) email invitations were sent to those participants who had not responded t0 the postal invitations and for whom we had an email address recorded. Non responders received a reminder email after two weeks.
iii) we also promoted True Colours on the BDRN website and in the annual BDRN newsletter that is sent by post to all participants who consent to receive it.

New participants: All individuals newly recruited into BDRN from January 2015 onwards were invited to join True Colours by a BDRN interviewer after taking part in the SCAN interview.

All participants who replied positively to a True Colours invitation received an email with an internet link to register to True Colours. A reminder email was sent to

participants who had not registered within two weeks of receiving their registration email.
Participants who responded to an invitation by declining to join True Colours were invited to provide feedback on their reasons for declining.

3. Results

3.1. Mood monitoring uptake among BDRN past participants

Postal invitations: Following three postal mail-outs to 4080/4285 BDRN participants recruited between January 2005 and December 2014 who met the inclusion criteria (consented to ongoing contact from the research group and known current contact details), 626 (15%) participants registered to True Colours.
Email invitations: A subsequent email invitation was sent to a total of 1364 BDRN participants. Of these, 189 participants (14%) registered to True Colours.
Therefore a total of 815 BDRN past participants registered for True Colours.
Overall uptake rate among past participants who were invited to join True Colours was 20% (n = 815/4080). The proportion of BDRN past participants who registered to True Colours according to the total number of participants recruited to BDRN per year is shown in Fig. 1A. The years of recruitment in which the highest proportion of past participants joined True Colours were the three years directly preceding the invitation to join True Colours (21% in 2012; 22% in 2013; and, 27% in 2014).

3.2. Mood monitoring uptake among new BDRN participants

Since January 2015 to date, 46% (n = 160/346) of newly recruited BDRN participants have registered to True Colours. The proportion of new BDRN participants who registered for True Colours as a proportion of the total number of participants recruited to BDRN during each recruitment period is shown in Fig. 1B. More recently recruited participants were most likely to register to True Colours, with highest proportion (61%) being in the most recent year compared to 32% in the first six months. The mean age of all BDRN participants who registered for True Colours was 49.7 years (sd 11.8, range 18–82 years), and 71% was female. DSM-IV diagnosis of participants was: 60.5% bipolar I disorder; 37.1% bipolar II disorder; 1.3% schizoaffective disorder – bipolar type; and, 1.1% bipolar disorder not otherwise specified. The mean duration of illness was 29.7 years (sd 11.6, range 4–60 years), and nearly two thirds (66.0%) had been admitted to hospital for psychiatric treatment at least once during the course of their illness.

3.3. Length of engagement with mood monitoring

To date, the range of number of weeks of True Colours data provided by each participant is 1–165, with mean number of weeks 58 (standard deviation (sd) 48.4, median 46.5). These figures include all BDRN True Colours users, including new users who have only had the opportunity to contribute data for a few weeks. Fig. 2 shows the percentage of participants who have provided at least 4, 12, 26 and 52 weeks data as a proportion of those who have had the opportunity to complete for that

number of weeks. Among past participants, 91%(734/815) completed at least four weeks, 78% (637/815) at least 12 weeks, 65% (533/815) at least 26 weeks and 51% (413/808) at least 52 weeks data. Among new participants, 92% (133/144) completed at least four weeks, 82% (116/141) at least 12 weeks, 54% (76/124) at least 26 weeks and 44% (40/91) at least 52 weeks data. There was no significant difference between the proportion of past and new participants completing for each length of time.

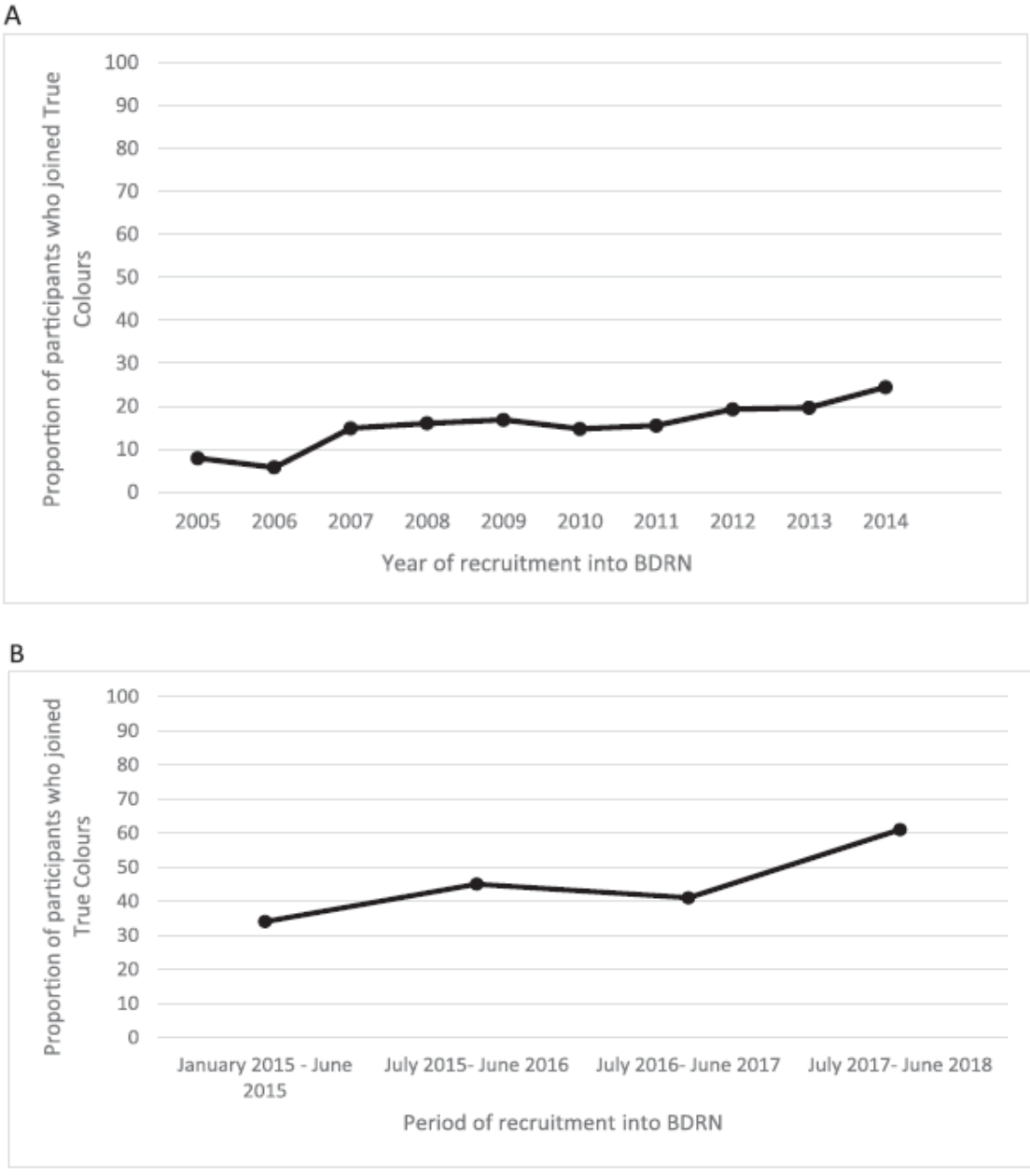

Fig. 1. (A). Percentage of past BDRN participants (recruited Jan 2005 to Dec 2014) registered for True Colours as a proportion of the total number of participants recruited to BDRN per year. (B). Percentage of new BDRN participants (recruited since Jan 2015) registered for True Colours as a proportion of the total number of participants recruited to BDRN in the time periods shown.

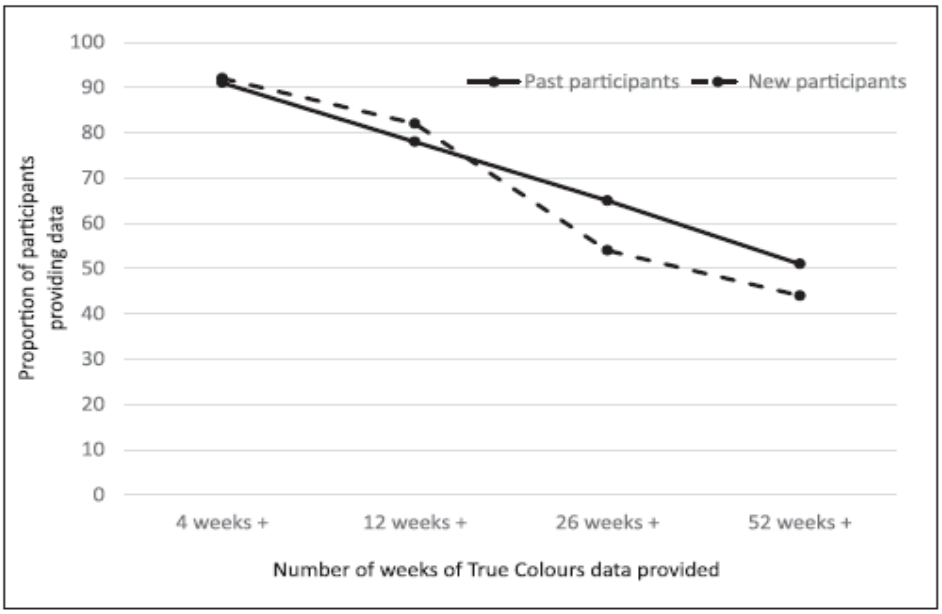

Fig. 2. Percentage of BDRN participants providing True Colours data for at least 4, 12, 26 and 52 weeks as a proportion of number of participants registered for each length of time (i.e., participants with the opportunity to provide data for each time length), by past or new participant group.

3.4. Comparison of participants who did / did not register for mood monitoring

There was no significant difference in the sex distribution or age at interview of BDRN participants who registered for True Colours com-pared to those who did not register. There was a significantly higher proportion of individuals with a DSM-IV diagnosis of bipolar II disorder who registered compared to individuals who did not register (37% vs 29% respectively, $p < 0.001$).

3.5. Feedback from participants declining to join mood monitoring

A total of 123 BDRN participants declined the invitation to join True Colours. Of these, 108 provided feedback on their reasons for declining, which we coded into categories (see Table 1).

4. Discussion

We have demonstrated that large-scale electronic longitudinal mood monitoring in affective disorders for research purposes is feasible. One in five of our large sample of past participants registered for True Colours, and just under half of newly recruited participants registered. Very few participants who engaged with mood monitoring did so for less than one month (<10%), the majority remained engaged for much longer with the mean length of engagement to date being over one year (58 weeks). Some participants have already contributed data for over three years (maximum period to date is 165 weeks) and continue to do so.

It is evident that newly recruited participants who were invited to join True Colours at the same time they were recruited into BDRN were the most likely to register, which is likely because they were invited to participate in person and therefore had the opportunity to discuss True Colours with a BDRN researcher face-to-face. Among both past and new participants the most recent recruits were more likely to join True

Colours with the highest uptake being among new participants recruited in the preceding year (61%). We suggest this may be due to how connected participants feel to the research programme and research team, as we find a similar pattern of engagement with other new studies within the BDRN research programme. The particularly large increase in participation rate over time among the new BDRN participants is likely due to increased awareness about BDRN True Colours through publicity via our website and newsletters, and via the UK support charity, Bipolar UK. For example, some participants report joining BDRN specifically to join True Colours, and we have observed that this peaks following national publicity, such as a Bipolar UK on-line blog written by a BDRN True Colours user. There was no significant difference in the length of engagement with mood monitoring between previously recruited and newly recruited participants – approximately half in both groups remained engaged after one year.

While we did not find any evidence to suggest that BDRN participants who sign-up for mood monitoring are demographically different from those who do not, we did find that significantly more True Colours participants had a diagnosis of bipolar II disorder (37%) than those who did not sign-up (29%). Reasons for this are currently unclear, although higher levels of affective instability among our bipolar II participants (Marwaha et al., 2016) could mean that this group feels mood monitoring is particularly relevant for them. The representativeness of research participants who engage with electronic longitudinal measures must continue to be examined.

The feedback from participants who declined to register for mood monitoring shows that the most common reason for declining was feeling it would not be personally relevant, and the most frequent ex-planation for this was stability of mood. We have been able to address this in our recruitment materials by explaining that we are interested in even very subtle changes in mood, and we will monitor whether this seems to address potential participant's concerns. Other reasons given for declining are expected and understandable, for example, concerns about required commitment and no internet access. It is of note that almost 1 in 5 participants who provided a reason for declining said they were concerned that longitudinal monitoring may adversely affect their mood. This possibility could be explored with participants who are or have previously engaged with mood monitoring.

A limitation of the methods we have reported here in relation to the past BDRN participants is that they may not be generalisable to all research cohorts. We keep in at least annual contact with BDRN participants by means of a research newsletter and requests to complete questionnaires. Other existing cohorts who have less or more ongoing contact with the research team may have worse or better uptake rates for online longitudinal mood monitoring systems. We also note that the reasons given for not registering for True Colours were from participants who actively declined to register, and therefore may not be representative of participants who simply did not respond to invitations to register.

The real-time longitudinal participant-reported data we continue to obtain using True Colours in our large BDRN sample is unique and valuable for studying

naturalistic mood variability and illness trajectory in affective disorders, including potential triggers and early warning signs of illness episodes as well as how mood changes with other factors that vary over time, for example, sleep patterns and menstrual cycle. There is also potential to incorporate other important aspects of mood disorders that would benefit from longitudinal monitoring, such as adherence to medication (Pompili et al., 2013). Other mood disorder research cohorts should consider incorporating longitudinal real-time remote capture of mood as we have demonstrated that it is possible to engage participants in mood monitoring for research purposes without clinical feedback. Future research may maximise participation by focusing on personal face-to-face invitations to prospectively recruited participants.

Table 1
Feedback received from BDRN participants who declined invitation to join mood monitoring (n = 108).

	N*
Not relevant (mood stable, change in diagnosis, using another similar mood monitoring system, felt there would be no benefit)	50 (46.3%)
Practical/technical reasons (no internet access, problems registering, do not like use of questionnaires to gather mood data)	31 (28.7%)
Too much commitment (including physically unwell, other commitments)	19 (18.0%)
Concerns about potential negative impact on mood	19 (18.0%)
Not comfortable providing personal information online	9 (8.3%)

* Where participants gave more than one reason, all are counted in the table.

Conflicts of interest

None of the authors declares any conflicts of interest.

Contributors

All authors designed the study, wrote the protocol and collected the data. KGS and LJ conducted the statistical 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 funding source

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.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.jad.2018.12.099.

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