Development of an app for lung cancer survivors (iEXHALE) to increase exercise activity and improve symptoms of fatigue, breathlessness and depression

Running title: Development of an exercise app for lung cancer survivors

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Abstract

Objective

Exercise-based self-management interventions are recommended for lung cancer survivors and can provide physical, psychosocial and emotional relief. Mobile health technologies can encourage self-management; however, currently no cancer-related apps address exercise specific needs of lung cancer *survivors.* This paper details the design, development and testing of an exercise app for lung cancer survivors (iEXHALE) which aims to increase exercise activity and improve symptoms.

Methods

The research had two stages: 1) focus groups with healthcare professionals, patients and family members (n=21) 2) app development and usability study with lung cancer survivors (n=6). The Capability, Opportunity, Motivation-Behaviour model was used as a theoretical framework; data were thematically analysed.

Results

Focus group findings identified many helpful exercises for managing lung cancer survivors' symptoms. These findings, alongside relevant literature, informed iEXHALE's content and design. The usability study found that lung cancer survivors valued iEXHALE's self-management capabilities, but identified potential modifications, including improved self-monitoring diaries and navigation.

Conclusions

iEXHALE's development has been theoretically and empirically informed, showing value as a self-management tool. Next, we will test its effectiveness, acceptability and cost-effectiveness.

Keywords: Cancer, Depression, Exercise, Fatigue, Lung Cancer, Mobile Health, Oncology, Qualitative Research, Self-Management, Survivorship

Background

Lung cancer is the most prevalent cancer globally, contributing to around 13% of cancer cases [1]. Europe and North America have the highest incidence [1], with 36,761 new cases in England in 2016 [2]. Over a third of lung cancer patients in England and Wales survive for one year or more and 10% survive five years or more [2-3].

Despite advances in survival rates many lung cancer survivors (LCS) have unmet mental, physical and psychosocial needs following treatment [4], which includes surgery, immunotherapy, chemotherapy and radiotherapy [5]. Treatment can exacerbate breathlessness, fatigue and depression due to enforced lifestyle changes and the struggle to accept a 'new normality' [5-7]. Lung cancer's 'stigma' [8] and feelings of isolation following treatment can result in reduced activities of daily living, increased social isolation, decreased health and fitness and ability to return to work [9-10]. Most LCS feel they lack support from health or social care services once treatment finishes [4].

A systematic review examining the effectiveness of exercise interventions in improving breathlessness, fatigue and depression in LCS [11] highlighted the need for tailored self-management support to optimise treatment outcomes and symptom control. Key findings suggested many exercise interventions are beneficial and generally acceptable to LCS, can be adopted daily and that different treatment pathways can impact on their effectiveness [11]. Exercise can relieve physical, psychosocial and emotional burdens from cancer [4], increasing empowerment, self-efficacy, quality of life, coping mechanisms, health behaviours and outcomes and decreasing fatigue and depression [12-17]. However, less than one third of LCS meet recommended exercise guidelines to reduce time spent sedentary, increase strength and balance building activities and undertake 150 minutes aerobic activity per week [18, 19].

Mobile health technologies can encourage patients to self-manage their health behaviours and are feasible, acceptable and effective approaches to providing supportive care [20-24]. However, mobile health interventions to enhance exercise for cancer survivors remain uncommon [25] and of the cancer-related apps available [26, 27], none are aimed at, or address, the specific exercise needs of lung cancer *survivors* [28].

This paper reports on a programme of research consisting of focus groups, app development and a usability study which aimed to design, develop and test an exercise app for LCS (iEXHALE) to help increase exercise activity and improve symptoms of breathlessness, fatigue and depression.

We provide an overview of the steps undertaken to create a tailored, evidence-based e-health resource for LCS, divided into two studies: 1) qualitative focus groups 2) prototype app development and usability study (Figure 1). STROBE reporting guidelines [29] enhanced transparency of the research process.

Study 1: Focus groups

Methods

Focus groups explored how exercise can improve breathlessness, fatigue and depression in LCS. Key objectives were to identify:

- exercise interventions that improve symptoms
- facilitators and barriers to exercise
- behavioural change techniques to inform iEXHALE's development

Separate focus groups were organised for primary and secondary care professionals, LCS and their families. A combined focus group was conducted for LCS and family members, due to the different perspectives gathered through shared experiences of illness. In addition, some LCS relied on family to accompany them. Separate primary and secondary care focus groups were held due to differing time commitments.

The focus groups took place at an NHS Foundation Trust and a primary care centre in South West England. The trust is a tertiary centre and large teaching hospital, with an established cancer centre, whilst the primary care centre comprised a large multi-disciplinary team.

NHS HRA Ethics approvals were obtained (17/LO/1576; IRAS ID 231738).

Convenience sampling was used; lung cancer nurse specialists screened clinic lists to identify eligible LCS treated at the cancer centre. Eligible participants were over 18 years old, had

completed curative intent treatment within six months of study entry, had stable disease and were able to provide written informed consent. Eligible patients were provided with participant information leaflets (PILs) and, if interested, were put in touch with the researchers (CH/ZD).

Primary and secondary care staff were accessed by contacting a local general practitioner and lung cancer nurse specialist, respectively, who distributed PILs to colleagues. Participants were selected using convenience sampling: any healthcare professionals who worked with cancer patients were invited to participate.

Focus groups for patients/families were held at a Maggie's centre on the hospital premises; participants were offered travel reimbursements. The secondary care focus group was held in a hospital meeting room and the primary care focus group at the primary care centre. Refreshments were provided. Prior to commencing, participants provided written informed consent. Focus group discussions were moderated and facilitated by the researchers (CH/ZD) and were guided by a semi-structured topic guide (supplementary file). This was informed by systematic review findings examining the effectiveness of exercise interventions in improving symptom control in LCS [11]. Focus groups lasted one hour, were digitally recorded and were transcribed by a local transcription company.

Data analysis was two-fold. During stage one, data were analysed thematically using the Framework Method [30]. Focus group transcripts were coded (ZD); two were double-coded (ZD, CH). Emerging themes were critiqued during study meetings to ensure transparency and consistency in data analysis and interpretation.

During stage two, data were mapped against and theoretically underpinned by the COM-B Framework for Behaviour Change and the Theoretical Domains Framework [31], using a deductive framework for analysis. This is an integrative theoretical framework for understanding target behaviours and designing interventions, including e-health and m-health interventions, instead of looking to single theoretical models. The framework splits influences on behaviour change into three components: 'C'apability, 'O'pportunity and 'M'otivation. These components are matched with 'intervention functions' such as 'incentivisation' and 'training', which link to appropriate behaviour change techniques such as 'rewards' and

'goal-setting'. This approach has been used by healthcare researchers to develop and implement tailored interventions [32, 33].

Findings

Participant characteristics

Twenty-one participants were recruited (Table 1). Four focus groups were undertaken, one with secondary care professionals (n=5), one with primary care professionals (n=6) and two with patients/family members (n=8). The size of the focus groups is in line with the literature on focus group methodology and allowed data saturation to be achieved [34]. Face-to-face interviews (n=2) were undertaken with patients who could not attend focus groups. All patient participants had a performance status of 0-1.

Main findings

Participants identified many exercises that they felt helped LCS to manage symptoms, including activities of daily living, yoga, tai chi, walking, cycling, exercise classes, running, resistance and strength training, golf, pilates, light stretching, breathing techniques, mindfulness and swimming. Supervised and unsupervised, group and individual, and low (e.g. walking) and high (e.g. running) intensity exercise activities were considered useful.

Themes relating to COM-B emerged from the dataset which were relevant for developing iEXHALE:

Capability

Physical skills

All patient participants reported being affected by at least one debilitating symptom of breathlessness, fatigue or depression. All participants recognised that differences in performance status and symptom experience could affect which exercises LCS might want, or be able to, participate in.

> "It's a very broad group of patients that we're talking about, from someone that's a performance status zero to four, so it's very dependent on the person" (Healthcare professional FG2)

Knowledge

Most participants felt that LCS usually knew of the importance of exercise in recovery; however, they emphasised the relevance of timely, structured, tailored and professional advice for managing symptoms and accessing exercise interventions. Patients valued information from healthcare professionals and noted that knowledge provision via an app could be a convenient information provider.

> "If you can go on[line] and find out your bits and pieces and whatever you need to, then it's got to be a good thing…We are living in an age now, aren't we, that everything is done online really." (Patient/family FG3)

Behavioural regulation (self-monitoring, action-planning, habit formation, breaking habit)

Health professionals stated that exercise guidance that facilitated patients' decision-making might be helpful, whilst patients noted benefits of following exercise programmes.

> "She'd give me a program every week...She used to put me on the bike and then I did some weights...Then she put me on the treadmill…Actually I didn't want to come off it." (Patient/family FG1)

All participants felt that patients who engaged in exercise prior to diagnosis would find it easier to exercise post-treatment than those needing to initiate new exercise habits.

> "Someone down the road may not attend because it's their history of poor exercising" (Healthcare professional FG2)

Opportunity

Environmental context/resources

Healthcare professionals felt that location and access to transport were key to exercise engagement. Similarly, patients/family members commented that, although willing to travel to exercise, distance, time, transport links, assistance with transportation and parking influenced this decision. Cost was not considered a factor. However, patients reported varying preferences around exercising at home, in group, or individual settings and many were frustrated at the lack of hospital-based exercise provision.

> "[The hospital exercise class] ended…I wanted to [continue], but I couldn't." (Patient/family FG1)

Social influences

All participants commented that patients' levels of social engagement, with family, carers, colleagues or pets, could influence exercise uptake. Patients identified the role of healthcare professionals and other role models (e.g., personal trainers) in continued exercise engagement, by setting and redefining targets, reducing anxiety and providing an element of accountability.

> "Having the accountability helps. It's the same if you compare it to a Weight Watcher's group…The people that attend the groups every week tend to do the best." (Healthcare professional FG2)

Motivation

Professional/social and role identity

Gender, age, role obligations, lung cancer's stigma and disrupted feelings of normality were considered potential barriers to exercise engagement, often impacting on mood and motivation.

> "The people that engage at the higher levels of intervention have been female and within an age thing…People do think, well, I've had a good innings anyway." (Healthcare professional FG2)

Beliefs about capabilities and optimism

Patients reported various beliefs about their capability and optimism for exercise which fluctuated throughout recovery according to changes in fitness, health status or prognosis.

> "I don't go too far. I'll stop and take a couple of deep breaths and then move on. Or I'll slow up." (Patient/family FG1)

Beliefs about consequences

Patients/family members displayed positive beliefs about and experiences of the impact of exercise on symptom control, as well as wider benefits to overall health and wellbeing, and were generally willing to explore new exercises.

> "If there is anything there that can assist you, then why not use it…If it makes you feel better" (Patient/family FG3)

However, caution and fear of causing damage was apparent.

> "Because of the surgical emphysema I had… Of course, I don't want that to come back. And I'm conscious of that when I'm thinking about exercise. " (Patient/family FG1)

Intentions and Goals

Most participants commented that exercise intent was influenced by changing health status, symptom experience and progress in survivorship. They felt exercise goals should focus on improving fitness, symptom management, avoiding illness, or improving quality of life and these goals should be realistic, self-set, specific and clear.

> "Feeling better…whether that's physically or psychologically…For some patients it might be that they're leaving the house and meeting people, and for others it might be that they're doing something that's hopefully going to improve their symptoms." (Healthcare professional FG2)

Reinforcement

Remote monitoring and feedback were recognised as potential incentives to exercise by healthcare professionals.

> "A lot of people have smart phones…[Or] come with in-built health pedometers...I think there definitely is the utilisation of that piece of equipment." (Healthcare professional FG2)

Emotions

All participants perceived negative emotional reactions to symptom experience and exercise, including fear and pain, as exercise deterrents.

> "They would think this is horrible because it reminds of what lung cancer is like, and this is why I'm short of breath. It makes me anxious and I'm going to die. So they don't want to do it. It's that sort of cognitive cycle rather than I'm going to be push and be strong." (Healthcare professional FG1)

Study 2: Prototype development and usability study

Methods

Findings of study 1 and the systematic review [11], enabled iEXHALE prototype 1 to be developed with an app development company (Phase 0), adopting a user-centred approach focusing on user-flow through the app. Design features and content were theoretically grounded (using COM-B) and targeted at the needs and preferences of LCS. Prototype 1 included four core sections: an introduction containing information about lung cancer; a section for generating recommended exercises by rating symptoms and inputting preferences; a section containing information about recommended exercises; a self-monitoring diary for recording activity (Table 2). The evidence-based algorithm underpinning the self-rating symptom section was designed specifically for the app, and used information inputted by users to generate three exercises that are known to benefit the symptoms experienced, as well as responding to user preferences for exercise location, intensity, and individual/group type. Google analytics software was embedded within the app to examine participants' interactions with the different sections.

A usability study was designed to test the app's effectiveness, efficiency and simplicity. The usability study protocol has been detailed elsewhere [35]. The study consisted of three consecutive phases, each interspersed with elements of data analysis and app prototype redevelopment. NHS HRA Research Ethics Committee approvals were obtained (IRAS number: 239116).

Patients/family members from Study 1 were invited to participate, provided they had access to a smartphone or electronic device. Eligible participants were posted or emailed a PIL and were contacted one week later by a researcher to confirm their participation.

The study took place at Oxford Brookes University; all participants provided written informed consent. During phase 1 (figure 1), participants completed a pre-test Mobile Device Proficiency (MDPQ-16) survey [36] to assess smartphone usage. Participants then completed tasks in a university setting using prototype 1, which were quantitatively and qualitatively evaluated. Metrics, including task completion, completion attempts, completion time, clicks/touches to complete, error rate, type and severity, were used to assess technical usability of the app. The 'think aloud' technique was used to assess the user's experience of the app. 'Think aloud' behaviours and video recordings of participants hands on the device were recorded for analysis. Participants also completed a post-test Systems Usability Scale (SUS) [37], a reliable questionnaire using a 5-point likert scale (strongly agree-strongly disagree) that measures user perceptions of web-based applications ease of use. Findings informed the app's redevelopment (prototype 2), before phase 2 commenced, replicating phase 1's activities. During phase 3, participants used prototype 2 for two weeks before attending individual, semi-structured interviews to describe their user-experiences.

Qualitative data from the 'think aloud' tasks and interviews were analysed thematically using the Framework Method [30]. Descriptive statistics were produced for quantitative metrics and examined against literature on thresholds for acceptability (usability), effectiveness (completion and error rates) and efficiency (task-times) [38].

Findings

Participant characteristics

Six participants were recruited, enough for maximising the expected level of problem discovery within technical application development [39]. Table 3 presents participant demographics, pre- and post-task survey data. One participant (UX3) was a family member.

Main findings

One participant (UX1) was excluded from the analysis due to incomplete data. MDPQ-16 scores indicated low to moderate mobile device proficiency. SUS scores increased or remained consistent between phases 1 and 2 in four participants, with most phase 2 scores achieving okay (50 > SUS > 70) or good (SUS > 70) levels of acceptability. Phase 1&2 tasks

highlighted issues with participants' accuracy, completion of logins and self-monitoring diaries. However, the overall task completion rate was high for tasks completed in under 10 minutes, with changes observed between phase 1 (83%) and phase 2 (87%). Most participants completed tasks after one attempt (85%). Overall relative efficiency changed from 95% in phase 1 to 96% in phase 2. The app appeared simple to use, with errors per task ranging from 0.4 – 2.6; these consisted predominantly of participants selecting the wrong icon, making incorrect gestures, or making navigation errors (70%). User frustration per task was rated by researchers as 'zero to little frustration' for 67% of participants in phase 1 and 77% in phase 2, with the remainder rated as 'medium/high frustration' or 'point of failure'. 'Think aloud' commentary from participants was minimal and primarily consisted of comments about app navigation.

During phase 3, participants identified app strengths and weaknesses across four themes: Access, format, and presentation; self-rating symptoms and exercise recommendations; self-monitoring diaries; future use.

Access, format and presentation

Participants liked the app's aesthetics and incorporating it into daily life. Most participants used the app regularly and those who accessed the app least were not accessing it via a mobile device.

> "It's nice and friendly…I like the logo on it" (UX1)

Individual preferences for content presentation emerged. However, participants were positive about text and audio-visual content that established links with healthcare professionals.

> "It gives you that sense of safety because of course they know what they're talking about." (UX5)

The app pathway was not always clear to participants who felt that better sign-posting would have improved navigation and facilitated better use of app sections.

> "I'm having to sort of go into the menu… and you're scrolling away and reading, and you go, hang on, I've done this" (UX4)

Self-rating symptoms and exercise generation

Participants liked customising their exercise preferences and ranking their symptom severity to produce bespoke exercise recommendations, finding this useful and motivating.

> "You can put in pretty much every day how you're feeling… I think it's brilliant. I think it does give you a little push to actually think perhaps I ought to go for a walk" (UX5)

Self-monitoring diaries

Whilst the diaries worked well for some, most participants felt they lacked complexity, interactivity, and flexibility and were not being utilised fully.

> "It's not reacting to information that I'm putting in, it's not an interactive app." (UX4)

Future use

Participants believed the app could help LCS during follow-up and those with other cancers or chronic respiratory conditions and highlighted its benefit as a motivating self-management tool. Some participants said they would use the app frequently, although they believed the length of time this would continue was limited.

> "If I was a physician or surgeon…This would be definitely something I would say well, there are one or two things we can do. The NHS can't cope…But here is something you could do for yourself, which would be incredibly valuable if it suits you." (UX6)

Conclusions

We have developed an empirically and theoretically informed exercise app to help LCS increase their exercise activity and improve symptom control. Using COM-B [30], relevant capabilities, opportunities and motivations associated with exercise engagement were identified [30], which enabled relevant app features to be identified during iEXHALE's development. iEXHALE's development is timely, as whilst numerous apps have aimed to enhance physical activity in people with chronic illnesses such as diabetes and heart failure [25], few apps are available to cancer survivors. Where these apps do exist [26, 27] they fail

to focus specifically on the exercise needs of lung cancer *survivors*, something iEXHALE has achieved.

The usability study enabled iEXHALE's features to be assessed by LCS, allowing the researchers to identify which features are favoured and which need improvement. Specifically, the self-monitoring diaries, although identified as useful, were deemed ineffective in their current form, highlighting a need for prototype redevelopment.

Participants' shared consensus of iEXHALE as a useful self-management tool for LCS, providing flexible, customised exercise information that can be utilised and adapted to meet individual needs and preferences, is encouraging, and demonstrates its value to this population group. However, all patient participants had a performance status of 0-1 and were relatively active. Further research into iEXHALE's usefulness for patients with performance statuses of ≥2, would confirm its generalisability to the wider LCS population.

iEXHALE has been developed for use in the NHS and aligns with recent National Institute for Health and Care Excellence (NICE) evidence standards for digital health technologies (40), which emphasise a dynamic, value driven approach to their development and commissioning to ensure relevance to patients (40). NICE also state that rehabilitation from cancer should promote patients' ability to function, independence and adaptation to their condition (41) and that this can be enabled through active self-management (41), something that is central to iEXHALE.

Study Limitations

The lack of ethnic diversity and the older age of participants provide study limitations, as the population sampled was not representative of the general population; however, it was representative of a large demographic of LCS. Social desirability bias during the usability study interviews was possible, if participants perceived a favourable response about the app to be more acceptable. However, the quantitative usability findings suggested regular use of the app in general, indicating that it was helpful to participants. Finally, no secondary care consultants or primary care nurses participated in the focus groups; their perspectives may have added insights to the findings.

Clinical implications

Findings have widespread implications on an international level, by demonstrating the potential for an interactive, tailored digital resource to provide symptom management support to LCS. We have detailed a methodology for developing technologies targeted at older people with chronic conditions. Our approach can be applied to other disease groups and older people who are not traditionally engaged with e-health interventions; this is especially pertinent at a time when the ageing population is increasing globally.

iEXHALE has been designed with patients, for patients, has utilised the wider literature [11] and the views of those central to LCS' follow-up pathways. The app can benefit both LCS entering follow-up and healthcare professionals looking to provide a supportive, self-management resource to patients. We intend to make modifications to iEXHALE based on the usability findings, before testing its effectiveness, acceptability and cost-effectiveness in a multi-centre study, to enhance generalisability. This will determine whether the app should be made widely available to LCS entering follow-up. Future work will explore the potential for iEXHALE to be adapted for patients with other cancer types and respiratory diseases.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Data are available on reasonable request from the corresponding author (CH) (chenshall@brookes.ac.uk) and is comprised of deidentified focus group data and usability study data from participants.

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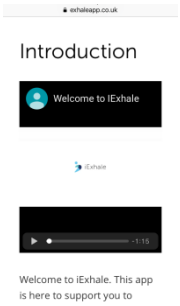
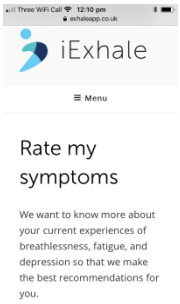
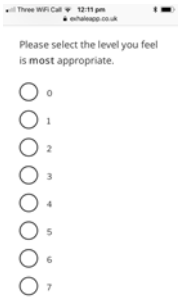
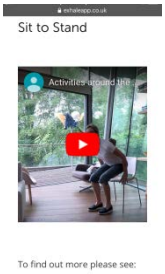
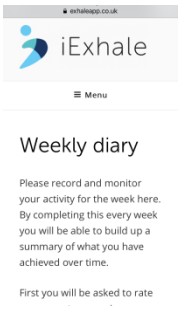
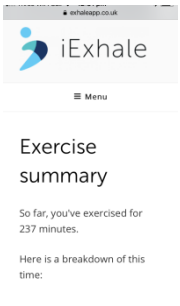
Tables

Table 1: Focus group participant demographics

Participant characteristics		Patients (n=7)	Family members (n=3)	Primary care health professionals (n=6)	Secondary care health professionals (n=5)	Total participants (n=21)
Age (years)	18-39	0	0	1	2	3
	40-59	0	0	2	2	4
	60-79	5	2	-	-	7
	80+	2	1	0	0	3
Ethnicity	White	7	3	5	5	20
	Asian	0	0	1	0	1
Sex	Male	3	2	3	1	9
	Female	4	1	3	4	12
Cancer type	Non-small cell	2				
	Not known	5				
Treatment type	Chemo and radiotherapy	1				
	Chemo and surgery	2				
	Surgery	4				
Clinical role	General practitioner			5	0	5
	Practice Manager			1	0	1
	Lung cancer nurse specialist			0	4	4
	Physiotherapist			0	1	1
Years in healthcare profession	1-5			1	-	0
	6-10			1	2	3
	11-15			-	-	0
	>15			1	2	3

582 **Table 2: Core sections of iEXHALE (prototype 1)**

Section	Content	Screenshot	
Introduction	Information about lung cancer and its treatment, common symptoms of fatigue, breathlessness and depression, and benefits of exercise for improving symptoms.		
Self-rating symptoms	Users rate symptom severity, preferred activity level, and preferences for group/individual exercise activities. This information is used to generate three recommended exercises.		
Exercise information	Users are provided with further information about three recommended exercises. Including information about how to access these exercise and, where necessary, video demonstrations on how to complete these.		
Self-monitoring diaries	Participants rate their current symptoms and indicate how often they have undertaken recommended exercise activities each week (type, duration, subjective rating). Email reminders sent to participants.		

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590 **Table 3: Participant demographics and usability metrics**

Demographics	UX1	UX2	UX3	UX4	UX5	UX6
Age	61-70	>70	>70	>70	51-60	>70
Gender	Female	Female	Female	Male	Female	Male
Skill level	Intermediate	Intermediate	Intermediate	Novice	Novice	Novice
Use frequency	Daily	Hardly ever	Daily	Daily	Daily	Hardly ever
Home Device	N.K.	Computer	Apple iPhone	Apple iPhone	Sony Xperia	Computer
MDPQ	N.K.	15.5	21.5	39	23.5	11.5
SUS Phase 1	87.5	37.5	57.5	80	100	57.5
SUS Phase 2	NK	57.5	75	80	100	45

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593 ## Figure Legends

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595 **Figure 1:** Study flow diagram depicting the sequential phases of development of the iEXHALE app

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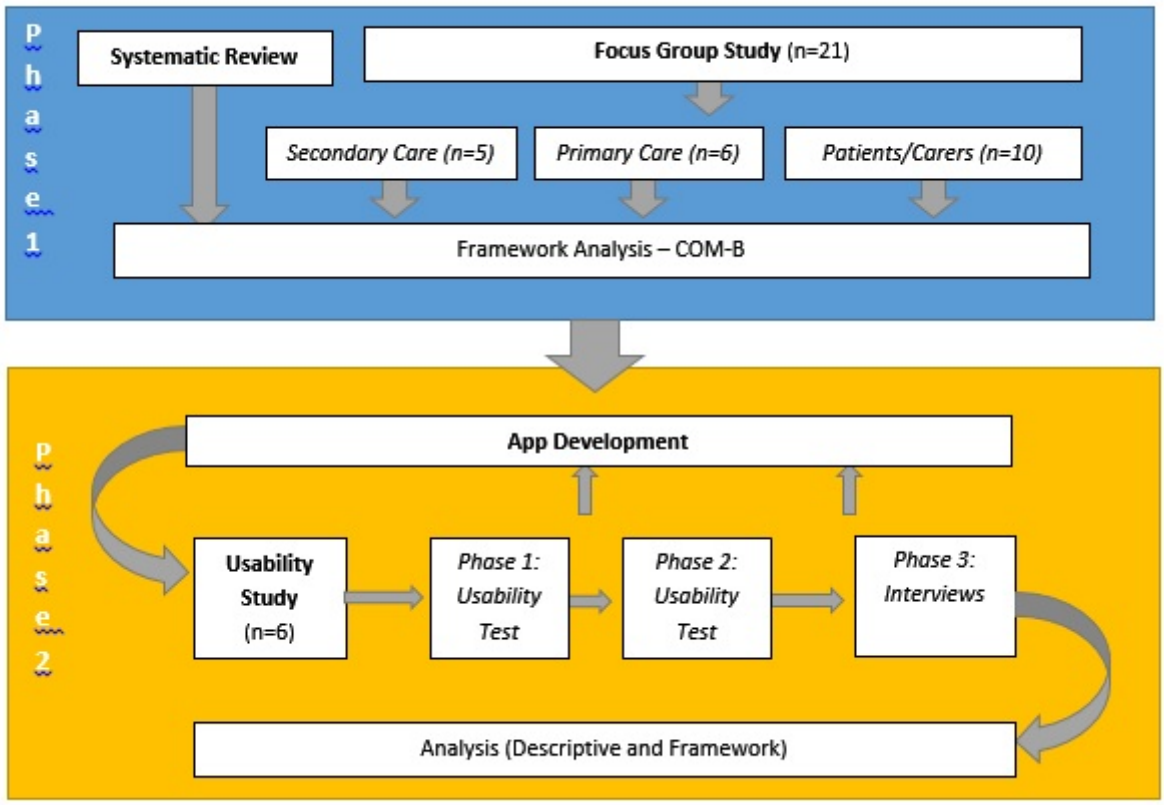
Figure 1: Study flow diagram



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