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1 **An exploration of stroke survivors' perspectives on cycling and the use of**
2 **electric bikes.**

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152 **An exploration of stroke survivors’ perspectives on cycling and the use of**
153 **electric bikes.**

154 **ABSTRACT**

155 **Background**

156 New and innovative approaches are needed to overcome the barriers to engaging people in
157 physical and leisure activity after stroke. Outdoor cycling, including the use of adapted or
158 electric bicycles, may be one approach. However, perceptions of stroke survivors on this
159 topic have not yet been explored.

160 **Purpose**

161 To explore a sample of stroke survivors’ perspectives, who expressed an interest in cycling,
162 about cycling and the use of electric bicycles.

163 **Methods**

164 A convenience sample of stroke survivors were identified through focus groups at a ‘Cycling
165 after Stroke’ event, local stroke support groups, and structured interviews at a national
166 conference for stroke survivors. Quantitative data were analysed descriptively and qualitative
167 data analysed thematically.

168 **Results**

169 Data were collected from 21 stroke survivors, seven of whom were current cyclists. All
170 participants were independently mobile with, or without, the use of a walking aid. Themes
171 oriented around the value of cycling (e.g. getting out of the house, doing something for
172 yourself, and feeling part of a community); concerns and challenges (safety and negotiating
173 adaptations); and how they could be overcome (starting slowly and identifying sources of
174 assistance).

175 **Conclusion**

176 Outdoor cycling may be a worthwhile approach to increasing physical and leisure activity
177 after stroke. However, barriers still exist and need to be addressed to provide inclusive
178 opportunities for adapted and electric cycling for stroke survivors. Due to the small sample
179 size and bias population, further research is needed to explore stroke survivors' perspectives
180 on cycling to provide solutions to overcome the barriers identified.

181

182 **INTRODUCTION**

183 Despite a wealth of evidence supporting the role of physical activity in post-stroke recovery
184 [1] and the prevention of recurrent strokes [2], low levels of physical activity persist amongst
185 stroke survivors [3]. Six months after a stroke, over half of stroke survivors also report that
186 their lives are lacking some aspect of social, recreational, or purposeful activity [4, 5].

187 Returning to outdoor activities has been identified as a particular concern for people after

188 stroke [6], with nearly half of stroke survivors experiencing outdoor mobility restrictions [7].
189 Barriers to activity after a stroke include concerns around balance and fear of falling [8], and
190 a lack of services, transport and support [9, 10, 11]. Novel and innovative approaches are
191 needed that can support stroke survivors in achieving recommended levels of physical
192 activity (i.e. 150 minutes or more of moderate intensity physical activity per week [12]).

193 Cycling may be a feasible and acceptable way of increasing outdoor leisure opportunities for
194 some stroke survivors. Some of the advantages of cycling are that of being seated whilst
195 exercising [13], and the option of being in either an upright or semi-recumbent position [14]
196 depending on the requirement of the user. Cycling is also a functional, repetitive activity [15]
197 and encourages use of the affected side [14]. There is a growing body of evidence
198 demonstrating the increased beneficial effects on wellbeing and self-esteem when exercising
199 in natural environments opposed to synthetic or clinical environments [16, 17, 18]. Yet, the
200 current evidence base for cycling after stroke is limited to stationary cycling in the early
201 phases of rehabilitation [15, 19, 20, 21]. Additionally, there are recent developments in
202 cycling, including the development of motor-assisted bicycles that have yet to be explored in
203 the context of stroke. Electric bicycles (e-bikes) for example, have a battery-operated electric
204 motor that can be utilised to assist the cyclist during cycling. Sales of e-bikes are increasing
205 in the UK [22] with the reported benefits including a reduction in muscle fatigue, exertion,
206 and physiological stress [23]. However, the use of these bikes and the perceptions of stroke
207 survivors towards cycling on e-bikes has not yet been explored within in Ireland, the UK or
208 worldwide to the authors' knowledge.

209 The aim of our study was to explore perspectives of a sample of stroke survivors' who
210 expressed an interest in cycling, about cycling and the use of electric bicycles.

211 **METHODS**

212 This was a sequential exploratory mixed-method design [24] consisting of two phases - focus
213 groups (phase 1) and structured interviews (phase 2) (see Figure 1).

214 **Participants**

215 For phase one, we identified a sample of stroke survivors with a range of post-stroke cycling
216 experiences using a convenience sampling strategy. A flyer advertising the 'Cycling after
217 Stroke' event was circulated to existing contacts who work with people with stroke. A local
218 stroke support group expressed interest in the event but were unable to attend on the day so a
219 follow-up visit to the group was organised. Participants were recruited for the focus groups
220 through (1) a one-off 'Cycling after Stroke' event held at a university sports arena in July
221 2016; (2) a visit to a local stroke support group.

222 For phase two, participants were recruited for structured interviews at an exhibition stand at a
223 national conference for people after stroke. Stroke survivors at the conference were asked if
224 they were interested in taking part in a structured interview. To be eligible to participate in
225 the study the person had to have had a stroke. Carers were allowed to be present. The
226 researchers explained that by participating in the structured interview the participant was
227 giving their voluntary consent to be part of the research project.

228 **Data collection**

229 During phase one, we held one focus group at the ‘Cycling after stroke’ event and two focus
230 groups at the local stroke support group. Focus groups were selected to allow for interactive
231 discussion [25] between participants who were likely to have a range of experiences of
232 outdoor cycling after their stroke. A short topic guide consisting of open questions was used
233 to structure discussions (Appendix I) which were audio recorded.

234 In the second phase, we collected data using structured interviews with consenting attendees
235 at a UK Stroke Assembly, which is a national conference with a target audience of anyone
236 who is affected by stroke. Focus group data, together with findings from the literature, were
237 used to inform the development of the structured interview guide (Appendix I). In the
238 exhibition area of the conference, both the research team and an electric bike company
239 known to the team each had a stand. Due to the proximity of the electric bike stand to the
240 research team’s stand, and to minimize any bias, it was made clear to all potential participants
241 on initial introduction that the researchers were conducting independent research relating to
242 cycling and the use of electric bicycles after stroke. A member of the research team (JJ, OG)
243 read each question of the structured interview aloud and recorded on paper the answers given
244 and any extra verbal information provided by the participants.

245 **Data analysis**

246 Audio-recordings of the focus groups were transcribed and imported into NVivo11 for
247 thematic analysis. The approach to analysis was deductive in nature, with a view to
248 identifying and reporting patterns in the data set that reflected participants’ perspectives on

249 the feasibility of participating in outdoor cycling and the potential utility of electric bicycles.
250 Following the guidance by Braun and Clarke [26], transcripts were read a number of times
251 for understanding. Two members of the research team (MF, AK) then independently analysed
252 the transcripts to produce an initial set of codes. These codes were reviewed in conjunction
253 with (NM) and collated into preliminary themes. The extent to which preliminary themes
254 reflected the data set was checked, prior to producing a refined set of themes. To reduce the
255 burden of participation, member checking was not carried out.

256 The quantitative data collected in the structured interviews were analysed descriptively (JJ,
257 NG, OG) and compared with the themes from the focus groups.

258 **Ethical approval and reporting**

259 All participants had the opportunity to read an information sheet and then provided written
260 informed consent to allow audio recording of focus groups prior to data collection. For the
261 structured interviews, the researchers explained that the participant was giving their voluntary
262 consent to be part of the research project as stated at the beginning of the structured interview
263 sheet (Appendix I). This study conformed to the Declaration of Helsinki and received
264 approval from the University of Central Lancashire Research Ethics Committee, number
265 STEMH 474 (focus groups) and number STEMH 647 (structured interviews).

266 **RESULTS**

267 **Characteristics of the sample**

268 In total 21 stroke survivors took part, 14 males and 7 females. Eleven stroke survivors
269 participated in phase one (three focus groups), and ten stroke survivors completed a
270 structured interview for phase two (Figure 1). Of the eleven participants in the focus group,
271 two were actively cycling, one using a custom recumbent three-wheeled bicycle and the other
272 using a standard road bicycle. The remaining nine focus group participants were not currently
273 cycling, but had recently had the opportunity to trial-adapted bicycles.

274 Of the ten participants in the structured interview, seven were male, three were female and
275 50% were over the age of 60 years. The average number of years since having their stroke
276 was 9, ranging from 3 to 30 years. Five of the ten participants in the structured interviews
277 were currently cycling, one using a balance bike, one using a tandem, one using an electric
278 bicycle, and two using a standard bicycle. All participants were independently mobile with,
279 or without, the use of a walking aid.

280 **Insert Figure 1 here**

281 **Figure 1: Overview of data collection**

282

283 **Value of cycling**

284 When asked about reasons for taking up cycling, or returning to cycling after their stroke,
285 three themes were evident in the focus group discussions: (i) improved mood through being
286 outdoors, (ii) doing something for yourself and (iii) being part of a community. These
287 findings also emerged in the structured interviews; five participants identified that doing
288 something for yourself and being part of a community as important. Health and fitness was
289 the main reason for cycling, and three of the five reported social reasons for cycling.

290

291 During the focus groups, participants discussed how finding themselves stuck in the house
292 after a stroke contributed to problems of low mood. Taking part in an outdoor activity, in the
293 form of cycling, provided a valuable opportunity to counter this and enhance their wellbeing.

294 I wanted to get out of the house, you feel cooped up in the house after a while, you
295 want to be outside you want to breathe the fresh air and be away from being cooped
296 up. That being cooped up adds to feeling a little bit more down as time goes on
297 doesn't it #*Current cyclist using road bike*

298 Focus group participants stressed the importance of having the opportunity to do something
299 for themselves after their stroke. A number of participants provided detailed reflections on
300 their time in rehabilitation, where they felt their opportunity to assess risk, and make
301 decisions for themselves, was often revoked. One participant provided the following example
302 to illustrate their experience:

303 ...one weekend I thought 'I know! I'll get out the wheelchair and see if I can get up
304 the stairs'...so I went up on my bum one step at a time and I got to the top I felt really
305 great, like I achieved something. When I got back to rehab and I happen to mention to
306 a physio passing or an OT, I don't know who to blame [laughter], a week or two later
307 when they had a case conference and I was sitting here listening to them that I had
308 done this awful thing and gone upstairs and I felt naughty as if I shouldn't have done
309 it...and I think the whole pressure of 'be careful' and 'don't do that' I think needs to
310 change with rehab, you know 'try this', 'do this', 'push yourself a little'; okay you fall
311 over you're not going to break well not too badly anyway *#Currently cyclist using*
312 *custom recumbent bicycle*

313 Experiencing a sense of achievement after participating in cycling activities was evident
314 across all of the focus group discussions. Participants emphasised the importance of 'giving it
315 a go' by themselves and highlighted that the resulting tiredness was experienced positively.

316 You know I wanted to do it independently I didn't want to go on one with the two
317 seats, one of the helpers wanted to go one with me but I said no, it won't prove I have
318 done it, I have got to prove I can do it *#Non-cyclist but recently trialled cycling*

319 I was so fatigued after the stroke that it was nice to have the cycling to create a
320 different tiredness, a tiredness that I remembered from pre-stroke was because I
321 was physically having a go, it was nice to feel that tired instead of fatigued from
322 the stroke *#Current cyclist using road bike*

323 The final aspect discussed by participants was how cycling afforded them the opportunity to
324 feel part of a wider community.

325 You know, since I've had this trike, one of the things that sort of amazed me when
326 I'm cycling along and proper cyclists come past they wave...you are part of that
327 group...and you're not labelled you know, we're all in this together! *#Currently cyclist*
328 *using custom recumbent bicycle*

329 ...but the joy of it, the joy, like fitting helmets you know [laughter] took me ages to fit
330 a helmet, and she's [coordinator] going "Don't take that bike, don't take that bike,
331 I've got to check the tyres!" You know, so there was a lot of camaraderie with it
332 which was the enjoyable bit. *#Non-cyclist but recently trialled cycling*

333 **Concerns around cycling**

334 Participants reported a number of concerns that were most often oriented around safety and
335 practical issues during both phases. Although some focus group participants were able to try
336 two wheeled bicycles, the majority opted for a three-wheeled bicycle to accommodate
337 concerns around balance. Five of the ten structured interview participants reported fear of
338 falling as a discouraging factor, with three of the non-cyclists reporting additional concerns
339 relating both to keeping hold of handlebars, and keeping feet on the pedals. Participants in the
340 focus groups, who had the opportunity to trial bicycles, also expressed some concerns over
341 adaptations that intended to overcome stroke related impairments, but could inadvertently
342 increase anxiety or risk of falls for participants.

343 ...because I thought maybe these bikes would be, depending if you've had a stroke,
344 you can put a strap on the pedals, put a strap around the left hand side, put a strap
345 around the right hand side depending on which foot is difficult, that's the best route

346 for you. But then I thought afterwards, you can't stop because if that foots on the
347 pedal you have to stop that way, getting your feet out you'll be collapsed and hit on
348 the floor. *#Non-cyclist but recently trialled cycling*

349 Most participants said during the focus groups that they would be unlikely to cycle on their
350 own or on the roads due to safety concerns. Traffic was the primary reason for avoiding
351 cycling on roads and one participant joked:

352 On the cars coming too close I was told there is research, proper research, that showed
353 that cars go closer to cyclists in Lycra than they do to people not dressed in Lycra
354 [laughter]...so the secret is to look as unprofessional as possible! *#Currently cyclist*
355 *using custom recumbent bicycle*

356 These findings were echoed in the structured interview data where four of the ten participants
357 reported other road users as a discouragement from cycling.

358 **Overcoming challenges**

359 Focus group participants reported that (i) starting slowly, and (ii) having help could assist in
360 overcoming some of the identified concerns. For example, one participant discussed the
361 option of starting on an indoor training device to get used to being on a bike, with another
362 participant outlining that the local authority cycling sessions provided an opportunity to test
363 out cycling before potentially progressing to purchasing a bicycle of your own:

364 If you practice on these [bicycles in group sessions] I suppose and you're good with
365 them you could think, ah, maybe I could buy my own bike now that I'm used to it, so

366 it's a good way of testing if you could do it isn't it and then you can buy your own if
367 you progress *#Non-cyclist but recently trialled cycling*

368 Participants in the focus groups also spoke about the need for practical support for
369 transporting, and getting on and off the bicycles. However, only two of the ten participants in
370 the structured interviews identified this as an issue. Perspectives on the potential value of
371 motor assistance were generally positive as many participants felt that they were unable to do
372 as much as they would have liked on the bicycles. Additionally, participants identified
373 disadvantages such as weakness in particular positions, being unable to stand on the pedals to
374 generate additional force, and other non-stroke related problems that affected their ability to
375 pedal that could be helped by using a motor assisted bicycle.

376 I persevered, I had it the same as him, I did two laps and the first lap was fairly easier
377 than the second one. It was just ... it was impossible and I would have loved to carry
378 on but that was that. *#Non-cyclist but recently trialled cycling*

379 Because I have something wrong with my groin, I had a fractured pelvis you see and
380 it's my left groin a bit. So then it [my leg] was so high I couldn't get my leg back
381 down with the pedal to get that going so electrical would have made it easier in that
382 instance *#Non-cyclist but recently trialled cycling*

383 In the structured interviews, eight of the ten participants expressed that they would be
384 interested in using an electric bicycle but identified the price as the most discouraging factor.
385 The one participant who already owned an electric bicycle found it to be useful and practical.

386 **DISCUSSION**

387 We identified three themes in this study that captured the stroke survivors' perspectives of
388 outdoor cycling. The themes related to the value of cycling, the concerns and challenges of
389 cycling, and then how these concerns may be overcome. Values of cycling that were
390 highlighted included getting out of the house and enjoying the fresh air. Participants also
391 highlighted the potential social element provided when cycling in a group setting, and
392 through feeling part of the wider cycling community. The benefits of group exercise that
393 provide an opportunity for social engagement, especially with people who are experiencing
394 similar health conditions, has been highlighted in the literature [8,27]. Additionally, greater
395 engagement in valued activities has been shown to be positively associated with
396 improvements in emotional well-being after stroke [28]. None of the participants in this study
397 reported an interest in cycling for practical purposes, which is reflective of the common UK
398 population [29].

399 Participants did however identify numerous concerns, the primary one being safety whilst
400 cycling. Safety is often considered the most important factor influencing cycling participation
401 in the general population, particularly for women, children and the elderly [29]. Although
402 some participants felt confident to cycle on the road, the majority of participants identified
403 that they would prefer cycling in spaces where no traffic would be present. Safety also
404 included concerns around balance, falling, and being able to keep upper and lower limbs
405 safely in position when cycling. A correct bespoke setup is said to be essential for optimising
406 performance [30]. However, for many participants this involves the use of large and weighty
407 adapted bicycles with implications for manoeuvring the bicycles, and for transportation.

408 Having assistance from others was identified as a crucial element to overcome some of the
409 identified challenges. Participants, in this small sample sized study, had generally positive
410 perspectives on the use of motor assistance. Power assisted, or electric bicycles, are becoming
411 increasing popular in some parts of the world [31]. More recently, there are examples of how
412 electric bicycles have been adapted to accommodate impairments resulting from other
413 neurological conditions (e.g. cerebral palsy [32]) which may provide some insight into the
414 optimisation of motor assisted bicycles for a stroke population. Some of the perceived
415 benefits of electric bicycles in the general population include an improved sense of health and
416 wellbeing and being able to cover greater distances in a shorter period of time with less effort
417 [22]. However, various barriers are still present, most notably the high cost, which was
418 identified by the sample of stroke survivors in this study.

419 All participants in this study self-selected to take part at the events ‘Cycling After Stroke’,
420 local stroke support groups and a national stroke conference. Therefore, bias was introduced
421 to the convenient sample of participants recruited, due to the individuals attending the events
422 being actively engaged in their rehabilitation and interested in cycling already. As such, the
423 results may represent an overly positive view. All participants were also independently
424 mobile with, or without, the use of a walking aid. There are likely to be additional limitations
425 for more severely impaired stroke survivors that are therefore not represented in this study.
426 Study participants had a mix of experiences of cycling, and the perspectives of the majority
427 was based on a one-off recent experience of trialling adapted bicycles. Additionally,
428 perspectives on the utility of electric bicycles are based on speculation, rather than
429 experience, for the majority of participants.

430 **CONCLUSION**

431 Outdoor cycling may be a worthwhile approach to increasing physical activity after stroke,
432 but further work is needed to develop solutions to existing barriers to participation. The likely
433 benefits of this approach may include increased opportunities to get out of the house,
434 participation in ‘green exercise’ and increased social contact with other stroke survivors and
435 the wider cycling community. This study has highlighted that barriers still exist for people
436 after stroke who are interested in cycling, and would need to be addressed to provide
437 inclusive opportunities for adapted and electric cycling for stroke survivors. However, due to
438 the small sample size and bias population used, the findings of this study cannot be
439 generalised. Therefore, more research is needed to explore stroke survivors’ perspectives on
440 cycling to provide solutions to overcome the current barriers identified.

441

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451 **Declaration of interest**

452 The authors report no conflicts of interest.

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- 539
- 540

541 **Appendix I: Data collection tools**

542 **A. Focus group topic guide**

543 • What made you/would make you want to start cycling in the first instance?

544

545 • What were/would be your concerns/anxieties around cycling?

546

547 • How could these concerns/anxieties be overcome?

548

549 • What would you think about having a bicycle with motor assistance?

550

551 • What would your preferences be for participating in cycling?

552

553

554 **B. Cycling after Stroke: Structured Interview**

555 By completing this structured interview and returning it to the principal researcher, you give
556 your voluntary consent to be a part of the research project and agree that the information
557 collected can be used for further analysis as a part of the project.

558

559 You are able to withdraw from the study at any time during the structured interview.

560 However, as all information you give is anonymous, once the completed structured interview
561 has been filed you will not be able to withdraw.

562 We would really appreciate your feedback regarding cycling after stroke. All responses given
563 will remain anonymous.

564 Interviewer's name: _____

565 Please answer all the questions as fully and as honestly as possible.

566 Age group

- 18-25 26-35 36-44
 45-60 60+ Prefer not to say

567 Gender

- Male Female Prefer not to say

568 How long is it since you had your stroke? _____ years _____ months

569

570

Cycling

571 Q1. Do you currently cycle?

Yes No Prefer not to say

572

573 If yes, for what reason(s) do you cycle? Tick all that apply.

Social
(e.g. cycling with
others, networking)

Practical
(e.g. commuting)

Fitness/
health &
wellbeing

574

575 If no, would you be interested in cycling?

Yes No Prefer not to say

576 Q2. Do you or have you ever owned or used a bicycle?

Yes No Prefer not to say

577 Q3. Is there anything that is discouraging you from cycling at present?

Yes No Prefer not to say

578 If yes, please tick all that apply:

579 Physical limitations:

- Feet slide off the pedals
 - Unable to hold onto handlebars
 - Afraid of falling off due to poor balance
 - Not enough strength or endurance
 - Other health issues, (eg, poor vision or hearing, other medical conditions, etc). **Please specify below:**
-

580 Safety concerns:

- Other road users
- Nowhere safe to cycle locally
- Other _____

581

582 Other considerations:

- Lack of confidence

- Fear of being judged by others for riding a bike
- Practicalities, (e.g. needing to plan ahead for this, difficulties transporting bike).

Please specify below:

- Other: _____

583

584

Electric bikes

585 Q4. Have you heard of an electric bike?

- Yes No Prefer not to say

586 Q5. Would you be interested in using an electric bike to cycle either as a hobby or form of
587 exercise?

- Yes No Not applicable

588 Q6. Is there anything that is discouraging you from cycling on an electric bike?

589 Safety concerns:

- Speed of an electric bike

Other: _____

590

591 Other considerations:

- Lack of confidence
- Fear of being judged by others for riding an electric bike
- Price of the electric bike
- Practicalities, (eg, charging the battery, concerns about battery running out and needing to plan ahead for this, difficulties transporting electric bike, weight of the electric bike).

Please specify below:

Other: _____

592

593 Q7. Looking at the adaptations shown please tell us which of the following you would
594 consider acceptable to use? **Tick all that apply.**

Arm/Hand	Leg/Foot	Balance
1 <input type="checkbox"/>	6 <input type="checkbox"/>	11 <input type="checkbox"/>
2 <input type="checkbox"/>	7 <input type="checkbox"/>	12 <input type="checkbox"/>
3 <input type="checkbox"/>	8 <input type="checkbox"/>	13 <input type="checkbox"/>
4 <input type="checkbox"/>	9 <input type="checkbox"/>	
5 <input type="checkbox"/>	10 <input type="checkbox"/>	

595 If you would require any other adaptations, please write below.

596 _____

597 Q8. Have you tried the electric bike today?

Yes No Prefer not to say

598 Q9. Would you recommend this electric bike to others?

Yes No Maybe Don't know

599 Q10. An electric bike costs around £1,000. Having seen this electric bike with adaptations
600 today, how likely would you be to buy it?

<input type="checkbox"/>				
Extremely unlikely	Not very likely	Quite likely	Extremely likely	Prefer not to say

601 Q11. How affordable is this electric bike for you?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Completely unaffordable	Not very affordable	Quite affordable	Completely affordable	Prefer not to say

602 Q12. How practical would using an electric bike be for you?

<input type="checkbox"/>				
Extremely impractical	Not very practical	Quite practical	Extremely practical	Prefer not to say

603 Q13. How useful would it be for you to have an electric bike?

<input type="checkbox"/>				
Extremely useless	Not very useful	Quite useful	Extremely useful	Prefer not to say

604 Q14. How acceptable is this electric bike with adaptations to you?

<input type="checkbox"/>				
Extremely unacceptable	Not very acceptable	Quite acceptable	Extremely acceptable	Prefer not to say

605 Q15. How concerned are you about safety when using this electric bike?

<input type="checkbox"/>				
Extremely	Not very	Quite	Extremely	Prefer not

unconcerned concerned concerned concerned to say

606 Q16. How likely is it that this electric bike would reduce any imbalances between you and
607 those around you?

608

<input type="checkbox"/>				
Extremely unlikely	Not very likely	Quite likely	Extremely likely	Prefer not to say

609 Q17. Do you have any other comments about cycling, the electric bike or the adaptations?

610 _____
611 _____
612 _____

613

614 Thank you for completing this structured interview!

615

616

617

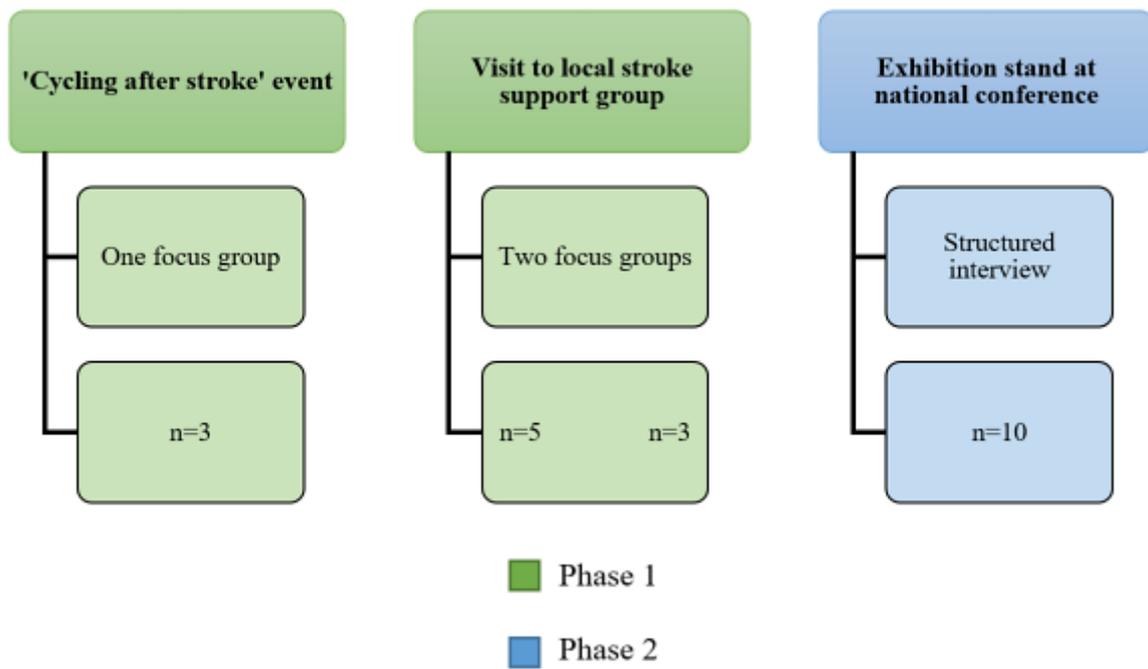
618

619

Figure 1

620

Figure 1: Overview of data collection



621

622