“CaFI Digital”: Co-designing a digital platform to support a Culturally-adapted Family Intervention (CaFI) for African and Caribbean people diagnosed with psychosis and their families.

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Abstract

Background: People from Sub-Saharan African and Caribbean backgrounds are significantly more likely to be diagnosed with psychotic disorders than other ethnic groups in the UK. The National Institute for Health and Care Excellence (NICE) in the UK recommends family therapy as a clinically effective treatment for the management of psychosis. NICE also recommends that family interventions should be culturally informed to meet the needs of an increasingly ethnically diverse population. However, people from minoritised backgrounds are rarely offered family therapy. The rise in digital mental health worldwide offers unique opportunities to support culturally informed approaches at scale and low cost.

Objective: The overarching aim of CaFI:Digital was to help address inequalities in the provision of mental healthcare for people from Black African and Caribbean populations, by building a digital platform ‘CaFI:Digital’ to support delivery of a Culturally-Adapted Family Intervention (CaFI). The purpose of developing CaFI:Digital was to provide an accessible, user-friendly, and engaging website for service users, their families and therapists as an alternative or adjunct to in-person therapy.

Methods: We used an iterative Agile co-design approach to develop a user-friendly and inclusive website. Co-design workshops (n = 2), semi-structured interviews (n = 2), and collaborative research team meetings (n = 3) were used to capture and prioritise end user feedback on the clinician and service-user-facing components of the platform. The software was developed using Agile sprints, with each sprint lasting 3-weeks, allowing feedback to be integrated rapidly and revised software prototypes to be shared with end users for review, revision, and approval.

Results: Key software requirements were identified in the co-design activities and were implemented to maximise accessibility and usability of the website. Following the software development, we successfully beta-tested the software with our target end user population to ensure it was defect-free and ready for use with the target population.

Conclusions: A digital platform to support delivery of Culturally-Adapted Family Intervention (CaFI) for psychosis was rapidly developed in a series of co-design activities. To our knowledge, this is the first bespoke digital therapy platform that has been co-designed with and for people of Black African and Caribbean descent who experience psychosis. This is important given the disproportionate rates of diagnosis and lack of access to psychological therapies experienced by this population. Clinical Trial: N/A

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Abstract

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Keywords: health inequalities; digital mental health; psychosis; mental illness; accessibility; co-design methods; family therapy; culturally-adapted

Introduction

In the UK, people of Black African and Caribbean descent have an elevated risk of diagnosis with schizophrenia and related psychoses compared with White British peers [1,2]. Black African and Caribbean service users attributed this risk to the buildup of stressors directly

linked to ethnic minority status [1]. Disparities in diagnostic rates are compounded by sub-optimal care and negative experiences of services which are characterized by high rates of involuntary hospitalization and inferior access to evidence-based treatments [1,3]. There is strong evidence for the cost- and clinical-effectiveness of psychological or 'talking' therapies such as Family Intervention (FI) for psychosis [4,5]. However, and despite NICE recommendations, such treatments are rarely culturally informed [6,7]. Moreover, while there are studies highlighting ethnically-based inequalities, we are not aware of *any* robustly evaluated digital mental health interventions specifically designed for Black populations with a diagnosis of schizophrenia or psychosis. This population is therefore under-served both *digitally* and in access to evidence-based care.

The Culturally-adapted Family Intervention (CaFI) project was co-designed with people of Black African and Caribbean descent diagnosed with schizophrenia and associated psychoses and other key stakeholders [8]. It aims to provide culturally appropriate group psychological therapy for people who have experienced longstanding inequalities in mental healthcare [9,10], including rarely being offered talking treatments [9,11]. In-person therapies may also increase concerns amongst Black African and Caribbean communities, as there is a history of fear and mistrust around engaging with statutory mental health services [12]. People living in the UK with these backgrounds use diverse terminology to self-identify their ethnicity, which may include e.g., 'Black British', 'Mixed heritage', 'Black African', and 'Black Caribbean' amongst other descriptors. For simplicity, 'people of African and Caribbean descent', 'African and Caribbean populations' shall be used interchangeably to describe the study populations in this article.

In the UK, NICE recommends culturally sensitive approaches for the treatment of psychosis, as well as family intervention therapy [13]. Funding from the National Institute of Health and Social Care Research in the UK [14] supported the original development of the CaFI [15] and subsequently funded a randomized controlled trial (RCT), the 'CaFI Trial', to investigate the effect on relapse of Culturally-Adapted Family Intervention (CaFI) compared to usual care among Sub-Saharan African & Caribbean people diagnosed with psychosis in the UK [16].

The CaFI trial was originally planned to commence in July 2020 but was postponed due to the COVID19 pandemic. As evidence emerged of higher rates of COVID19 infections and mortality among Black Caribbean, African, and other ethnic minority populations in the UK [17]; it became apparent that delivering in-person therapy was neither feasible nor ethical. In our work to develop CaFI, community members cited examples of Black people's exploitation in research – most notably, the use of Henrietta Lacks' cells [18] and Tuskegee syphilis study [19]. Thus, development of a digital alternative was explored with former service users and community members and determined to be a potentially viable approach to improving the likelihood of engagement and participation in the study [20].

CaFI:Digital (a new sub-component of the CaFI Trial: ISRCTN12622538) was created to support the delivery of online group therapy enabling the study to continue while face to face consultations were not possible. The purpose of developing CaFI:Digital was to provide an accessible, user-friendly, and engaging website for service users, their families and therapists as an alternative or adjunct to in-person therapy. CaFI:Digital is a web-based platform that provides access to specially designed, co-created therapy resources. It was anticipated that CaFI:Digital would be useful for service users even after in person therapy could resume. The CaFI trial was underpinned by the ethical imperative to support a population that was under-served and CaFI:Digital employed a co-design approach that placed service users and their

carers at the heart of the digital development process. This paper outlines the development of CaFI:Digital using a co-design approach with key stakeholders.

Methods

Ethical Approval

Ethical approval was obtained for the co-design workshops from the Health Research Authority in the UK (19/NW/0385. IRAS ID 254857, approved 24th July 2019).

Study Setting, Participants, and Recruitment and Sample

This Participants were recruited through the participating National Health Service's (NHS) community mental health teams (CMHTs) and collaborating third sector organisations. Demographic data of participants in each research activity were not recorded consistently. The website was co-designed using an iterative, user-centred process over a six month period. Three workshops were held consisting of (1) service users and carers (n=7); (2) therapists (n=4); and (3) a mixed stakeholder workshop. Two individual semi-structured interviews were also conducted separately with therapists during the design process. Research team meetings (n=3) were also held to capture and prioritise end user feedback on the clinician and service-user-facing components of the website. Workshops were conducted using Microsoft Teams and lasted between 60 and 90 minutes. The workshops followed a similar structure starting with an overview of the project followed by a discussion of key features, requirements and priorities for Cafi:Digital. Design prototypes were presented at each workshop to allow participants to see what the website would look like, and enable the participants to provide feedback on each iteration of the designs. The prototype user interface was designed in Adobe XD [21], and interactivity was added using Marvel [22]. Usability testing was conducted using Maze [23].

Co-Design and Agile Approaches

A co-design approach was combined with Agile software methodologies [24] to support collaboration between people with lived experience, software developers, researchers and designers. The co-design and User Research approach followed the UK Government Service Design Guidelines across the three setup stages: Discovery, Alpha, Beta [25]. In the Discovery phase workshop service users and carers (n=7) were asked to input and feed back provided on key requirements and features for the website. The Alpha phase involved a workshop with therapists (n=4) to provide feedback on the website prototypes which had been developed from the service user and carer feedback. In addition to this, two therapists provided feedback through individual discussions at critical timepoints during the design process. Further feedback was also provided at a subsequent mixed stakeholder workshop consisting of service users; carers, and therapists. A beta-test phase was conducted with nine participants (including service users, carers, therapists, researchers and software team staff) to ensure the website was defect free and ready for use. The beta-test phase also asked users to report on the usability and accessibility of the platform. Figure 1 shows the development stages of the prototype.

Figure 1. Flow chart showing the development stages of the interactive prototype.

Accessibility

An accessibility discussion was included in the focus group to identify and review the specific accessibility needs participants might experience when using the website. Participants were specifically asked if they anticipated encountering any barriers to accessing or using the website; and also which kinds of devices they would find it most useful to access the website

from.

MoSCoW Prioritisation

Aligned with Agile approaches [24], we adopted the MoSCoW (Must have, Should have, Could have, Won't have) prioritisation system [26] to triage requirements. The MoSCoW approach is widely used in software development to determine the most important features/deliverables across mixed stakeholder groups. In the MoSCoW approach, design features of the website were ranked as "must have," "should have," "could have," and "won't have." Features which were ranked as "must have" were considered as essential by stakeholders; "should have" features were deemed important, however would not affect the functionality of the website if they were not included; "could have" features were not necessarily related to the key aims of CaFI:Digital, but were seen as additional desirable features; finally, features classified as "won't have" were either not priorities for stakeholders, or not feasible to deliver within the scope of this study. Workshop facilitators supported discussion when different priorities were identified, aiming to arrive at a consensus decision. Where decisions were outstanding after the workshops, the research team and technical teams made the final decisions, guided by the necessity to deliver the project on time and budget.

Tracking usage and engagement metrics

Usage and engagement analytics were embedded within the platform following the AMUsED framework for digital health interventions [27]. The main goal was to track analytics within the platform that could be useful in understanding which elements of content were most visited by participants.

Results

The co-design workshops generated user needs-led software design requirements and modifications to prototypes that were demonstrated by the project UX designer. A summary of requirements and changes are included the tables below.

Table 1. Workshop 1 Input Design Changes – Service User and Carer Workshop – Discovery Phase.

Feedback Item	**Design / Software Modification**	**Project Solution**
Accessibility		
Ensure navigation of the site is as simple and clear as possible for service users.	Navigation of the site simplified and updated.	Therapists trained to email/ text a simple weblink to service users to navigate to the required webpage.
Ensure website works well	Website reviewed to be Web	Training about how to

for people with visual impairments. The option to make the text larger through the browser is really helpful as many people have visual impairments.	Content Accessibility Guidelines 2.1 [18] compliant. Larger than usual font size used. Colour contrast used to ensure readability.	increase font size through the browser provided to research team and therapists.
Provide 'Help Page' to guide users on how to engage with the content and materials.	Development of 'Help Page'.	'Help Page' included on the website.
Some service users will not have access to technology to look at CaFI:Digital.		Tablets purchased and provided to service users and families where needed. Study purchased mobile data plans to ensure the website could be accessed.
Some service users will not have the skills to engage with a website.	An emphasis on simplicity of design and implementation was maintained throughout.	Volunteer Digital Navigators at the Lead NHS Trust joined the project team to support service users with basic literacy skills to enable service users to access and use the website with support if they wished to do so. Volunteer Digital Navigators receive appropriate NHS training to support service users develop and use digital skills.
The therapist would need to explain up front what the website does.		Training to therapists provided to ensure they pass on key information to service users before the

		website is recommended for use.
Diverse Content		
There should be more diversity in the images of people displayed across the website – specifically a greater range of skin tones should be included.		The images were updated to include a broader range of people representing diverse ethnic backgrounds. This included people from North African communities, incorporating a variety of skin tones, as well as individuals wearing culturally significant clothing, such as hijabs.
Positive Feedback		
The website is very exciting and the first time such a resource has been developed for this population	No action required.	No action required.
The site is visually appealing.	No action required.	No action required.
The site looks very simple to use.	No action required.	No action required.
Note: Providing audio versions of all materials was discussed, however this was not supported in this project due to time and cost limitations.		

Table 2. Workshop 2 – Design Changes – Therapist Feedback – Alpha Phase.

Feedback Item	Design / software modification	Project solution
Accessibility		
The navigation of the site must be very simple for services users and for therapists.	A simple link to navigate to relevant webpages was developed. This removed the need for services users to navigate large sections of the website as the link took them to exactly the content that was designed for them at that stage in the therapeutic process.	Service Users received the individual links by email. Therapists were provided with 'Copy Link' button to enable them to paste into an email.
Embed training in the website for therapists.	Training video created for the therapist. Development of 'Help Page'.	'Help Page' and training video included on the website.
Some service users will not have access to digital devices or data plans to access CaFI:Digital.		Tablets purchased and provided to service users where needed. Study purchased mobile data plans to ensure the website could be accessed.
Service users will also require printed materials to ensure equity of access to those who prefer to work with hardcopy materials.		Printer materials were prepared for use with all service users.
Positive Feedback		
The site looks very good.	No action required.	No action required.

Table 3. Workshop 3 – Mixed Stakeholder – Feedback – Alpha Phase (Consensus).

Feedback Item	**Design / software modification**	**Project solution**
The site is visually appealing	No action required.	No action required.
The site looks very easy to use for everyone.	No action required.	No action required.
The site looks very good.	No action required.	No action required.
Queries about whether the website worked across different kinds of devices (tablets, mobile, desktop)	Confirmed that website worked across multiple devices.	No action required.

Workshop feedback

Feedback in the service user/carer workshops focused on the need to ensure that the website was easy to usable and simple to navigate. An emphasis was placed on accessibility: making the font size large to support people with visual impairments, making the text easy to read and providing adequate support and training for people unfamiliar with digital technologies. Diversity in the images portrayed on the website was also requested, particularly in terms of diversity of skin tones depicted.

Figure 2. 4 images of people from the original prototype (left), and 4 updated images (right) incorporating a variety of skin tones, as well as individuals wearing culturally significant clothing.

Feedback in the therapist workshops included recommendations to: prioritise simplicity of design; ensure ease of site navigation; embed training within the site; and to ensure supplementary printed materials were provided to participants. The service user and carer workshop identified the positives of using digital technology to supplement therapy delivery including reporting how digital 'offered a way to engage with the world' even when people felt very unwell. Poor accessibility of some digital platforms was raised as a concern by service user

participants in the workshops, several of whom mentioned the need to ensure the website worked well for those with visual impairments.

Prioritising workshop feedback

Workshop feedback was reviewed by the project team using the MoSCoW prioritisation method [28] and actioned by the software team or wider research team as appropriate. A small number of items were deemed 'out of scope' due to the time and cost implications of implementation – detailed in the tables above.

Digital inequities

Participants across all workshops expressed concern about people who had no access to digital technology and/or had poor digital literacy skills, stressing the need for equity in the delivery of digital solutions and therapeutic interventions more widely.

Beta-test results

After all the changes from the co-design workshops had been addressed as described in the tables above, nine volunteers were asked to test the website on their own devices. The purpose of this phase was to identify any critical or major technical defects with the website that needed to be resolved. Volunteers represented service users (1), families (2), therapists (2), and critical friends of the research team (4). A major problem was reported on a specific version of the iPhone, which blocked users from logging in. This was resolved by the software team, and the website was re-tested on this iPhone version. No other critical or major defects were reported by beta testers. Positive feedback on the beta-testing is reported in the table below.

Accessibility related changes

Accessibility was identified as a key area of focus throughout the codesign and development work packages. The website prototypes shown in the workshops had been designed and tested to be Web Content Accessibility Guidelines (WCAG) 2.1 compliant [29]. Additional accessibility needs were identified through the workshops. In the co-design workshops, visual impairment was identified as a common problem among the target population. To respond to this, a larger than usual font size was used as the default and training was included with the trial roll-out to advise how to increase the font of the website on common web browsers. Colour contrast was also assessed to ensure the website worked well for people with visual impairments – a point raised by service users in Workshop 1 and by the wider research team in team meetings.

Discussion

Principal Results

To our knowledge, this is the first study to co-design a culturally-informed digital mental health intervention with and for Black populations who experience psychosis. The co-design activities have been designed to ensure that the priorities of the end users of the platform are met. The target population for CaFI has historically been under-served digitally through lack of provision of digital mental health tools as well as in terms of access to evidence based psychological interventions. CaFI:Digital is an attempt to redress this imbalance. The CaFI:Digital intervention will be evaluated as part of the process evaluation of the Randomised Controlled Trial.

Given lack of provision of digital mental health interventions for the CaFI target population and digital mental health inequities more generally, the CaFI trial offered an opportunity to develop

and evaluate a digital mental health intervention that was co-designed with a population that has been underserved digitally as well as in terms of access to mental healthcare. Digitisation also provides an opportunity to engage family members in therapy who many live far away from each other. This is particularly relevant for the CaFI target population, many of whom have family members located in different locations around the world. Moreover, unlike face-to-face interventions, the CaFI:Digital platform can be readily adapted and scaled for worldwide delivery. This aligns with national and international policy and practice to address ethnically-based inequalities, aligning with both NHS priorities in the UK [30] and global approaches to enhancing delivery of healthcare using digital tools [31].

The findings of this study are consistent with recent policy shifts in the UK, notably the NHS Long Term Plan (2019) and NHS England's Inclusive Digital Healthcare Framework (2023), which advocate for the increased use of digital tools to enhance accessibility and equity in healthcare delivery [32,33]. Furthermore, CaFI: Digital aligns with NHS inclusive research practice foregrounding cultural competence, stakeholder engagement and the reduction in health inequalities [34]. The co-design approach used in the platform's development reflects the NHS's commitment to involve diverse, underrepresented communities in research and interventions are tailored to meet the needs of Black and Caribbean populations.

The combination of co-design and Agile software approaches used for CaFI:Digital enabled the software team to identify and respond to requirements and refinements identified by service users, their families/carers, and the therapists, despite the constraints on face-to-face meetings during the COVID19 pandemic. The use of the MoSCoW prioritisation system supported the rapid development cycle required to respond to the pandemic, and stakeholder needs. This was particularly helpful when time-consuming or resource intensive recommendations were identified. A key concern for participants during the development phase of the website was ensuring the website was simple to use and accessible to all and dedicated workstreams were developed to whoaddress specific accessibility concerns raised. The beta-test ensured that the software was defect free and ready to use in the live trial. Inevitably, more suggestions were made at the co-design workshops than there was time or budget to implement. Future versions of the software could seek to address these recommendations (e.g., by providing audio versions of all the website materials).

At the time of writing, the CaFI:Digital is being used in a live trial, so it is not possible to report trial outcomes, or to present analysed data on usage and engagement data. However, the co-design and development phases have sought to make the website as usable and accessible as possible by working with service users, their families, and therapists throughout the co-design process. CaFI:Digital provides access to psychological therapies for people in underrepresented populations.

Analysis from the CaFI trial using the engagement analytics embedded within the website combined with qualitative research on user experiences of the platform will enrich our understanding of how participants experienced the CaFI:Digital platform during the trial. Evaluating online group therapy interventions with underserved populations will enhance our understanding of how technology enhances care or perpetuates inequalities for already underserved and 'seldom heard' populations.

The CaFI:Digital platform presents unique opportunities to respond to NICE recommended policy guidelines in the UK [13] by enabling remotely-delivered culturally-adapted family therapy. Policy recommendations stemming from this research should prioritise the integration

of digital health solutions within national and international healthcare frameworks, particularly in relation to ethnic minority groups who experience disproportionately high rates of mental health conditions and systemic healthcare exclusion.

Conclusions

CaFI:Digital aspires to be at the forefront of efforts to address the gap in access to mental healthcare for UK Black communities, as an evidence based digital therapy platform, working towards conforming to the NICE evidence standards framework for health technologies. There is potential for the platform to be rolled out internationally at scale and at a competitive cost to provide access to treatment to historically excluded and underserved groups. While digital approaches can sometimes widen inequalities (by restricting access to treatment for people who are digitally excluded), there is also the potential for digital technologies to address inequalities. NHS England (2023) acknowledges this potential in their published guidance on designing and implementing inclusive digital healthcare. The guidance outlines ways to make digital healthcare more accessible by e.g., maximising on the relatability of the technologies, conducting mixed-methods research in the digital space, and actioning user feedback, many of which have been addressed in the development of CaFI:Digital. Moreover, for a population who often have family members located internationally, the remote therapeutic delivery enables the inclusion of family members previously excluded. This is important given the disproportionate rates of diagnosis and lack of access to psychological therapies experienced by this population. Our hope is that CaFI:Digital can begin to address this historic gap in provision of culturally adapted family interventions for Black populations.

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Conflicts of Interest

Dr Whelan is a director and shareholder of a for-profit digital mental health company CareLoop Health Ltd, and a director and shareholder of Prism Life Ltd, small consultancy company.

Abbreviations

CMHT: Community Mental Health Teams
MoSCoW: "Must Have", "Should Have", "Could Have", and "Won't Have"
NHS: National Health Service
NICE: National Institute for Health and Care Excellence
NiHR: National Institute for Health Research
UK: United Kingdom

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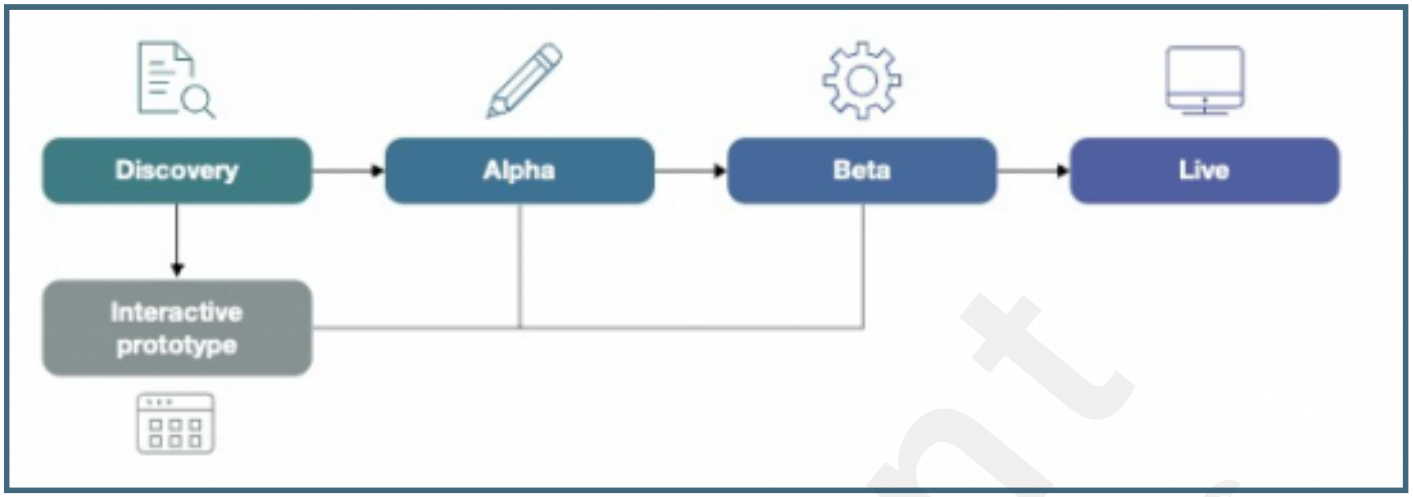
Supplementary Files

Figures

Flow chart showing the development stages of the interactive prototype.



Four images of people from the original prototype (left), and 4 updated images (right) incorporating a variety of skin tones, as well as individuals wearing culturally significant clothing.