

A caregiver digital intervention to support shared decision making in child and adolescent mental health services: Development process and stakeholder involvement analysis

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Abstract

Background: Parents and caregivers are generally recognized by literature and the law as key to child and adolescent mental health decisions. Digital interventions are increasingly being used to support care and treatment in child and adolescent mental health services (CAMHS). However, evidence of the design and development process is generally not made available.

Objective: In light of calls for more transparency, this paper aims to describe the development of an evidence-based, theoretically informed digital decision support intervention for parents and caregivers of young people accessing CAMHS.

Methods: The intervention was developed in line with the UK Medical Research Council framework for developing complex interventions. The process incorporated the steps for developing patient decision aids, as follows: assessing need, assessing feasibility; defining objectives; identifying the framework of decision support; and selecting the methods, designs, and dissemination approach. We synthesized theory, research, international guidelines, and input from relevant stakeholders using an iterative design approach.

Results: The development steps resulted in Power Up for Parents, a decision support intervention, with five key features (ie, decisions, goals, journey, support, and resources). The intervention aims to encourage discussion, allow parents to ask questions during sessions or seek further information between sessions, and allow service providers to tailor the shared decision-making process to accommodate the needs of the parent and child.

Conclusions: We confirmed that it is possible to use input from end users—integrated with theory and evidence—to create digital interventions to be used in CAMHS. Key lessons with implications for practice, policy, and implementation science, along with preliminary findings, are presented.

Keywords: digital health intervention, caregivers, parents, child mental health

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Introduction

Digital health interventions have been increasingly used in child and adolescent mental health services (CAMHS) [1–3]. Power Up, a mobile phone app to support young people in shared decision making (SDM) has shown some evidence of promise that young people who used Power Up reported greater levels of SDM after the intervention period [4,5]. SDM is central to person-centred care and describes a process where service users and service providers collaborate to make treatment decisions [6]. Depending on the age of the child, parents (including non-biological primary caregivers) sometimes report feeling excluded from the decision-making process, and therefore may also benefit from receiving additional support [7]. Previous research highlighted that parents' decision support needs include information, talking to others, and feeling a sense of control over the decision-making process [8,9].

In addition, parents of children with mental health difficulties report experiencing an 'emotional roller coaster' [10]. Further, researchers have identified parents' emotions as a possible influencing factor to the SDM process [11,12]. A review of parent-targeted SDM interventions for use in CAMHS revealed that existing interventions rarely addressed this concern, and only one available intervention explicitly addressed emotional support [13]. Counseling in Dialogue is a face to face intervention found to lower decisional conflict and promote acceptance of recommended treatments [14]. However, concerns about stigma and confidentiality, shame or embarrassment in attending services, financial costs, time, appropriateness or limited access to services are usually among the many barriers to accessing in-person CAMHS [15,16]. As a result, existing efficacious face to face interventions are adopting digital technology as a means of addressing these barriers [17,18]. Three interventions identified in the previous review [13] were considered digitally accessible. Two targeted parents of children with Autism Spectrum Disorders [19,20] and one targeted parents of children with Attention-Deficit and Hyperactivity Disorder [21]. However, recommendations to

develop interactive digital interventions that promote well-being factors in addition to the targeted behaviour change are gaining momentum [22].

Despite the growing interest in digital health interventions, detailed descriptions of the development process of digital interventions used in CAMHS are limited [23], with implications for clinical and research reproducibility. Nonetheless, recent reviews of the extant literature have described innovative technological applications in parent management training programs [24,25], and programs to promote child health [26]. Although this research shows great efficacy for the use of parent targetted technology in child health care, to the best of our knowledge, there are presently no parent-targeted interactive mobile apps designed for and tested in CAMHS, that support an affective-appraisal SDM process [13]. The affective-appraisal approach refers to the ability to include key decision-makers (i.e. child or young person, parents and service providers), and incorporate and address the influence of parental affective states on the SDM process [62].

Further, healthcare quality standards and guidelines identify and define SDM as an essential characteristic of good quality care endorsing support and interventions for both service users and service providers [27]. Experts highlight that for SDM to occur the process should include nine essential elements: patient values/preferences, options, professional knowledge/recommendations, make or explicitly defer a decision, define/explain the problem, check/clarify understanding, explore benefits/risks, discuss patient's ability/self-efficacy, and arrange follow-up [28]. However, available interventions meet an average of 4.57 SDM elements [13]. Further, the majority of the work on defining, facilitating, and supporting SDM has focused on adult healthcare and dyad relationships between the primary service user and healthcare provider [28,29]. In CAMHS, parents are sometimes surrogate decision-makers or the parent, child and healthcare provider engage in a triad decision-making process. Owing to the many perceived challenges associated with decision-making in paediatric care, researchers commonly highlight the lack of an evidence-based holistic conceptualisation of SDM [30]. Therefore, in line with the broader health literature, it is recommended that all efforts are made to improve SDM. In so doing, experts call for clinicians to

recognise SDM as an ethical imperative, stimulate a bi-directional flow of accurate and tailored information, and give patients and their families resources that facilitate an effective SDM process [31].

Given the importance of SDM, and the feasibility of digital interventions in CAMHS, it is essential that theoretically-informed interventions are developed. The overall aim of this paper was to describe the development of an evidence-based digital intervention for use by parents accessing CAMHS. Consequently, the following sub-objectives were addressed.

1. Develop a logic model outlining how the intervention is proposed to work.
2. Consolidate evidence-based content to support the affective-appraisal model of SDM.
3. Involve end-users in the design and development of an SDM intervention to be used in CAMHS.
4. Highlight key learning and recommendations.

Method

Framework for intervention development

The UK Medical Research Council (MRC) framework for the development and evaluation of complex interventions was adopted. The intervention was described as complex, in line with the conventional definition describing complex interventions as interventions with several interacting components. The MRC framework proposes that during the development stage, it is important to: identify the evidence base, identify theory and model the process and outcomes [32]. Alongside the MRC framework, activities were guided by the steps for developing decision aids [33].

Assessing need

A broad overview of the literature explored existing evidence for prevalence of child mental health problems, influencing factors to SDM, and potential impact on the family. Another systematic review aimed to better understand the emotional experiences of having a child with mental health

problems and explored how those experiences may influence parent involvement in care and treatment decisions (findings submitted for publication). Additionally, existing decision support interventions available for parents of children with mental health problems were identified and assessed against SDM elements [13]. Qualitative interviews were also conducted to obtain insight into how clinicians and parents perceived and described experiences of SDM and to identify support systems used (findings submitted for publication).

Assessing development feasibility

As this research was part of a PhD project, it was agreed that the 3-year timeline was appropriate to develop and evaluate an intervention. Secondly, a pre-existing relationship with the technology company (Create Health) made it suitable to undertake the development of a digital intervention [5]. Additionally, the financial resources necessary to develop the intervention was available through the PhD project funding. Furthermore, preliminary evidence from the original Power Up for young people suggested that it was feasible to develop and evaluate a novel digital intervention for CAMHS [4].

Defining the objectives of the decision support tool

Based on the overview of the literature and feedback from parents, practitioners and researchers (described later in the article), the following primary objectives were considered necessary to guide the intervention's development process:

1. Encourage discussion (i.e. Three-talk model proposed by Elwyn and colleagues [34]).
2. Allow parents to ask questions during sessions or seek further information within sessions.
3. Provide a space for parents to identify their feelings/moods and receive support.
4. Allow service providers to tailor the SDM process to accommodate the needs of the parent and child (e.g. informed vs involved).

Identifying the framework of decision support

In general, the development process of the intervention was conducted in line with the International Patient Decision Aids Standards (IPDAS). These guidelines encourage using a systematic development process, disclosing conflicts of interest, internet delivery, using plain language, and basing information on up to date evidence, among others [35,36]. More specifically, in line with an affective appraisal approach [62], The Youth SDM model [37], The Integrative model of SDM in medical encounters, highlighting the nine essential elements of SDM [18], and The Ottawa Decision Support Framework [38] informed the content of the intervention. The Ottawa Decision Support Framework has been used to develop and evaluate over 50 patient decision aids, measures (e.g. Decisional Conflict Scale), and training in providing decision support.

The Youth SDM model highlights three key SDM functional areas: setting the stage for youth SDM, facilitating youth SDM and supporting youth SDM. The authors recommended that setting the stage for youth SDM should involve providing an introduction to the concept of SDM and inviting and acknowledging the service user's preference for involvement. To facilitate this, a co-design process to develop a webpage, to define and explain SDM was undertaken (discussed later in this article). Consequently, the webpage became the welcome screen of the intervention to "set the stage" for SDM.

The Integrative Model of SDM was used to "facilitate the SDM process". The current intervention was designed to incorporate all nine elements of SDM. Examples are reflected in the results section. In addition, The Ottawa Decision Support Framework was used to inform "support" for the SDM process. The framework proclaims that participants' decisional needs will affect decision quality which in turn affects actions or behaviours (e.g. delay), health outcomes, emotions (e.g. regret, blame) and appropriate use of health services. This framework was pertinent to the intervention as previous research highlighted the potential impact of parents' emotions on the SDM process.

Selecting the methods, designs and planning for the feasibility and pilot study

Stakeholder Involvement

The remaining 3 steps outlined by O'Connor and Jacobsen [33] were collapsed under the sub-heading 'stakeholder involvement'. There is an overarching consensus that involving end-users in the development of health interventions is critical to successful implementation. Developers and researchers converge on the understanding that patient and public involvement (PPI) can benefit uptake and usage of interventions. More specifically, the involvement of end-users is known to improve idea generation and creativity [39-41]. The following sections describe how various stakeholders were involved in the development of the intervention.

Steering Committee

From conception, a steering committee was formed consisting of a senior researcher, a colleague with experience in the development of digital interventions, three parents with experience of having a child with a mental health problem and chaired by the primary author. The parents were appointed as part of the steering committee after expressing interest in the study at various presentations undertaken by the primary author. The committee was ideal for consensus forming and was mainly responsible for ensuring the development process was transparent and unbiased. The steering committee also guided the feasibility and pilot study for the intervention by offering strategies to promote recruitment. Meetings covered virtually for a total of 6 times throughout the intervention design and development phase.

Patient and public involvement

The overall objective of the consultations were to obtain parents' expert advice on the research and intervention design. However, gaining insight into how parents may use digital health interventions and obtaining input on how to improve the intervention before the study began was necessary. First, an email consultation was conducted with the Family Research Advisory Group (FRAG) at the National Children's Bureau (NCB). Information about the aims of the study and plans

for an intervention with specific questions to generate ideas were shared with the research team at the NCB. The team contacted nine parents who provided input on the value of the intervention, what support might be needed and which group of parents we should target for recruitment. Prototype development began based on input received. Secondly, the study design and an example of how the intervention might be used were presented to the group at a scheduled meeting. The pros and cons of digital versus other formats of decision-making tools were discussed along with general thoughts and concerns on the study and intervention design. The prototype was then refined and updated before the final meeting. At the final meeting, a group discussion, including a presentation of the prototype was conducted, to examine the penultimate version of the intervention and the study design. There were further discussions on how parents could use and benefit from the intervention in practice. Further refinement of the prototype was carried out based on feedback received.

Showcase Pollinator event with Clinicians and Researchers

At a showcase pollinator event, which was held in Austria at the Technology Enabled Mental Health (TEAM-ITN) Summer School, the prototype was then presented to clinicians, researchers and intervention developers who were asked to provide feedback, and specifically provide input to improve the interactivity of the intervention. Three round table discussions followed, and input was obtained from a total of 12 experts in the area of child mental health. Attendees at the event had a specific interest in digital interventions to prevent, treat and promote policies for children and youth mental health.

Public engagement

A collaborative approach was taken to develop and design a webpage to promote SDM in CAMHS. Firstly, a survey to elicit the public's opinion on the preferred mode of delivery for an SDM resource was conducted via social media. Responses from clinicians, parents, children and young people, school staff and others were in favour of a web resource. Consequently, three Parent

Champions and four Young Champions from the Anna Freud National Centre for Children and Families attended two workshops and provided email feedback on two versions of the webpage before agreeing on the final versions. At the first workshop participants explored what SDM meant and a consensus was reached for a family-friendly definition that could be displayed on the webpage. At the second workshop participants were involved in designing paper prototypes of the webpage. Consequently, the webpage was designed, and content updated based on feedback received. The communications team at the Centre was then involved to ensure the content and design were in line with the Centre's standards. The webpage presented as the welcome screen for parents upon accessing the intervention.

App developers

The app developers at Create Health were responsible for the technical development of the intervention. However, design specific components such as swipe versus touch features, labels for the settings menu of the app, and data security were proposed by the developers and included only after it was agreed by the primary author and the steering committee. Based on feedback from the steering committee, PPI sessions and parent experts, a series of paper prototyping and digital designs were developed before the final version was adopted.

Ethics

Ethical approvals for the development and pilot testing of Power Up for Parents was granted by University College London, and by the London Surrey Research Ethics Committee (IRAS 236277).

Results

Evidence-Base

The development process highlighted a need for an SDM intervention targeting parents of children with any mental health concern. Decisions could include, but not be limited to, medications, types of therapy or service needs. The literature reviews revealed a high prevalence of child mental health problems, several decision-making opportunities, barriers and facilitators to

SDM and positive outcomes when SDM was adopted in care. The potential influence of a parent's emotional state on the decision making process was also identified [8-12,42-44]. Quantitative findings also highlighted a large number of parents reporting involvement in SDM, and possible associations between ethnicity, relationship to the child and the presence of conduct problems or learning difficulties. Nonetheless, the importance of including parents in the decision-making process was expressed by parents and service providers. Existing parent-targetted decision support tools identified met an average of 4.57 SDM elements out of a possible nine [13]. Furthermore, that review reported time, accessibility and appropriateness of the intervention as factors influencing usage and implementation of interventions, providing additional support for a digital mode of delivery. Table 1 presents an overview of how the evidence informed the intervention's design objectives and key features.

Table 1 Overview of the intervention's objectives and key features

Research Evidence	Intervention design objective	Key features of the intervention
<p>Recognising the need for help can be challenging as carers' perceptions of their child's mental health difficulties differ from those of their child teachers and health professionals. These disagreements are reflected in carers reporting not feeling listened to or respected, further adding to frustrations and disappointment.</p>	<p>Encourage discussion.</p> <p>Allow parents to ask questions during sessions or seek further information within sessions.</p>	<p>Decisions/Goals</p> <p>Decisions/Resources</p>
<p>Findings suggest that parents are 'expected to, but not always able to' engage with CAMHS due to the 'emotional roller coaster' they experience.</p>	<p>Provide a space for parents to identify their feelings/moods and receive support.</p>	<p>Support/Journey</p>
<p>Findings suggest the triad relationship is unique and can be challenging in CAMHS. Recommendations are made to explore opportunities for varying levels of involvement such as "informed" versus "actively involved" parents.</p>	<p>Allow service providers to tailor the SDM process to accommodate the needs of the parent and child (i.e. informed vs involved).</p>	<p>Decisions/Resources</p>

Findings indicated that time, accessibility and appropriateness of the intervention emerged as factors influencing usage and implementation of parent-targeted SDM interventions.

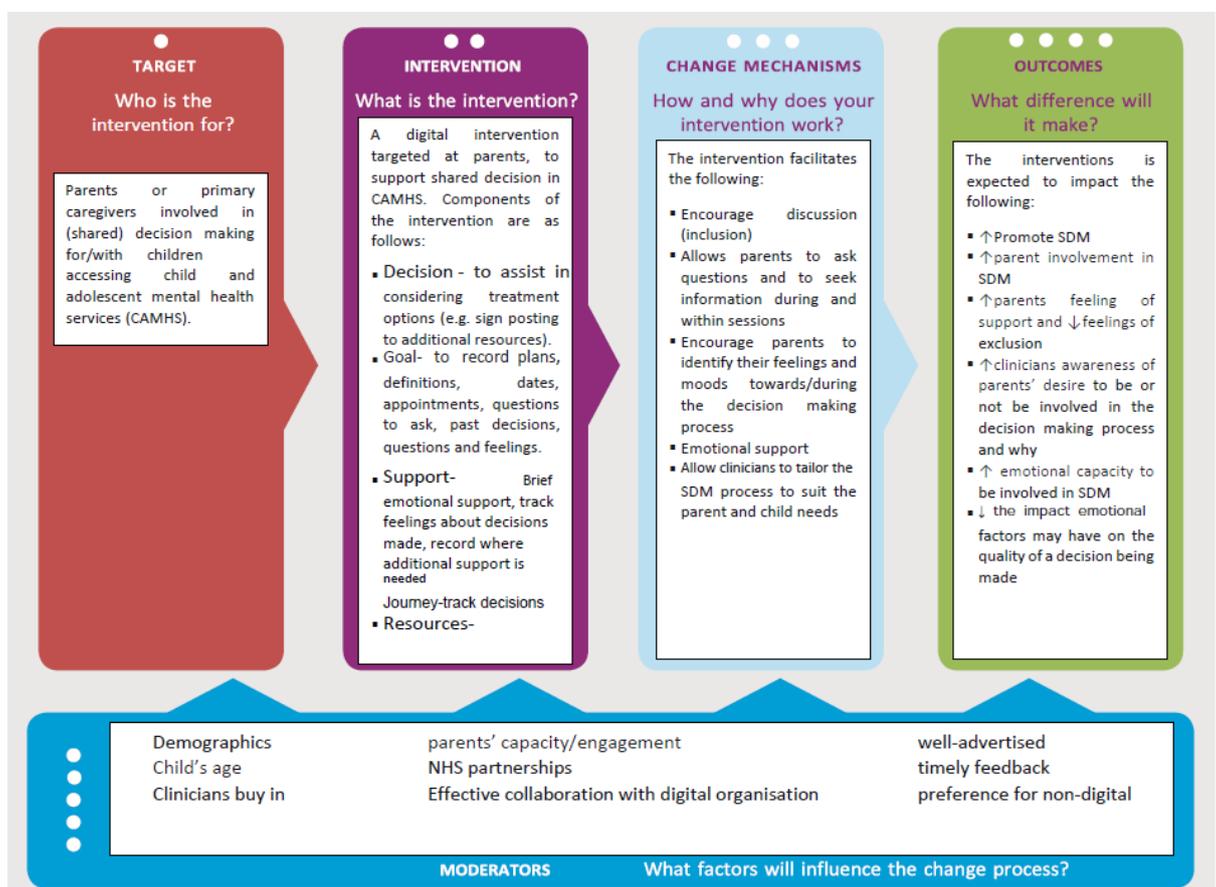
Be suitable and accessible to parents.

Digital mode of delivery

Logic Model

The above evidence was explored in detail and presented in a logic model to outline the purpose of the intervention. Figure 1 provides an overview of the adapted Evidence-Based Practice Unit Logic Model [45], consisting of four parts that describe the intervention and the target audience. The logic model also highlights the aims of the intervention and expected outcomes once implemented. Additionally, a list of potential moderators that may influence usage and implementation were reported.

Figure 1 Logic model outlining the intervention process



Outline of the intervention

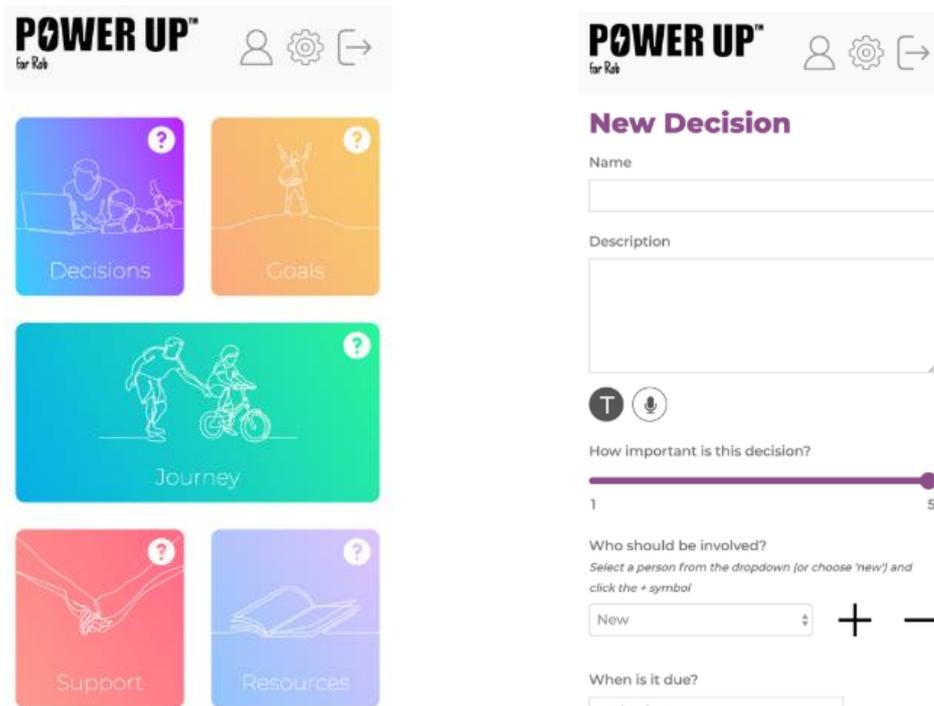
This section summarises the key features of the resulting prototype and user manual (Multimedia Appendix A). The Power Up for Parents title was adopted as this project was an amended version of the original Power Up intervention for young people that supports and

promotes SDM in CAMHS [4,5]. Although the current prototype is being referred to as Power Up for Parents, the feedback from PPI sessions indicated that non-biological caregivers may feel excluded. In response to this, the prototype included a customisation feature to change the word “Parents”. Therefore, it can be labelled “Power Up for Rob” to reflect the child’s or parent’s name (see Figure 2). The overall structure of the app’s content is as follows.

Decisions

This is a decision aid that guides users to seek information about treatment options, to review the benefits and risks of each option, to track decisions, and to record where more information or support is needed (see Figure 2). Additionally, as the research focused on the triad relationship, parents were encouraged to involve others in the decision-making process by seeking preferences from the clinicians, their child, or other relevant persons. This section uses the nine essential elements of SDM to “walk” users through the decision-making process prompting users to answer questions such as: “Do you have sufficient information about the options available to you?” and “Do you feel ready to make this decision?”. The other sections below provides additional support throughout the decision-making process in line with the affective appraisal model of SDM.

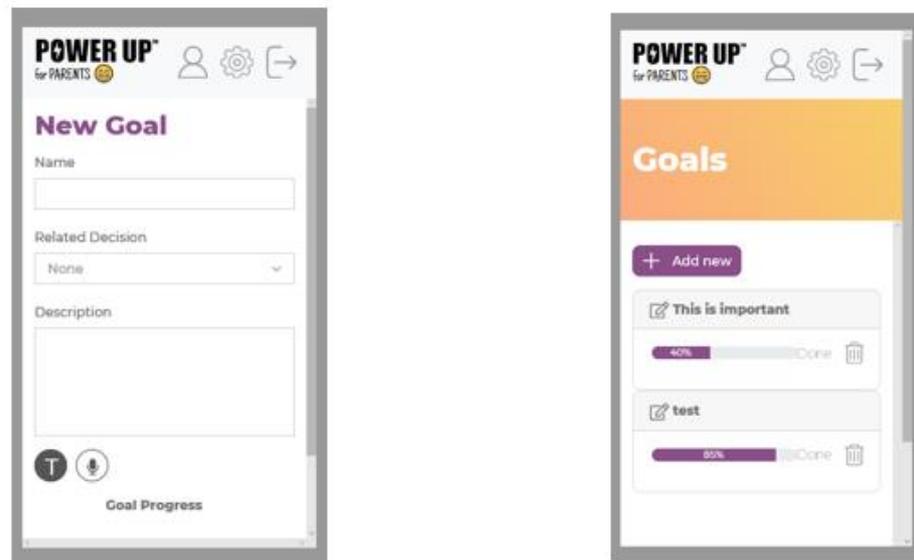
Figure 2 Example of the home screen and decision tab



Goals

This feature is used in sessions or between sessions to record and track goals as they are discussed with service providers and the young service user. It allows users to set individual or consensus goals and explore plans to achieve these goals (see Figure 3). Additionally, parents could record any questions or concerns to address at the following session. Research findings suggest that goal-setting and tracking progress is associated with higher self-efficacy [46], and is one approach to promoting shared decision making in CAMHS [47].

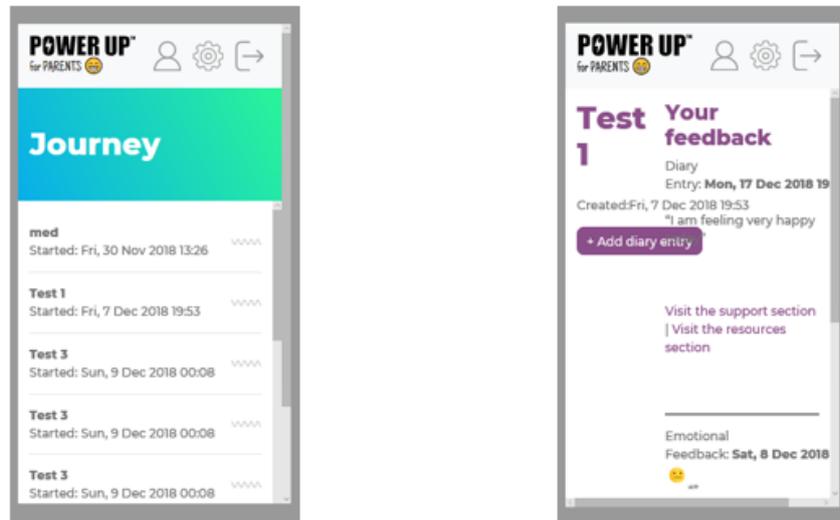
Figure 3 Example of the goal tab



Journey

This feature allows parents to reflect on their emotions or issues that may affect the decision-making process. A parent could decide to share the content with the child and the clinician, and it could be used during and within sessions to keep track of the decision-making journey from user readiness to outcomes. Expectations, experiences, and reflections are recorded here using the diary function (see Figure 4). The usefulness of implementing case-tracking and the documenting of client journeys have been highlighted in previous research [48]. Although previously explored in primary care services, the authors highlighted its importance in monitoring the comprehensiveness of service responses and the experiences of clients.

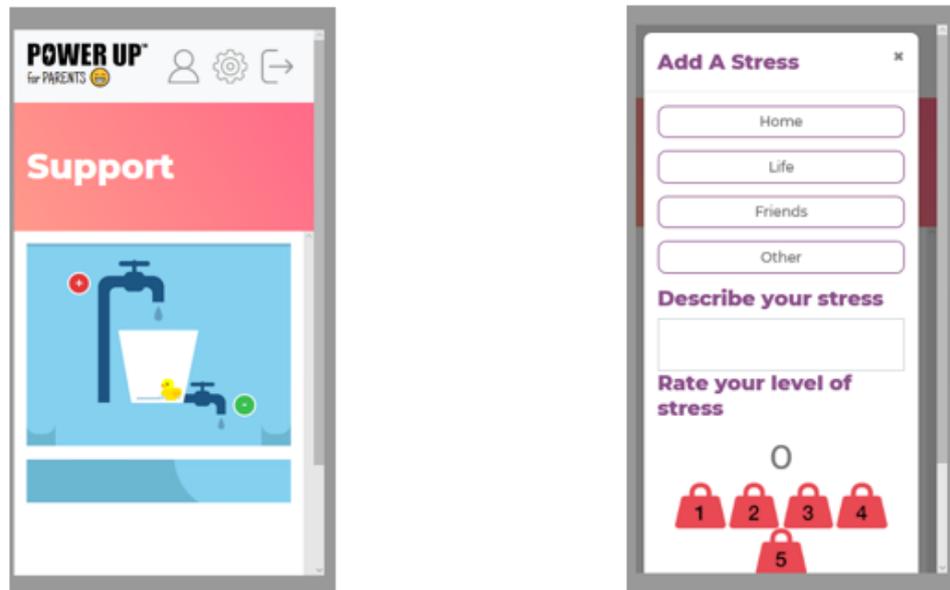
Figure 4 Example of the journey tab



Support

This section hosts a tool to allow parents to identify and express their views about various stressors affecting the decision-making process. Users are encouraged to think about things that are stressful and explore ways to manage them. They are able to track feelings towards decisions and explore where additional emotional support is required (see Figure 5). The stress bucket concept has been endorsed across health care and well-being settings with positive feedback across age groups [49].

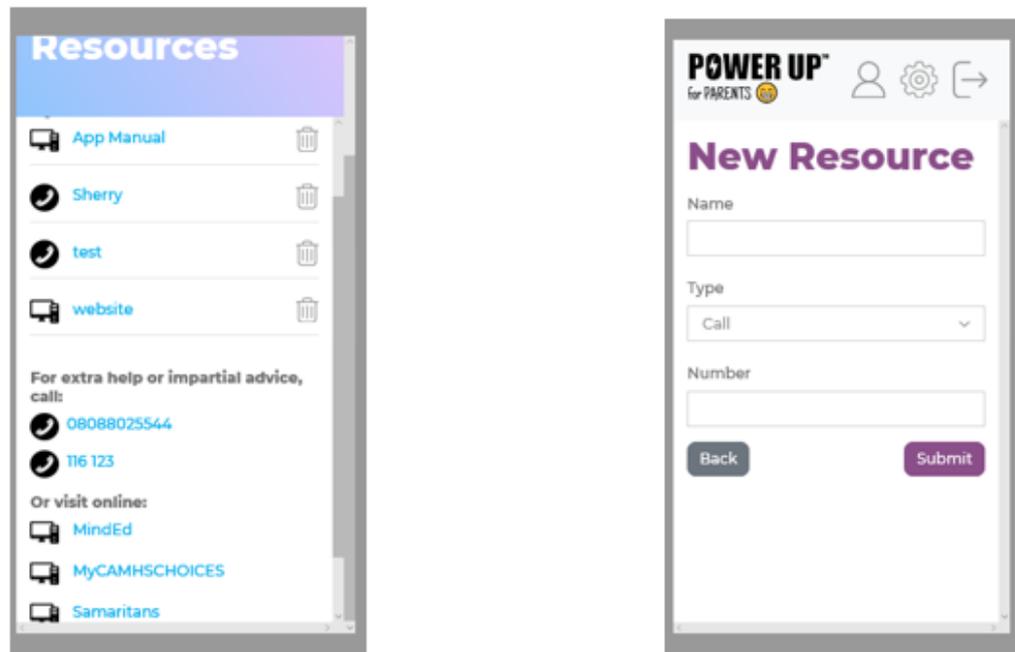
Figure 5 Example of the support tab



Resources

This section includes useful contact details that signpost users to further support and guidance. Parents could upload their own resources to help with the decision-making process and include contacts they find most helpful (see Figure 6). Parents involved in previous CAMH research indicated the benefits of receiving information and expressed feeling more included when provided with adequate evidence [7]. However, parents reported feeling overwhelmed when too much information was given at once. This section allows parents to work with service providers to identify and obtain tailored resources.

Figure 6 Example of the resources tab



Discussion

This paper described an evidence-based process for the development of a complex intervention, referred to as Power up for Parents, based on the MRC framework [32] and guided by the workbook for developing and evaluating decision aids [33]. Stakeholder input from parents, service providers, researchers and young service users informed the design and content of the intervention. The intervention was developed in accordance with the IPDAS guidelines [35,36] and grounded in three popular SDM models: The Youth SDM model [37], The Ottawa Decision Support Framework [38], and The Integrative model of SDM in medical encounters [28]. The intervention's objectives were informed by empirical studies and literature reviews which highlighted a need to provide additional support for parents of children with mental health problems who are involved in child mental health decisions. The resulting prototype aimed to: (1) encourage discussion, (2) allow parents to ask questions during sessions or seek further information within sessions, (3) provide a space for parents to identify their own feelings/moods and receive support, and (4) allow service providers to tailor the SDM process to accommodate the needs of the parent and child. To address

the design aims five key sections were embedded into the intervention. These features were: “Decisions”, “Goals”, “Journey”, “Support” and “Resources”.

Comparison with existing literature

The development process described in this paper is consistent with the development process briefly outlined in other parent-targetted SDM interventions [50–53]. Developers generally reported utilising end-user feedback, literature reviews, established guidelines, and empirical studies to inform the intervention. Overall, researchers reported adopting one or a subset of these approaches to inform the intervention development process. However, only Hayes and colleagues [53] reported using the MRC guidelines to inform the development of the i-THRIVE Grids. The current development process is in line with recommendations to promote well-being factors (e.g. emotional regulation) in addition to the targeted behaviour change (e.g. SDM) [22]. The iterative and collaborative approach adopted also supports other “user-based” frameworks, embedded in Human-Computer Interaction, such as the multiphase optimization strategy framework [54].

Key learnings

Common themes were identified across the steps in the development process of Power Up for Parents. These were interpreted to develop a list of eight recommendations to inform guidelines for policy and practice. The recommendations were initially developed by the primary author and reviewed using an iterative process by six independent reviewers (i.e. two practitioners, one child development policy officer, one parent with experience of having a child with mental health problems and two child mental health researchers) before reaching a consensus to include. In line with the Salzburg statement on SDM [31], the following eight perceived key learnings were highlighted.

1. Ensure primary carers and young service users are invited to be part of the care and treatment decision-making process while considering the following:
 - a. Age and capacity of the child

- b. How much the child wishes to have the parent involved or informed
 - c. How much or what support the family needs in order to be involved
2. Review clinicians' time schedules so they can provide sufficient time and encourage primary carers to ask questions and raise concerns during and within sessions
3. Highlight the need for emotional support to be provided to primary carers especially at the initial stages of accessing CAMHS or at crucial decision-making time-points
4. Propose a need for a key person in CAMHS that can provide answers to more general questions or be a liaison between clinicians and families especially during periods when there is a changeover of service providers
5. Consider the inclusion of the primary carer or key person (i.e. an advocate for the family who is not the primary service provider) at multidisciplinary meetings when care and treatment options are being considered
6. Review the role of parent support groups and explore the potential for further responsibilities
7. Highlight the need for SDM support interventions as an adjunct to routine care
8. Suggest that when SDM interventions are being developed to be used with the CAMHS populations that the following are considered:
 - a. PPI is at the core of design, development, testing and implementation
 - b. Equal voices are given to service users and service providers
 - c. Interventions are accessible, acceptable, suitable and appropriate for the population, easy-to-use, useful and do not incur additional time burden to the service providers and the service users.

Implications for implementation science

Interventions addressing mental health concerns or SDM could replicate this development process if the intervention is found to be effective in later studies. With the high prevalence of child mental health problems and the alarming emotional state of parents, CAMHS could benefit from

offering virtual support to parents in the absence of the resources to facilitate face to face sessions with such large numbers of families. Additionally, developing an intervention that encourages service users to collaborate with service providers can be empowering for service users.

Implications for research

In keeping with the MRC framework, the intervention then entered the pilot and feasibility phase for testing the intervention as discussed in the study protocol [55]. Preliminary results of the feasibility study [61] indicated that the intervention itself is generally acceptable by parents and healthcare professionals. Findings also indicate there is scope for further development of Power Up for Parents. Results from the feasibility and pilot study have been integrated into refinements of the intervention and the plans for further research.

Strengths and limitations

The main strength of this development process is the adoption of participatory design methods, where researchers, app developers, service providers, parents and young people were involved as partners at various stages to determine the content and design of Power Up for Parents. Secondly, adhering to the MRC framework and following the workbook for developing decision aids provided a solid foundation for an evidence-based intervention. Additionally, the theoretical underpinning and the evidence-base informing the content of Power Up for Parents provided a basis for potential success when the intervention is tested for effectiveness. Another strength is the dynamic nature of web-applications to integrate into electronic health record systems or be embedded in NHS websites if found to be effective. Lastly, incorporating all nine elements of SDM, instead of the average 4.57 contained in similar interventions, was viewed as a major strength.

However, the complexity of the intervention and the comprehensive approach taken to inform development resulted in a process that lasted almost 28 months. Although this may be viewed as a time-consuming process, developers aiming to develop similar interventions can utilise fewer empirical studies and incorporate rapid prototyping techniques [56]. In hindsight, another

possible limitation could be the selection and combination of SDM models and theories. Other researchers in the field of SDM may criticise the chosen models and have a preference for alternatives. However, for the purpose of this research project, they seemed appropriate, and because they overlap in some areas were readily combined. Similarly, the parents and young persons involved in the PPI sessions could represent a biased sample of persons who volunteer their time and expertise to inform research [57]. Therefore, they may not provide a broad representative view of families having a child with mental health problems. Also, it can be costly to develop digital interventions. For that reason, it is recommended that cost-effectiveness be integrated into future study designs when evaluating the intervention. Once proven effective the cost can be justified as digital interventions have the ability to be scalable, affordable, and easily accessible for users [58–60]. Lastly, the key learnings and recommendations were based on a synthesis that went beyond the individual steps in the development process and a brief consultation exercise, and as such should be taken with caution.

Conclusion

A multidimensional process was adopted, including an in-depth exploration of existing literature, empirical studies, theoretical underpinnings and patient and public input to develop an evidence-based intervention to support parents involved in child and adolescent mental health decisions. The resulting intervention demonstrates and confirms that it is possible to use input from end-users, integrated with theory and research evidence to create digital health interventions to be used in CAMHS. The intervention then entered the pilot phase aimed at obtaining end-users input for further development, views on acceptability, and an exploration of feasibility for conducting a randomised control trial. The lessons learned from this process may broadly inform the development of other interventions.

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Authors' Contributions

SL and JEC developed the initial idea for the intervention. SL worked with the staff at Create Health (HW and RM) to develop, adapt, and refine Power Up for Parents. SL drafted the manuscript, and both authors revised the manuscript and have read and approved the final version.

Conflicts of Interest

None declared.

Abbreviations

CAMH -Child and adolescent mental health

CAMHS -Child and adolescent mental health services

FRAG -Family Research Advisory Group

MRC -Medical Research Council

NCB -National Children's Bureau

SDM -Shared decision making

References

1. Grist R, Porter J, Stallard P. Mental Health Mobile Apps for Preadolescents and Adolescents: A Systematic Review. *Journal Of Medical Internet Research* 2017;19(5). [doi: 10.2196/jmir.7332]
2. Hollis C, Falconer CJ, Martin JL, Whittington C, Stockton S, Glazebrook C, Davies EB. Annual Research Review: Digital health interventions for children and young people with mental health problems – a systematic and meta-review. *Journal of Child Psychology and Psychiatry and Allied Disciplines*. 2017. [doi: 10.1111/jcpp.12663]
3. Liverpool S, Mota CP, Sales CMD, Čuš A, Carletto S, Hancheva C, Sousa S, Cerón SC, Moreno-Peral P, Pietrabissa G, Moltrecht B, Ulberg R, Ferreira N, Edbrooke-Childs J. Engaging Children and Young People in Digital Mental Health Interventions: Systematic Review of Modes of Delivery, Facilitators, and Barriers. *Journal of medical Internet research*. 2020. [doi: 10.2196/16317]
4. Edbrooke-Childs J, Edridge C, Averill P, Delane L, Hollis C, Craven MP, Martin K, Feltham A, Jeremy G, Deighton J, Wolpert M. A feasibility trial of power up: Smartphone app to support patient activation and shared decision making for mental health in young people. *Journal of Medical Internet Research* 2019; [doi: 10.2196/11677]
5. Chapman L, Edbrooke-Childs J, Martin K, Webber H, Craven MP, Hollis C, Deighton J, Law R, Fonagy P, Wolpert M. A Mobile Phone App to Support Young People in Making Shared Decisions in Therapy (Power Up): Study Protocol. *JMIR Research Protocols* 2017; [doi: 10.2196/resprot.7694]
6. Barry M, Edgman-Levitan S. Shared decision making—the pinnacle of patient-centered care. *New England Journal of Medicine* [Internet] 2012 [cited 2017 May 18]; Available from: <http://www.nejm.org/doi/full/10.1056/NEJMp1109283>

7. Association of Young People's Health (AYPH). "There for you": The role of parents in supporting young people with mental health problems: Results of a survey [Internet]. 2016. Available from: <http://www.youngpeopleshealth.org.uk/wp->
8. Jackson, C., Cheater, F. M., & Reid, I. (2008). A systematic review of decision support needs of parents making child health decisions. *Health Expectations : An International Journal of Public Participation in Health Care and Health Policy*, 11(3), 232–251.
<https://doi.org/10.1111/j.1369-7625.2008.00496.x>
9. Lipstein EA, Brinkman WB, Britto MT. What is known about parents' treatment decisions? A narrative review of pediatric decision making. *Medical decision making : an international journal of the Society for Medical Decision Making* [Internet] 10/03. 2012;32(2):246–258. PMID:21969136
10. Corcoran J, Schildt B, Hochbrueckner R, Abell J. Parents of Children with Attention Deficit/Hyperactivity Disorder: A Meta-Synthesis, Part I. *Child and Adolescent Social Work Journal* 2017;34(4).
11. Brinkman WB, Sherman SN, Zmitrovich AR, Visscher MO, Crosby LE, Phelan KJ, Donovan EF. Parental angst making and revisiting decisions about treatment of attention-deficit/hyperactivity disorder. *Pediatrics* [Internet] 2009;124(2):580–589. PMID:2010-03468-016
12. Hayes Daniel, Edbrooke-Childs Julian, Town Rosa, Wolpert Miranda, Midgley Nick. Barriers and facilitators to shared decision-making in child and youth mental health: Exploring young person and parent perspectives using the Theoretical Domains Framework. *Counselling and Psychotherapy Research* 2020;20:57–67. [doi: 10.1002/capr.12257]
13. Liverpool S, Pereira B, Hayes D, Wolpert M, Edbrooke-Childs J. A scoping review and assessment of essential elements of shared-decision making of parent-involved interventions in child and adolescent mental health. *European Child and Adolescent Psychiatry*. 2020.

14. Westermann GMAA, Verheij F, Winkens B, Verhulst FC, van Oort FVAA. Structured shared decision-making using dialogue and visualization: A randomized controlled trial. *Patient Education and Counseling* [Internet] 2013;90(1):74–81. Available from: <http://www.sciencedirect.com/science/article/pii/S0738399112003874>
15. Gulliver A, Griffiths KM, Christensen H. Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC Psychiatry* 2010, 10:113
16. Clement S, Schauman O, Graham T, Maggioni F, Evans-Lacko S, Bezborodovs N, et al. What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. *Psychol Med* 2015 ;45(1):11-27
17. Silfvernagel K, Gren-Landell M, Emanuelsson M, Carlbring P, Andersson G. Individually tailored internet-based cognitive behavior therapy for adolescents with anxiety disorders: A pilot effectiveness study. *Internet Interventions* 2015; [doi: 10.1016/j.invent.2015.07.002]
18. Wangelin BC, Szafranski DD, Gros DF. Telehealth Technologies in Evidence-Based Psychotherapy. *Computer-Assisted and Web-Based Innovations in Psychology, Special Education, and Health* 2016. [doi: 10.1016/B978-0-12-802075-3.00005-X]
19. Carlon S, Carter M, Stephenson J. Pilot study of a parent guided website access package for early intervention decision-making for autism spectrum disorder. *Australasian Journal of Special Education* [Internet] 2017;41(2):141–156. PMID:2017-53133-006
20. Grant N. Assisting parents of children with autism to make intervention decisions by improving their health literacy about evidence [Internet]. The University of Queensland; 2016. Available from: <https://core.ac.uk/download/pdf/43393047.pdf>
21. Ossebaard HC, van Gemert-Pijnen JEW, Sorbi MJ, Seydel ER. A study of a Dutch online decision aid for parents of children with ADHD. *Journal of Telemedicine and Telecare London, England*; 2010;16(1):15–19. [doi: 10.1258/jtt.2009.001006]
22. Calvo R, Peters D. *Positive computing: technology for wellbeing and human potential*. The MIT Press. Sydney; 2015. [doi: 10.5860/choice.189530]

23. Das JK, Salam RA, Lassi ZS, Khan MN, Mahmood W, Patel V, Bhutta ZA. Interventions for Adolescent Mental Health: An Overview of Systematic Reviews. *Journal of Adolescent Health*. 2016. [doi: 10.1016/j.jadohealth.2016.06.020]
24. Baumel A, Pawar A, Kane JM, Correll CU. Digital Parent Training for Children with Disruptive Behaviors: Systematic Review and Meta-Analysis of Randomized Trials. *Journal of Child and Adolescent Psychopharmacology*. 2016. [doi: 10.1089/cap.2016.0048]
25. Breitenstein SM, Gross D, Christophersen R. Digital delivery methods of parenting training interventions: A systematic review. *Worldviews on Evidence-Based Nursing* 2014; PMID:24842341
26. Nieuwboer CC, Fukkink RG, Hermanns JMA. Peer and professional parenting support on the internet: A systematic review. *Cyberpsychology, Behavior, and Social Networking*. 2013. [doi: 10.1089/cyber.2012.0547]
27. National Institute for Health and Care Excellence. Shared decision making [Internet]. 2019. Available from: <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>
28. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Education and Counseling* 2006;60(3):301–312. PMID:16051459
29. Bomhof-Roordink H, Gärtner FR, Stiggelbout AM, Pieterse AH. Key components of shared decision making models: a systematic review. *BMJ Open* [Internet] 2019 Dec 1;9(12):e031763. [doi: 10.1136/bmjopen-2019-031763]
30. Kon AA, Morrison W. Shared decision-making in pediatric practice: A broad view. *Pediatrics*. 2018. [doi: 10.1542/peds.2018-0516B]
31. Salzburg Global Seminar. Salzburg statement on shared decision making. *BMJ (Clinical research ed)* 2011; [doi: 10.1136/bmj.d1745]

32. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and Evaluating Complex Interventions [Internet]. 2011. Available from:
<https://www.bmj.com/content/337/bmj.a1655.short>
33. O'Connor, A., & Jacobsen, M. (2003). *Workbook on developing and evaluating patient decision aids*. https://decisionaid.ohri.ca/docs/develop/develop_da.pdf
34. Elwyn G, Durand MA, Song J, Aarts J, Barr PJ, Berger Z, Cochran N, Frosch D, Galasiski D, Gulbrandsen P, Han PKJ, Härter M, Kinnersley P, Lloyd A, Mishra M, Perestelo-Perez L, Scholl I, Tomori K, Trevena L, Witteman HO, van der Weijden T. A three-talk model for shared decision making: Multistage consultation process. *BMJ (Online)* 2017;359. [doi: 10.1136/bmj.j4891]
35. Ottawa Health Research Institute. International Patient Decision Aid Standards (IPDAS) Collaboration [Internet]. 2005. Available from: http://ipdas.ohri.ca/IPDAS_checklist.pdf.
36. Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *Bmj [Internet]* 2006 [cited 2017 May 18]; Available from:
<http://www.bmj.com/content/333/7565/417?variant=full>
37. Crickard EL, O'Brien M, Rapp CA, Holmes CL, O'Brien MS, Rapp CA, Holmes CL. Developing a framework to support shared decision making for youth mental health medication treatment. *Boston*; 2010;46(5):474–481. [doi: 10.1007/s10597-010-9327-z]
38. O'Connor A, Stacey D, Jacobsen M. Ottawa Decision Support Tutorial (ODST): Improving Practitioners' Decision Support Skills Ottawa Hospital Research Institute [Internet]. 2011. Available from: <https://decisionaid.ohri.ca/odsf.html>
39. Bagley HJ, Short H, Harman NL, Hickey HR, Gamble CL, Woolfall K, Young B, Williamson PR. A patient and public involvement (PPI) toolkit for meaningful and flexible involvement in clinical trials – a work in progress. *Research Involvement and Engagement* 2016; [doi: 10.1186/s40900-016-0029-8]

40. Blackburn S, McLachlan S, Jowett S, Kinghorn P, Gill P, Higginbottom A, Rhodes C, Stevenson F, Jinks C. The extent, quality and impact of patient and public involvement in primary care research: A mixed methods study. *Research Involvement and Engagement* 2018; [doi: 10.1186/s40900-018-0100-8]
41. INVOLVE. What is public involvement in research? [Internet]. 2017 [cited 2020 Mar 30]. Available from: <http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>
42. Gondek D, Edbrooke-Childs J, Velikonja T, Chapman L, Saunders F, Hayes D, Wolpert M. Facilitators and Barriers to Person-centred Care in Child and Young People Mental Health Services: A Systematic Review. 2017;24(4):870–886. [doi: 10.1002/cpp.2052]
43. Hayes Daniel, Edbrooke-Childs Julian, Town Rosa, Wolpert Miranda, Midgley Nick. Barriers and facilitators to shared decision making in child and youth mental health: clinician perspectives using the Theoretical Domains Framework. *European Child and Adolescent Psychiatry* [Internet] 09/18. Springer Berlin Heidelberg; 2019;28(5):655–666. PMID:30229306
44. Polanczyk G v., Salum GA, Sugaya LS, Caye A, Rohde LA. Annual research review: A meta-analysis of the worldwide prevalence of mental disorders in children and adolescents. *Journal of Child Psychology and Psychiatry and Allied Disciplines* 2015; PMID:25649325
45. Wolpert M., Sharpe H., Humphrey N., Patalay P. & Deighton, J. (2016) EBPU Logic Model. London: CAMHS Press
46. Chang, B. P. I., Webb, T. L., Benn, Y., & Stride, C. B. (2017). Which factors are associated with monitoring goal progress? *Frontiers in Psychology*, 8, 434. <https://doi.org/10.3389/fpsyg.2017.00434>
47. Cheng H, Hayes D, Edbrooke-Childs J, Martin K, Chapman L, Wolpert M. What approaches for promoting shared decision-making are used in child mental health? A scoping review. *Clinical Psychology and Psychotherapy* 2017;24(6). [doi: 10.1002/cpp.2106]

48. Barton E, Freeman T, Baum F, Javanparast S, Lawless A. The feasibility and potential use of case-tracked client journeys in primary healthcare: A pilot study. *BMJ Open* 2019; [doi: 10.1136/bmjopen-2018-024419]
49. Brabban A, Turkington D. Mental Health UK [Internet]. 2002 [cited 2020 Mar 20]. Available from: <https://mentalhealth-uk.org/blog/the-stress-bucket/>
50. Ahmed R, Raynor DK, McCaffery KJ, Aslani P. The design and user-testing of a question prompt list for attention-deficit/hyperactivity disorder. *BMJ Open British Medical Journal Publishing Group*; 2014;4(12). [doi: 10.1136/bmjopen-2014-006585]
51. Brinkman WB, Hartl Majcher J, Poling LM, Shi G, Zender M, Sucharew H, Britto MT, Epstein JN. Shared decision-making to improve attention-deficit hyperactivity disorder care. *Patient Education and Counseling [Internet]* 05/10. 2013;93(1):95–101. PMID:23669153
52. Grant N, Rodger S, Hoffmann T. Intervention decision-making processes and information preferences of parents of children with autism spectrum disorders. Bowker Carlon, Carpenter, Elsabbagh, Elwyn, Grant, Grant, Green, Krefting, Leininger, Lipstein, MacDermott, Mackintosh, Mathieu, Murphy, O'Connor, O'Reilly, Patton, Reichow, Stacey, Thackeray, Valentine, Valentine B, editor. *Child: Care, Health and Development [Internet]* Grant, N.: School of Health and Rehabilitation Sciences, University of Queensland, St Lucia, QLD, Australia, 4067, nicole.grant@uqconnect.edu.au: Wiley-Blackwell Publishing Ltd.; 2016;42(1):125–134. Available from: <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=psyc13a&AN=2016-02973-007>
53. Hayes D, Town R, Lemoniatis E. Developing and piloting i-THRIVE grids [Internet]. 2018. Available from: <http://www.implementingthrive.org/i-thrive-grids/>
54. Collins LM. Optimization of behavioral, biobehavioral, and biomedical interventions: The Multiphase Optimization Strategy (MOST). Springer. 2018. ISBN:3319722069

55. Liverpool S, Webber H, Matthews R, Wolpert M, Edbrooke-Childs J. A mobile app to support parents making child mental health decisions: Protocol for a feasibility cluster controlled trial. *Journal of Medical Internet Research* 2019;21(8). [doi: 10.2196/14571]
56. McGurk M, Amis AA, Potamianos P, Goodger NM. Rapid prototyping techniques for anatomical modelling in medicine. *Annals of the Royal College of Surgeons of England*. 1997. PMID:9196336
57. Staniszewska S, Denegri S. Patient and public involvement in research: Future challenges. *Evidence-Based Nursing*. 2013. [doi: 10.1136/eb-2013-101406]
58. Alvarez-Jimenez M, Alcazar-Corcoles MA, González-Blanch C, Bendall S, McGorry PD, Gleeson JF. Online, social media and mobile technologies for psychosis treatment: A systematic review on novel user-led interventions. *Schizophrenia Research*. 2014. [doi: 10.1016/j.schres.2014.03.021]
59. Diehl JJ, Schmitt LM, Villano M, Crowell CR. The clinical use of robots for individuals with Autism Spectrum Disorders: A critical review. *Research in Autism Spectrum Disorders*. 2012. [doi: 10.1016/j.rasd.2011.05.006]
60. Donker T, Petrie K, Proudfoot J, Clarke J, Birch MR, Christensen H. Smartphones for smarter delivery of mental health programs: A systematic review. *Journal of Medical Internet Research*. 2013. [doi: 10.2196/jmir.2791]
61. Liverpool, Shaun, & Edbrooke-Childs, Julian. (2021). Feasibility and Acceptability of a Digital Intervention to Support Shared Decision-making in Children's and Young People's Mental Health: Mixed Methods Pilot Randomized Controlled Trial. *JMIR Formative Research*, 5(3), E25235.
62. Liverpool, Shaun, Hayes, Daniel, & Edbrooke-Childs, Julian. (2021). An Affective-Appraisal Approach for Parental Shared Decision Making in Children and Young People's Mental Health Settings: A Qualitative Study. *Frontiers in Psychiatry*, 12, 626848.

