

Development of an exercise app for lung cancer survivors

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

4
5
6 **Running title: Development of an exercise app for lung cancer survivors**

7
8
9 **Authors:**

10 Catherine Henshall (corresponding author) Email: chenshall@brookes.ac.uk Tel: 07768
11 918298

12 Zoe Davey

13
14
15 **Author Affiliations**

16
17 Oxford Institute of Nursing Midwifery and Allied Health
18 Faculty of Health and Life Sciences, Oxford Brookes University
19 Jack Straw's Lane, Marston
20 Oxford, OX3 0FL

50 **Abstract**

51 **Objective**

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

58 **Methods**

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

63 **Results**

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

69 **Conclusions**

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

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

75

76

77 **Background**

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

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

90 A systematic review examining the effectiveness of exercise interventions in improving
91 breathlessness, fatigue and depression in LCS [11] highlighted the need for tailored self-
92 management support to optimise treatment outcomes and symptom control. Key findings
93 suggested many exercise interventions are beneficial and generally acceptable to LCS, can
94 be adopted daily and that different treatment pathways can impact on their effectiveness
95 [11]. Exercise can relieve physical, psychosocial and emotional burdens from cancer [4],
96 increasing empowerment, self-efficacy, quality of life, coping mechanisms, health
97 behaviours and outcomes and decreasing fatigue and depression [12-17]. However, less
98 than one third of LCS meet recommended exercise guidelines to reduce time spent
99 sedentary, increase strength and balance building activities and undertake 150 minutes
100 aerobic activity per week [18, 19].

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

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

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

114 **Study 1: Focus groups**

115 **Methods**

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

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

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

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

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

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

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

136 Primary and secondary care staff were accessed by contacting a local general practitioner
137 and lung cancer nurse specialist, respectively, who distributed PILs to colleagues.

138 Participants were selected using convenience sampling: any healthcare professionals who
139 worked with cancer patients were invited to participate.

140 Focus groups for patients/families were held at a Maggie's centre on the hospital premises;
141 participants were offered travel reimbursements. The secondary care focus group was held
142 in a hospital meeting room and the primary care focus group at the primary care centre.

143 Refreshments were provided. Prior to commencing, participants provided written informed
144 consent. Focus group discussions were moderated and facilitated by the researchers
145 (CH/ZD) and were guided by a semi-structured topic guide (supplementary file). This was
146 informed by systematic review findings examining the effectiveness of exercise
147 interventions in improving symptom control in LCS [11]. Focus groups lasted one hour, were
148 digitally recorded and were transcribed by a local transcription company.

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

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

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

163 **Findings**

164 **Participant characteristics**

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

171 **Main findings**

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

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

179 **Capability**

180 *Physical skills*

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

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

188 *Knowledge*

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

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

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

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

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

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

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

207 **Opportunity**

208 *Environmental context/resources*

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

215 “[The hospital exercise class] ended...I wanted to [continue], but I couldn’t.”

216 (Patient/family FG1)

217 *Social influences*

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

223 “Having the accountability helps. It’s the same if you compare it to a Weight

224 Watcher’s group...The people that attend the groups every week tend to do the

225 best.” (Healthcare professional FG2)

226 **Motivation**

227 *Professional/social and role identity*

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

231 “The people that engage at the higher levels of intervention have been female and

232 within an age thing...People do think, well, I’ve had a good innings anyway.”

233 (Healthcare professional FG2)

234 *Beliefs about capabilities and optimism*

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

237 “I don't go too far. I'll stop and take a couple of deep breaths and then move on. Or

238 I'll slow up.” (Patient/family FG1)

239 *Beliefs about consequences*

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

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

245 However, caution and fear of causing damage was apparent.

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

249 *Intentions and Goals*

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

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

258 *Reinforcement*

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

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

264 *Emotions*

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

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

271

272 **Study 2: Prototype development and usability study**

273 **Methods**

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

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

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

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

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

314 **Findings**

315 **Participant characteristics**

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

319 **Main findings**

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

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

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

338 *Access, format and presentation*

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

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

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

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

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

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

352 *Self-rating symptoms and exercise generation*

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

355 “You can put in pretty much every day how you’re feeling... I think it’s brilliant. I
356 think it does give you a little push to actually think perhaps I ought to go for a walk”
357 (UX5)

358 *Self-monitoring diaries*

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

361 “It’s not reacting to information that I’m putting in, it’s not an interactive app.” (UX4)

362 *Future use*

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

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

370 **Conclusions**

371 We have developed an empirically and theoretically informed exercise app to help LCS
372 increase their exercise activity and improve symptom control. Using COM-B [30], relevant
373 capabilities, opportunities and motivations associated with exercise engagement were
374 identified [30], which enabled relevant app features to be identified during iEXHALE’s
375 development. iEXHALE’s development is timely, as whilst numerous apps have aimed to
376 enhance physical activity in people with chronic illnesses such as diabetes and heart failure
377 [25], few apps are available to cancer survivors. Where these apps do exist [26, 27] they fail

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

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

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

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

397 **Study Limitations**

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

406

407 **Clinical implications**

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

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

423 **Acknowledgements**

424 We would like to thank all the participants who took part in this research. CH acknowledges
425 the support of the NIHR Oxford cognitive health Clinical Research Facility.

426 **Conflicts of Interest**

427 The authors declare no conflicts of interest.

428 **Data Availability Statement**

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

432

433

434

435 **References**

436

- 437 1. Lung cancer statistics. London: World Cancer Research Fund International; c2018-19
438 [Cited 2018 August 18]. Available from [https://www.wcrf.org/int/cancer-facts-](https://www.wcrf.org/int/cancer-facts-figures/data-specific-cancers/lung-cancer-statistics)
439 [figures/data-specific-cancers/lung-cancer-statistics](https://www.wcrf.org/int/cancer-facts-figures/data-specific-cancers/lung-cancer-statistics)
- 440 2. Royal College of Physicians. National Lung Cancer Audit annual report 2017 (for the
441 audit period 2016). London: Royal College of Physicians; 2018.
- 442 3. Lung Cancer Statistics. London: Cancer Research UK; c2018 [Cited 2019 March 13].
443 Available from [https://www.cancerresearchuk.org/health-professional/cancer-](https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/lung-cancer)
444 [statistics/statistics-by-cancer-type/lung-cancer](https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/lung-cancer).
- 445 4. Department of Health, Macmillan Cancer Support, NHS Improvement. Living with and
446 beyond cancer: Taking action to improve outcomes (an update to the 2010 The
447 National Cancer Survivorship Initiative Vision. London: National Cancer Survivorship
448 Initiative; 2013.
- 449 5. Findley P, Sambamoorthi U. Preventive Health Services and Lifestyle Practices in
450 Cancer Survivors: A Population Health Investigation. *J Cancer Surviv* 2009; 3:43-58.
- 451 6. Boon H, Olatunde F, Zick S. Trends in Complementary/Alternative Medicine Use by
452 Breast Cancer Survivors: Comparing Survey Data from 1998 and 2005. *BMC Womens*
453 *Health* 2007; 7: 4.
- 454 7. Sirois F, Gick M. An Investigation of the Health Beliefs and Motivations of
455 Complementary Medicine Clients. *Social Science and Medicine* 2002; 55:1025-1037.
- 456 8. Kendrick K. 'Normalizing' Female Cancer Patients: Look Good, Feel Better and Other
457 Image Programs. *Disability & Society* 2008; 23(3):259-269.
- 458 9. Henshall C, Greenfield S, Gale N. The role of self-management practices as
459 mechanisms for re-establishing normality in cancer survivors. *Qual Health Res* 2016;
460 27(4): 520-533. doi:10.1177/1049732316651252.
- 461 10. Osborn R, Demoncada A. Psychosocial Interventions for Depression, Anxiety and
462 Quality of Life in Cancer Survivors: Meta-analyses. *IntJ Psychiatry Med* 2006;
463 36(1):13-34.
- 464 11. Henshall C, Allin L, Aveyard H. A systematic review and narrative synthesis to explore
465 the effectiveness of exercise based interventions in improving fatigue, dyspnoea and
466 depression in lung cancer survivors. *Cancer Nurs* 2018; doi:
467 10.1097/NCC.0000000000000605
- 468 12. Shneerson C, Taskila T, Holder R, Greenfield S, Tolosa I, Damery S, Gale N. Patterns of
469 self-management practices undertaken by cancer survivors: variations in
470 demographic factors. *Eur J Cancer Care* 2015;24(5):683-694.
- 471 13. Loh S-Y, Ong L, Ng L-L, Chew S-L, Lee S-Y, Boniface G. Qualitative Experiences of
472 Breast Cancer Survivors on a Self-Management Intervention: 2 Year post-
473 Intervention. *ASJCP* 2011; 12:1489-1495.
- 474 14. Korstjens I, May A, van Weert E, Mesters I, Tan F, Ros Wea. Quality of Life After Self-
475 Management Cancer Rehabilitation: A Randomised Controlled Trial Comparing
476 Physical and Cognitive-Behavioural Training Versus Physical Training. *PsychosomMed*
477 2008; 70:422-429.
- 478 15. Damush T, Perkins A, Miller K. The Implementation of an Oncologist Referred,
479 Exercise Self-Management Program for Older Breast Cancer Survivors.
480 *Psychooncology* 2006; 15:884-890.

- 481 16. Brown J, Huedo-Medina T, Pescatello L, Pescatello S, Ferrer R, Johnson B. Efficacy of
482 Exercise Interventions in Modulating Cancer-Related Fatigue among Adult Cancer
483 Survivors: A Meta-Analysis. *Cancer Epidemiol Biomarkers Prev* 2011; 20(1):123-133.
- 484 17. Speck R, Courneya K, Mâsse L, Duval S, Schmitz K. An Update of Controlled Physical
485 Activity Trials in Cancer Survivors: A Systematic Review and Meta-Analysis. *Jour Can*
486 *Surviv* 2010; 4:87-100.
- 487 18. Courneya KS, Katzmarzyk PT, Bacon E. Physical activity and obesity in Canadian
488 cancer survivors: population-based estimates from the 2005 Canadian Community
489 Health Survey. *Cancer*. 2008;112:2475–2482.
- 490 19. Bower JE, Bak K, Berger A, Breitbart W, Escalante CP, Ganz PA, et al. Screening,
491 assessment, and management of fatigue in adult survivors of cancer: An American
492 Society of Clinical Oncology clinical practice guideline adaptation. *J Clin Oncol*
493 2014;32:1840–50.19
- 494 20. Brown-Johnson CG, Berrean B, Cataldo JK. Development and usability evaluation of
495 the mHealth Tool for Lung Cancer (mHealth TLC): A virtual world health game for
496 lung cancer patients. *Patient Educ Couns* 2015; 98(4):506-511.
- 497 21. Seiler A, Klass V, Troster G, Fagundes CP. eHealth and mHealth interventions in the
498 treatment of fatigued cancer survivors: A systematic review and meta-analysis.
499 *Psychooncology* 2017;26:1239-53
- 500 22. Haberlin C, O'Dwyer T, Mockler D, Moran J, O'Donnell DM, Broderick J. (2018). The
501 use of eHealth to promote physical activity in cancer survivors: a systematic review.
502 *Support Care Cancer*; 26(10): 3323-3336
- 503 23. Hernandez Silva E, Lawler S, Langbecker D. The effectiveness of mHealth for self-
504 management in improving pain, psychological distress, fatigue, and sleep in cancer
505 survivors: a systematic review. *J Cancer Surviv* 2019 13(1), 97-107
- 506 24. Escriva Bouley G, Leroy T, Bernetiere C, Paquensegguy F, Desfriches-Doria O, Preau
507 M. eDigital health interventions to help living with cancer: A systematic review of
508 participants' engagement and psychosocial effects. *Psychooncology* 2018; 27: 2677-
509 2686
- 510 25. Kuijpers W, Groen WG, Aaronson NK, van Harten WH. A systematic review of web-
511 based interventions for patient empowerment and physical activity in chronic
512 diseases: relevance for cancer survivors. *J med Internet Res* 2013; 15(2): e37.
- 513 26. Foster C, Grimmett C, May CM, Ewings S, Myall M, Hulme C et al. A web-based
514 intervention (RESTORE) to support self-management of cancer-related fatigue
515 following primary cancer treatment: a multi-centre PoC RCT. *Support Care Cancer*
516 2016;24:2445-2453
- 517 27. Ciani O, Cucciniello M, Petracca F, et al. Lung Cancer App (LuCApp) study protocol: a
518 randomised controlled trial to evaluate a mobile supportive care app for patients
519 with metastatic lung cancer. *BMJ Open* 2019;9:e025483. doi:10.1136/bmjopen-
520 2018-025483
- 521 28. Aaronson NK, Mattioli W, Minton O, Weis J, Johansen C, Dalton SO et al. Beyond
522 treatment: Psychosocial and behavioural issues in cancer survivorship research and
523 practice. *EJC Suppl* 2014; 12 (1): 54-64
- 524 29. von Elm E, Altman DG, Egger M, Pocock SJ, Gotsche PC, Vandenbroucke JP. The
525 Strengthening the Reporting of Observational Studies in Epidemiology (STROBE)
526 Statement: guidelines for reporting observational studies. *J Clin Epidemiol* 2008;
527 61(4):344-9. doi: 10.1016/j.jclinepi.2007.11.008

- 528 30. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method
529 for the analysis of qualitative data in multi-disciplinary health research. *BMC Med*
530 *Res Methodol* 2013; 13: 117
- 531 31. Michie S, Atkins L, West R: *The behaviour change wheel: A guide to designing*
532 *interventions*. Great Britain: Silverback Publishing; 2014
- 533 32. Henshall, C, Goodwin, L, Taylor, B, Kenyon, S. Improving the quality and content of
534 midwives' discussions with low-risk women about their options for place of birth: co-
535 production and evaluation of an intervention package. *Midwifery* 2018; 59:118-126
536 DOI10.1016/j.midw.2018.01.016
- 537 33. Barker, F, Atkins, L, de Lusignan, S. Applying the COM-B behaviour model and
538 behaviour change wheel to develop an intervention to improve hearing-aid use in
539 adult auditory rehabilitation. *International Journal of Audiology* 2016; 5: suppl3
540 <https://doi.org/10.3109/14992027.2015.1120894>
- 541 34. Bryman, A. *Social Research Methods*. 3rd Ed. Oxford: Oxford University Press; 2008.
- 542 35. Henshall, C, Davey, Z, Jacelon, C, Martin, C (2019). A usability study to test the
543 effectiveness, efficiency and simplicity of a newly developed Exercise focused Health
544 App for Lung cancer survivors (iEXHALE): protocol paper. *Health Informatics Journal*.
- 545 36. Roque, NA, Boot, WR. A new tool for assessing mobile device proficiency in older
546 adults: The mobile device proficiency questionnaire. *Journal of Applied Gerontology*
547 2016; 37 (2): 131-156. doi: [10.1177/0733464816642582](https://doi.org/10.1177/0733464816642582)
- 548 37. Brooke, J. SUS: a 'quick and dirty' usability scale, In Jordan, PW, Thomas, B,
549 Weerdmeester BA, McClelland IL. (eds.) *Usability evaluation in industry*. London:
550 Taylor and Francis; 1997
- 551 38. Bangor A, Kortum PT, Miller JT. An empirical evaluation of the System Usability Scale.
552 *International Journal of Human-Computer Interaction* 2008; 24 (6): 574-594.
- 553 39. Macefield R. How To Specify the Participant Group Size for Usability Studies: A
554 Practitioner's Guide. *Journal of Usability Studies*. 2009; 5: 34-45.
- 555 40. National Institute for Health and Care Excellence. Evidence standards framework for
556 digital health technologies (2019); London. Available at:
557 [https://www.nice.org.uk/about/what-we-do/our-programmes/evidence-standards-](https://www.nice.org.uk/about/what-we-do/our-programmes/evidence-standards-framework-for-digital-health-technologies)
558 [framework-for-digital-health-technologies](https://www.nice.org.uk/about/what-we-do/our-programmes/evidence-standards-framework-for-digital-health-technologies)
- 559 41. National Institute for Clinical Excellence (2004). *Guidance on Cancer Services:*
560 *Improving Supportive and Palliative Care for Adults with Cancer* (2019); London.
561 Available at: [https://www.nice.org.uk/guidance/csg4/resources/improving-](https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005)
562 [supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005](https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005)
- 563
- 564
- 565
- 566
- 567
- 568
- 569

570 **Tables**571 **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

572

573

574

575

576

577

578

579

580

581

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.	

583

584

585

586

587

588

589

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

591

592

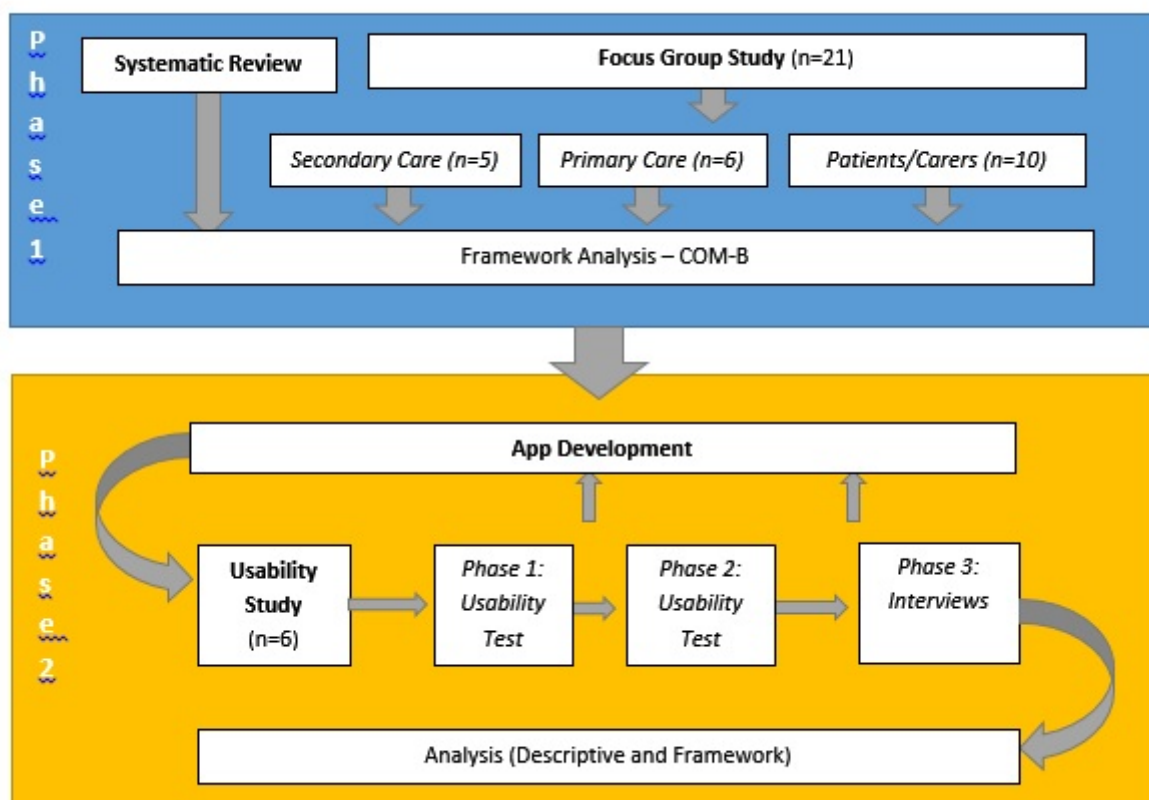
593 **Figure Legends**

594

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

596

Figure 1: Study flow diagram



597