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Perspectives on adapting a mobile application for pain self-management in neurofibromatosis type 1: results of online focus group discussions with individuals living with neurofibromatosis type 1 and pain management experts

Lauretta E Grau ,[1] Kaitlyn Larkin,[2] Chitra Lalloo,[3,4] Jennifer N Stinson,[4,5] William T Zempsky,[6,7] Samuel A Ball,[2] Frank D Buono[2]

For numbered affiliations see end of article.

Correspondence to
Dr Lauretta E Grau;
lauretta.grau@yale.edu

ABSTRACT

Objective Neurofibromatosis type 1 (NF1) is a genetic disorder in which chronic pain commonly occurs. The study sought to understand the needs of individuals with NF1 and pain management experts when adapting a pain self-management mobile health application (app) for individuals with NF1.

Design We conducted a series of online, audio-recorded focus groups that were then thematically analysed.

Setting Online focus groups with adults currently residing in the USA.

Participants Two types of participants were included: individuals with NF1 (n=32 across six focus groups) and pain management experts (n=10 across three focus groups).

Results Six themes across two levels were identified. The individual level included lifestyle, reasons for using the mobile app and concerns regarding its use. The app level included desired content, desired features and format considerations. Findings included recommendations to grant free access to the app and include a community support feature for individuals to relate and validate one another's experience with pain from NF1. In addition, participants noted the importance of providing clear instructions on navigating the app, the use of an upbeat, hopeful tone and appropriate visuals.

Conclusions Both participant groups endorsed the use of iCanCope (iCC) as an NF1 pain self-management mobile app. Differences between groups were noted, however. The NF1 group appeared interested in detailed and nuanced pain tracking capabilities; the expert group prioritised tracking information such as mood, nutrition and activity to identify potential associations with pain. In tailoring the existing iCC app for individuals with NF1, attention should be paid to creating a community support group feature and to tailoring content, features and format to potential users' specific needs.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Achieved data saturation, ensuring a deep understanding of the stated research question.
⇒ Online focus group format permitted a time-efficient and cost-efficient opportunity to enable wide geographical representation among participants.
⇒ Unverified neurofibromatosis type 1 status and low representation among members of minority communities may have limited the credibility and transferability of the findings.
⇒ Online focus groups limit the ability to observe in-person dynamics or subtle reactions to the various discussion topics.

INTRODUCTION

Neurofibromatosis type 1 (NF1) is an autosomal dominant genetic disorder affecting an estimated 1 in 3000 individuals worldwide.[1] Common presentations of NF1 can include plexiform neurofibroma tumours, café au lait macules[2 3] and extensive dermal neurofibromas.[4] Over 50% of individuals with NF1 report significant pain and discomfort,[5] often stemming from the plexiform neurofibroma tumours.[6] In addition, frequent headaches and orthopaedic and other tumour-related pain[4] may also impair NF1 patients' quality of life.[7]

Current treatment recommendations for chronic pain related to NF1 are limited to pharmacological and surgical methods due to the complexity of the tumours.[8] It is common for individuals with NF1 to employ complementary pain management approaches (eg, yoga, physical therapy and massage therapy)

to manage their pain symptoms.[9] However, there are also challenges to receiving treatment for NF1-related chronic pain such as healthcare system barriers and limited access to self-management techniques,[10] creating a need for innovative, effective and accessible treatment options.

Mobile health applications (apps), with over 325 000 currently available, have become increasingly popular,[11] including some for self-management of many chronic illnesses.[12 13] A systematic review concluded that mobile health interventions improved clinical outcomes across varying chronic diseases and increased access to pain management resources at low cost,[14] but once established, they can also be tailored to specific illnesses and conditions.

iCanCope (iCC) is an innovative mobile app originally developed to address pain self-management needs of adolescents and young adults with chronic pain.[15 16] The iCC platform was created through a user-centred design approach that involved end users at every stage and is founded on the principles of cognitive–behavioural therapy and the use of mind–body approaches. The core iCC features include daily symptom tracking, personalised goal setting to improve pain and functioning, and a toolbox of disease education and pain self-management strategies. A pilot study of iCC demonstrated feasibility of deploying the app among adolescents with chronic pain[17] and has since been expanded to support pain self-management in youth and young adults with juvenile idiopathic arthritis,[18] sickle cell disease[19] and postoperative pain,[20] with each adaptation reporting clinically meaningful reductions in pain intensity.

The use of mobile technology to address the needs of patients with NF1 is a promising strategy to expand access to pain self-management interventions. We therefore proposed to adapt the iCC platform. As a first step, we sought recommendations about the desired features and content that adults with NF1 and pain management experts considered important to include when adapting the iCC mobile health app as well as the perceived acceptability and barriers/facilitators to its use. We reasoned that the multiple perspectives of these individuals would yield a richer and more nuanced assessment of the desired features and content to include in the adaptation.

METHODS
Study sample
The study involved two participant groups: adults with NF1 (n=32) and experts in the treatment and management of NF1-associated pain (n=10). Inclusion criteria for the NF1 group were (1) age 18–45 years with an NF1 diagnosis, (2) pain severity aggregate score of ≥3 on the Brief Pain Inventory–Short Form (BPI-SF)[21 22] for pain experienced in the previous 2 weeks, (3) being proficient in English at the fifth grade level and competent to provide informed consent, (4) agreeing to audio-recording of the focus group session and (5) residing in the USA. The exclusion criteria consisted of (1) moderate to

severe cognitive deficits or (2) evidence of moderate to severe depression or anxiety, as assessed by the Patient Health Questionnaire (PHQ),[23] SCID-Self-report (SCID-SR)[24] and Generalised Anxiety Disorder 7-Item (GAD-7) scale.[25] Inclusion criteria for the expert group were (1) providing healthcare to patients with NF1 (eg, physicians, nurse practitioners and psychologists) and (2) agreeing to audio-recording of the focus group session.

Patient and public involvement
Patients or the public were not involved in the design, conduct, reporting or dissemination plans of this study.

Recruitment procedures
Recruitment for the NF1 group consisted of posting an announcement briefly describing the study on the Facebook pages for two NF advocacy groups (NF Northeast and NF Network) and emailing all members of both group registries. Membership in both registries requires self-report of having received an NF diagnosis. Individuals interested in participating were directed to an online survey (www.qualtrics.com) that collected demographic and contact information as well as responses to the BPI-SF, PHQ, GAD-7 and SCID-SR. The research team reviewed the results of these clinical measures, and individuals meeting the inclusion requirements then received a list of focus group discussion (FGD) dates/times from which to select. Recruitment for the expert group occurred via website postings about the study on the US Association for the Study of Pain and the NF Network clinician pages. Prior to beginning each FGD, the participants were provided with a brief description of the study and were informed of the voluntary nature of their participation. All participants provided verbal informed consent prior to participating in the FGD session.

After completing the FGD, participants in the NF1 and expert groups received $25 and a $100 gift card, respectively.

Data collection and analysis
Each FGD session lasted approximately 1 hour and occurred via a secure, password-enforced video conference (www.zoom.com). Two members of the research team (FDB and KL) with prior training in conducting focus groups jointly facilitated the sessions.

An interview guide was developed specifically for this study (see the online supplemental file 1). Only the NF1 group sessions began by asking whether participants owned smartphones. All participants were then asked their opinions about using a phone-based app to address NF1 pain management. A brief presentation then occurred that described the existing iCC mobile app and included four screenshots from the app. The remaining session time was guided by that description, the four screenshots and the four domains included in the FGD guide: (1) perceived barriers and facilitators to using a mobile app to manage pain, (2) perceived acceptability and benefits of the proposed app, (3) contexts within which the app

would most likely be used, and (4) recommendations for possible additions or modifications to the app. Demographic information for the NF1 group included age and gender, collected at eligibility screening, and that for the expert group included professional training/title, years in practice and gender, collected at the beginning of each FGD. The audio-recorded transcripts were professionally transcribed verbatim.

An existing codebook from a prior iCC study[26] was modified for use in the current study. Members of the data analysis team (FDB, KL, LEG, JNS and CL) met regularly to review transcripts and discuss codebook development. Interviews continued until data saturation had been achieved.[27 28] The final codebook included 29 codes, 3 of which were new codes from the expert group sessions. Acceptable intercoder agreement was established after independently coding two transcripts. The remaining transcripts were then independently coded by both coders (FDB and KL). The coding team continued to meet periodically to resolve coding discrepancies (through consensus), address coding questions and further refine code definitions as needed. The coded transcripts were then entered into Dedoose V.8.3.47 (www.dedoose.com) for analysis. The coding and analysis process continued in an iterative fashion using thematic analysis.[29 30] Negative instances where the data did not fit the existing themes were identified as part of the confirmability process.[31] Descriptive statistics were calculated for the demographic data. The entire research team reviewed all analytical findings.

RESULTS

A total of nine FGDs—six NF1 groups (n=32) and three pain management expert groups (n=10)—occurred between January and May 2020. Previous research has shown intrinsic motivation[32] to be the critical, first step in promoting future goal-oriented behaviours.[33] We therefore sought to identify themes that shaped motivation to use the proposed mobile app and generated a total of six themes across two levels (ie, individual and app) as seen in the conceptual model in figure 1. The themes of lifestyle, reasons for using the mobile app and concerns regarding use of the mobile app were identified at the individual level. The app level included the themes of desired content, desired features and format considerations.

Description of the study sample

A total of 42 individuals participated in the study (table 1). Overall, the NF1 group was generally young and predominantly female. Except for one participant, all owned smartphones. Most within the NF1 group were experiencing moderate pain at screening. The expert group consisted entirely of individuals with postgraduate training in their respective fields and had, on average, over 19 years of professional experience. Similar to the NF1 group, the majority of expert participants were female.
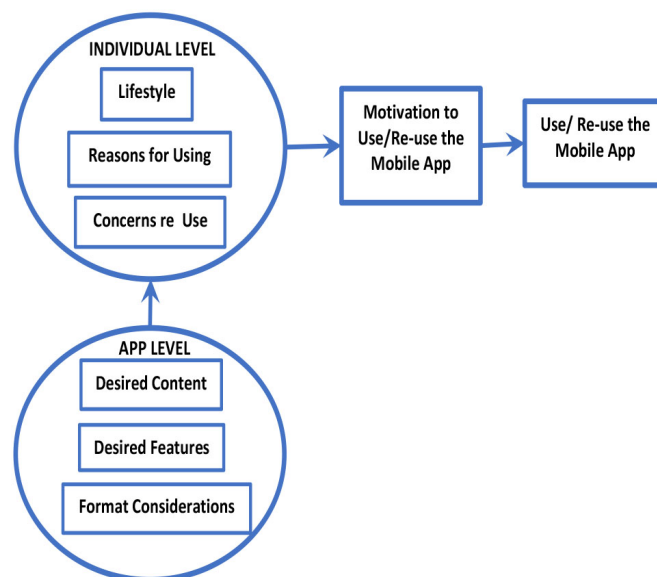
Figure 1 Conceptual framework and themes for motivation to use the mobile application.

Individual-level themes

The individual level focused on the life situations of individuals with NF1 that were thought to influence motivation to use the proposed mobile app.

Theme 1: lifestyle (individual level)

Two subthemes were identified within the lifestyle theme (table 2): affordability/accessibility and time. The former focused on financial or other considerations that could influence ease of access. Both groups recognised that the mobile app needed to be 'very cheap' or free and not consume much data (ie, bottlenecking). Access issues related to geographical location or app use that depended on external factors such as internet signal strength or workplace access policies were also mentioned but were beyond what could be addressed within the app.

Time, the second subtheme, focused on the busy lifestyles of most NF1 group members, usually involving parenting or work responsibilities. Both participant groups recognised that use of the app needed to easily fit into users' schedules. Barriers to its use included forgetting to access the app during busy times or when confronted with unexpected outside demands.

Theme 2: reasons for using the mobile app (individual level)

This theme concerned potential factors thought to directly increase motivation to use the mobile app, primarily through rapid user engagement with programme content and activities. It included two subthemes: engagement and hope (table 2).

The engagement subtheme focused on the fact that users would be more likely to use the app if they achieved improvements or successes early on. As one expert noted, 'The ultimate aim is showing progress'. Both participant groups also believed that earning rewards (eg, badges and points) can promote engagement with and continued use

Table 1 Characteristics of the study sample (N=42)

	NF1 group (n=32)	Expert group (n=10)
Age (years)*	31.2 (4.9)	--
Range	18–39	--
Gender, n (%)†		
Male	6 (19)	4 (40)
Female	25 (78)	6 (60)
Other	1 (4)	–
Aggregate pain severity[1 3]	4.8 (1.7)	–
Aggregate pain interference[1 4]	4.9 (2.6)	–
Professional training/title, n (%)†		
Pain psychologist	–	2 (20)
Neurologist	–	5 (50)
Primary care physician	–	2 (20)
Neuro-oncologist	–	1 (10)
Years in practice*	–	19.2 (7.2)
Range	--	7–38

*Mean (SD).
†N (%).
‡BPI-SF; four items for pain severity, possible range of scores is 0–10.
§BPI-SF, seven items for pain interference, possible range of scores is 0–10.
BPI-SF, Brief Pain Inventory–Short Form.

of the app. Participants often referred to this as 'buy-in' and viewed it as critical to programme uptake.

Similarly, instilling a sense of hope was seen as essential to promoting engagement and continued use of the programme. Instilling hope was not considered to be limited to explicit messages of hope but could also result from individuals with NF1 recognising improvements in function, quality of life or having their NF1 pain validated by others.

Theme 3: concerns regarding use of the mobile APP (individual level)

The NF1 group seemed particularly concerned about privacy and access. They worried about who would have access to their health data and whether access to such data could jeopardise health insurance coverage or pose an unforeseen risk (table 2). As previously mentioned in the affordability/accessibility subtheme, participants were also concerned that internet coverage or work restrictions could limit use of the app. Members of the expert group were concerned that if goals were not realistic and achievable within an appropriate timeframe, some users might discontinue using the mobile app.

Application-level themes

The three themes included at the app level focused on elements in the proposed mobile app that could increase users' motivation to use the product. The themes primarily concerned the content to be included and the functionality and features of the proposed product.

Theme 4: desired content (app level)

Participants identified the important types of information about chronic pain and its management that are needed by individuals with NF1. It included the subthemes of 'pain 101', self-care and clinical care (table 3).

The experts believed that accurate knowledge about the topic of pain was important in motivating individuals to use the mobile app—'a very essential piece of this work, not sufficient, but necessary' and referred to it as 'pain 101' information. This included information on the physiological basis of pain, neuropathic and nociplastic pain, the difference between acute and chronic pain, and NF1-specific pain. They also noted that users should receive instruction about how to successfully navigate the healthcare system and effectively interact with their healthcare providers.

By contrast, the NF1 group appeared most interested in learning about symptom recognition, recommended analgesics and strategies for targeting specific types of pain.

The self-care subtheme dealt with pain treatment approaches potential users could learn and then do independently or in group settings. Both participant groups offered many suggestions about possible pain mitigation strategies. These could be divided into two types of self-care strategies: physical and psychobehavioral. The former, endorsed by both groups, included movement-based activities such as martial arts, yoga or 'grounding exercises' and pacing. Only the expert group suggested improvement of sleep hygiene and use of heat and ice as physical approaches to self-management of NF1 pain. Both groups suggested psychobehavioral approaches (ie, those requiring only brief training with a qualified professional) such as deep, circular or meditational breathing and music or aroma therapy.

The final subtheme, clinical care, focused on pain treatments that required meeting with a trained professional for longer periods than typically required in self-care approaches. Yet, similar to the self-care subtheme, the treatments could be divided into physical and psychobehavioral approaches. Only the expert group identified physical approaches such as physical therapy or nutrition care. Longer-term psychobehavioral approaches included cognitive–behavioral therapy, acceptance and commitment therapy, guided imagery, biofeedback and mindfulness training.

Theme 5: desired features (app level)

The desired features theme included four subthemes: (1) tracking capabilities, (2) community, (3) external resources and (4) future features. This theme focused on the functionality of the mobile app and the desire for links to external resources (table 3).

Tracking of various events and information was considered by both participant groups to be an important

Table 2 Individual-level themes and quotes

Theme 1: lifestyle	
Affordability/accessibility subtheme	Where I work there's certain applications that are blocked so it would be really a pain for lack of a better term for me to have to kind of remember everything and write it down later. (Participant 26, NF1 group)
	Unfortunately, in rural areas such as southwest Pennsylvania where I live or West Virginia a lot of people just don't have connections that are that strong sometimes. (Participant 24, NF1 group)
	There's always a lot of barriers in terms of access, economics, et cetera. (Participant 103, Expert group)
Time subtheme	Sometimes I get up late and it's just something that I need to do every day but tend to forget if I'm hustling out the door or something. (Participant 7, NF1 group)
	I'm very bad about inputting stuff and keeping diaries and stuff because I have two toddlers at home, so that takes a lot of my time, too. (Participant 17, NF1 group)
	Other barriers are typically time… (Participant 106, Expert group)
Theme 2: reasons for using the mobile app	
Engagement subtheme	I like apps that give me badges and awards for accomplishing my goals. (Participant 10, NF1 group)
	There has to be a way that they can, early in their treatment, start to see positive change, positive success so they get these little wins in the beginning and that's just the psychology of motivation and how you sort of really start to get that ball rolling. (Participant 104, Expert group)
Hope subtheme	They have to be able to hold hope that they have the opportunity to be efficacious in improving the situation. (Participant 104, Expert group)
Theme 3: concerns about using the app	
	Who could potentially access that information? Could health insurance companies access…I'm worried about who has access to that and how they could potentially use it. (Participant 14, NF1 group)
	(Use of stars or points) can be very effective if they're tooled in the right way…but they (users) have to feel like that the goals are attainable. (Participant 104, female, Expert group)

feature of the mobile app. It included tracking and monitoring pain level, mood, activity, sleep and stress, all considered to be important potential pain triggers. Both groups also believed that maintaining notes or a diary was important but for somewhat different reasons. The NF1 group viewed this feature as a potential memory aid that could enable patients to 'talk about (pain symptoms) more intelligently to a provider'. It could serve as a reminder for exercising, logging information in the app, or tracking meditation and physical activity. The NF1 group also expressed interest in recording their surgical and medication histories and having the capability of tracking pain details such as onset, location, quality and level of pain.

By contrast, the expert group appeared to be interested in a less detailed approach to tracking pain, although sufficiently detailed to be able to identify associations between pain and such things as mood, activity or treatment efficacy.

Both participant groups were enthusiastic about creating an online community that could serve as a resource for socioemotional support and NF1-relevant information (eg, local events and providers). Members of the expert group cautioned that it should not be a venue for complaining about having the disease, however. The NF1 group offered many suggestions about the format (eg, group size, age restrictions, creation of a buddy system), although none emerged as the preferred format. Both groups also agreed that sharing experiences could help normalise having NF1 and help individuals feel less isolated.

Participants believed that external resources such as links to other mobile apps could be helpful to patients with NF1. The NF1 group was interested in links to relevant articles and treatment guidelines. The expert group suggested links that could assist individuals with NF1 in self-management of their disease, including relaxation and pain sites.

Both groups identified some features that were currently not feasible to include in the mobile app, as they would require extensive resources, negotiations with other apps or lengthy modifications to the current iCC. They can be considered for future modifications to the app. Suggestions included automatic data upload at the next sign-in to make it more convenient for users whose internet access is blocked at work or in certain

Table 3 Application-level themes and quotes for desired content and desired features

Theme 4: desired content	
'Pain 101' subtheme	I do think the pain education piece and how pain works in the brain would be really great for NF patients. (Participant 101, Expert group)
	…how to work through and navigate the healthcare system, how to talk to healthcare providers about their pain and options. (Participant 106, Expert group)
	It's the specific exercises…To have it be specific, broken down like a menu. Headaches? Do this. (Participant 2, NF1 group)
Self-care subtheme	I think the mindfulness or meditation, yoga, breathing techniques would be extremely helpful. (Participant 26, NF1 group)
	…just getting them exposed to different complementary and alternative therapies has value, so even if you don't teach it in the app… (Participant 108, Expert group)
Clinical care subtheme	I did a study for NF with ACT, that's Acceptance and Commitment Treatment. I liked it because I think if you were going to do something with CBT(cognitive-behavior therapy), if you could incorporate some ACT as well, that would be great because to help you rethink about your pain might be… (Participant 10, NF1 group)
	…evidence-based treatment for chronic pain involves a whole host of cognitive and behavioral strategies including pacing for pain and mindfulness, relaxation, catching catastrophic thoughts about pain and about the future, as well as lifestyle changes like nutrition and sleep hygiene. (Participant 101, Expert group)
Theme 5: desired features	
Tracking capabilities subtheme	I had to go through boxes of medical records to figure out and remember all the different doctors…so if there was a way to store some information… (Participant 3, NF1 group)
	I think one cool thing would be if there was an outline of a body that you could blow up and click on the part exactly that hurts and kind of color it in or shade it in or something" (Participant 19, NF1 group)
	But if here's a graph then he or she also says here's the pain I was having and here's what else what was going on at that time and what I think may have contributed, then I may be able to offer some further intervention. (Participant 109, Expert group)
	I think tracking mood is hugely important. We know that anxiety and depression very commonly and understandably co-occur with chronic pain and medical conditions. We also know that mood and stress and anxiety and depression impact and amplify pain. (Participant 101, Expert group)
Community subtheme	…things where we could actually keep up with one another, talk to one another, just get things off our chest. I think that would be incredibly beneficial. (Participant 6, NF1 group)
	I think having positive or some opportunities to connect with other people that really understand the disease entity can be helpful too, as long as they're all working toward making gains and not just being really steeped and sad about the disease process. (Participant 104, Expert group)
	It was years before I ever met anybody else with NF and it's nice to know that there are other people out there…it would be nice on this app to be able to have maybe a comment section so that people can say, yup, I was there, or this is how I cope. (Participant 14, NF1 group)
	…people share incredible stuff on (message boards), so sharing pain may be nothing compared to sharing their personal stories… (Participant 107, Expert group)
External resources subtheme	I think of it as a way to maybe link certain maybe research articles or advice [that]…afterwards if you log a specific instance of pain and there's something that could pop up that you could read… (Participant 6, NF1 group)
	We use [name of app] …And it's been really helpful for things like CRPS [complex regional pain syndrome], potentially amputation pain, and so it's part of cognitive retraining for the disorganized cognitive input from a missing limb or a dysfunctional limb. (Participant 105, Expert group)
Future features subtheme	One thing I'd like to see for the physical activity, if it could import data from say [names of activity apps] or whatever. If you use one of those apps, it would be one less thing for the user to do. (Participant 20, NF1 group)
	I want my app to be able to function at least as good as it can with no Internet connection and automatically update the database when I get connection. (Participant 24, NF1 group)
	One of the apps I used to use was for water and as you drank water it grew a plant. Well, maybe something interactive based on the age ranges of who might use it. (Participant 9, NF1 group)
	…if [patients] can print out a graph or somehow send the graphical representation that we've like scanned that into the medical record, that's been helpful (Participant 108, Expert group)
	I think one really important feature that a lot of other applications that I use lack is integration with MyChart and other things that my doctors would have access to so that everybody can just see it rather than having to go back and forth with all the different doctors (Participant 26, NF1 group)

Table 4 Application-level theme and quotes for format considerations

Theme 6: format considerations	
User interface subtheme	I need consistency. Kind of like if you're going to do updates and stuff like that, it needs to not be completely reconfigured. (Participant 1, NF1 group)
	If I can add in my own entries along with that, that would motivate me to use it more. (Participant 18, NF1 group)
	…then you want a very simple front page and then links or tabs. (Participant 105, Expert group)
Presentation/tone subtheme	I think having some visuals as well would be useful. Yeah, visual, not horrid looking. (Participant 1, NF1 group)
	I would want it to be simple and fun and use language that I use, not language a doctor would use. I can look up words, but sometimes I don't want to. (Participant 4, NF1 group)
	I think considering color is important…We didn't really talk about that but, the whole visual appeal. Because if it's not appealing or if it's going to make a person feel worse then that's counter, then that's going against what [the goal of the application is]. (Participant 102, Expert group)
	When I was looking at your app, it made me think about music and how that can be useful for people's state of mind, which you can't separate the body from the mind so I think that would be great in chronic pain. (Participant 103, Expert group)

geographical locations, printable reports, 24/7 access to medical advice and a visual graphical representation of progress toward a specific goal.

Other suggestions, primarily from the NF1 group, were currently unrealistic to implement because they required formalising agreements with healthcare institutions. For example, they mentioned wanting the capability to automatically share information with healthcare providers or access existing X-rays when at another location.

Theme 6: format considerations (app level)

The final theme included two subthemes (table 4): user interface and presentation/tone. The first addressed issues that would increase users' ease of use, and the second focused on the visual appeal and tone of the content presented.

Both groups understood the importance of user interface, that motivation to use the mobile app could be heavily influenced by its ease of use. The expert group suggested having explicit instructions on how to navigate and use the app. Participants from both groups recommended tailoring the app to users' specific preferences on pain-tracking measures and format (eg, numeric vs figural, pain descriptors) and including an 'other' option so users could further qualify their responses to forced-choice questions. They also identified features to enhance time efficiency such as autopopulation of key information, use of drop-down menus, and consistency in format and content when updating.

Critical elements in motivating individuals to use the mobile app were tone and presentation, the final subtheme. Participants described the ideal app as being 'approachable and digestible' and 'simple and fun'. Visual appeal was important, noting that the font and use of colour could influence use. Careful selection of NF1 photographs and language could also be used to set an appropriate tone. Members of the NF1 group believed that daily tips or inspiring quotes could enhance engagement, and experts recommended varying the messages to keep the content fresh. Both groups agreed that music could help set a positive tone as well.

DISCUSSION

Few studies have examined the perceived benefits, desired content and features, or efficacy of mobile health apps on coping with NF1-related chronic pain. To our knowledge, the current study is the only one to examine some of these issues from the perspectives of the targeted end users and pain management experts. We believe that this is essential information to ensure that the product is scientifically accurate and relevant while also satisfying targeted end users' needs and preferences.

Both groups were enthusiastic about the prospect of adapting the iCC mobile app for individuals with NF1 with chronic pain. They believed that tailoring the programme to accommodate users' lifestyle needs and affordability, incentivising its use, fostering an NF1 community support group, and using appropriate and acceptable tone and format features will encourage uptake and continued use of the mobile app. In addition, offering NF1 and coping skills information and an online support community in a single mobile app renders it both convenient and comprehensive in scope.

Participants believed that flexibility in fitting into potential users' current situation was important. They noted that the app should be affordable, easy to use and convenient; it should fit users' schedules, efficiently capture the desired data and be modifiable as users' life situations change. These findings support previous research on

features needed to ensure uptake and ease of use of the mobile app[34 35] as well as health-related mobile app users' privacy and security concerns.[36 37]

With respect to the issue of promoting sustained use of the app, participants from both groups noted the importance of including realistic and achievable goals. Early improvements might involve pain reduction or changes in pain attitudes that could improve mood, function or quality of life. Consistent with the notion of contingency management,[38 39] participants identified strategies involving points, levels, prizes or well-established reinforcement schedules to incentivise continued use. These findings suggest the importance of considering contingency management when developing an app to promote health behaviours.[40 41]

Regarding the pain symptom tracking feature, the two groups had somewhat different views on what type of pain data are most desired. The NF1 group appeared interested in gathering as detailed and nuanced pain information as possible. By contrast, the expert group appeared more interested in tracking information that might identify potential associations between pain, mood, nutrition, activity and stress levels; they believed that noting these patterns would be more useful than tracking pain intensity, duration, quality and directionality. Consistent with previous research,[42] the two participant groups expressed different perspectives on and desires for tracking chronic pain. The data suggest that to accommodate these disparate views, the pain tracking feature should permit simultaneous tracking of several constructs (eg, pain, mood and activity) while also providing a flexible format so that patients can select the level of detail and pain metrics they prefer. One cautionary note, however, would be to avoid the potential for users to become fixated on their pain symptoms to the detriment of recognising the associations between their pain and the other constructs. Based on input from our expert group, we plan to develop an app that is engaging without overfocusing on tracking or complaining about symptoms and subsequently assess its effectiveness and potential positive/negative effects.

Community support, particularly for individuals with rare diseases such as NF1, can be an important coping resource.[43 44] Previous research on online community support platforms for individuals with rare diseases has noted that they are used for both informational and socioemotional support purposes.[45 46] The value of community support has been identified within the context of cultural and racial socialisation,[47 48] and the study corroborates these findings. Both groups noted how the creation of an online NF1 community would provide users the opportunity to share and thereby validate their experiences with the disease and chronic pain, provide socioemotional encouragement and potentially motivate continued use of the mobile app.

The study supported previous findings about visual appeal, tone, ease of use, instructions on effectively navigating app options, tailoring mHealth interventions to personal needs and preferences and the use of appropriate visuals.[49 50] This last feature is particularly important with a potentially disfiguring disease such as NF1. A novel finding from this study, however, is the importance of establishing an upbeat tone that instils hope.

We note several study limitations. First, the findings may have limited transferability, given the modest racial and ethnic diversity of the study sample. Second, lack of external confirmation of self-reported NF1 diagnoses may have limited the credibility of the results. Third, the myriad of suggestions proffered may be attributed to social desirability wherein participants sought to identify as many options as possible in order to 'please' the group facilitators. Nonetheless, these options made possible a deeper analysis of potential format and content considerations when adapting the iCC app. Finally, virtual FGDs limit the ability to observe subtle, in-person dynamics during discussions. We chose this format, however, prior to the onset of the COVID-19 pandemic, based on our desire to collect data in a time-efficient and cost-efficient manner across diverse geographical regions and living situations.

CONCLUSIONS

The study findings suggest that adapting the iCC mobile app for use in the self-management of NF1-associated chronic pain was seen by adults with NF1 and chronic pain experts as a welcome addition to the armamentarium of NF1 treatment resources. Careful attention should be paid to the creation of a community support group option as well as programme content, format and ability to tailor it to users' specific needs.

Author affiliations

[1]Department of Epidemiology of Microbial Diseases, Yale University Yale School of Public Health, New Haven, Connecticut, USA
[2]Department of Psychiatry, Yale School of Medicine, New Haven, Connecticut, USA
[3]Child Health Evaluative Sciences, The Hospital for Sick Children, Toronto, Ontario, Canada
[4]Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, Ontario, Canada
[5]Child Health Evaluative Sciences, Toronto SickKids, Toronto, Ontario, Canada
[6]Department of Pediatrics and Nursing, University of Connecticut School of Medicine, Farmington, Connecticut, USA
[7]Division of Pain and Palliative Care, Connecticut Children's Medical Center, Hartford, Connecticut, USA

ORCID iD
Lauretta E Grau http://orcid.org/0000-0003-4985-8019

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