

Assessing the feasibility of a web-based outcome measurement system in child and adolescent mental health services – myHealthE a randomised controlled feasibility pilot study

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Background: Interest in internet-based patient reported outcome measure (PROM) collection is increasing. The NHS myHealthE (MHE) web-based monitoring system was developed to address the limitations of paper-based PROM completion. MHE provides a simple and secure way for families accessing Child and Adolescent Mental Health Services to report clinical information and track their child's progress. This study aimed to assess whether MHE improves the completion of the Strengths and Difficulties Questionnaire (SDQ) compared with paper collection. Secondary objectives were to explore caregiver satisfaction and application acceptability. **Methods:** A 12-week single-blinded randomised controlled feasibility pilot trial of MHE was conducted with 196 families accessing neurodevelopmental services in south London to examine whether electronic questionnaires are completed more readily than paper-based questionnaires over a 3-month period. Follow up process evaluation phone calls with a subset ($n = 8$) of caregivers explored system satisfaction and usability. **Results:** MHE group assignment was significantly associated with an increased probability of completing an SDQ-P in the study period (adjusted hazard ratio (HR) 12.1, 95% CI 4.7–31.0; $p = <.001$). Of those caregivers' who received the MHE invitation ($n = 68$) 69.1% completed an SDQ using the platform compared to 8.8% in the control group ($n = 68$). The system was well received by caregivers, who cited numerous benefits of using MHE, for example, real-time feedback and ease of completion. **Conclusions:** MHE holds promise for improving PROM completion rates. Research is needed to refine MHE, evaluate large-scale MHE implementation, cost effectiveness and explore factors associated with differences in electronic questionnaire uptake.

Key Practitioner Message

- Patient-reported outcome measures (PROMs) are considered an important tool for measuring treatment success and outcomes in healthcare systems.
- Adherence to routine PROM guidance in Child and Adolescent Mental Health Services (CAMHS) remains low, largely driven by limitations associated with paper-based data collection.
- Paperless monitoring systems (i.e. digital) as an alternative to traditional outcome measure delivery and collection are growing in healthcare settings.
- Remote questionnaire completion using the myHealthE (MHE) system is feasible and acceptable to caregivers of children accessing CAMHS in South London. Results suggest a 12-fold increase in Strengths and Difficulties questionnaire reporting compared to standard practice.
- More research is required to understand whether MHE implementation affords similar improvements in remote PROM completion at scale and whether electronic questionnaire uptake is equal for different socio-demographic and clinical populations.

Keywords: Child and adolescent mental health; patient-reported outcome measures; remote monitoring; acceptability

Introduction

Patient-reported outcome measures (PROMs) enable standardised and direct collection of a patient's perceived health status (Devlin & Appleby, 2010). Used routinely, PROMs are recognised as a clinically valuable method to measure patient- or caregiver-rated symptoms, assess intervention success, and encourage shared patient and practitioner communication and decision making (Carlier, Meuldijk, Van Vliet et al., 2012; Lambert, Whipple, Hawkins et al., 2003; Soreide & Soreide, 2013). Child and Adolescent Mental Health Services (CAMHS) in England are encouraged to collect information about young people's presenting problems at entry to CAMHS and again within 6 months of receiving treatment (Department of Health (DoH), 2004, 2015; Morris et al., 2020) using PROMs. However, audit and survey studies demonstrate low guideline adherence, suggesting that CAMHS struggle to implement PROMs (Batty et al., 2013; Hall et al., 2013; Johnston & Gowers, 2005). Recent research investigating the electronic health records of 28,000 patients accessing CAMH services across South London identified paired use of the Strengths and Difficulties Questionnaire PROM (SDQ; Goodman, 1997), in only 8% of patients (Morris et al., 2020) and as few as 1% within specific clinical groups (Cruz et al., 2015).

Data collection using traditional paper questionnaires is associated with several time- and resource-intensive steps, including printing, postage and processing returned outcome measures. Although paper questionnaires are practical and easy to complete, already-burdened clinicians struggle with the administrative effort required to capture paper-based questionnaires (Boswell, Kraus, Miller, & Lambert, 2015; Hall et al., 2014; Johnston & Gowers, 2005). Response data are also easily compromised, for example, users can omit questions, select multiple responses per item, and mark outside the questions tick box margins, leading to missing or unusable data (Ebert, Huibers, Christensen, & Christensen, 2018).

A rapid rise in internet use has paved the way for electronic questionnaires (Lyon, Lewis, Boyd, Hendrix, & Liu, 2016). Electronic PROMs (ePROMs) are reported to be less time consuming (Cella et al., 2015), require fewer administrative duties (Black, 2013; Coons et al., 2015; Eremenco, Coons, & Paty, 2014), cost less (Zuidgeest, Hendriks, Koopman, Spreeuwenberg, & Rademakers, 2011) and evoke more honest (Black & Ponirakis, 2000) and less erroneous responses; prompting patients to respond to all items within a questionnaire and only provide one response per question (Coons et al., 2015; Dillon et al., 2014; Eremenco et al., 2014; Jamison et al., 2001).

Feasibility trials of web-based monitoring systems report positive outcomes relating to patient engagement, satisfaction and clinical value (Ashley et al., 2013; Barthel et al., 2016; Nordan et al., 2018; Schepers et al., 2017). However, less research is available on the

development and application of ePROM systems in CAMHS. Interviews with mental health service users demonstrate positive attitudes toward the use of technology to assist traditional care (Borzekowski et al., 2009). However, patients have highlighted barriers to web-based portal acceptability, including computer literacy, perceived usefulness, suitability, confidentiality, feedback and the effect application use has on their capacity to manage their condition and therapeutic relationships (Niazkhani, Toni, Cheshmekaboodi, Georgiou, & Pirnejad, 2020).

The myHealthE (MHE) system was built to enable remote PROM monitoring in CAMHS. This system aims to automate the communication, delivery and collection of ePROMs at predefined post-treatment periods, providing caregivers with a safe and engaging way to share clinically relevant information about their child with their allocated care team with minimal human input. MHE architecture, development and implementation methodology, including key aspects of data safety and governance, have been described previously (Morris et al., 2021). MHE external web-development was provided by Digital Marmalade (see Acknowledgements). Novel healthcare applications require feasibility and acceptability testing to ensure that the technology is understandable and can be used successfully by the target end-user in real-world clinical surroundings before conducting a large-scale system evaluation (Steele Gray et al., 2016). As described in our protocol [(ISRCTN) 22581393], the primary purpose of this trial was to understand whether MHE use should be assessed in CAMHS on a wider scale. Therefore, we conducted a feasibility pilot study to evaluate whether introducing MHE increased completion of PROMS over the course of CAMHS treatment compared to standard data collection procedures, as measured by the proportion of ePROMS relative to paper questionnaires completed over a 3-month period. Secondly, we aimed to assess caregiver satisfaction with the MHE system via individual caregiver phone consultations. Given resource constraints we were unable to assess the economic benefit of MHE compared to standard data acquisition as per our protocol. We hypothesised that MHE implementation would afford a substantial increase in completed standardised caregiver-reported follow-up data and caregiver satisfaction with CAMHS services compared to routine data collection.

Methods

Design

The current study comprised a single-blind parallel group feasibility pilot randomised control trial (RCT) of MHE. Outcome, sociodemographic and service level data were obtained from the Clinical Record Interactive Search (CRIS) system. CRIS contains de-identified medical record history from the South London and Maudsley (SLaM) National Health Service Foundation Trust, one of Europe's largest mental health care organisations providing services to over 34,400 children and adolescents between the 1 January 2008 and 1 December 2019 (Downs

et al., 2019; Perera et al., 2016; Stewart et al., 2009). This research tool was established by SLaM's National Institute of Health Research Biomedical Research Centre (NIHR BRC) in 2008, to enable information retrieval for the purpose of approved research (Fernandes et al., 2013). Comprehensive electronic health record (EHR) information is available for SLaM services from 2006.

Setting and participants

The trial was conducted at Kaleidoscope, a community paediatric mental health centre, based in Lewisham, South London, between the 11 February 2019 and the 14 May 2019. Eligible participants were caregivers of CAMHS patients aged between 4 and 18 years old with a diagnosis of autism spectrum disorder (ASD). Patients were under the care of Lewisham Neurodevelopmental Team and had at least one SDQ present in their EHR. Caregivers were recruited if they had contact details (mobile phone number and/or email address) recorded in their child's EHR. The MHE data collection process was directly comparable to current paper-based practice, except for its electronic basis and only collected data which was ordinarily requested from families by their treating clinical team. Caregivers did not have to provide informed consent to participate in this trial, but could choose to opt-out via email or phone call to the trial research assistant (ACM). Recruitment was achieved through SLaM EHR screening. A Microsoft SQL script was developed and implemented by a senior member of the SLaM Clinical Systems Team and automatically provided an extract of eligible patients to the research team. Subsequently, computerised condition allocation and simple randomisation assigned eligible caregivers to either receive PROM outcome monitoring as usual (MAU; control group) or enrolment to the MHE platform (intervention group) on a 1:1 basis. Clinicians were blinded to condition allocation, and not informed which patients on their case load had been allocated to receive MHE or MAU.

Measures, sociodemographic and clinical characteristics

The primary outcome variable was time to completed follow-up caregiver SDQ (SDQ-P; electronic vs. paper SDQ-P) within the 3-month observation period. The SDQ-P (Appendix 1) is a structured 25-item questionnaire screening for symptoms of childhood emotional and behavioural psychopathology (Goodman, 1997). SLaM holds a sub-licence to use the SDQ to support clinical service via NHS Digital Copyright Licensing Service. It is current clinical practice to collect SDQ-P for young people, either by post before their first face-to-face meeting, or on site during a clinical appointment to inform their baseline assessment and again 6 months after starting treatment or upon discharge from CAMHS. Other variables extracted from CRIS are presented in Table S1.

Process evaluation: usability testing

To evaluate MHE usability, we contacted by telephone a subset of caregivers randomly assigned to MHE. This subset included a convenience sample of six caregivers who had engaged with MHE and two caregivers who had not. Caregivers were asked to access the MHE portal and complete the System Usability Scale (SUS; Brooke, 1996) to examine subjective usability. SUS comprises 10 statements reported on a 5-point Likert scale ranging from strongly disagree to strongly agree. The total score is presented as a figure from 0 to 100, with a greater score reflecting higher usability. Mean SUS score was computed and ranked using Bangor, Kortum, and Miller's (2008) acceptability scale defined as 'not acceptable', 'marginal' and 'acceptable'. Following administration of the SUS, caregivers were invited to ask questions about the platform or provide any further comments about their experience of using MHE.

Sample size

The current trial aimed to inform the development of a larger, adequately powered RCT by providing precise estimates of acceptability and feasibility, in addition to outcome variability.

A threshold of clinical significance was decided a priori to be 15% between MAU and MHE groups for SDQ-P completion within 3-months, based on consensus from Kaleidoscope staff and previous research indicating an expected baseline completion rate of 8% SDQ-P in the control group (Morris et al., 2020). For a fixed sample size design, the sample size required to achieve a power of $1 - \beta = .80$ for the two-tailed chi-square test at level $\alpha = .05$, under the prior assumptions, was $2 \times 91 = 182$ on a 1:1 allocation ratio. The power calculation was carried out using Gpower 3.1.7. To increase power and reduce the risk of chance imbalance between MHE and non-MHE groups, we followed recent guidance on covariate adjustment within RCTs of moderate sample size (Kahan, Jairath, Doré, & Morris, 2014), and included in our analyses, several factors which could have potential influence on PROM completion (Morris et al., 2020).

Intervention and procedure

Figure 1 provides an overview and description of the MHE data flow. All caregivers of patients receiving care from Lewisham Neurodevelopmental Team were contacted by letter. This letter informed them of potential changes to clinical information collection (i.e. electronic rather than paper questionnaires) and provided with an information sheet and MHE information leaflet (Appendix 7a,b). After group assignment, caregivers allocated to receive MHE were contacted with a text (Appendix 2a) or email message (Appendix 3a) inviting them set up a personalised web-portal (Appendix 4) and complete an SDQ-P (Appendix 5a,b, caregivers were enrolled in the trial irrespective of whether they registered their MHE account). Caregivers who did not register were sent an automated weekly prompt to enrol and complete an SDQ-P (see Appendix 2b and 3b). Once an online questionnaire was completed, caregivers were presented with infographics based on their responses (Appendix 6a–c), and they were then contacted monthly to provide follow-up SDQ data. In the control group caregivers were requested to complete paper SDQ-P face-to-face or by post according to clinician discretion. Apart from electronic SDQ-P completion for the intervention group, treatment remained the same for all participants. Information collected through MHE was stored in the child's EHR and managed in the same way as all other confidential information. SDQ-P data were checked daily by ACM and promptly entered to the patient's EHR. Post intervention, all participants received a letter thanking them for their participation.

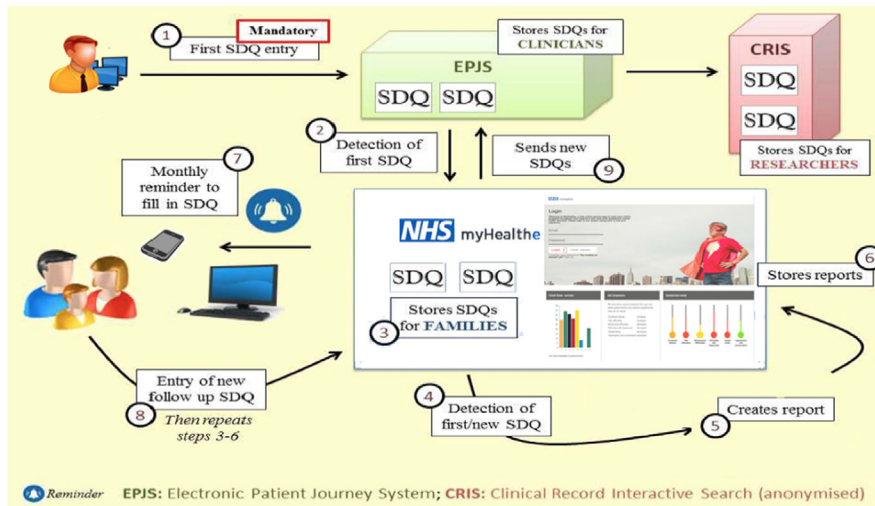
Strategy for analysis

All analyses were conducted using STATA version 14 (StataCorp., 2015). Analyses were conducted to determine differences in SDQ-P completion between paper based (MAU, monitoring as usual) approaches and MHE. Analysis was performed subject to intention-to-treat like principles (intention-to-contact), whereby all participants were analysed according to their initially assigned intervention arm, irrespective of protocol adherence or deviations. Cox regression was used to examine the relationship between MAU versus MHE group assignment and SDQ-P completion rates. Using a Kaplan–Meier curve, we checked whether group assignment (as predictor) satisfied the proportional hazards assumption. Our first analysis examined the association between treatment group only and SDQ-P completion. The second model adjusted for demographic and clinical covariates captured in this trial. An inverse Kaplan–Meier curve was plotted to visualise the probability of SDQ-P completion, comparing caregivers who completed electronic and paper SDQ-P. For the intervention group the MHE website–SDQ-P completion conversion rate was reported as a percentage by measuring the number of caregivers that register on MHE and subsequently completed a follow-up SDQ-P.

Results

Enrolment and baseline characteristics

Within study, participant flow and data collection rates are provided in Figure 2. A total of 342 caregivers were



- 1) Clinicians entered baseline SDQ-P information to their patient's EHR.
- 2) MHE automatically detected and extracted SDQ-P data, caregiver mobile numbers and email addresses held within SLAMs HER.
- 3) MHE stored SDQ-P data, caregiver mobile numbers and email addresses.
- 4) MHE identified a new SDQ-P.
- 5) MHE generated a report from new SDQ-P information.
- 6) MHE stored this report.
- 7) MHE sent the caregiver a text message (Appendix 2a) and email (Appendix 3a) inviting them to register on a personalised web-portal (Appendix 4) and after registration MHE prompted caregivers to complete follow-up SDQ-P (7; Appendix 5a and 5b).
- 8) Caregivers completed new SDQ-P via MHE, then steps 3 to 6 were repeated at monthly intervals. If a request for an SDQ-P to be completed are left unattended, caregivers received reminders at weekly intervals until each requested from was filled (Appendix 2b and 3b). Then new SDQ-P scores were automatically scored by the application (Appendix 6a and 6b) and sent to the patients' EHRs (initially via manual entry, and then entered via an automated system which was available for use 4 weeks into the trial).
- 9) SDQ-P data were stored and available to patients treating clinicians in the same way as standard data collection, as well as to the CRIS platform in de-identified format. Results were displayed on patient portal in the form of basic graphs and visualisations (Appendix 6c).

Figure 1. myHealthE data flow-diagram

screened for eligibility of which ($n = 196$) met the inclusion criteria. Of the 146 excluded, the majority were due to lack of baseline SDQ ($n = 132$). During eligibility screening caregiver contact information was often missing or located in an area of the patients' EHRs different from expected, therefore manual contact detail collection was carried out to enable digital communication via MHE. In some cases, no current parental mobile phone number nor email address was found within the EHR ($n = 14$). Caregivers were enrolled and randomly assigned to the intervention group (MHE $n = 98$) and the control group (MAU $n = 98$). Of caregivers assigned to MHE and MAU, 30 (36.3%) did not receive notifications from MHE, with the text monitoring system logging these mobile numbers were incorrect or not in use. The conversion rate from account registration to SDQ completion was 98% (47/48). Table S2 outlines account registration issues and opt-out preferences reported by caregivers.

Table 1 presents sociodemographic and service characteristics for the whole sample. Participants were

ethnically diverse, predominantly male and at the older end of the age range accepted by CAMHS.

Electronic versus paper SDQ-P collection

During the trial 47 caregivers [47.9% of intention-to-contact (total $n = 98$), 69.1% of actually contacted (total $n = 68$)] registered an account on the MHE platform and completed at least one follow-up SDQ-P. In the corresponding timeframe 6 (intention to contact = 6% ($n = 98$) and actually contacted = 8.8% ($n = 68$) caregivers assigned to receive MAU completed at least one follow-up SDQ-P. Second follow-up was due for 43 of the MHE cohort by the end of the study period (at least 1 month had elapsed since completing their first online SDQ-P) and of these 31 caregivers completed this (72%). Overall, 87 follow-up SDQ-Ps were completed via the MHE platform: Figure 3 provides a breakdown of SDQ-P completion within each 7-day notification reminder period.

The ITC Cox regression models are presented in Table 2, and graphically depicted in Figure 4. MHE

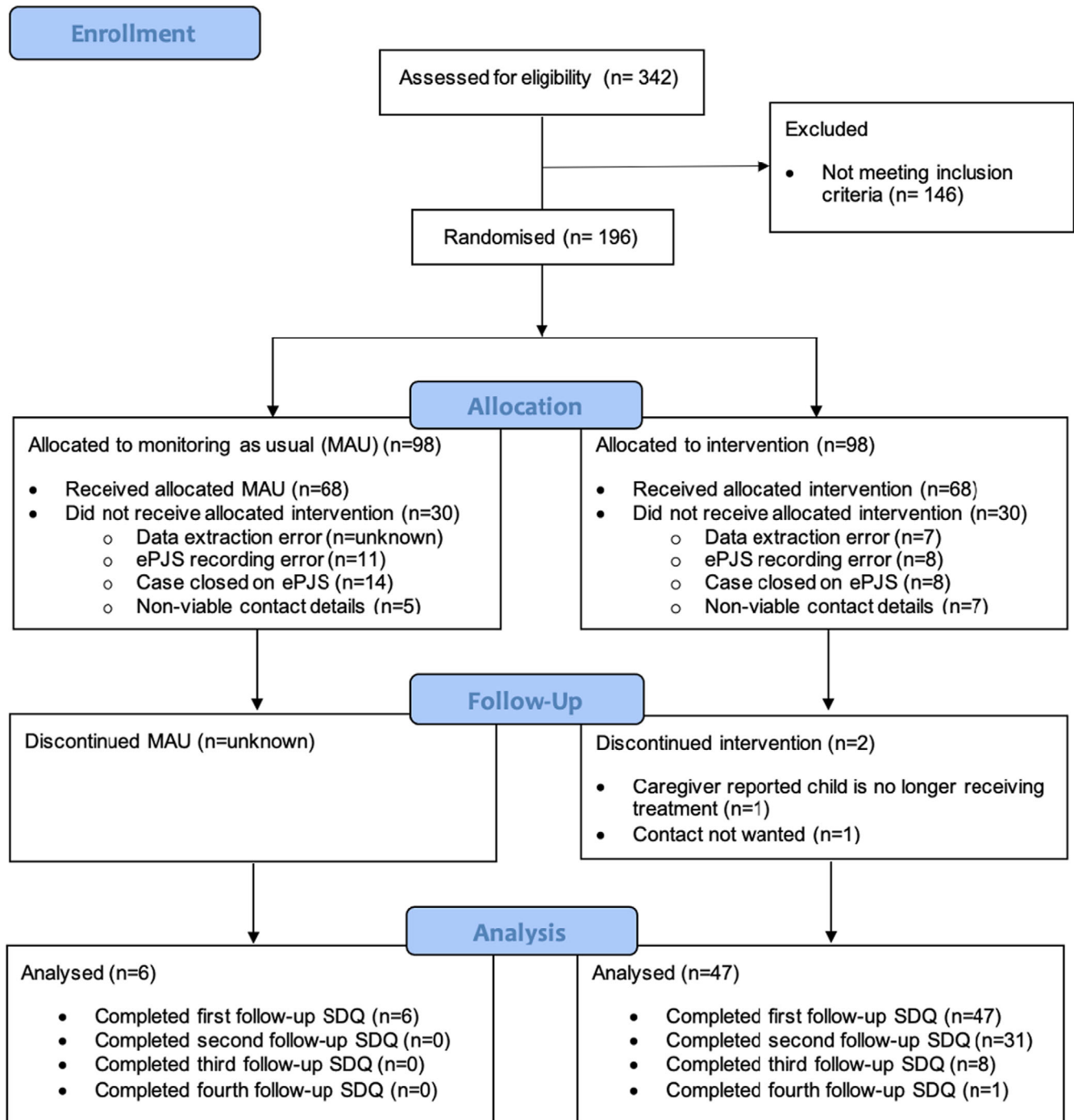


Figure 2. Consort diagram presenting recruitment and rate of data collection for MHE and MAU

group assignment was significantly associated with an increased probability of completing an SDQ-P in the study period (adjusted hazard ratio (HR) 12.1, 95% CI 4.7–31.0; $p < .001$). This was observed after controlling for potentially confounding socio-demographic characteristics and clinical factors including, gender, age at the start of the trial, baseline CGAS (Schaffer et al., 1983) and SDQ profiles, co-morbid ADHD, learning disability, and emotional disorders as well as number of days of active care and attended face-to-face events. No significant interaction was found between ethnic status (white and non-white ethnic groups) and SDQ-P completion by group.

Caregiver perspective of MHE implementation

A total of eight SUS questionnaires and usability interviews were completed. The mean SUS score for users of the website was 78/100 indicating that the application was ‘acceptable’ to users. Figure 5 provides a summary of caregiver’s comments regarding MHE.

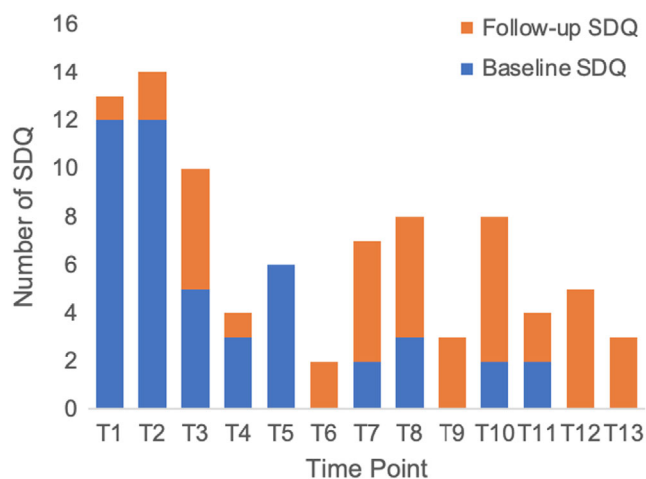
Discussion

This feasibility pilot showed that the collection of electronic PROMs using web-based technology is feasible in CAMHS practice. Implementation of MHE, a novel remote monitoring platform afforded considerable rates

Table 1. Baseline patient and clinical characteristics of MHE versus MAU following randomisation ($n = 196$)

	Total sample $n = 196$	
	MAU = 98	MHE $n = 98$
Gender, n (%)		
Male	74 (75.5)	74 (75.5)
Mean age at trial start (SD)	14.3 (2.7)	14.3 (2.8)
Ethnicity, n (%)		
White	39 (39.8)	46 (46.9)
Black	35 (35.7)	23 (23.5)
Asian	2 (2.0)	1 (1.0)
Mixed	13 (13.3)	15 (15.3)
Other or not stated	9 (9.2)	13 (13.3)
Level of deprivation, n (%)		
1st (least deprived)	22 (23.2)	25 (25.8)
2nd	21 (22.1)	27 (27.8)
3rd	24 (25.2)	24 (24.7)
4th (most deprived)	28 (29.5)	21 (21.7)
Co-morbid diagnosis, n (%)		
ADHD	48 (49.0)	39 (39.8)
LD	14 (14.3)	11 (11.2)
Emotional disorder	14 (14.3)	17 (17.4)
Mean CGAS score (SD)	53.1 (10.7)	54.6 (8.8)
Mean days of active care (SD)	592.1 (196.4)	563.0 (210.4)
Mean attended F2F events (SD)	6.0 (10.2)	9.1 (21.0)
Mean baseline SDQ Scores (SD)		
Emotional	5.3 (2.5)	5.5 (2.8)
Conduct	4.3 (2.3)	4.5 (2.4)
Hyperactivity	7.5 (2.3)	7.7 (2.1)
Peer difficulties	4.8 (2.3)	5.2 (2.3)
Prosocial	5.2 (2.6)	5.4 (2.3)
Impact score	5.9 (3.4)	5.6 (2.9)
Total difficulties	22.1 (5.5)	23.0 (5.3)

SD, standard deviation.

**Figure 3.** Baseline and follow-up SDQ completion within each 7-day notification period

of SDQ-P completion (69%) for caregiver's who received an invitation to register for MHE compared to 12% paper-based SDQ-P completion. By way of contrast, a comprehensive audit of over 28,000 young people services accessing CAMHS found paired SDQ-P completion rates of 8%. By automating unassisted delivery of PROMs at specified time points, MHE may address several fundamental challenges inherent to paper-based information gathering in busy clinical settings, such as

Table 2. An Intention to contact Cox-regression analysis of the relationship between electronic compared to paper-based SDQ-P assignment and SDQ-P completion rates ($n = 195$), adjusted model taking into account participant characteristics

Group (MHE vs. MAU)	Crude H.R (95% CI)	p -Value	Adjusted model H.R (95% CI)	p -Value
		10.1 (4.3–23.6)	<.01	12.1 (4.7–30.9)
Gender				
Male			0.4 (0.2–0.8)	.02
Ethnicity				
White			Reference	–
Black			0.5 (0.2–1.2)	.13
Asian ^a			na	na
Mixed			1.1 (0.4–2.5)	.88
Other or not stated			0.5 (0.2–1.4)	.16
Age at trial start			1.0 (0.9–1.1)	.90
Co-morbid diagnosis				
ADHD			0.8 (0.4–1.6)	.47
LD			1.5 (0.6–4.0)	.44
Emotional disorder			2.5 (1.0–5.8)	.04
Days of active care			1.0 (1.0–1.0)	.77
Attended F2F events			1.0 (1.0–1.0)	.61
Baseline SDQ scores				
Emotional			1.0 (0.9–1.2)	.61
Conduct			1.0 (0.9–1.1)	.85
Hyperactivity			1.1 (1.0–1.3)	.17
Peer difficulties			1.0 (0.9–1.2)	.94
Prosocial			1.1 (0.9–1.2)	.94

^aCovariate dropped due to <5 cell size value.

processing burden, lack of supportive infrastructure and poor administration guideline knowledge (Boswell et al., 2015; Duncan & Murray, 2012; Waldron, Loades, & Rogers, 2018; Wolpert, 2014).

In post-trial interviews caregivers rated MHE as 'acceptable', suggesting good levels of usability. Many caregivers favoured the ease and speed of using MHE to complete outcome measures compared to paper-based methods, while barriers included how readily information provided through the platform was used by clinicians to identify children with worsening symptoms and data privacy concerns. However, only a small number of caregivers were contacted to provide their views on the system; therefore, it is possible that other undetected usability issues influenced the results of this trial, for example: language, literacy level, disability, and cultural sensitivity difficulties (Bodie & Dutta, 2008; Kontos, Bennett, & Viswanath, 2007; Lindsay, Bellaby, Smith, & Baker, 2008; Morey, 2007).

Historically, low engagement with eHealth has been attributed to unequal internet access (Latulippe, Hamel, & Giroux, 2017) but did not appear to account for non-engagement in the current trial. This finding is likely to reflect the substantial increase in mobile phones and other internet-enabled mobile technology availability (Pew Research Center, 2019), reduced cost of internet subscriptions and widening availability of free public

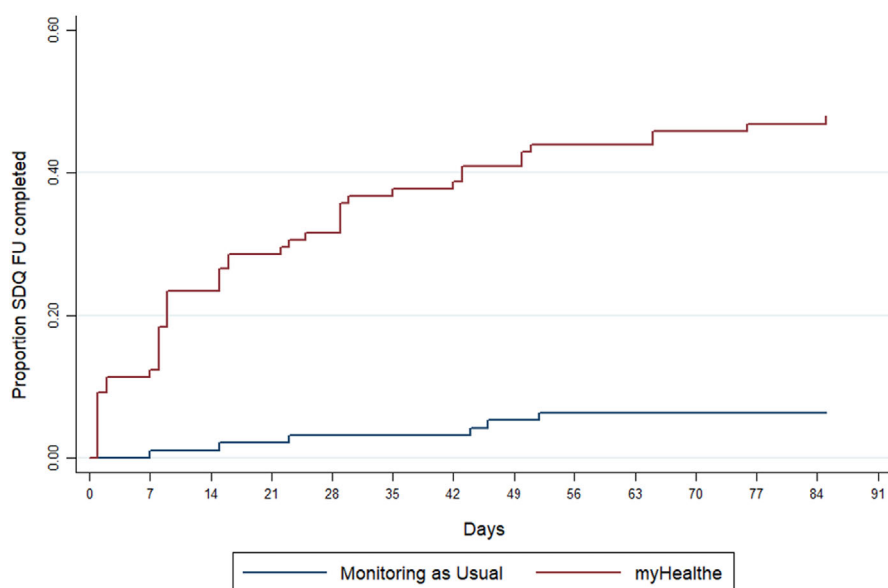


Figure 4. Kaplan-Meier curve illustrating the probability of SDQ-P within study period between caregivers assigned to complete electronic compared to paper SDQ-P

- Practicalities of safe electronic data collection – it is useful, easy, and quick
- Simplicity of use depends on existing computer skills – needed to ask their child for assistance
- Self-management – visualisation feedback improved symptom knowledge
- Want information to be reviewed by clinicians and symptom deterioration to be prioritised
- Platform engagement issues – not suitable at discharge or following negative treatment experiences
- Want support service information specific to their community to be included
- Want accessible versions of MHE developed

Figure 5. Summary of patient feedback following MHE use

Wi-Fi (Kontos et al., 2007; McAuley, 2014). However, despite physical internet access, end-users may not have the skills necessary to fully engage with digital technologies (Hargittai, 2002). This was the case for several caregivers who reported that their limited information technology capabilities and knowledge, making it hard to navigate MHE without assistance from family members. This disparity may deepen as digital platforms are increasingly integrated into routine clinical practice (Van Dijk, 2005) and should be iteratively considered during the design and implementation of emerging digital health platforms, paying particular attention to the role of co-design (Andersen, 2019).

Strengths and limitations

This trial was conducted in a naturalistic manner independent of clinical practice to ensure that clinician's behaviour, for example, promoting MHE use did not inflate observed rates of engagement. Moreover, the

research was conducted in a socio-demographically diverse geographical area, resulting in a broad range of caregivers testing the system. Finally, condition allocation was computerised meaning that all participants were instantly allocated to either receive MAU or MHE. Therefore, it was unlikely that allocation bias would have influenced the trial findings.

Limitations include the fact that families only had the opportunity to enrol to the trial if they had a baseline SDQ present in their child's EHR, which relies on this being initiated by a clinician in the first instance. In the future, using MHE to capture baseline and follow up SDQ-P data may afford a more realistic assessment of ePROM feasibility. It is also possible that neurodevelopmental team service users perceived the SDQ-P as less useful than a disorder specific questionnaire, which may have resulted in lower rates of completion level. As we were primarily focused on developing an interface for parents, co-design sessions with clinicians were limited.

Further work is needed to examine what is potentially lost using ePROMS compared pencil and paper approaches, and how this could be mitigated by improved design within later versions of myHealthE. Lastly, owing to resource constraints phone interviews were conducted after the trial ended meaning that responses could be influenced by recall bias.

Future research and MHE refinement

The next phase of this research is to extend this feasibility study across multiple-healthcare sites and other child mental health specialties and additional pertinent PROMs. Plans are already in place to extend MHE introduction to national and specialist teams and further SLAM CAMHS teams across Southwark, Lambeth and Croydon. Recent funding secured from the National Institute for Health Research (NIHR; <https://fundingawards.nihr.ac.uk/award/RP-PG-0618-20003>) and the Medical Research Council (MRC) Mental Health Pathfinder award to King's College London has enabled MHE to be converted into a scalable NHS software as a service (SaaS) product, with a roadmap to implement MHE across four other Trusts in England. Collecting data from a larger number of caregivers will enable us to explore the effects of various patient factors on ePROM engagement. Research investigating differential uptake in PROM collection suggests that several patient characteristics including ethnicity and social deprivation are associated with inequitable PROM use (Latulippe et al., 2017; Morris et al., 2020). While this was not the case in the current small-scale trial, it is essential that further research is conducted to determine whether these systems sustain possible health inequalities with larger sample sizes. System refinements are also required to enable alternative methods for acquiring and inputting caregiver contact information to circumvent the difficulties encountered with automatic data extraction in this study.

In-depth interviews are needed to explore how ePROM platforms can be adapted to meet different service user and clinician needs. Qualitative work is needed to provide more general insights into: (a) caregivers' reasons for deciding to complete or not complete electronic questionnaires; (b) clinicians' perspectives on how digital collection systems and analysis of outcomes could enhance decision making at individual level; (c) clinician and caregivers' views on the concept, design and delivery of MHE, the barriers and facilitators for MHE implementation and identify potential harms and study protocol refinement (e.g., platform design and frequency of questionnaire completion); and (d) young people's perspective on whether the MHE could be adapted as self-reported outcome collection system, and if trialled, how it should be evaluated.

Conclusion

Routine PROM collection is essential for delivering personalised health services that reflect clinical need from the perspective of young people and their families. This study supports the feasibility of a remote PROM monitoring platform within a real-world outpatient setting providing treatment to a demographically diverse population. Intimating that web-platforms may provide an

acceptable and convenient method to maintain and scale up improved patient monitoring, service-user communication, and service evaluation. A future multisite trial of MHE is required to evaluate this e-system at scale.

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Ethical information

Approval for the study was given by the South London and Maudsley NHS Foundation Trust CAMHS Clinical Audit, Service Evaluation and Quality Improvement Committee (approval date: 07/04/2017). Extraction and analysis of deidentified outcome data were carried out using the CRIS platform and security model approved by Oxford Research Ethics Committee C (reference 18/SC/0372).

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Supporting information

Additional Supporting Information may be found in the online version of this article:

Table S1. List of socio-demographic and clinical variables extracted from CRIS.

Table S2. Description of caregiver opt-out preferences and technical difficulties encountered at MHE registration.

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Appendix 1

Strengths and Difficulties Questionnaire

Strengths and Difficulties Questionnaire

P 4-17

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months.

Child's Name Male/Female

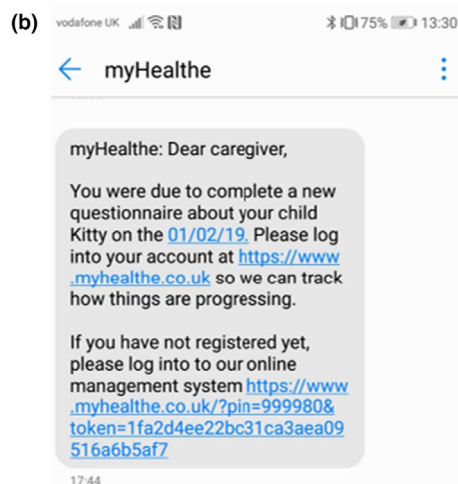
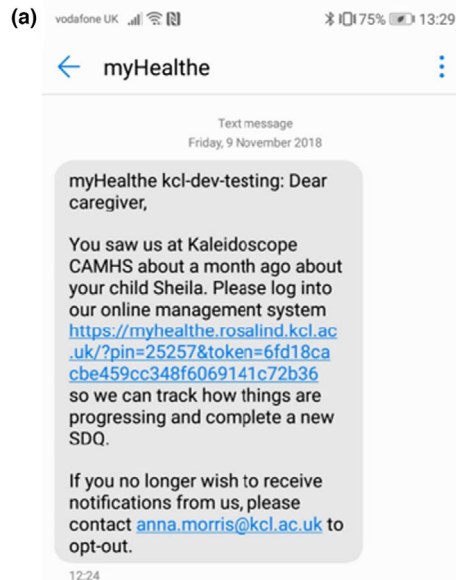
Date of Birth.....

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless, overactive, cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often complains of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shares readily with other children (treats, toys, pencils etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often has temper tantrums or hot tempers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather solitary, tends to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally obedient, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many worries, often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often fights with other children or bullies them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally liked by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily distracted, concentration wanders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous or clingy in new situations, easily loses confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often lies or cheats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picked on or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often volunteers to help others (parents, teachers, other children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinks things out before acting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steals from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets on better with adults than with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many fears, easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sees tasks through to the end, good attention span	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any other comments or concerns?

Appendix 2

(a) MHE invitation text message; (b) MHE reminder text message



Appendix 3

(a) MHE invitation email; (b) MHE reminder email

(a) Follow up report on Anne

Show blocked content

Flag for following up. Start by 19/11/2018. Due by 19/11/2018.

MK myHealthe kcl-dev-testing <myhealth
e.kcldevtesting@notifications.service.g
ov.uk>
Fri 16/11/2018 12:47
Morris, Anna

NHS myHealthE

Dear caregiver,

You saw us at Kaleidoscope CAMHS about a month ago and completed a SDQ.

Please log into to our online management system
<https://myhealthe.rosalind.kcl.ac.uk/?pin=25253&token=1408ce8071f5ae50a118e49d0b831f07>
to access this report and track how things are progressing and complete a new SDQ.

If you no longer wish to receive notifications from us, please contact anna.morris@kcl.ac.uk to opt-out.

(b) Reminder report on Joseph

Getting too many emails? Unsubscribe

M myHealthe
Tue 30/04/2019 17:43
Morris, Anna

NHS myHealthE

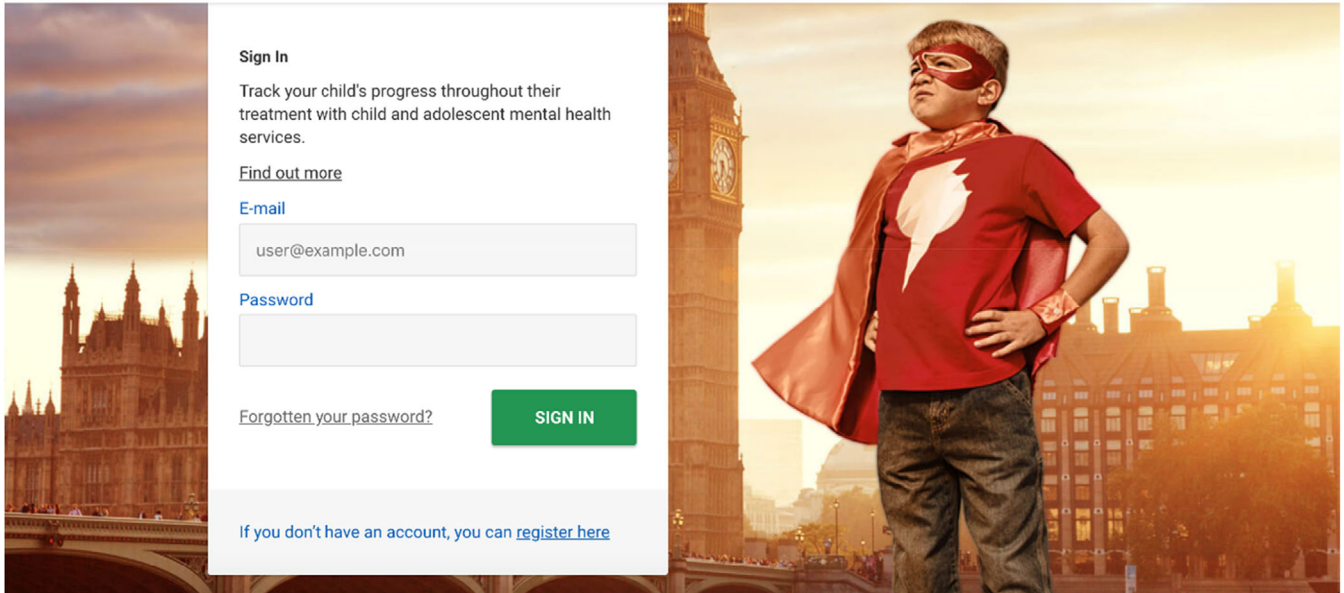
Dear caregiver,

You were due to complete a new questionnaire about your child on the 07/02/19. Please log into your account at <https://www.myhealthe.co.uk> so we can track how things are progressing.

If you have not registered yet, please log into to our online management system <https://www.myhealthe.co.uk/?pin=379193&token=fb52b9f9155573cbbd2b6d1a70f570f1>.

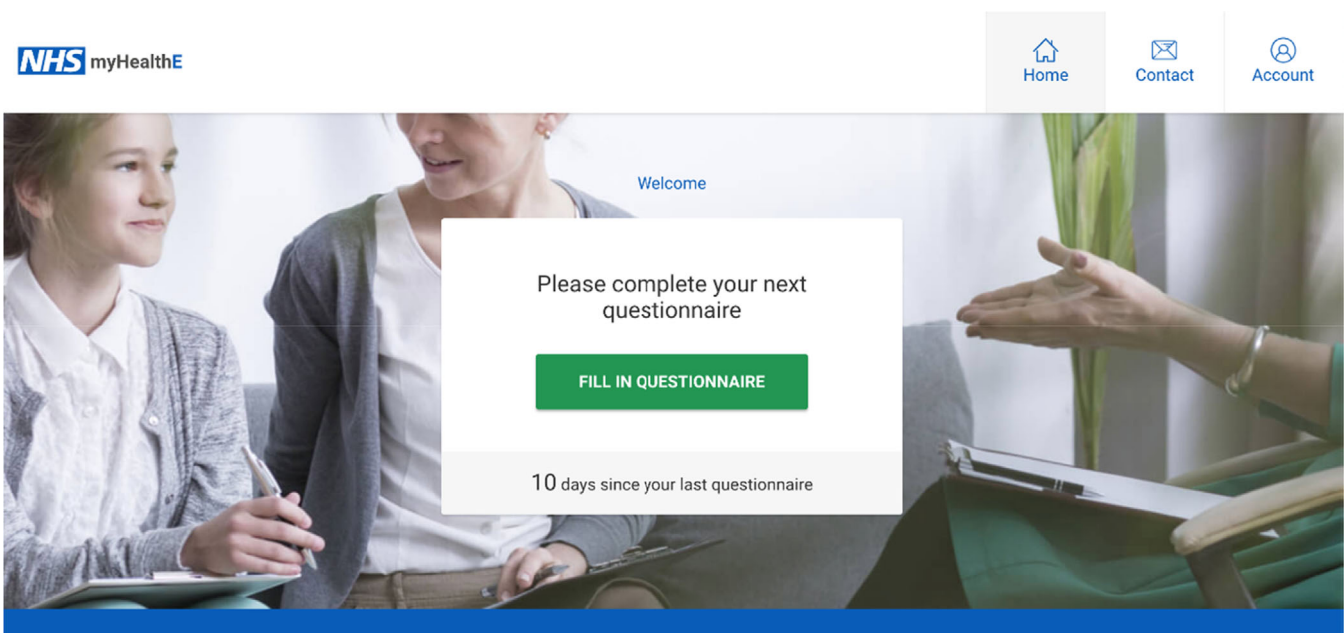
Appendix 4

MHE login page



Appendix 5

(a) MHE home page (when questionnaire is due to be completed)



(b) Electronic Strengths and Difficulties Questionnaire



Questionnaire

Please give your answers based on the child's behaviour over the last few months.

Please note that results of the SDQ will be different depending on how your child is feeling on that particular day, the information you provide will be used to inform the care plan as discussed with your child's care-coordinator

Any information you provide on this website will not be received promptly by your child's care-coordinator.

1 — 2 — 3 — 4

Considerate of other peoples feelings

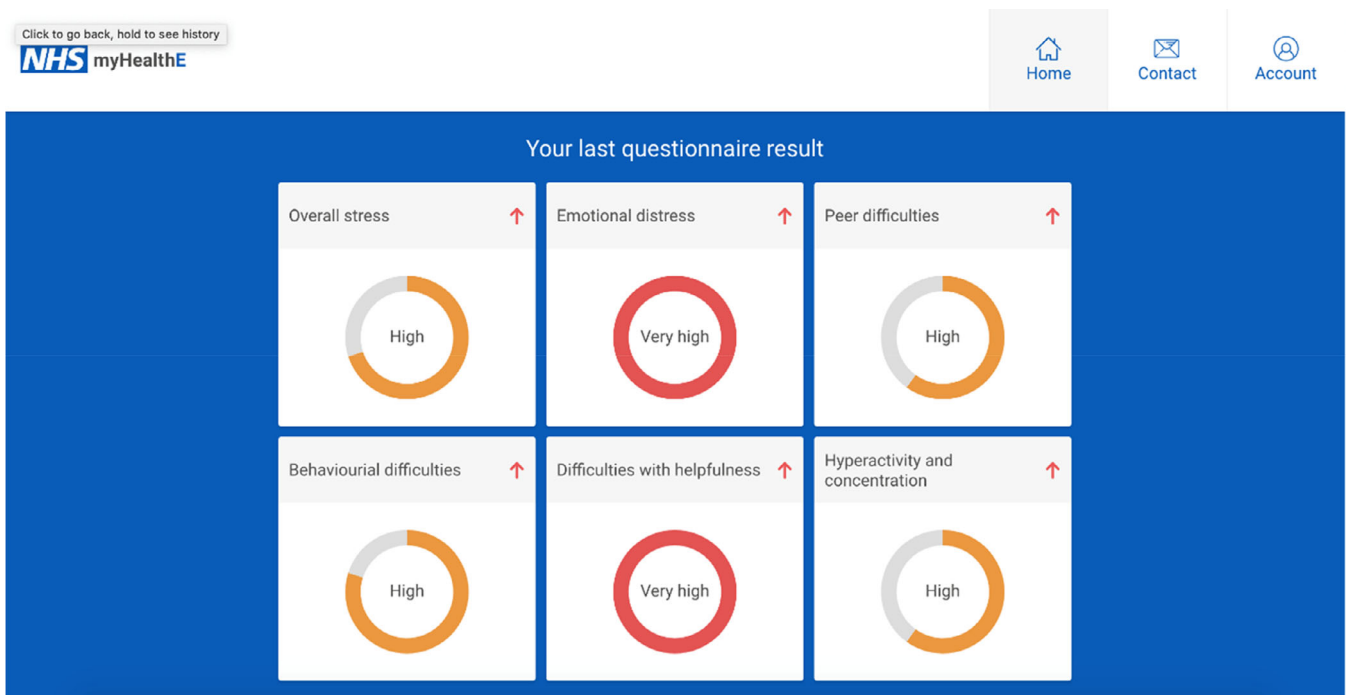
Not True
Somewhat True
Certainly True

Restless, overactive, cannot stay still for long

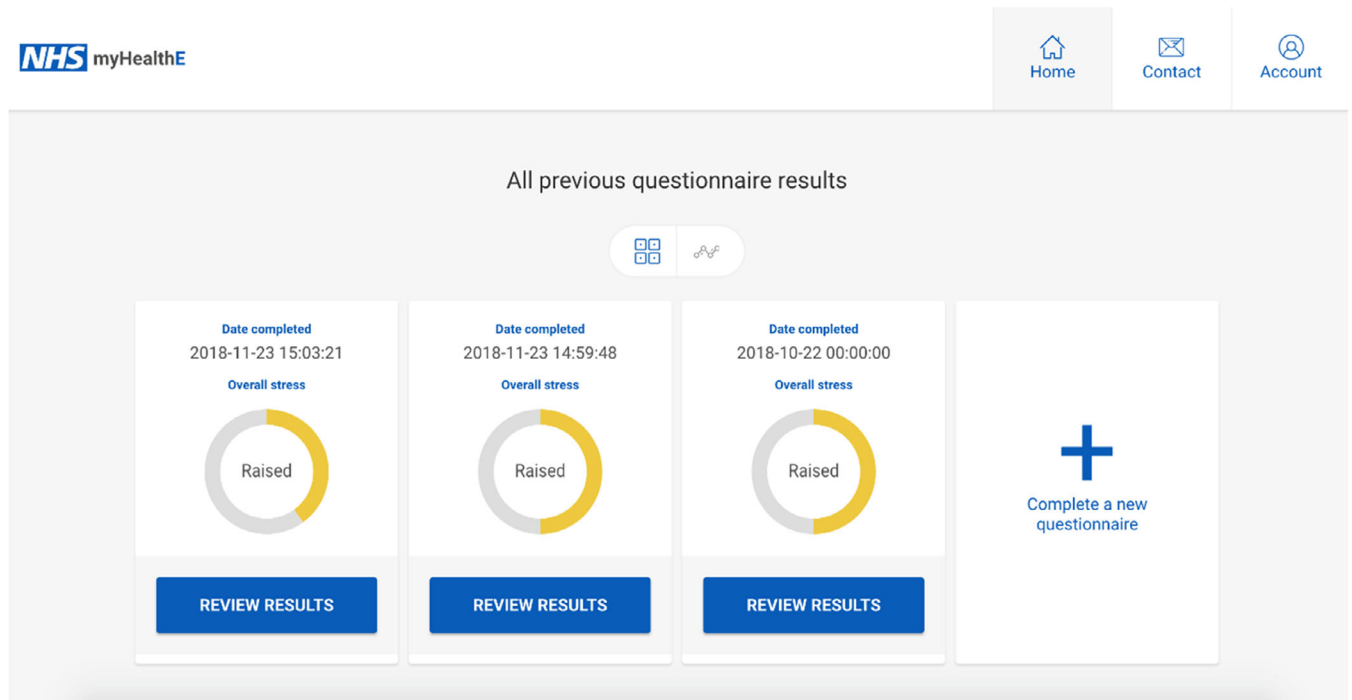
Not True
Somewhat True
Certainly True

Appendix 6

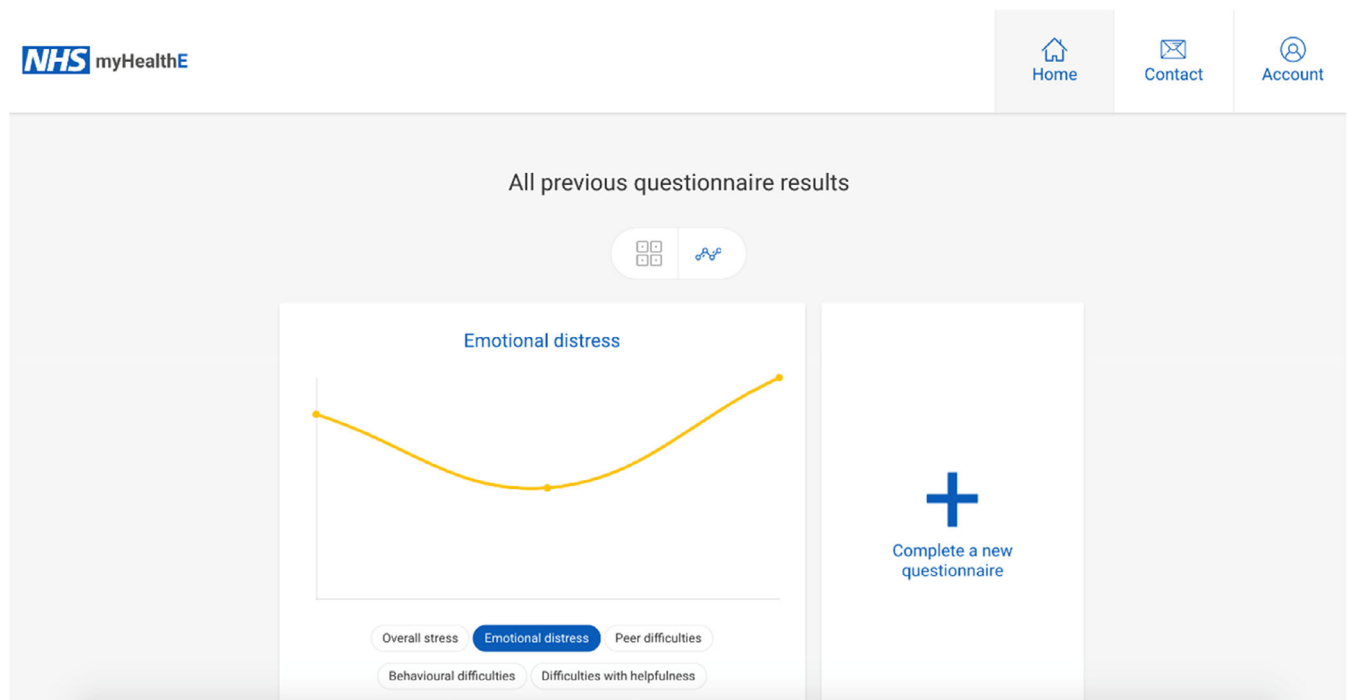
(a) Strengths and Difficulties Questionnaire results summary



(b) Strengths and Difficulties Questionnaire previous results summary



(c) Strengths and Difficulties Questionnaire results visualisation



Appendix 7

(a) MHE feasibility trial caregiver information sheet



Me_Health_e

Enhancing the Collection of Electronic Outcome Measurement in Child and Adolescent Mental Health Services

Patient Information Leaflet

Date:

Overview

We are conducting an evaluation of an NHS online questionnaire system called Me_Health_e. This system aims to improve how child and adolescent mental health services (CAMHS) monitor changes in children and young people's emotional and behavioural difficulties over time. The evaluation is being conducted by South London and Maudsley Hospital Foundation Trust (SLaM). Below we explain why this evaluation is being done and what your participation involves. If you have any questions, please do not hesitate to speak to your CAMHS worker or please get in contact with member of the evaluation team whose details are provided at the end of this information sheet.

Collecting Routine Outcome Measures

CAMH services are required to gather clinical information via questionnaires about your child from their first appointment until their discharge. These are called routine outcome measurements. Collecting this information allows our services to monitor your child's progress, personalise care and ensure that you and your child's opinions are accurately recorded when making decisions about care.

Why is this evaluation being conducted?

We are trying to improve the way we collect routine outcome measures in CAMHS. In particular we want to make it easier for you to provide information to clinicians. At the moment, we ask you to complete a 25 item paper based questionnaire called the Strengths and Difficulties Questionnaire (SDQ). We normally ask for this questionnaire to be completed in your first few appointments with CAMHS. After this, we ask for these questionnaires to be completed every 3-6 months or at the end of treatment. At present, these questionnaires are often not completed. Most CAMH services (in SLaM and across the UK) report that only 30% of the children they see, have 1 or more questionnaires collected at follow up.

In this evaluation we are testing the added value of an electronic system called the Me_Health_e to collect the SDQ. The Me_Health_e system works by automatically detecting when you are due to complete a SDQ and sends you an email or text reminder to complete an online version of the questionnaire.

How is this system being evaluated?

To understand whether Me_Health_e improves how we do things currently, we need to compare our standard way of collecting the SDQ with the Me_Health_e system. In order to do this, you will either continue with the standard method of collecting SDQ information or will be selected to complete the online survey. Whether you are allocated to conventional questionnaire completion or the online survey your child receives exactly the same mental health care.

Why have I been invited to take part?

You have been invited to take part because you have at least one child attending kaleidoscope either with the Lewisham CAMHS or Neurodevelopmental Team (NDT), and you have already completed a paper based SDQ around your child's first assessment with us.

What are the possible benefits of taking part?

We would encourage you to take part, as the information you provide does have an impact on how we track your child's symptoms and allows us to measure the effectiveness of the CAMHS services as a whole.

If you choose to opt out and not complete the online SDQ it will not affect the level of care your child will receive. You will then be invited to complete SDQs in the standard way. If you decide to take part and change your mind at a later date, you will still be able to withdraw yourself without reason and care for your child will remain unchanged.

What will my participation involve?

If you are asked to complete the SDQ online via the Me_Health_e system, we will need to have record of your most up to date email and/or mobile phone number. If these details are not already recorded in your child's electronic health records, a member of our team will ask you to provide an email address and mobile phone number that you are happy to be contacted on. You can choose whether you would rather the Me_Health_e system contacts you on your email address or mobile phone number. Regardless of whether you are asked to complete a paper or online questionnaire, you will have already been asked or will be first asked to complete a paper SDQ. This will happen during your first session or shortly after. The number of times you will be asked to complete a new SDQ in addition to your baseline SDQ depends on which group your child has been assigned to. The maximum amount of SDQs you will be asked to complete is 6 over 6 months (1 per month).

Paper questionnaire (current practice)

If you are chosen to receive conventional paper based SDQ completion, after completing a first pen and paper SDQ, you will receive a reminder via post, phone or face-to-face to fill in a new paper SDQ. If your child's treatment comes to an end before this six month period you may be asked to complete the SDQ sooner than this.

Online questionnaire

If you are chosen to receive the SDQ online you will be assigned to one of four groups. In all of these groups you will be asked to create a personal account in the Me_Health_e system. To do this, you will be emailed instructions and a link to the Me_Health_e website; this email will also contain a unique username and password which will allow you to make an account.

The next step will vary according to which group your child has been assigned to.

- **Group 1:** After completing the first SDQ for your child, every month you will receive an email or text asking you to fill in a follow-up SDQ, this message will contain a link which will take you to an online version of the measure, you will receive a weekly reminder until the SDQ is filled. This will happen for a period of six months and you will be provided with a brief, automatically generated feedback report for each SDQ you complete which will be saved to your Me_Health_e account for you to access at any time.
- **Group 2:** After completing the first SDQ for your child, every month you will receive an email or text asking you to fill in a follow-up SDQ, this email will contain a link which will take you to an online version of the measure, you will receive a weekly reminder until the SDQ is filled. This will happen for a period of six months and you will not receive the brief feedback for any of the SDQs you complete.

- **Group 3:** After completing the first SDQ for your child, you will receive one reminder to fill in a follow-up at the end of 6 months. You will receive a feedback report for both SDQs you complete, which will be saved to your Me_Health_e account for you to access at any time.
- **Group 4:** After completing the first SDQ for your child, you will receive one reminder to fill in a new SDQ at the end of 6 months and you will not receive feedback for any of the SDQs you complete.

If you decide at any point that you no longer want to receive emails from Me_Health_e there is an opt out option in the Me_Health_e navigation toolbar which you can tick to remove your details from this system.

Who will see the information collected from me?

As per normal clinical care, the clinical team working with your child will have access to the report generated from your responses on the SDQ. You can ask to see or discuss this at any time with CAMHS worker. Any analysis that is conducted on the information collected in this evaluation will be anonymised and carried out by approved SLAM staff, under SLAM Information Governance protocols.

What are the possible risks of taking part/where is my data being stored?

Participating in this evaluation will not affect the level of care we provide for your child. All information provided via the online SDQ will be stored and protected on a secure server within the South London and Maudsley firewall. It will be treated as confidential information in the same way all your child's health care records are managed.

What will happen to the findings of the research evaluation?

The findings from this evaluation will help us understand whether we should extend this system across other SLAM CAMH services. The findings will also be presented in medical journals and at meetings and conferences with other health care professionals. We will keep you informed of any updates during the evaluation and send you a summary of our findings once the evaluation is complete. All information presented are under strict data protection and SLAM governance protocols. No information will be presented that breaches patient confidentiality or identifies any individuals.

Who can I talk to if I have any questions?

Please feel free to discuss any questions you have about the evaluation or your involvement with your clinician during your appointment or contact our project lead Dr Johnny Downs (johnny.downs@kcl.ac.uk or 020 3228 8553) or project support officer Anna Morris (anna.morris@kcl.ac.uk).

Who has reviewed this service evaluation?

This service evaluation has received approved as a Service Evaluation and Quality Improvement Project by the SLAM Clinical Audit Ethical approval office.

Who is leading and funding the research?

The research is being led by Dr Johnny Downs a Clinical Research Training Fellow and Honorary Child and Adolescent Psychiatrist at South London and Maudsley NHS Foundation Trust. The evaluation is being funded by Guy's and St Thomas' Charity Health Innovation Fund.

Thank you for taking the time to read this information sheet and we thank you in advance for your help with this evaluation.

(b) MHE feasibility trial caregiver leaflet

Who will see the information collected from me?

The clinical team working with your child will have access to the summary report generated from your responses on the SDQ. You can ask to see or discuss this at any time with CAMHS worker. Any analysis that is conducted on the information collected in this evaluation will be anonymised and carried out by approved South London and Maudsley (SLaM) staff, under SLaM Information Governance policy.

Are my records kept confidential?

All the information you provide via the online SDQ will be stored and protected on a secure server within the SLaM firewall. It will be treated as confidential information in the same way all your child's health care records are managed.

Who can I talk to if I have any questions or want more information?

If you would like to know more, look out for leaflets and posters in the waiting area at your next appointment or ask your CAMHS worker for more details about the myHealthE evaluation.

If you have any questions or concerns about the myHealthE evaluation or your involvement, please speak with your CAMHS worker, or contact our project support officer:

Anna Morris

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 Telephone : 0203 288 8586
 or email: anna.morris@kcl.ac.uk

The myHealthE team



Dr Johnny Downs: myHealthE project Clinical research lead. Honorary Consultant Child and Adolescent Psychiatrist, King's Health Partners



Dr Omar Moghraby: Lead Psychiatrist, Lewisham Child and Adolescent Mental Health Services



Dr Zina Ibrahim: myHealthE software developer and technical lead. Applied Intelligence Lead, King's College London



Anna Morris: myHealthE project support officer. Clinical Research Assistant, King's College London



Margaret Heslin: myHealthE health economist. Research Fellow in Health Economics, King's College London

The research is being led by Dr Johnny Downs a Clinical Researcher and Honorary Child and Adolescent Psychiatrist at South London and Maudsley NHS Foundation Trust. The evaluation is being funded by Guy's and St Thomas' Charity Health Innovation Fund.

Introducing myHealthE for CAMHS brochure—December 2018

South London and Maudsley NHS Foundation Trust

Introducing the myHealthE system for CAMHS

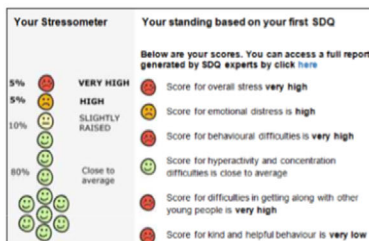
Enhancing the way we use data to improve mental health care for children and young people

myHealthE

KING'S HEALTH PARTNERS
 Powering better health for all

How does myHealthE work?

myHealthE automatically detects when you are due to complete a SDQ and sends you an email or text reminder to complete an online version of the questionnaire.



You complete SDQ online by logging into your personal account in the myHealthE. When new SDQ is submitted you will be provided with feedback report summarising your responses like this:

How well does each statement describe how he has been over the last 6 months?	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Restless, overactive, cannot stay still for long	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Often complains of headaches, stomach aches, or sickness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Do I have to take part?

We would encourage you to take part, as the information you provide does have an impact on how we track your child's symptoms and allows us to measure the effectiveness of the CAMHS services as a whole.

If you choose to opt out and not complete the online SDQ it will not affect the level of care your child will receive. You will then be invited to complete SDQs in the standard way. If decide to take part and change your mind at a later date, you will still be able to withdraw yourself without reason and care for your child will remain unchanged.

What is myHealthE?

We have developed an online questionnaire system called myHealthE that will help us to collect clinical information about your child children during your time with our services.

All Child and Adolescent Mental Health Services (CAMHS) are required to collect routine information via questionnaires to help assess and track change for the young people they see.

We currently ask you to complete a paper based questionnaire called the Strengths and Difficulties Questionnaire (SDQ) during your child's first appointment and on several occasions throughout their time at CAMHS. This system aims to make this task easier by allowing you to fill in these questionnaires electronically at your chosen time and location.

How is this system being evaluated?

To understand whether myHealthE improves how we do things currently, we are first working with caregivers to compare our standard way of collecting the SDQ with the myHealthE system. To do this, you will either continue to complete paper SDQ information or be asked to complete SDQ information online.

Whether you are complete the paper based or the online survey your child receives exactly the same care. If it works well we would like to extend this to include young people, and across other parts of Trust.