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**TITLE:** Patient experience of supported computerised CBT in an inner-city IAPT service: a qualitative study.

**Running head:** Patient experience of eCBT

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### **Ethical Standards**

The study was approved by the South London and Maudsley MAP CAG Executive Clinical Governance Audit Committee (2<sup>nd</sup> December 2015). It was carried out according to the British Psychological Society's Code of Human Research Ethics.

### **Conflict of Interest**

The authors have no conflict of interest with respect to this publication.

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## **Abstract**

Computerised cognitive behavioural therapy (cCBT) has been developed to address economic and clinical issues around limited access to evidence-based therapy. Supported cCBT (variously termed iCBT or eCBT) has been developed to address issues with the effectiveness of, and engagement with, cCBT. There has been no in-depth qualitative exploration of the patient experience of eCBT within the UK, which might aid improving its effectiveness. **Study objective:** The aim of this study was to explore patient experience of eCBT in one inner-city National Health Service (NHS) Improving Access to Psychological Therapies (IAPT) service using a semi-structured interview and Thematic Analysis methodology. **Results:** 10 patients took part. 6 main themes were identified: 1. Being Offered eCBT; 2. How eCBT Compares to Self-help; 3. The Patient's State of Mind; 4. The Relationship with the Supporter; 5. Preferring to Talk; 6. eCBT's Value as a Treatment. **Discussion:** Participants in this study indicated a preference for face-to-face talking therapy, but were clear that they could form a therapeutic relationship via asynchronous messaging. They reported clinical benefit from the eCBT programme and online relationship, and acknowledged that accessing this immediately was valuable. Issues around the process of selecting patients for eCBT, including with regards to acknowledging or mitigating any negative emotional effects of eCBT, and how to offer and support users with it, are discussed.

## **Keywords**

internet-based CBT, eCBT, iCBT, SilverCloud, guided cCBT, patient experience

## **Learning Objectives**

After reading this article the reader should be able to:

- Be aware of the research and service background to supported computerised cognitive behavioural therapy (eCBT), including methodological limitations of previous studies;
- Have an understanding of the nature of the patient experience of eCBT within the UK;
- Consider the implications for services, training and research in terms of the selection of patients for eCBT, the process of offering it to them, and how best to support them with it;
- Use findings from this paper to address clinician attitudes towards eCBT in order to improve offering eCBT.

## Introduction

Depression and the anxiety disorders are common mental health problems that affect up to 15% of the population in the UK at any one time (National Institute for Clinical Excellence [NICE], 2011). However, rising demand for treatment, coupled with pressures on resources due to economic and political reasons, make it hard for National Health Service (NHS) psychological therapies services to meet demand (Office for National Statistics, 2009; Gilbert, 2015). In order to meet this increasing demand for therapy, in the UK and elsewhere, various forms of computerised cognitive behavioural therapy (cCBT) have been developed (Friesen *et al.* 2014). In theory, this allows for the knowledge and techniques of CBT to be disseminated more quickly and cheaply to a greater number of patients (Simon & Ludman, 2009). This is because cCBT requires either no or less therapist time than traditional face-to-face CBT (Richards *et al.* 2018b).

There is evidence for the effectiveness of the different types of cCBT. Pure or unguided cCBT, which involves patients working through self-help material via a computer (often but not necessarily over the internet), was the first to be developed. Initial studies and meta-analyses thereof suggested that cCBT can demonstrate effect sizes equivalent to that of face-to-face therapy when compared against (typically) waiting list controls (Andersson & Cuijpers, 2009; Griffiths *et al.* 2010). However, questions have been raised about whether cCBT's effectiveness might be less impressive and have shorter-term effect, and also be compromised by higher drop-out, than previously considered, when publication bias and detail of study findings are taken into account, according to the largest meta-analysis to date (So *et al.* 2013).

Due to some of the above limitations of cCBT, guided forms of cCBT (sometimes referred to as eCBT in the literature) were developed. This typically involves patients working through online modules that teach them CBT ideas and techniques, with support via email messaging from a clinician. This can also be termed "computerised CBT with asynchronous messaging support", to distinguish it from 'online' CBT which usually refers to standard CBT but offered over the Internet via, for example, Skype or instant messaging.<sup>1</sup>

There is developing evidence for eCBT (Sharry *et al.* 2013). There have been a number of efficacy studies (and meta-analyses of these) on eCBT. These tend to conclude that therapist-supported eCBT is an efficacious treatment (Wells *et al.* 2018). A systematic review and meta-analysis of 40 studies found a moderate post-treatment effect size (Richards & Richardson, 2012), which is a conclusion supported by other systematic reviews and meta-analyses (e.g. Cuijpers *et al.* 2010; Andersson *et al.* 2014). The most recent systematic review and meta-analysis examined 20 studies involving 1418 participants, and concluded eCBT is an equivalent treatment to face-to-face therapy (Carlbring *et al.* 2018).

However, these studies suffer from the following limitations: they use mainly waiting list control groups, or group CBT as a comparative treatment; the nature of the supporter can vary widely in terms of training and experience e.g. clinician, volunteer, peer mentor; they compare both synchronous and asynchronous support; and the disorders, countries and eCBT programme investigated are heterogeneous (Gratzer & Khalid-Khan, 2016; Olthuis *et al.* 2016; Carlbring *et al.* 2018; Richards *et al.* 2018b). A Cochrane review (just for anxiety disorders) concluded that whilst there is evidence that eCBT appears to be efficacious, it is low quality (Olthuis *et al.* 2016). It has been noted that even if the treatment is efficacious it suffers from high attrition rates, and that trials often do not report on adverse effects

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<sup>1</sup> eCBT was originally the term used by the developers of SilverCloud (the programme examined in this paper e.g. Richards & Timulak, 2013). Although iCBT has become more prevalent, we prefer eCBT as we believe that it helps make it clear we are discussing cCBT with asynchronous messaging, whereas iCBT can refer to a range of online interventions, including those with synchronous communication.

(Mogoase *et al.* 2017). Despite these limitations, cCBT is recommended by the NICE as a low-intensity intervention (NICE, 2018).

With regards to whether the inclusion of support affects outcome, an early review found that most evidence suggests that supported eCBT is more effective than cCBT, based on 4 controlled trials and 8 open studies of effectiveness (replicating efficacy studies in routine clinical practice), with a total of 3,888 patients, for a range of disorders i.e. not just depression (Andersson & Hedman, 2013). It now tends to be concluded that incorporating some form of therapist contact improves effectiveness and adherence (Johansson *et al.* 2015). However, these conclusions are largely based on small studies which advertise for participants, and so further studies in clinical settings have been called for (Fairburn & Patel, 2017), including specifically in Primary Care, and with a focus on the role of the supporter (Richards *et al.* 2018b; Wells *et al.* 2018). A need for more research into factors influencing the negative aspects of this treatment has been highlighted (Richards & Richardson, 2012).

One of these factors may be the patient experience of eCBT; researching patient experience of interventions is now considered important to improve adherence and efficacy, and is a central part of policy about the NHS (Department of Health, 2005). A systematic review of 29 studies found that, for cCBT for depression, mean completion was 67%, with a range of 27-100%; and mean dropout rates 32%, range 0-63%. Nonetheless 25 of the studies reported 'very high' or 'high' levels of 'acceptance' of the programmes (Rost *et al.* 2017). However, as discussed above, these studies vary markedly in their design, including which programmes were used, participant characteristics, and whether the cCBT was delivered alone or as a package of care. Studies also tended to be on cCBT that formed part of research programmes. This limits the ecological validity of the conclusions, as well as not providing much information about the patient experience, particularly as 'satisfaction' ratings do not provide much in-depth information about patient experience, particularly those who drop out.

Aspects of clinician support which may increase engagement have been briefly reported on, and include providing acknowledgement/listening, advice and compassion (Richards & Timulak, 2012). However, this research has solely used questionnaire methods. Further research on the patient experience of cCBT has therefore been called for (Rost *et al.* 2017). The use of more in-depth qualitative methods has been recommended (Waller & Gilbody, 2009). This is because qualitative data give more information about perspective than quantitative data from trials (Rost *et al.* 2017).

Qualitative studies on eCBT have found that patients report benefitting from the convenient and flexible accessibility of eCBT, learning CBT information and techniques, personalised feedback and empathy from the supporter which validates, encourages and comforts them, and that using eCBT results in them seeing improvement. They have also reported that patients can feel under pressure from external factors, experience a lack of identification with the eCBT materials, can have privacy concerns, and can feel that the supporter's feedback can seem inadequate or scripted. Previous studies have also indicated that eCBT is most beneficial for patients who are conscientious, high achieving and goal driven i.e. motivated, who have mild-moderate problems, and who are unwilling or unable to engage in face-to-face therapy (Richards & Timulak, 2013; Wilhelmsen *et al.* 2013; Richards *et al.* 2016; Earley *et al.* 2017; Holst *et al.* 2017; Walsh & Richards, 2017; Burke *et al.* 2018; Richards *et al.* 2018a). One study which focused on depression and generalised anxiety disorder in particular, found that patients can experience the treatment as demanding (in terms of content and concentration requirements); difficult without face-to-face support; and as lacking sufficient introductory information (Johansson *et al.* 2015).

However, these studies have suffered from a number of limitations which affect assuming their findings will automatically apply to the NHS IAPT setting. These limitations include having supporters who are not PWPs e.g. volunteers or licenced clinical psychologists (so

the supporters' training may not be equivalent); focusing on one disorder (anxiety or depression, or subclinical depression) rather than the range of common mental health problems; taking place in a particular setting (e.g. charity, university) meaning that the sample may systematically have differences from the primary care NHS population; being recruited from RCTs, which is important because these patients may have a different experience due to the different levels of preparation, assistance and follow-up of trial participants (Donkin & Glazier, 2012), but also because the usage of digital self-help programmes in clinical settings may vary from that reported in trials (Fleming *et al.* 2018); having limited amount of data from those who drop out of the programme; taking place in a country other than the UK e.g. Ireland, Norway, Sweden; variations in the nature of the eCBT programme, for example, purely e-mail-based treatment (Bendlin *et al.* 2011); and differing amounts and types of support offered e.g. some include telephone or face-to-face consultations (Lillevoll *et al.* 2013; Richards & Timulak, 2013; Wilhelmsen *et al.* 2013; Johansson *et al.* 2015; Richards *et al.* 2016; Earley *et al.* 2017; Walsh & Richards, 2017; Burke *et al.* 2018; Richards *et al.* 2018a). A number of studies have used questionnaire methods which limit the depth of analysis of patient experience possible (Richards & Timulak, 2013; Richards *et al.* 2016; Enrique *et al.* 2018; Burke *et al.* 2018; Richards *et al.* 2018a). Even studies which have used interviews to collect the data have not always used very 'deep' qualitative methodology, including how the data was analysed and presented (Holst *et al.* 2017). For example, focusing on the effects and memory of the treatment, rather than in-depth patient experience of it (Halmetoja *et al.* 2014).

Therefore, these studies need to be methodologically extended. Furthermore, a significant drawback to this research which is only sometimes acknowledged e.g. Earley *et al.* 2017, Richards *et al.* 2018, is that much of it has been conducted or supervised by people who have developed the eCBT programme under investigation, or who have connections to them e.g. Walsh & Richards, 2017. Particularly in qualitative research, this social desirability bias of the researcher might affect interpretation of the data. Some studies have acknowledged that patients can deteriorate whilst using eCBT, but this has not been discussed in much depth (Richards & Timulak, 2013; Enrique *et al.* 2018; Richards *et al.* 2018a).

So, the evidence about the effectiveness and patient experience of cCBT suggests that it can be beneficial, but is still limited by high dropouts and negative patient attitudes. However, most of this research has been on unguided cCBT, which is used less now. Research on the experience of 'guided' eCBT, which is now seen as more effective than unguided cCBT, has varied in the nature of the programme used, amount and type of support offered, and in which country this is, and has largely not used in-depth qualitative methods. There is thus a need for in-depth qualitative exploration of patient experience of the same kind of eCBT as is used in the UK within the NHS for a range of common mental health problems (Knowles *et al.* 2015). It will also be important for this to be with a representative sample of patients, including non-completers, who can be difficult to recruit from efficacy trials (Lillevoll *et al.* 2013).

Therefore, this study used a qualitative methodology to explore NHS patient experience of using Silvercloud (an eCBT programme offered by many UK Improving Access to Psychological Therapies (IAPT) services) supported by PWPs. It is the first to do so, is rare in that it is carried out by researchers separate from the programme developers, and provides information about the acceptability of the programme relevant to both therapists and service managers.

## **Method**

### *Sample*

All patients who had been offered eCBT within an inner-London IAPT service and either completed it, dropped out or been stepped up/across (at the point of recruitment, which was

in December 2015) who had consented to be contacted about research were emailed an information sheet about the study by a researcher not involved in providing eCBT, inviting them to take part. Reminders were sent one month later. Interviews were arranged at a time to suit the participant, at the main clinic of the psychological therapy service. Participants signed to demonstrate informed consent, including about withdrawal of data. Participants were paid £15.

### *SilverCloud*

The eCBT package used in this IAPT service is SilverCloud (Sharry et al. 2013). Clients are sent log-in details by their allocated PWP and encouraged to work through a set of eight to ten online modules which are matched to address their difficulties, at their own pace. Each module takes about 40 minutes to complete. Content is based on CBT, and includes psychoeducation on understanding the link between thoughts, feelings, and behaviours; exercises including thought challenging; and behavioural experiments. PWPs support clients by logging in to the programme and reviewing clients' progress, providing personalised messages. In addition, clients complete weekly standardised symptom measures of depression and anxiety routinely collected in IAPT services.

A PWP has an undergraduate degree, typically in Psychology, and often has some experience working as a healthcare assistant, support worker or honorary assistant psychologist. They then undertake one year of training (which involves university attendance and four days placed in an IAPT service) in delivering low-intensity CBT-based assessment and intervention. Training encompasses mainly anxiety disorders and depression.

### *Design*

Individuals were invited to take part in a semi-structured interview relating to their experience. The semi-structured interview schedule (which served as a guide for the conversation between interviewer and participant) was developed by the authors in consultation with other Team members, based on research into patient experience of cCBT (Mitchell & Gordon, 2007; Kaltenthaler et al. 2008; Waller & Gilbody, 2009). The main question "Bearing in mind the information that I've given you about the project, would you mind telling me about what your experience of using SilverCloud was like?" was always asked. Prompts for areas to be covered included how the person felt about being offered it; how they found the layout and content of online materials; perceived advantages and disadvantages; and how they found their relationship with their online supporter. Patients who had completed the programme were asked what helped them do this; participants who had dropped out were asked what might have helped them persist. Interviews were recorded, and transcribed anonymously. This approach is comparable to explorations of patient experience of pure cCBT in the UK (Knowles et al. 2015).

### *Analysis*

Thematic Analysis was chosen as the methodology to explore the participants' experiences. It allows for a rich summary of, and insight into, participant experience (Braun & Clarke, 2006). As recommended, we own our analytical position as critical realists (we believe the reality of the patient experience is filtered through the lens of the context of the study and our own experience); and is carried out at a semantic level (so looking at the surface-level meanings communicated by participants rather than underlying ideas or discourses); and inductive in nature (proceeding from the data set rather than imposing theoretical categories onto it). Thematic Analysis has been used in this way in previous studies of participants' subjective experience of CBT (e.g. Gerskowitch et al. 2015).

Transcripts were typed up in full by the interviewer. All transcripts were analysed by the first author. Analysis involved the first author familiarising himself with the data, by making the transcriptions, re-reading them, and making written summaries of the interviews. Then



Coding involved attaching labels to each section of the interviews to capture the essence of what participants said, keeping close to their own words at this stage. Themes were developed by writing each code on a separate piece of paper, and grouping them together (Green & Thorogood, 2014). All relevant extracts for the themes were collated, to check the themes against each other and the data set (Braun & Clarke, 2006). The second author then provided feedback on his analysis. No changes to the themes identified were made at this stage.

Because researchers can influence the collection and analysis of qualitative data, we here present information about the authors so that readers can for themselves identify any possible bias, as well as highlighting what we attempted to take account of in order to minimise bias. The first author is a male Clinical Psychologist with previous experience of conducting qualitative research. He identifies as being positive about the use of technology to enhance CBT, but is also politically active and so tried to remain aware of the influence of his beliefs about the economic context of eCBT and IAPT. The second author identified as a PWP in terms of profession, and was aware of holding strong beliefs around the importance of the therapeutic alliance. Prior to conducting the interviews she was sceptical about the efficacy of eCBT. However, she reflected on this with her clinical supervisor and the first author, and continued to work reflexively throughout the data collection and analytic process in order to remain as open and non-biased as possible.

## Results

### *Participants*

10 people responded out of 53 contacted (a 19% response rate). Interviews were conducted January-March 2016. The interview range was 18-40 minutes, with the mean time being 26 minutes. 8 interviews were conducted by the first author, and 2 by the second. Neither interviewer was involved in the treatment (either assessment or provision of eCBT or other interventions) of the participants they interviewed.

2 men and 8 women took part. The age range was 19-52 years, and the mean was 33 years. 7 identified as White British, 3 as White Other. 1 identified as gay, 1 bisexual, 8 heterosexual. None identified as having a disability.

4 had been diagnosed with Mixed Anxiety and Depression, 4 with Depression, and 2 with Social Anxiety. 6 had completed the eCBT programme (3 were stepped up to high intensity CBT, 2 were stepped across to guided self-help, and 1 had no further intervention); 3 dropped out; and 1 asked to change (to counselling).

### *Thematic Analysis*

Six main themes were identified: 1. Being Offered eCBT; 2. How eCBT Compares to Self-help; 3. The Patient's State of Mind; 4. The Relationship with the Supporter; 5. Preferring to Talk; 6. eCBT's Value as a Treatment. Themes were identified as such if they occurred in multiple instances across different transcripts, and related to the research questions. The **main themes** are described, and then followed by *sub-themes* with illustrative *quotations* attributed by [participant number].

### ***Theme 1: "Being Offered eCBT"***

There was a general sense of feeling disappointed, sceptical about or even 'fobbed off' by being offered eCBT. Several participants articulated an awareness that NHS finances were the context behind this. Participants had varying experiences of the level of explanation and choice they were given when offered eCBT, so the importance of these factors was emphasised, particularly being given information about eCBT's benefits, how to use it, and a sense that other patients had tried it and found it beneficial. Most participants expressed a

willingness to try it, if not always an enthusiasm. Several said that their experience was better than their expectation.

#### *Emotional reactions*

Being offered eCBT itself triggered thoughts and feelings in the patients.

*And when they told me, “no, it’s going to be just online, and you’re not going to see anyone”, well, I was thinking that it’s not going to be helpful because how am I going to get better if I don’t even see anyone and just read? [P1]*

*I feel like it was a bit disappointing... it just felt like you were a bit palmed off on this app. [P4]*

#### *Awareness of NHS Context*

Some patients reported feeling ‘short-changed’ by this offering.

*I felt it was cost-saving, to be honest with you, and I know the NHS is stretched for resources... it just feels like, ... it’s like in the wide world, it’s like getting rid of people isn’t it, it’s cheaper? Like in the supermarkets, they have those self-scans, so they don’t have to employ checkout people, but it kind of felt a bit like that, like it was a saving money exercise, rather than providing people with trained counsellors, it was like “oh here’s a computer programme”, and I felt a bit short-changed really [P8]*

#### *Importance of Explanation (of what eCBT is and other people's experience of it)*

Participants reported being given varying levels of information about eCBT.

*it was explained to me what the programme was and that I’d have the supporter who’d be responding to me weekly. I think it was quite well explained at the beginning, what it entailed. [P8]*

*Maybe explaining a bit better about the programme. That it’s helped other people, maybe some feedbacks from others, I think that could have been helpful, because I don’t think I was given a lot of information about that at the beginning, a lot of explanation, they just told me, “Oh online course” that’s all I was told. [P2]*

#### *Choice*

They also reported varying levels of choice in the matter.

*I just agreed because it was some sort of treatment that they had given me, and I didn’t want to have nothing instead of anything, so I took it. [P3]*

*they made it really clear that it wasn’t just a ‘and or’ you know, it wasn’t just this or that, it was like if I didn’t feel it was working I could then ask to see someone [P6]*

### **Theme 2: “How eCBT Compares to Self-Help”**

A lot of the participants reported feeling they already knew the information presented in eCBT, and that this was not tailored to their individual needs and situation. However, they acknowledged that it was more interactive than self-help (particularly the exercises and the videos), that even the act of logging on to work on something made it more reflective, and that the knowledge that the supporter was looking at it was more motivating than pure self-help.

#### *Knowing the information already*

Participants (who seemed to have all engaged in some self-help prior to eCBT) reported not necessarily learning new information from the programme.

*But there is nothing new from reading self-help book... [P1]*

*There were a lot of things I was already aware of, in terms of how to approach the worry... but I liked that it was quite detailed. [P2]*

*And it was just quite basic information like about thought patterns which just felt a bit like you were just sitting a test that was just so basic that you think this isn't really helping me. I was like I already know all this stuff anyway. [P4]*

#### *General - not individualised*

They also tended to report that this information was, understandably, generic and not tailored to them or realistic.

*Examples may be slightly kind of how do you say a lie? Not really difficult. People have more stressful examples of life. [P9]*

*It just felt like self-help guide that might be useful in terms of like if you feel like this here are some things you can read which may help you but it didn't feel like an 8 week replacement for a CBT course with a professional. [P4]*

*it was very general, it was not tailored to my needs, for example, it was just the theory and examples of other people, so I wasn't able to solve the issues that are personal to me [P2]*

#### *More interactive*

However, the interactive and multimedia nature of this particular eCBT programme was acknowledged as a benefit.

*There are real examples, from people, so there were 5 or 6 people who actually talk about their personal examples, also it's quite interactive, so you are asked to provide, set yourself goals, and write notes, and think about things, and comment in a general, trying to think what I've found really useful, so it's better than a book. A book you just read and don't really do anything, but there you have to do a little bit more effort. [P2]*

*something about going and logging in kind of makes you kind of stop and think about it rather than if you just quickly read something [P5]*

#### *Having a supporter makes the patient use it*

It was also motivating to know a clinician was involved in their care via the programme.

*It is better if I know someone is going to look every week, so I know it's not like I can just not do it that week. I know if someone asks me to read a document, I will do it." [P1]*

*I think because I did have the person I talked to every week, it kind of felt more because like I had a duty to do that, if they were going, if they were going to like give their time to me, I can't like pretend that I didn't do it, and that motivated me to stick at it. [P5]*

### **Theme 3: "The Patient's State of Mind"**

The importance of the patient being motivated was highlighted, and the fact that this might be problematic for patients who are depressed and, to a lesser extent, anxious, for whom motivation might be part of the problem. As well as the intensity of the problem for which help was being sought, the life circumstances of the patient e.g. work, study could also affect

their motivation. In turn, engaging with eCBT could have effects on mood and anxiety. Negatively, it could be experienced as a 'chore' or a pressure (many participants mentioned this), leading to further anxiety and stress. If the patient engaged but didn't find it helpful, this could also lead them to lose hope. Positively, if benefits were seen (which tended to take a few modules and a bit of effort), this could improve the patient's emotional state and their engagement with the programme, in a positive spiral.

#### *The Importance of Motivation*

Participants stressed the need for patients to have sufficient motivation to use and benefit from eCBT.

*The thing is, you have to be really motivated to do it, because you do it on your own, there is no set time, you have to find time to do it. [P2]*

*Cos initially the motivation is there to do it, but it's maybe it's a bit because I do it in my... I was doing it in my own time and I've got such a busy ...life that it was just really hard to [P6]*

*Well I just went through it, step by step... [P10]*

#### *The effect of mood/anxiety on engaging with eCBT*

Mood and anxiety could affect motivation.

*when I was feeling OK, it was easier to kind of use it, and when I was feeling quite anxious and quite depressed, it was really hard to log on, and I did find it then, it was a bit of a chore... I think you know it probably works for people who yeah aren't in a very bad way, cos I think when I was in a bad place I didn't want to engage with it, I didn't feel motivated to do it, I definitely found that [P8]*

*when you're in a deep mood you wouldn't do it because you tried to avoid all the information and just try to avoid everything [P9]*

#### *The effect of engaging with eCBT on mood/anxiety*

If the patient saw benefits from eCBT, this could improve their motivation.

*But the more I did it, the better I felt about the programme [P2]*

If not, however, or if it felt like eCBT wasn't meeting their needs, or interacted negatively with their beliefs, it could further worsen their emotional difficulties.

*I felt I wasn't getting the help that I needed, and then I sort of started getting down cos I didn't have anyone to talk to, so I started isolating myself [P3]*

*when I miss it I feel guilty [P9]*

*The feeling it's always hanging over you... It was kind of more of a hindrance, I think, erm. Yeah, cos you keep thinking "I've got something to do" in the back of your head [P7]*

#### **Theme 4: "The Relationship with the Supporter"**

Participants were clear that it was possible to form a therapeutic relationship online; to feel listened to, valued and cared for. This was reported to help reduce a sense of isolation. They gave detail about how encouraging, personalised messages from the supporter helped develop such a relationship, and were generally very positive about the supporters. A few were anxious about privacy concerns about communicating online, but this tended to be reflected in their wider attitude towards technology and social media.

### *It is possible to form a therapeutic relationship online*

Participants reported that they could form a relationship, feel listened to and held in mind, even online and asynchronously.

*I felt we really had a strong relationship, yeah. [P3]*

*the act of someone thinking about me was quite reassuring so I wasn't feeling so isolated and stuff so... [P6]*

*I: And did you get the sense that someone was listening, even if you're not talking to them*

*P1: Yes.*

### *How positive, personal messages help develop a relationship*

Participants gave detail about how encouraging, personalised messages helped them feel supported and motivated. These messages could be brief, and did not take a great level of detail or effort to make personal. All but 2 participants endorsed this theme.

*she sort of like always greeted me in a nice way, she always typed really nicely. She used to say how I was getting on... she always told me what I should do next which would probably help me, so she was just very supportive.... [P3]*

*I: How did you know it wasn't a standard message?*

*P1: Because they'd say, I saw you went to "the thing" and I saw you left "these thoughts" for yourself, I could see and so on.*

*P7: even though it was only brief, she was very interested and she was obviously erm wanted to know that I was improving, or that I was feeling better in myself, and so that was quite comforting really. Yeah.*

*I: Any other feelings it gave you?*

*P7: Valued by her.*

*I think the encouragement from the supporter, weekly emails from him, he was really interested in me and my progress, it really helped me having someone who was really interested and supportive. The tone was good. I was really looking forward to his emails... Words like, "well done" and "I'm really pleased that you've done that", "make sure you continue", "keep up the good work" things like that. I think it's really useful when someone praises you and gives you positive feedback, you feel encouraged and want to continue. [P2]*

### *How online communication can affect this including privacy concerns*

Nonetheless, online communication could detract from this, more for those with wider concerns about data security (which did not concern every participant).

*I knew there was a real person reviewing it every week, but it did feel yeah quite artificial at times yeah. [P8]*

*I didn't really like it because of the whole diary thing. I mean, I like writing in diaries but I don't trust the internet, so I wouldn't write how I was feeling in the diary part, cos I don't know who reads it [P3]*

*I: And what about sharing personal information online? What was that like?*

*P2: That's fine, absolutely fine, no problem with that yeah.*

### **Theme 5: “Preferring to Talk”**

Most participants (7 out of 10) indicated they would have had a preference to talk to a clinician. It was generally hard for them to articulate why this was, so it seemed to have intrinsic value. However, some were able to say that it was about immediacy of response (rather than waiting a week for the message); feeling more able to offload; and increasing the development of an emotional connection.

#### *Preferring to Talk*

*I have been OK since, like I didn't need the extra input, so probably maybe wouldn't have even needed to see someone 1:1, but it's just if you're going to choose between the two I would rather see someone face to face. [P7]*

*I would say it was useful and I would encourage people to give it a go because there is stuff they can learn that is helpful from it. But I always think you know it is better to have a person to speak to. [P8]*

*Sometimes I was thinking why should I do it online? When I can just meet someone and talk, you know face to face it's better. [P9]*

#### *Immediacy*

*I: What do you think that's about then, what is that crucial difference between the written text and hearing someone's voice or seeing someone via a webcam?  
P4: The response time I guess, it's an actual conversation so if you email someone you've got to wait like three days for them to reply*

*Well if you're speaking to a person one to one, it's immediate isn't it, you know, and they'll say “Oh yes, you're doing it right” or “Have you thought of looking at it this way?” [P8]*

*It took almost a week to wait for an answer, so I didn't have like a conversation [P1]*

#### *Offloading*

*I think it was just cos of the way I was feeling anxious and I needed to actually talk to someone about my feelings and not to a computer [P3]*

*It's actually meeting and talking to a person about your problems, getting them off my chest and stuff, it does feel like I'm offloading, and I do find that helpful [P8]*

#### *Personal Connection*

*cos I've had counselling through my work before, and it's just like a personal approach [P8]*

### **Theme 6: “eCBT's Value as a Treatment”**

Nonetheless, most participants had something positive to say about eCBT. It was recognised that the fact that it could be offered immediately was helpful. It was also seen as a useful first step. A number of its features were seen as positive. However, although for a few participants it had been the only intervention they received, there was a general sense that it was not a complete intervention, often summed up in a phrase (similar versions of which were used independently by different participants) to the effect that “It wasn't for me but could help someone else.”

### *It's an Immediate First Step*

Despite the negative awareness of the economic driver for eCBT, there was also a positive view of it in the context of long waiting lists for face to face therapy.

*I wouldn't say that it solved my issues... but it put me on a bus to recovery I would say. [P2]*

*definitely I think as a first step to getting help and it being quite immediate was really useful [P5]*

*I think that if there were a long waiting list it would have been quite a good ...and probably would have done the groundwork for the therapy [P6]*

*I think it's a very good first step... I started to do something, rather than just hiding and not doing anything about it [P1]*

### *Beneficial Features*

Box One lists specific features participants endorsed as beneficial.

BOX ONE HERE

### *Not for me but could help someone else*

Only one participant saw eCBT as being exactly what they needed. Most experienced some benefit, and were positive about the PWPs supporting them, but felt something more was wanted.

*I think it's a really good first step, but I'm not sure how helpful it's been for me. [P1]*

*the supporters are brilliant on there as well, cos they're really helpful, and getting the help that you need, and yeah overall I think it is a good programme, it just wasn't good for me. [P3]*

*I feel that it hasn't worked for me but it could be so good for someone else [P7]*

*The point I would want to make is that it's not an inferior substitute for something else, and if you try it you may actually find it works better than any other type of solution. It might not, depending on the case, it might be that someone needs that face to face contact, but for me, it was actually more what I needed than face to face, so I would encourage people to bear that possibility in mind when they try it. [P10]*

## **Discussion**

This study explored 10 participants' experiences of eCBT in an inner-London IAPT service. It is the first to do so, which makes its findings more relevant to UK therapists, PWP supervisors and service managers. It found that, whilst patients indicated a preference for face-to-face talking therapy, and something more than eCBT, they were clear that they could nonetheless form a therapeutic relationship via asynchronous messaging. They reported clinical benefit from the eCBT programme and online<sup>2</sup> relationship, and acknowledged that accessing this immediately was valuable. It seemed important to offer eCBT to patients in a way that acknowledged these factors, as well as the limitations and improvements of eCBT

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<sup>2</sup> Throughout this section, we use the term 'online' to refer to the internet-mediated, asynchronous intervention and relationship, as this is the term used by participants in the study and is more accessible than 'internet-mediated'.

in comparison to self-help. Careful selection of patients seems indicated, as individual motivation and circumstances affected patient experience; and the eCBT programme could have varying (including deleterious) effects on patients, which could be significant for clinical issues of risk.

#### *Offering eCBT*

Although participants reported experiencing how they were offered eCBT as significant, previous research into cCBT has found no consistent relationship between expressed preference for cCBT and subsequent experience of it (Knowles *et al.* 2015). Nonetheless, it has recommended that patient expectations about the treatment option be addressed. Framing online-delivered self-help for depression as a treatment that is expected to have positive results has been found to lead to better outcomes (Cludius *et al.* 2018). Previous studies have found that participants' need for prior information has not been matched by what they received, and has made recommendations about how this is presented, including in written, oral or video presentations (Johansson *et al.* 2015). Study participants generally request more information about the treatment option than they have received (Holst *et al.* 2017). In this study as in others (Rennick-Egglestone *et al.* 2016; Holst *et al.* 2017), being offered eCBT can actually offend or upset patients, so needs to be handled thoroughly and with clinical sensitivity.

#### *Experience of eCBT*

For some participants in previous research on cCBT, the lack of contact with a therapist has been a significant problem and led to expressions of need for greater support (Donkin & Glazier, 2012; Knowles *et al.* 2015; Rennick-Egglestone *et al.* 2016; Rost *et al.* 2017). A large-scale RCT found cCBT supplemented with encouragement to use it by telephone was not superior to GP care as usual in depression (Gilbody *et al.* 2015). Outcomes for patients who complete cCBT as opposed to eCBT are not necessarily superior (Morgan *et al.* 2017), but participants in other studies have stated that they find contact with a therapist to provide them with support and a push to continue with the programme when it gets difficult (Bendelin *et al.* 2011). This need for greater support has also been found for eCBT, even with telephone contact (Holst *et al.* 2017), so the finding that participants in this study felt they could form a therapeutic relationship online seems a significant improvement: Knowles *et al.* 2015 theorised that greater support could enhance the experience for patients, and this appears to be the case. The current study fleshes out and supports the findings of previous studies into eCBT by providing more detail about how patients can positively experience the supporter's presence and feedback (Richards & Timulak, 2013; Wilhelmsen *et al.* 2013; Richards *et al.* 2016; Earley *et al.* 2017; Walsh & Richards, 2017; Burke *et al.* 2018; Richards *et al.* 2018a).

However, some of the experiences of cCBT with and without support remain the same, such as feeling materials are not individualised (Knowles *et al.* 2015) and/or don't teach the patient anything new (Donkin & Glazier, 2012). Another experience that was shared in this study by other study participants is that guided cCBT can feel inflexible and like a set of work that has to be done (Donkin & Glazier, 2012; Johansson *et al.* 2015). This may be inevitable, given the nature of self-help, and the proliferation of its use. But perhaps developers of the technology could use new features to ameliorate this. In addition to the above negative experiences of eCBT, previous qualitative studies of eCBT have also found that some patients can report deteriorating in response to it (Richards & Timulak, 2013; Enrique *et al.* 2018; Burke *et al.* 2018; Richards *et al.* 2018a). However, it should be acknowledged that negative responses to therapy can occur with face to face therapy. One in twenty out of 14,587 respondents to a British Journal of Psychiatry survey reported lasting bad effects (Crawford *et al.* 2016). These negative effects can include worsening symptoms, dependency, stigma, hopelessness, a sense of failure, unpleasant memories, and anxiety (Rozental *et al.* 2016). Therapists can often underestimate this (Lilienfeld, 2007). Therefore,



we should not see negative participant experiences of eCBT as being particular to that therapeutic modality.

Furthermore, participants in this study could see some benefits from guided cCBT, which can also be found with unguided cCBT (Donkin & Glazier, 2012; Rennick-Egglestone *et al.* 2016) and conventional CBT which is supplemented with web-based materials (Lillevoll *et al.* 2013). It is important to note that, in this study, as in others, patients can have a range of responses to eCBT, from seeing it as perfect for their needs and reaping great benefits from it, to finding it disappointing in relation to their expectations, and subsequently not leading to any change (Bendelin *et al.* 2011). eCBT should therefore not be considered either unsuitable for all or a one-size-fits-all solution.

### *Service Context*

It has been highlighted in the Introduction that eCBT has been developed in an economic context. eCBT can help reduce costs by reducing the numbers of patients accessing high-intensity CBT; is more readily accessed by people who might find it difficult to attend face-to-face appointments for geographical, social, economic or physical health reasons; and can address the problem of patients spending a long time on a waiting list (Lovell *et al.* 2017). Participants in this study were aware of this context, and whilst this could be off-putting, it also made sense to some, and in fact could lead to the immediacy of the treatment being seen as a benefit. Acknowledging the reality of this offering might be something for services and clinicians to consider.

This could perhaps be enhanced by some clarity about the status of eCBT. It is recommended by NICE as a stand-alone low-intensity intervention (NICE, 2018), but has been described as a “good foundation” for further psychological treatment (Richards *et al.* 2016, p17) and a ‘prequel’ or waiting list intervention for those waiting for Step 3 CBT (Richards *et al.* 2018b). Based on the reported experiences of participants in this study, it appears that eCBT can be both/and – experienced as sufficient in itself, but not meeting the desire for something more.

### *Strengths and Limitations of the study*

This study provides information relevant to several of the top ten research priorities for digital technology in mental health care identified by the James Lind Alliance Priority Setting Partnership (Hollis *et al.* 2018), namely: “What are the benefits and risks of delivering mental health care through technology instead of face-to-face and what impact does the removal of face-to-face human interaction have?”, “How do certain mental health conditions (e.g. depression) affect how people engage with technology?”, and “Can the common elements of therapy (e.g. empathy, gestures, non-verbal cues) that come from person-to-person interactions be maintained with digital technology interventions?”

This study replicates a number of themes found in previous studies which involved different participants, different interventions, and different methodologies (Lillevoll *et al.* 2013; Richards & Timulak, 2013; Wilhelmsen *et al.* 2013; Johansson *et al.* 2015; Richards *et al.* 2016; Earley *et al.* 2017; Holst *et al.* 2017; Walsh & Richards, 2017; Burke *et al.* 2018; Richards *et al.* 2018a). These previous studies lend weight to the current study’s findings. The current study builds on previous studies by fleshing out the patient experience of eCBT, particularly by going beyond apparently high ‘satisfaction ratings’ to detail more nuanced positive and negative experiences. This may be due, in part, to the fact that the researchers are not employed by an eCBT developer; this also further strengthens the study.

Furthermore, those who were motivated to attend an interview and wanted to give feedback were probably always likely to be a sample skewed towards the more dissatisfied end of the spectrum. This further suggests that the study’s findings are balanced. However, transcripts and findings were not checked with study participants. This limits the robustness of the

analysis. As a qualitative analysis on a small sample, the study gives depth of insight but cannot guarantee generalisability.

However, the study occurred with participants shortly after they completed treatment, which is an improvement on previous studies which can have delays of 3-6 months (Johansson *et al.* 2015). It also recruited patients from within an NHS IAPT, rather than research trial, setting. The study used a convenience sample rather than requiring theoretical saturation. However, the sample size ( $n = 10$ ) is similar to the numbers at which theoretical saturation is reached in many other papers on the subject (Donkin & Glozier, 2012).

#### *Future Research*

Further studies seeking to extend this paper could nonetheless benefit from requiring theoretical saturation, across different IAPT services, with a more diverse sample, and check the transcripts and analysis with participants. The findings of this research could be used in training for PWPs and others offering eCBT, to see whether this improves the selection of patients and/or the uptake of the intervention, and improved patient experience as reported subjectively and as indicated by drop out and recovery rates. Staff beliefs about patient attitudes towards eCBT have been found to be a barrier to offering them eCBT, and in conflict with the wider evidence base (Morrison *et al.* 2014; Meisel *et al.* 2018); findings from this study could be used to update these attitudes, and the effects measured. Untrained psychology graduate students can share the beliefs of patients about cCBT; training has been shown to improve these and so possibly the way support is offered (Friesen *et al.* 2014). In particular, future research could test whether it would be beneficial to acknowledge concerns identified about eCBT in order to validate patient experience and encourage them to use eCBT nonetheless.

#### *Clinical Implications*

Clinicians should not let their perceptions that service users will not use or benefit from eCBT due to a preference for talking therapy (Meisel *et al.* 2018) stop them from offering it to patients, as despite this preference, participants in this and previous studies showed a willingness to use it, and experienced benefits. Box Two summarises how clinicians and services can make use of the findings of this and previous studies (Richards & Timulak, 2013; Wilhelmsen *et al.* 2013; Johansson *et al.* 2015; Rennick-Egglestone *et al.* 2016; Richards *et al.* 2016; Earley *et al.* 2017; Holst *et al.* 2017; Walsh & Richards, 2017; Burke *et al.* 2018; Richards *et al.* 2018a), including reviews which suggest supported rather than unguided eCBT is now considered more beneficial (Andersson & Hedman, 2013; Johansson *et al.* 2015; Fairburn & Patel, 2017).

BOX TWO HERE

#### **Conclusion**

Although it may not be staff or patients' preference or expectation, participants felt that presenting eCBT in a positive way, both in terms of evidence but also patient experience, can help engage patients with it. They indicated that whilst they may be disappointed they had been willing to try eCBT. It seems important to let them know it is not the only option but is regarded by other service users as a good first step. It can have some beneficial features and helpful impact on their difficulties. Even if they have used self-help before, it is more interactive than self-help, and the presence of the supporter is likely to motivate. Some patients may not be suitable for it, or not want what eCBT has to offer, participants highlighting particularly those who are very unmotivated and/or unable to form a therapeutic relationship online, or whose life circumstances or technological literacy suggests eCBT would not be beneficial, so selection is an issue. It may be helpful for PWPs to (at the beginning and in reviews) encourage patients that it might take a few modules to get the hang of it and see benefit. PWPs can be encouraged by the feedback about the role of the supporter, as patients really do appreciate in a meaningful way the personalised, empathic,

encouraging messages they receive. Participants also appreciated that this benefit could be accessed quickly, given the current demands on and limitations of the NHS.

### **Summary of the main points**

Despite preferring to talk, patients can be willing to engage with eCBT.

This can be facilitated by giving them a choice when offering it, and providing information about what the programme and support involves, including evidence and quotations which show that it has helped other patients.

Patients should be carefully selected so that eCBT is likely to meet their needs.

PWPs can best support users with personalised, encouraging, empathic messages.

This can result in quickly-accessible clinical benefit, which is relevant in the current economic climate.

### **Further reading**

**Carlbring P, Andersson G, Cuijpers P, Riper H, Hedman-Lagerlöf E** (2018). Internet-based vs. face-to-face cognitive behavior therapy for psychiatric and somatic disorders: an updated systematic review and meta-analysis, *Cognitive Behaviour Therapy*, **47:1**, 1-18, DOI: 10.1080/16506073.2017.1401115

**Fairburn, CG, Patel, V** (2017). The impact of digital technology on psychological treatments and their dissemination. *Behaviour research and therapy* **88**, 19-25.

**Olthuis JV, Watt MC, Bailey K, Hayden JA, Stewart SH** (2016). Therapist-supported Internet cognitive behavioural therapy for anxiety disorders in adults. *Cochrane Database of Systematic Reviews*, **Issue 3**. Art. No.: CD011565. DOI: 10.1002/14651858.CD011565.pub2.

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### **Box One: Reported Beneficial features of eCBT**

Mindfulness and Relaxation exercises

Cognitive and Behavioural content

Being able to log in anywhere, anytime

Discreet

Being able to revisit it

Easy to understand

Particular topics: criticising yourself, thinking patterns, understanding stress

Interactivity

Quotations and personal stories

### **Box Two: Clinical and Service Implications**

- Offer supported eCBT rather than unguided cCBT;
- Train clinicians in the evidence base, so they can work with the technology in a constructive and positive way;
- Select patients to whom eCBT is offered carefully – quantitative and qualitative evidence suggests that their difficulties need to be mild-moderate, and that they need to be motivated, comfortable with computers, and to be willing to try to form a therapeutic relationship without talking;
- Give those patients clear information about what eCBT involves (both describing the programme, work and support involved, perhaps with screenshots or videos to illustrate; but also the benefits other patients have reported, including that it is immediately-available and can be used any time they want, the specific skills learnt, that it is more interactive than self-help, and that this can lead to noticeable improvement);
- Support users with personalised (but not necessarily overlong) encouraging and empathic messages;
- Be clear within your service whether eCBT is a stand-alone intervention or a potential waiting list intervention, and give patients the choice to request further intervention if they clinically need it;
- Be aware that patients can worsen whilst using eCBT, so symptom monitoring should be taken seriously.