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Understanding engagement and non-engagement: A longitudinal qualitative study of participant experiences of an exercise referral scheme

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Understanding engagement and non-engagement: A longitudinal qualitative study of participant experiences of an exercise referral scheme

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ABSTRACT

Objectives: Exercise referral schemes are internationally widespread. This study examined experiences of patients referred by healthcare professionals to one such scheme, in order to understand whom it served well, or poorly, and why.

Design: The study employed a qualitative longitudinal approach using semi-structured interviews, with results reported using COREQ guidelines.

Setting: Two leisure centres providing an 'emerging best-practice' exercise referral scheme in northeast England.

Participants: Referred patients (n = 11) who had not yet commenced the scheme, were recruited on a voluntary basis. Seven females and four males, with a range of non-communicable diseases: cardiovascular disease, mental health issues, diabetes, overweight/obesity and musculoskeletal problems participated.

Intervention: 24-week, twice weekly supervised exercise sessions and three one-to-one assessments (pre-scheme, 12-weeks and 24-weeks) for patients referred from primary and secondary care.

Primary outcome measures: Two longitudinal semi-structured interviews, prior to commencement and 12-20 weeks later, were thematically analysed using the framework approach. Analysis comprised seven stages: transcription, familiarisation, coding,

development and application of an analytical framework, charting data using a matrix, and interpretation of data. Interpretation went beyond descriptions of individual cases to develop themes, which identified and offered possible explanations for differing participant experiences.

Results: Three overarching themes emerged. First, ‘success’, with engaged participants focused on health outcomes and reported increases in physical activity. Second, ‘struggle’, with short-term success but concerns regarding continued engagement. Participants reported scheme dependency and cyclical needs. Finally, ‘defeat’, where ill health, social anxiety, and/or poor participation experience made engagement difficult.

Conclusion: Some success in engaging those with non-communicable diseases was reported, resulting in positive effects on health and wellbeing. The study highlights complexity within exercise referral schemes, and inequality of access for those with challenging health and social circumstances. Improved, or different, behaviour change support is required for referrals finding engagement difficult.

ARTICLE SUMMARY

Strengths and limitations of this study

- Advancing the predominantly quantitative or cross-sectional literature on participant adherence to exercise referral schemes (ERS), this study explored in-depth experiences over time.
- The study contributes to reducing the evidence gap identified, for example, by the UK National Institute of Health and Care Excellence, about which sub-groups ERSs work for and why.
- Results highlighted the need for discussions about suitability of referrals and delivery practices of this type of intervention, which is internationally widespread.
- The study failed to engage some of the original participants in second interviews, meaning that the experiences of some who may have been the least well-served by the intervention are unknown.
- Results are based on a sample of participants recruited from only one, albeit large-scale, ERS and since provider practices may vary, other scheme structures may impact experiences in different ways.

INTRODUCTION

Regular physical activity (PA) has a beneficial effect on cardiovascular disease risk, diabetes, some cancers and all-cause mortality.¹ Despite this global levels of PA are low, hence the cost of PA to health-care systems in 2013 was estimated to be 53.8 billion international dollars.² Increasing population PA levels is therefore a high priority to reduce non-communicable diseases.³ Understanding participation is important in planning action and this has been widely described in terms of demography, with inequalities apparent.⁴ For example, there is an inverse relationship between PA and indicators of disadvantage such as socio-economic status⁵ and multiple co-morbidities.⁶ PA promotion initiatives must therefore consider how to target the least active.

An understanding of whether current PA programmes disproportionately benefit disadvantaged groups is required. Emerging evidence indicates the converse; with lower socioeconomic status, and increasing number of health conditions, medications and depressive symptoms negatively predicting adherence.⁷ Factors affecting participation are complex, however, with personal and social factors also known to be barriers or facilitators to being active.⁸⁻¹² Understanding how and why existing programmes engage, or do not engage, participants with differing personal circumstance can inform future equitable practice.

An exercise referral scheme (ERS) is one option for health professionals to promote PA for those with non-communicable diseases.¹³ Such schemes are internationally widespread, existing for example, in the United Kingdom (UK),¹⁴ Denmark,¹⁵ Spain¹⁶ and Mexico.¹⁷ In the UK, leisure providers usually deliver ERSs, directing participants into 10-24 weeks of supervised PA. The present study focused on one large scale ERS identified as emerging best

practice by Public Health England.¹⁸ Although ERSs are broadly aimed at those with non-communicable diseases, there is limited understanding of effective targeting. Exploring whether sub-groups of participants are more or less likely to engage therefore has value in informing practice.¹⁹ This is important because cost-effectiveness analyses indicate that ERSs need to reduce costs by 60%.²⁰ However, lack of evidence about effectiveness for participant sub-groups may have resulted in an underestimation of benefits. Indeed, the UK National Institute for Health and Care Excellence has identified a requirement to understand better what ERS elements work best and for whom.²¹

To implement successful and equitable ERSs, there is a need to better understand who existing programmes work or do not work for, and why. Demographic evidence contributes to understanding the first two of these questions;^{20 22} however, the third requires a more in-depth analytical approach. This study, a longitudinal examination of participant experiences of taking part in an ERS, therefore aims to gain in-depth understanding of differential engagement.

METHODS

The study employed a qualitative approach and longitudinal design to explore experiences of participants referred to a northeast England ERS. Results were reported using the COREQ guidelines.²³ Overarching themes, encompassing a variety of participants with differing social contexts and motives for referral, were established. Northumbria University Faculty of Health and Life Sciences Ethics Committee granted study ethical approval (Ref: 15-03-131781). Participants gave written informed consent.

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3 **Context**

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7 The ERS received primary and secondary care referrals for those with cardiovascular disease,

8 overweight/obesity, mental health issues, metabolic disease, and musculoskeletal, respiratory

9 and neurological conditions. Previous analysis (n=2233) reported a significant increase in

10 self-reported PA for those who adhered, with being aged ≥ 55 years a predictor of successful

11 engagement.²⁴ Scheme design was based on the Transtheoretical Model,^{25 26} (Figure 1). Staff

12 held an industry standard exercise referral qualification.

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22 **Figure 1: Scheme Process**

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26 The study took place in two of nine leisure centres providing the ERS. Referrals to these

27 leisure centres were representative of the demographic spectrum of participants. This

28 included a broad adult age range, males and females, and a range of economic circumstances

29 and medical conditions. All those referred to the two leisure centres during May and June

30 2013 (n=102) were eligible to take part.

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40 **Patient and Public Involvement**

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44 Previous quantitative ERS performance analysis informed the study. Participants were not

45 involved in study design. A results summary was available for study participants.

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50 **Sample**

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Early sampling of participants was by convenience.²⁷ All those invited to attend initial consultations during the first two weeks of the recruitment period (n=25) received an invitation to participate. During initial telephone contact, ERS staff informed referrals that the study consisted of two semi-structured interviews about their ERS experience. The first was conducted prior to starting, the second later in the 24-week period. Postal information was sent to interested referrals, who signed and returned the consent form to register for the study. ERS staff arranged interviews and the researcher had no access to personal details until consent was given. Participants were informed that the researcher was an employee of the scheme provider and that a research objective was to improve service delivery. There was no obligation to take part and ERS involvement was not dependent on this decision. Eight of those initially invited agreed to participate. Later sampling was purposeful, based on emergent themes from earlier initial interviews.²⁸ Recruitment continued until the emergence of new concepts from initial interview analysis ceased.

Data collection and analysis

Data were collected via two longitudinal semi-structured interviews conducted between May and December 2013, which were audio-recorded and transcribed verbatim. CLH, a PhD student who was employed by the scheme provider as a strategic manager, conducted all interviews. Prior to undertaking interviews, CLH completed qualitative interviewing training and received mentoring from LJA, an experienced qualitative researcher. Initial interviews took place in private immediately prior to initial consultations at the participants' leisure venue. One pilot interview using a semi-structured guide was conducted and analysed by CLH and LJA. The guide remained unchanged and the pilot interview deemed suitable for study inclusion. Initial interviews focused on circumstances leading to referral and

perceptions of the ERS. Second interviews, which took place 12-20 weeks later, focused on participation or non-participation experiences. Participants checked attendance at sessions with scheme staff and reported this during second interviews. Individual interviews ranged in length from 22-62 minutes (median 48 minutes). Participants checked transcripts for accuracy. Detailed field notes focused on participants' social context, the quality of the interaction and potential researcher bias due to insider knowledge.

Interviews were subject to thematic analysis using the framework approach.²⁹ The use of pseudonyms ensured anonymity. CLH and LJA familiarised themselves with transcripts through reading and rereading, and by listening to audio-recordings to check accuracy. Using manual processes and Microsoft Excel to organise data, they openly recorded preliminary concepts and patterns for three transcripts. After discussion between all authors (n=4), the establishment of agreed codes formed an initial analytical framework. Three more transcripts were analysed before refinement and finalising of the framework to allow comparison within and across all cases. The creation of a matrix allowed for the mapping and exploration of connections within and between participants and categories. During interpretation, analysis went beyond descriptions of individual cases to develop themes identifying and offering possible explanations for types of ERS experience. Participants did not provide feedback on findings, but themes were checked with ERS staff via a workshop.

RESULTS

Participant characteristics

Fifteen referrals took part in initial interviews and 11 completed both interviews. Only participants who completed both interviews were included in the final analysis (Table 1). Four participants did not complete the second interview. Two participants responded stating that they had dropped out and did not have time for the interview due to a new job or caring commitments. The other two did not respond.

Table 1: Participant Characteristics

Participant Pseudonym	Age Group (years)	Gender	Primary reason for referral	Source of referral	Participation status*	Overarching theme
Alice	70+	Female	CVD Secondary Prevention	Cardiac Rehabilitation	Adherer	Success
Amy	20-29	Female	Overweight/obesity	Primary care	Adherer	
Julie	50-59	Female	Overweight/obesity	Primary care	Adherer	
Patricia	60-69	Female	Overweight/obesity	Primary care	Adherer	
Brian	60-69	Male	CVD Secondary Prevention	Cardiac Rehabilitation	Adherer	Struggle
Margaret	60-69	Female	Mental Health	Primary care	Dropout	
Peter	50-59	Male	CVD Secondary Prevention	Cardiac Rehabilitation	Adherer	
Paul	50-59	Male	Overweight/obesity	Primary care	Non- starter	Defeat
Jackie	40-49	Female	Overweight/obesity	Primary care	Non- starter	
Dorothy	60-69	Female	Musculoskeletal	Primary care	Dropout	
Dan	50-59	Male	Mental Health	Primary care	Dropout	

***Non-starter:** attended initial consultation, but no exercise sessions
Dropout: attended initial consultation and some exercise sessions but informed researcher they had stopped attending
Adherer: attended initial consultation and informed researcher they were still attending exercise sessions

Overarching themes

Three overarching themes emerged, each conveying a different referral experience (Figure 2).

Figure 2: Thematic analysis of ERS experiences

The first was *success*, with motivated participants focused on health outcomes. The second described a *struggle*, with some level of short-term success. Cyclical changes in circumstances such as health status, and overall concerns regarding continued engagement were evident. The final theme centred on *defeat*, where ill health, social anxiety and/or poor experiences of participation made engagement difficult or unsuccessful. Short excerpts from transcripts give an indication of typical experience, with [...] signifying the joining of different sections. A participant case study illustrates each theme in more depth.

Success: increased physical activity and improved health

Success illustrated how the ERS worked very well for some, with sub-themes of improved health, increased PA and support. These participants tended to have had positive early experiences of sport and were motivated to improve or maintain health. Participation was mainly enjoyable, with peer and/or staff support being important attendance facilitators. Julie highlighted the ‘*very helpful*’ staff and how ‘*enjoying Pilates has motivated me to be coming more*’. Although personal goals, for example weight loss, were not always as anticipated, the experience was rewarding and there was a celebration of success. There was an expectation that activity would continue via signposted exit route sessions or independent exercise: ‘*I will just come on my own. They (other participants) have finished but they still come at the same time*’ (Patricia).

Illustrating this theme is Alice. She had completed cardiac rehabilitation prior to starting:

Alice: *'I loved sport, I used to cycle to work, then I started doing yoga, but I also like aqua fit, and I love walking around. I couldn't believe when I had a heart attack. [...] You have this fear, I don't walk anywhere where I'm going to fall down and nobody's going to see us. [...] I feel confident about the scheme. I'll move straight on (from cardiac rehabilitation). [...] I'm overweight; I've got to lose at least a stone. [...] You've got to use it or lose it, I've always believed that.'*

During her second interview, Alice reported 91% attendance and was very positive. Staff and social support were important in encouraging adherence:

Alice: *'I've really enjoyed it, I feel much healthier again, and I've made loads of new friends. I think the most important thing is I feel that I have got my confidence back. It has definitely lifted all that was frightening. [...] I haven't lost weight but I haven't put any on. I am more content with my life again. More realistic. [...] I love the class, and I like the talking. Yes the mouth exercises, they are very good. [...] It makes you feel as though you belong in a club. [...] (Staff member) is full of fun as well. She does push you along.'*

Within the theme of success, there were elements of struggle. Before starting the scheme, there were concerns about how perceived physical limitations and personal situations would affect attendance. Amy discussed self-esteem issues and how she made *'sure that I have got someone with us because I don't feel very confident going out by myself.'*

Participants described using social comparisons³⁰ to make judgments about their personal situation. Both upward and downward comparisons positively reinforced participation. For example, Amy developed positive views of older people's fitness, which encouraged her to

do more: *'I've seen what they have got their treadmills on and I'm thinking, I'm only lower than them, I'd best turn it up'*. Overall there was a steady improvement in perceptions about ability to be active, and the associated health and social benefits. Enjoyment was both an important facilitator of success and a positive outcome of participation.

Struggle: cyclical needs and scheme dependency

Struggle illustrated how the ERS worked in the short-term for some but highlighted different approaches, or additional measures, may be necessary to encourage sustained increases in PA. Sub-themes of cyclical needs, scheme dependency and multiple barriers indicated that this theme was more complex than *success*. Resulting experiences were more divergent, with difficult life circumstances and/or complex health conditions influencing participation. For these participants, frequently life events had caused a breakdown of their social order (e.g., the death of a loved one or loss of a job), and the ERS enabled a regaining of structure and control. Strugglers perceived the scheme as a way to get lives *'back on track'* (Margaret). This, when combined with complex health problems, meant disengagement could be difficult. Brian, a widower with depression and a history of myocardial infarction, had: *'trouble with my left foot, I am partially blind now, diabetic.'* He reported a lack of confidence to move on, indicating scheme dependency: *'I'm letting (staff member) set my programme. I might jigger myself up. The scheme is fine. It's ideal. I've been asking him can I stop in it?'* Margaret, in contrast, felt her mental health had improved so she no longer needed to attend but recognised that this was cyclical, and that she may need future support.

Within *struggle*, participants reported increased PA and health gains *'I feel 100% better'* (Brian); however, longer-term positive continuation post-scheme appeared unlikely.

Peter's experiences illustrate the theme of struggle. For him, social circumstance was particularly influential. His attendance was sporadic (63% of potential sessions). He was unemployed at his first interview and saw a potential return to work as an adherence barrier:

Peter: *Well I don't know exactly what is going to happen. I'll just see what it is and how it goes. If I enjoy it, I will stick with it as long as I can. [...] If I find work, I would stop attending.*

During his second interview, it was difficult to gauge his enthusiasm due to his natural reticence: *'I come because it is there and it's available. Or I would be just moping around the house all day doing nothing.'* His intermittent attendance was due to a work-related course and a short period of employment. Cost was an issue:

Peter: *'It's pretty hard because I have got no wages coming in. I've just got Job Seekers Allowance and that doesn't even pay my mortgage, so money is really tight. I did have a little insurance but that money has now run out and I really am starting to struggle. It is fairly cheap, but saying that, when you haven't got a lot of money coming in then it is a lot of money to pay out.'*

Peter stated he would continue to attend until he found employment, when he *'might try and come with my partner and play badminton once or twice a week.'* His enthusiasm for this appeared to be lacking and therefore long-term change in PA was unlikely.

Defeat: inappropriate referral or poor participation experience

The third theme was *defeat*. Within this, subthemes of poor health, social anxiety and poor participation experience were apparent. Some participants never attended an exercise session, prevented by ill health (Paul and Dan) or social anxieties: *'The thought of coming here on my own, with nobody else, I like staying in my comfort zone'* (Jackie). Poor participation experience (Dorothy) indicated weaknesses in scheme delivery. Defeated by the barriers faced, they felt ostracised from participation. There was a sense of failure and, for some, shame. For these participants the ERS did not work.

Illustrating this theme is Dorothy, who had been previously referred to the scheme on two occasions. The first time she completed the scheme but did not continue via signposted exit route activities because her friend stopped attending. On the second occasion, she dropped out due to a foot problem. She did not like PA:

Dorothy: *'At school I wasn't very good at PE. I never liked it very much, only did what I had to do. [...] I've been to be the scheme twice before; other than that I don't think I really did any exercise. [...] I've got a real problem with my back. I'm sort of hoping that if I do exercise it will strengthen the muscles in my back and I will be able to do more things.'*

During her second interview, Dorothy described how she felt unable to cope with the sessions due to back pain:

Dorothy: *'I did tell her that I'd got a back problem and I was waiting for these injections, but she said 'well start'. [...] I was quite disappointed because I couldn't do much of what they*

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3 *was asking us to do. It was a class and it was where you do sort of aerobics first and then go*
4 *to all these sort of stations. I found it really hard.'*
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Discussing one session, she described a lack of staff support: *'She just said do what you can do and if you can't do whatever it is, just keep your feet moving.'* This contrasted with her experience with another staff member: *'She knew when you couldn't do it and she would give you an alternative. So she was really good but she was only there once.'*

The scheme had a system of telephone support, but in Dorothy's case, implementation appeared to be lacking:

Dorothy: *'I phoned in several times to explain. I left messages but nobody got back to me. I think if maybe someone had phoned me back and said 'well come in and you can do the things a different way' it might have encouraged me to go back in again.'*

Dorothy raised delivery issues and highlighted the need for a better understanding of protocol implementation by staff. She was very upset by her experience, stating *'It makes you feel like a failure sometimes. I don't think I could go to the doctors and say 'I failed last time can you refer me again'?''* Her experience was complex however. She felt unable to access the peer support described by those who engaged successfully. During her first interview, Dorothy described how she found socialising difficult: *'I'm not really a good mixer so I find it quite hard.'* During her second interview, she reported that the group felt unwelcoming: *'She was really nice, one lady that was there. Apart from her, I don't think any of the others were welcoming or said anything. Like I said they got into their little twos or threes or whatever.'*

Lack of social confidence contributed to dropout, although in Dorothy's case it does not appear to have been the primary influence. Defeat illustrates how some participants may struggle to access the peer support identified by others as an important facilitator for adherence.

DISCUSSION

The purpose of this study was to understand experiences of an ERS to give insight regarding what worked, or did not work, to encourage engagement, and for whom. This is important because existing literature questions ERS effectiveness,^{20 22} without exploring adequately how to focus implementation to better personalise support. Three overarching themes emerged. First, *success*, with engaged participants focused on health outcomes. Second, *struggle*, short-term success but with concerns regarding continued engagement. Finally, *defeat*, where illness, social anxiety, and/or poor participation experience prevented engagement. Within the identified themes, similarities in factors affecting engagement and non-engagement were evident. For those who experienced some measure of success, there were shared enablers such as peer support, achievable and enjoyable activities, staff knowledge and staff/peer support. These are reflected to some extent in systematic review findings of engagement facilitators for ERS.³¹ What this paper adds is insight regarding whom these facilitators worked best for within the ERS context. Specifically, participants who were able to access social support, had positive previous experiences of PA, and were motivated by improving or maintaining their health. Participants often described success in terms of improvements in mental health and self-esteem, perceptions about ability to be active, and the social benefits of participation. Social and psychological benefits were perceived to be as meaningful as measurable physical health benefits, similar to other

reported findings.³² Success illustrated the value of exercise referral for some participants with non-communicable diseases. This was not universal however. The study highlighted unequal abilities to access the scheme, along with differing support requirements, which suggests the need to provide more tailored support for some. The issues identified are reflective of other studies examining barriers to PA irrespective of the presence of a medical condition.^{7 11}

Adults with complex lives embarked on the ERS with expectations of positive changes in health. While ERS delivery training courses include elements of behaviour change, the training does not appear to be sufficient preparation for staff to deal with identified complex psychological barriers. Indeed the high levels of responsibilities that fitness professionals undertake has led to concerns about adequacy of education and training.³³ Further development of behaviour change elements within national occupational standards for promoting PA could partially address matters. This represents only part of the problem however. This study illustrates how a 'one size fits all' model does not adequately cater for the complex range of referrals received. Indeed, the existing model of universal referral to a common programme is potentially setting such schemes up to fail. This is because current measures of success are typically quantified as uptake and adherence,³⁴⁻³⁶ and/or self-reported changes in PA.^{15 37} Regardless of suitability, providers may feel obliged to 'shoehorn' referrals into schemes if the continuation of funding is reliant on achievement of such key performance indicators. This type of approach fails to consider the complex health and social circumstances of ERS participants, leading to an inadequate focus on what works, and for whom.

In the case of ERS, there is a need to understand what different approaches are required to support change for those experiencing struggle or defeat. The themes presented in this study may resonate with ERS commissioners and providers and should encourage reflection of approaches to support. *Success* can reinforce good practice, while highlighting potential improvements. *Struggle* can initiate conversations about alternative delivery for those who require more or different support in order to make sustained behaviour change. This may include mechanisms for cyclical support to reengage those who relapse into inactivity and 'weaning' to reduce ERS dependency. Finally, *defeat* can initiate conversations about appropriate referrals, improvements to existing provision and alternative models of care. At a broad level, approaches may include support from multiple agencies,³⁸ the use of technology,³⁹ or broader system change.⁴⁰

Readers can make choices about whether the identified themes resonate with their own intuitive understanding of such situations, which arguably can improve practice through the process of naturalistic generalization.⁴¹ That said, it is not known whether the experiences of those who declined to participate or dropped out of the study were different to those who took part. For example, we previously established that those under 55 years of age were less likely to engage in the scheme in the first instance and more likely to dropout when they did.²⁴ However, only one participant from this demographic completed a second interview. Additionally, this piece of work did not examine barriers to scheme access for non-starters. Understanding this group, however, is critical for determining who current services are failing and why.

Qualitative analysis is inherently subjective since it is influenced by the assumptions, beliefs and biases of the researcher.⁴² In this case, the researcher was experienced in the management

and delivery of the ERS studied. Potential biases were explored by the use of reflective field notes and in group discussions with all authors. Particular attention was paid to how existing knowledge may have affected discussion with participants and interpretation of results. That said, while in the past an outsider, objective stance was considered desirable in research terms to guard against identification, insider insight can now be considered legitimate and desirable due to the potential for increased empathy with participants.⁴³ After reflection, it was felt that researcher knowledge contributed to the interpretation of data.

CONCLUSION

Overall, the data support arguments that ERSs can disproportionately engage with, and benefit, some disadvantaged groups. Importantly they can successfully engage those with non-communicable diseases, and positively affect health and wellbeing. The value of current ERSs appears to be for those with social confidence and previous positive experiences of PA. Conversely, such schemes may fail those who struggle to access social support due to varying health condition demands, or complex or impaired social circumstances. For those who are unable to adhere, feelings of ostracism and failure may further exacerbate outcome differentials. Ultimately, even programmes that target disadvantaged sub-groups (in the case of ERSs, those with non-communicable diseases) appear at risk of reinforcing inequalities. This study therefore highlights a need for services and systems that better provide for those with dynamic health and social circumstances.

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Participant consent: obtained

Ethics approval: Northumbria University Faculty of Health and Life Sciences Ethics Committee (Ref: 15-03-131781)

Provenance and peer review: Not commissioned; externally peer reviewed.

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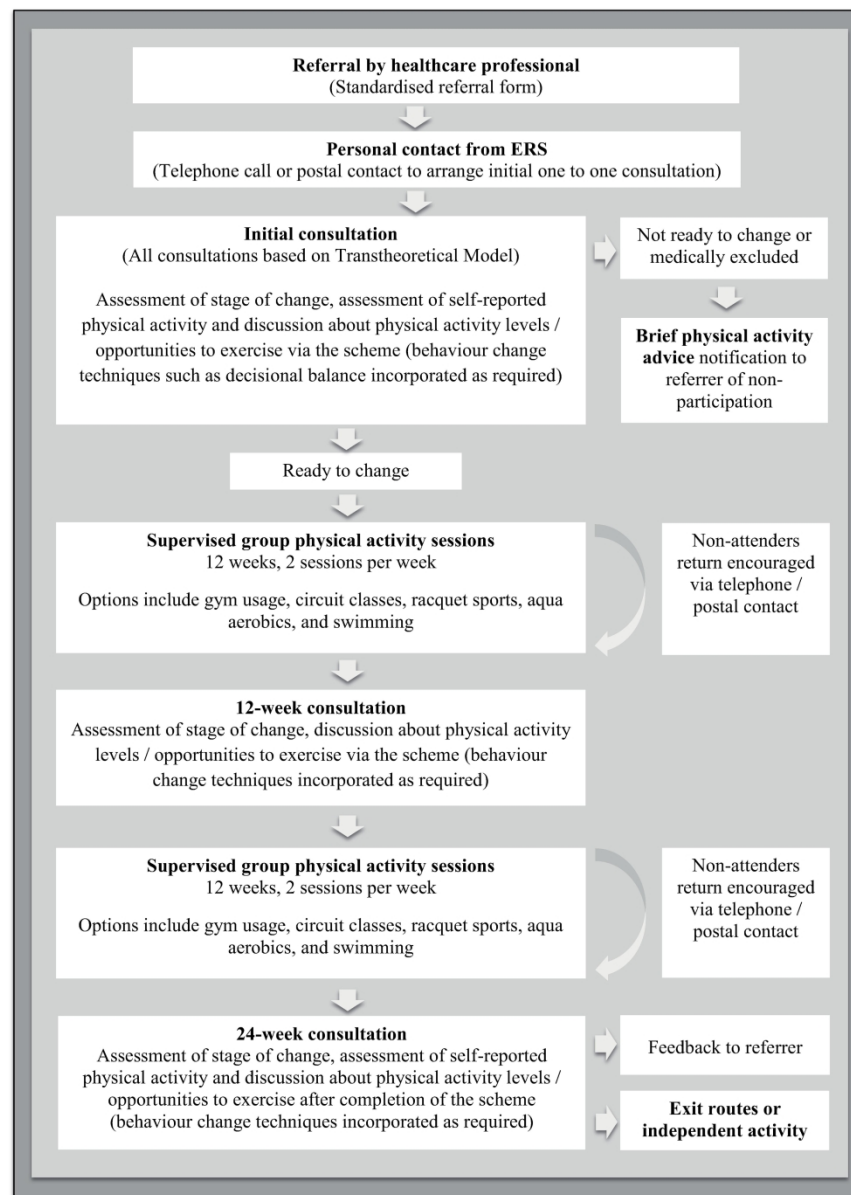


Figure 1: Scheme Process

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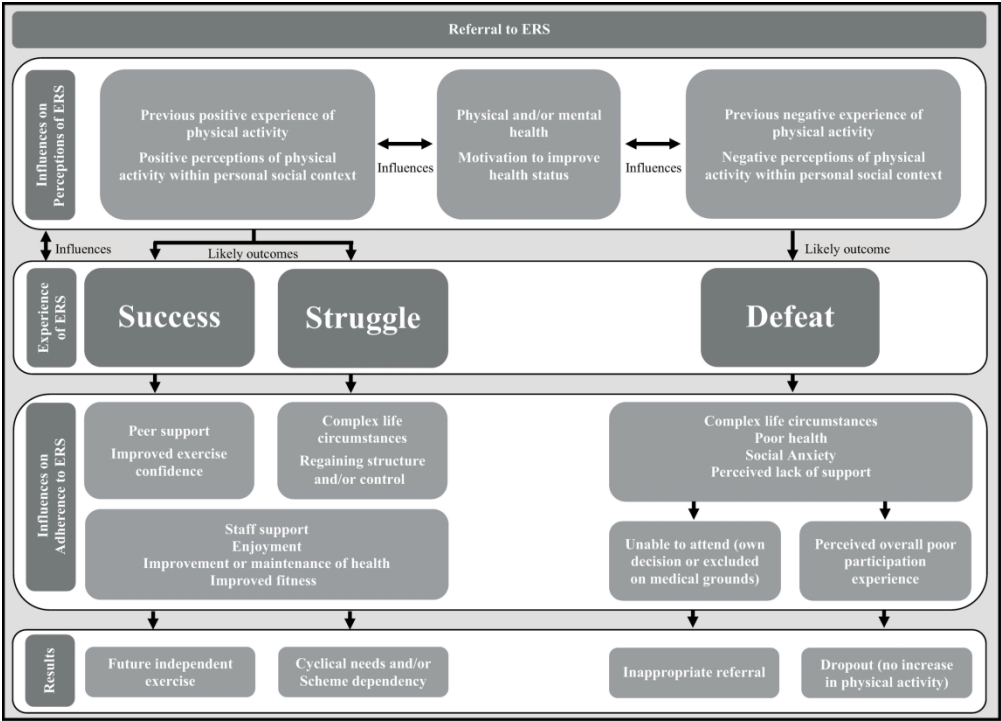


Figure 2: Thematic analysis of ERS experiences

206x148mm (300 x 300 DPI)

COREQ GUIDELINES REPORTING CHECKLIST: Understanding engagement and non-engagement: A longitudinal qualitative study of participant experiences of an exercise referral scheme

No	Item	Guide questions/description	Information	Reported in manuscript
Domain 1: Research team and reflexivity				
Personal Characteristics				
1	Interviewer/facilitator:	Which author/s conducted the interview or focus group?	CLH	√
2	Credentials	What were the researcher's credentials?	CLH PhD student and experienced in working in intervention studied. LJA experienced qualitative researcher	√
3	Occupation	What was their occupation at the time of the study?	PhD student and strategic manager in the ERS provider organisation	√
4	Gender	Was the researcher male or female?	Female (referred to as she)	√
5	Experience and training	What experience or training did the researcher have?	CLH: Qualitative research training and support from experienced researcher (LJA)	√
Relationship with participants				
6	Relationship established	Was a relationship established prior to study commencement?	No, participants were approached by ERS staff to explain the study and seek consent.	√
7	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	Participants were informed of researcher's employment status and that the research aimed to improved service delivery	√
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	Acknowledgement of potential bias due to insider knowledge. Interest in service improvement and employment status of interviewer disclosed in study invitation information.	√
Domain 1: Study design				
Theoretical framework				
9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Thematic analysis using the framework approach	√
Participant selection				
10	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive,</i>	Initially convenience from a defined group, then purposive	√

		<i>snowball</i>		
11	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>	By telephone by scheme provider	✓
12	Sample size	How many participants were in the study?	15 initially but only 11 completed both interviews	✓
13	Non-participation	How many people refused to participate or dropped out? Reasons?	Of initial invitees 13/25 refused. Of 15 initial participants, 4 dropped out. (no response n=2, too busy n=2)	✓
	Setting			
14	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	Leisure centre where ERS was attended	✓
15	Presence of non-participants	Was anyone else present besides the participants and researchers?	No, interviews were conducted in private	✓
16	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	Gender, age group, medical reason for referral and date range for interviews reported	✓
	Data collection			
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Semi-structured interview guide used. Pilot tested	✓
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	Yes, one further interview after 12-20 weeks	✓
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Yes, the interviews were audio recorded	✓
20	Field notes	Were field notes made during and/or after the interview or focus group?	Yes detailed field notes were made directly after interviews	✓
21	Duration	What was the duration of the interviews or focus groups?	Range and median length reported: 22-62 minutes (median 48 minutes)	✓
22	Data saturation	Was data saturation discussed?	Recruitment stopped when no new themes were emerging	✓
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Transcripts were checked by participants.	✓
	Domain 3: analysis and findings			
	Data analysis			
24	Number of data coders	How many data coders coded the data?	N=2 (CLH and LJA) independently N=4 in total at data workshops	✓
25	Description of the coding tree	Did authors provide a description of the coding tree?	Yes figure 2 visually describes the coding tree	✓
26	Derivation of themes	Were themes identified in advance or derived from the data?	Identified from data	✓
27	Software	What software, if applicable,	No software used, data	✓

		was used to manage the data?	analysed manually using an excel spreadsheet	
28	Participant checking	Did participants provide feedback on the findings?	No, but themes were checked with ERS staff at a workshop.	√
	Reporting			
29	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	Yes, participants identified using a pseudonym	√
30	Data and findings consistent	Was there consistency between the data presented and the findings?	Themes were illustrated by participant quotations	√
31	Clarity of major themes	Were major themes clearly presented in the findings?	Three major experience themes were identified: success, struggle and defeat	√
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Minor themes identified within each major theme: For success: improved health, increased PA, enjoyment and support For struggle: scheme dependency, multiple barriers and cyclical needs For defeat: inappropriate referral, poor participation experience, social anxiety. Diverse cases discussed within themes	√

BMJ Open

How do participant experiences and characteristics influence engagement in exercise referral? A qualitative longitudinal study of a scheme in Northumberland, United Kingdom.

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1 How do participant experiences and characteristics influence engagement in exercise
2 referral? A qualitative longitudinal study of a scheme in Northumberland, United
3 Kingdom.

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20

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22 Medicine, Physical Activity

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ABSTRACT

Objectives: Exercise referral schemes are internationally widespread. This study aimed to gain an insight into differential engagement through understanding participant experiences of patients referred by healthcare professionals to one such scheme in the United Kingdom

Design: The study employed a qualitative longitudinal approach using semi-structured interviews, with results reported using COREQ guidelines.

Setting: Two leisure centres providing an 'emerging best-practice' exercise referral scheme in northeast England.

Participants: Referred patients (n = 11) who had not yet commenced the scheme, were recruited on a voluntary basis. Seven females and four males, with a range of non-communicable diseases: cardiovascular disease, mental health issues, diabetes, overweight/obesity and musculoskeletal problems participated.

Intervention: 24-week, twice weekly supervised exercise sessions and three one-to-one assessments (pre-scheme, 12-weeks and 24-weeks) for patients referred from primary and secondary care.

Primary outcome measures: Two longitudinal semi-structured interviews, prior to commencement and 12-20 weeks later, were thematically analysed using the framework approach. Analysis comprised seven stages: transcription, familiarisation, coding,

development and application of an analytical framework, charting data using a matrix, and interpretation of data. Interpretation went beyond descriptions of individual cases to develop themes, which identified and offered possible explanations for differing participant experiences.

Results: Three overarching themes emerged. First, 'success', with engaged participants focused on health outcomes and reported increases in physical activity. Second, 'struggle', with short-term success but concerns regarding continued engagement. Participants reported scheme dependency and cyclical needs. Finally, 'defeat', where ill health, social anxiety, and/or poor participation experience made engagement difficult.

Conclusion: Some success in engaging those with non-communicable diseases was reported, resulting in positive effects on health and wellbeing. The study highlights complexity within exercise referral schemes, and inequality of access for those with challenging health and social circumstances. Improved, or different, behaviour change support is required for referrals finding engagement difficult.

ARTICLE SUMMARY

Strengths and limitations of this study

- This study advances the predominantly quantitative literature on participant adherence to exercise referral by using a longitudinal qualitative design to gain a deeper understanding of the experience of patients with non-communicable diseases referred to an exercise referral scheme (ERS).
- The study provides insight into the complexity of ERS engagement and the experiences of a group that has been little researched; those who did not successfully engage with the ERS.
- The study was unable to engage some of the original participants in second interviews, meaning that the experiences of some who may have been least well-served by the intervention are unknown.
- The sample of participants were recruited from only one, albeit large-scale, ERS, meaning that findings relate to this particular scheme and sample.
- Qualitative interviews can only provide information on what participants recall or are prepared to reveal about their perceived experiences within a particular interview context, meaning that the potential for recall bias is always present.

1 INTRODUCTION

Regular physical activity (PA) has a beneficial effect on cardiovascular disease risk, diabetes, some cancers and all-cause mortality.¹ The global cost of inactivity to health-care in 2013 was estimated to be 53.8 billion international dollars² and therefore increasing PA levels is a high priority to reduce non-communicable diseases.³ Participation in PA has been widely described in terms of demography, with inequalities apparent.⁴ For example, there is an inverse relationship between PA and indicators of disadvantage such as socio-economic status⁵ and multiple co-morbidities.⁶ In order to have the greatest impact, PA promotion initiatives must therefore consider the context, and barriers and facilitators to engagement specifically in disadvantaged populations.

Emerging evidence indicates that current PA programmes can fail to engage or retain more disadvantaged participants. Lower socioeconomic status, and increasing number of health conditions, medications and depressive symptoms have been reported to negatively predict adherence.⁷ Factors affecting participation are complex, however, with personal and social factors such as positive childhood PA experience and social support for PA known to positively influence activity levels.⁸⁻¹² Understanding how and why existing programmes engage, or do not engage, participants with differing personal circumstance can inform future equitable practice.

An exercise referral scheme (ERS) is one option for health professionals to promote PA for those with non-communicable diseases.¹³ Such schemes are internationally widespread, existing for example, in the United Kingdom (UK),¹⁴ Denmark,¹⁵ Spain¹⁶ and Mexico.¹⁷ In the UK, leisure providers usually deliver ERSs, directing participants into 10-24 weeks of

1 supervised PA. The present study focused on one large scale ERS identified as emerging best
2 practice by Public Health England.¹⁸ Although ERSs are broadly aimed at those with non-
3 communicable diseases, there is limited understanding of effective targeting. Exploring
4 whether sub-groups of participants are more or less likely to engage therefore has value in
5 informing practice.¹⁹ This is important because cost-effectiveness analyses indicate that ERSs
6 need to reduce costs by 60%.²⁰ However, lack of evidence about effectiveness for participant
7 sub-groups may have resulted in an underestimation of benefits. Indeed, the UK National
8 Institute for Health and Care Excellence has identified a requirement to understand better
9 what ERS elements work best and for whom.²¹

10
11 To implement successful and equitable ERSs, there is a need to better understand who
12 existing programmes work or do not work for. Demographic evidence contributes some
13 knowledge;^{20 22} but a more in-depth analytical approach is required to increase understanding
14 of other factors influencing engagement. This longitudinal qualitative study aimed to gain an
15 insight into differential engagement through understanding participant experiences of an
16 ERS.

17 18 **METHODS**

19
20 The study employed longitudinal qualitative design to explore experiences of participants
21 referred to the Northumberland ERS. Results were reported using the COREQ guidelines.²³
22 Overarching themes, encompassing a variety of participants with differing social contexts and
23 motives for referral, were established. Northumbria University Faculty of Health and Life
24 Sciences Ethics Committee granted study ethical approval (Ref: 15-03-131781). Participants
25 gave written informed consent.

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Context

The ERS received primary and secondary care referrals for those with cardiovascular disease, overweight/obesity, mental health issues, metabolic disease, and musculoskeletal, respiratory and neurological conditions. Previous analysis (n=2233) reported a significant increase in self-reported PA for those who adhered, with being aged ≥55 years a predictor of successful engagement.²⁴ Scheme design was based on the Transtheoretical Model.^{25 26} It consisted of three one-to-one consultations and 24 weeks of twice-weekly PA sessions (Figure 1). During consultations, participants chose which PA sessions to attend. Those who did not attend activity sessions for one week were contacted by telephone or post. Each ERS session cost £3.40. Participants could purchase a discounted direct debit fitness and swimming membership while taking part and after completion (£24.00/month). Staff held an industry standard exercise referral qualification.

Figure 1: Scheme Process

The study took place in two of nine leisure centres providing the ERS. Referrals to these leisure centres were representative of the demographic spectrum of participants. This included a broad adult age range, males and females, and a range of economic circumstances and medical conditions. All those referred to the two leisure centres during May and June 2013 (n=102) were eligible to take part.

Patient and Public Involvement

Previous binary logistic regression analysis of demographic and personal factors associated with engagement and adherence to the ERS²⁴ informed the study. Participants were not involved in study design. A results summary was available for study participants.

Sample

The Northumberland ERS provided a convenient sample,²⁷ which was easily accessible to CLH, given her employment. All those invited to attend initial consultations during the first two weeks of the recruitment period (n=25) received an invitation to participate. During initial telephone contact, ERS staff informed referrals that the study consisted of two semi-structured interviews about their ERS experience. The first was conducted prior to starting, the second later in the 24-week period. Postal information was sent to interested referrals, who signed and returned the consent form to register for the study. ERS staff arranged interviews and the researcher had no access to personal details until consent was given. Participants were informed that the researcher was an employee of the scheme provider and that a research objective was to improve service delivery. There was no obligation to take part and ERS involvement was not dependent on this decision. Eight of those initially invited agreed to participate. Later sampling was purposeful, based on developing themes (those with multiple medical conditions and referrals under 50 years old) from earlier initial interviews.²⁸ ERS staff were asked to invite referrals with only these characteristics to take part later in the study. Recruitment continued until no new –overarching themes developed from initial interview analysis.

Data collection and analysis

1 Data were collected via two longitudinal semi-structured interviews conducted between May
2
3 and December 2013, which were audio-recorded and transcribed verbatim. CLH, a PhD
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5 student who was employed by the scheme provider as a strategic manager, conducted all
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7 interviews. CLH had 15 years' experience of working for the ERS but was not involved in
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9 delivery during the study. Prior to undertaking interviews, CLH completed qualitative
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11 interviewing training and received mentoring from LJA, an experienced qualitative
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13 researcher. Initial interviews took place in private immediately prior to initial consultations at
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15 the participants' leisure venue. One pilot interview using a semi-structured guide
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17 (supplementary file 1) was conducted and analysed by CLH and LJA. Topics covered
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19 included PA history, motivators for referral, perceptions and expectations of the ERS, and
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21 perceived barriers and facilitators to taking part. The guide remained unchanged and the pilot
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23 interview deemed suitable for study inclusion. Initial interviews focused on circumstances
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25 leading to referral and perceptions of the ERS. Second interviews, which took place 12-20
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27 weeks later, focused on participation or non-participation experiences (supplementary file 2).
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29 Participants checked attendance at sessions with scheme staff and reported this during second
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31 interviews. Individual interviews ranged in length from 22-62 minutes (median 48 minutes).
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33 Participants checked transcripts for accuracy. Detailed field notes focused on participants'
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35 social context, the quality of the interaction and potential researcher bias due to insider
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37 knowledge.
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46 Interviews were subject to thematic analysis using the framework approach.²⁹ The use of
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48 pseudonyms ensured anonymity. CLH and LJA familiarised themselves with transcripts
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50 through reading and rereading, and by listening to audio-recordings to check accuracy. Using
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52 manual processes and Microsoft Excel to organise data, they openly recorded preliminary
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54 concepts and patterns for three transcripts. After discussion between all authors (n=4), the
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establishment of agreed codes formed an initial analytical framework. Three more transcripts were analysed before refinement and finalising of the framework to allow comparison within and across all cases. The creation of a matrix allowed for the mapping and exploration of connections within and between participants and categories. During interpretation, analysis went beyond descriptions of individual cases to develop themes identifying and offering possible explanations for types of ERS experience. Participants did not provide feedback on findings, but themes were checked with ERS staff via a workshop.

RESULTS

Participant characteristics

Fifteen referrals took part in initial interviews and 11 completed both interviews. Only participants who completed both interviews were included in the final analysis (Table 1). Four participants did not complete the second interview. Two participants responded stating that they had dropped out and did not have time for the interview due to a new job or caring commitments. The other two did not respond. Three of the four were under 50 years old.

Table 1: Participant Characteristics

Participant Pseudonym	Age Group (years)	Gender	Primary reason for referral	Source of referral	Self-reported PA history	Employment status	Participation status*	Overarching theme
Alice	70+	Female	CVD Secondary Prevention	Cardiac Rehabilitation	Previously very active, enjoyed PA	Retired	Adherer	Success
Amy	20-29	Female	Overweight/obesity	Primary care	Previously active, enjoyed PA	Home-maker	Adherer	
Julie	50-59	Female	Overweight/obesity	Primary care	Previously very active, enjoyed PA	Employed	Adherer	

Patricia	60-69	Female	Overweight/ obesity	Primary care	Previously active, enjoyed PA	Retired	Adherer	
Brian	60-69	Male	CVD Secondary Prevention	Cardiac Rehabilitation	Previously active, enjoyed PA	Retired	Adherer	
Margaret	60-69	Female	Mental Health	Primary care	Intermittently active, enjoyed PA but hated sport	Retired	Dropout	Struggle
Peter	50-59	Male	CVD Secondary Prevention	Cardiac Rehabilitation	Previously active, enjoyed PA	Un- employed	Adherer	
Paul	50-59	Male	Overweight/ obesity	Primary care	Previously active, enjoyed PA	Receiving disability benefit	Medically excluded	
Jackie	40-49	Female	Overweight/ obesity	Primary care	Previously inactive, disliked PA	Carer	Non- attender	Defeat
Dorothy	60-69	Female	Musculoskeletal	Primary care	Previously inactive, disliked PA	Retired	Dropout	
Dan	50-59	Male	Mental Health	Primary care	Previously active, enjoyed PA	Employed	Dropout (health reason)	
<i>*Medically excluded:</i> attended initial consultation but was excluded from scheme participation due to medical reasons (physiological measures above scheme acceptance guidelines e.g. blood pressure $\geq 180/100$ mmHg or resting heart rate ≥ 100 beats per minute) <i>Non-attender:</i> attended initial consultation, but no exercise sessions <i>Dropout:</i> attended initial consultation and some exercise sessions but informed researcher they had stopped attending <i>Adherer:</i> attended initial consultation and informed researcher they were still attending exercise sessions								

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Overarching themes

Three overarching themes emerged, each conveying a different referral experience (Figure 2).

Figure 2: Thematic analysis of ERS experiences

The first was *success*, with motivated participants focused on health outcomes. The second described a *struggle*, with some level of short-term success. Cyclical changes in circumstances such as health status, and overall concerns regarding continued engagement were evident. The final theme centred on *defeat*, where ill health, social anxiety and/or poor experiences of participation made engagement difficult or unsuccessful. Short excerpts from

transcripts give an indication of typical experience, with [...] signifying the joining of different sections. A participant case study illustrates each theme in more depth.

Success: increased physical activity and improved health

Success illustrated how the ERS worked very well for some, with sub-themes of improved health, increased PA and support. These participants tended to have had positive early experiences of sport and were motivated to improve or maintain health. Participation was mainly enjoyable, with peer and/or staff support being important attendance facilitators. Julie highlighted the ‘very helpful’ staff and how ‘*enjoying Pilates has motivated me to be coming more*’. Although personal goals, for example weight loss, were not always as anticipated, the experience was rewarding and there was a celebration of success. There was an expectation that activity would continue via signposted exit route sessions or independent exercise: ‘*I will just come on my own. They (other participants) have finished but they still come at the same time*’ (Patricia).

Illustrating this theme is Alice. She had completed cardiac rehabilitation prior to starting:

Alice: ‘*I loved sport, I used to cycle to work, then I started doing yoga, but I also like aqua fit, and I love walking around. I couldn't believe when I had a heart attack. [...] You have this fear, I don't walk anywhere where I'm going to fall down and nobody's going to see us. [...] I feel confident about the scheme. I'll move straight on (from cardiac rehabilitation). [...] I'm overweight; I've got to lose at least a stone. [...] You've got to use it or lose it, I've always believed that.*’

During her second interview, Alice reported 91% attendance and was very positive. Staff and social support were important in encouraging adherence:

Alice: *'I've really enjoyed it, I feel much healthier again, and I've made loads of new friends. I think the most important thing is I feel that I have got my confidence back. It has definitely lifted all that was frightening. [...] I haven't lost weight but I haven't put any on. I am more content with my life again. More realistic. [...] I love the class, and I like the talking. Yes the mouth exercises, they are very good. [...] It makes you feel as though you belong in a club. [...] (Staff member) is full of fun as well. She does push you along.'*

Within the theme of success, there were elements of struggle. Before starting the scheme, there were concerns about how perceived physical limitations and personal situations would affect attendance. Amy discussed self-esteem issues and how she made *'sure that I have got someone with us because I don't feel very confident going out by myself.'*

Participants described using social comparisons³⁰ to make judgments about their personal situation. Both upward and downward comparisons positively reinforced participation. For example, Amy developed positive views of older people's fitness, which encouraged her to do more: *'I've seen what they have got their treadmills on and I'm thinking, I'm only lower than them, I'd best turn it up'*. Overall there was a steady improvement in perceptions about ability to be active, and the associated health and social benefits. Enjoyment was both an important facilitator of success and a positive outcome of participation.

Struggle: cyclical needs and scheme dependency

1 *Struggle* illustrated how the ERS worked in the short-term for some but highlighted different
2 approaches, or additional measures, may be necessary to encourage sustained increases in
3 PA. Sub-themes of cyclical needs, scheme dependency and multiple barriers indicated that
4 this theme was more complex than *success*. Resulting experiences were more divergent, with
5 difficult life circumstances and/or complex health conditions influencing participation. For
6 these participants, frequently life events had caused a breakdown of their social order (e.g.,
7 the death of a loved one or loss of a job), and the ERS enabled a regaining of structure and
8 control. Strugglers perceived the scheme as a way to get lives '*back on track*' (Margaret).
9 This, when combined with complex health problems, meant disengagement could be difficult.
10 Brian, a widower with depression and a history of myocardial infarction, had: '*trouble with*
11 '*my left foot, I am partially blind now, diabetic.*' He reported a lack of confidence to move on,
12 indicating scheme dependency: '*I'm letting (staff member) set my programme. I might jiggle*
13 '*myself up. The scheme is fine. It's ideal. I've been asking him can I stop in it?*' Margaret, in
14 contrast, felt her mental health had improved so she no longer needed to attend but
15 recognised that this was cyclical, and that she may need future support.
16
17 Within *struggle*, participants reported increased PA and health gains '*I feel 100% better*'
18 (Brian); however, longer-term positive continuation post-scheme appeared unlikely.
19
20 Peter's experiences illustrate the theme of struggle. For him, social circumstance was
21 particularly influential. His attendance was sporadic (63% of potential sessions). He was
22 unemployed at his first interview and saw a potential return to work as an adherence barrier:
23

1 Peter: *Well I don't know exactly what is going to happen. I'll just see what it is and how it*
2 *goes. If I enjoy it, I will stick with it as long as I can. [...] If I find work, I would stop*
3 *attending.'*

4
5 During his second interview, it was difficult to gauge his enthusiasm due to his natural
6 reticence: *'I come because it is there and it's available. Or I would be just moping around the*
7 *house all day doing nothing.'* His intermittent attendance was due to a work-related course
8 and a short period of employment. Cost was an issue:

9
10 Peter: *'It's pretty hard because I have got no wages coming in. I've just got Job Seekers*
11 *Allowance and that doesn't even pay my mortgage, so money is really tight. I did have a little*
12 *insurance but that money has now run out and I really am starting to struggle. It is fairly*
13 *cheap, but saying that, when you haven't got a lot of money coming in then it is a lot of*
14 *money to pay out.'*

15
16 Peter stated he would continue to attend until he found employment, when he *'might try and*
17 *come with my partner and play badminton once or twice a week.'* His enthusiasm for this
18 appeared to be lacking and therefore long-term change in PA was unlikely.

19 20 **Defeat: inappropriate referral or poor participation experience**

21
22 The third theme was *defeat*. Within this, subthemes of poor health, social anxiety and poor
23 participation experience were apparent. Some participants never attended an exercise session,
24 being medically excluded (Paul), prevented by ill health (Dan) or social anxieties (despite
25 telephone support):

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2 Jackie: *'The thought of coming here on my own, with nobody else, I like staying in my*
3 *comfort zone ...'(staff) phoned; she says about the sessions and that... and I was being*
4 *honest with her... so she left it a couple of weeks and then phoned back and she says... would*
5 *you not like to come along by yourself? And I went no'*

6

7 For others, poor participation experience (Dorothy) indicated weaknesses in scheme delivery.
8 This group were defeated by the barriers faced, they felt ostracised from participation. There
9 was a sense of failure and, for some, shame. For these participants the ERS did not work.

10

11 Illustrating this theme is Dorothy, who had been previously referred to the scheme on two
12 occasions. The first time she completed the scheme but did not continue via signposted exit
13 route activities because her friend stopped attending. On the second occasion, she dropped
14 out due to a foot problem. She did not like PA:

15

16 Dorothy: *'At school I wasn't very good at PE. I never liked it very much, only did what I had*
17 *to do. [...] I've been to be the scheme twice before; other than that I don't think I really did*
18 *any exercise. [...] I've got a real problem with my back. I'm sort of hoping that if I do exercise*
19 *it will strengthen the muscles in my back and I will be able to do more things.'*

20

21 During her second interview, Dorothy described how she felt unable to cope with the sessions
22 due to back pain:

23

24 Dorothy: *'I did tell her that I'd got a back problem and I was waiting for these injections, but*
25 *she said 'well start'. [...] I was quite disappointed because I couldn't do much of what they*

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1 was asking us to do. It was a class and it was where you do sort of aerobics first and then go
2 to all these sort of stations. I found it really hard.'

3

4 Discussing one session, she described a lack of staff support: *'She just said do what you can*
5 *do and if you can't do whatever it is, just keep your feet moving.'* This contrasted with her
6 experience with another staff member: *'She knew when you couldn't do it and she would give*
7 *you an alternative. So she was really good but she was only there once.'*

8

9 The scheme had a system of telephone support, but in Dorothy's case, implementation
10 appeared to be lacking:

11

12 Dorothy: *'I 'phoned in several times to explain. I left messages but nobody got back to me. I*
13 *think if maybe someone had 'phoned me back and said 'well come in and you can do the*
14 *things a different way' it might have encouraged me to go back in again.'*

15

16 Dorothy raised delivery issues and highlighted the need for a better understanding of protocol
17 implementation by staff. She was very upset by her experience, stating *'It makes you feel like*
18 *a failure sometimes. I don't think I could go to the doctors and say 'I failed last time can you*
19 *refer me again'?' Her experience was complex however. She felt unable to access the peer*
20 *support described by those who engaged successfully. During her first interview, Dorothy*
21 *described how she found socialising difficult: 'I'm not really a good mixer so I find it quite*
22 *hard.'* During her second interview, she reported that the group felt unwelcoming: *'She was*
23 *really nice, one lady that was there. Apart from her, I don't think any of the others were*
24 *welcoming or said anything. Like I said they got into their little twos or threes or whatever.'*

25

1 Lack of social confidence contributed to dropout, although in Dorothy's case it does not
2 appear to have been the primary influence. Defeat illustrates how some participants may
3 struggle to access the peer support identified by others as an important facilitator for
4 adherence.

6 DISCUSSION

7
8 The purpose of this study was to understand experiences of an ERS to give insight regarding
9 what worked, or did not work, to encourage engagement, and for whom. This is important
10 because existing literature questions ERS effectiveness,^{20 22} without exploring adequately
11 how to focus implementation to better personalise support. Three overarching themes
12 emerged. First, *success*, with engaged participants focused on health outcomes. Second,
13 *struggle*, short-term success but with concerns regarding continued engagement. Finally,
14 *defeat*, where illness, social anxiety, and/or poor participation experience prevented
15 engagement. Within the identified themes, similarities in factors affecting engagement and
16 non-engagement were evident. For those who experienced some measure of success, there
17 were shared enablers such as peer support, achievable and enjoyable activities, staff
18 knowledge and staff/peer support. These are reflected to some extent in systematic review
19 findings of engagement facilitators for ERS.³¹ What this paper adds is insight regarding
20 whom these facilitators worked best for within the ERS context. Specifically, participants
21 who were able to access social support, had positive previous experiences of PA, and were
22 motivated by improving or maintaining their health. Participants often described success in
23 terms of improvements in mental health and self-esteem, perceptions about ability to be
24 active, and the social benefits of participation. Social and psychological benefits were
25 perceived to be as meaningful as measurable physical health benefits, similar to other

1 reported findings.³² Success illustrated the value of exercise referral for some participants
2 with non-communicable diseases. This was not universal however. The study highlighted
3 unequal abilities to access the scheme, along with differing support requirements, which
4 suggests the need to provide more tailored support for some. The issues identified are
5 reflective of other studies examining barriers to PA irrespective of the presence of a medical
6 condition.^{7 11}
7
8 Adults with complex lives embarked on the ERS with expectations of positive changes in
9 health. While ERS delivery training courses include elements of behaviour change, the
10 training does not appear to be sufficient preparation for staff to deal with identified complex
11 psychological barriers. Indeed the high levels of responsibilities that fitness professionals
12 undertake has led to concerns about adequacy of education and training.³³ Further
13 development of behaviour change elements within national occupational standards for
14 promoting PA could partially address matters. This represents only part of the problem
15 however. This study illustrates how a 'one size fits all' model does not adequately cater for
16 the complex range of referrals received. Indeed, the existing model of universal referral to a
17 common programme is potentially setting such schemes up to fail. This is because current
18 measures of success are typically quantified as uptake and adherence,³⁴⁻³⁶ and/or self-reported
19 changes in PA.^{15 37} Regardless of suitability, providers may feel obliged to 'shoehorn'
20 referrals into schemes if the continuation of funding is reliant on achievement of such key
21 performance indicators. This type of approach fails to consider the complex health and social
22 circumstances of ERS participants, leading to an inadequate focus on what works, and for
23 whom.
24

1 In the case of ERS, there is a need to understand what different approaches are required to
2 support change for those experiencing struggle or defeat. The themes presented in this study
3 may resonate with ERS commissioners and providers and should encourage reflection of
4 approaches to support. *Success* can reinforce good practice, while highlighting potential
5 improvements. *Struggle* can initiate conversations about alternative delivery for those who
6 require more or different support in order to make sustained behaviour change. This may
7 include mechanisms for cyclical support to reengage those who relapse into inactivity and
8 'weaning' to reduce ERS dependency. Finally, *defeat* can initiate conversations about
9 appropriate referrals, improvements to existing provision and alternative models of care. At a
10 broad level, approaches may include support from multiple agencies,³⁸ the use of
11 technology,³⁹ or broader system change.⁴⁰ Promisingly, there is emerging evidence of
12 practice with the potential to better support patients with struggle or defeat-style narratives.
13 Those with poor health may benefit from individualisation of exercise,⁴¹ those with social
14 anxiety from more online delivery and support,⁴² and the complex needs of patients are more
15 likely to be catered for appropriately with increasing use of scheme co-production.⁴³ Calls at
16 national policy level for better use of triage or a 'stepped approach to delivery'²¹ may further
17 assist with both enhancing support for those with challenging circumstances and modifying
18 or reducing it for those that risk becoming scheme dependent. Testing the effectiveness of
19 these ideas should be a priority for future research.

20 21 **Methodological considerations**

22
23
24 Qualitative analysis is inherently subjective since it is influenced by the assumptions, beliefs
25 and biases of the researcher.⁴⁴ In this case, the researcher was experienced in the management

1 and delivery of the ERS studied. Potential biases were explored by the use of reflective field
2 notes and in group discussions with all authors. Particular attention was paid to how existing
3 knowledge may have affected discussion with participants and interpretation of results. That
4 said, while in the past an outsider, objective stance was considered desirable in research terms
5 to guard against identification, insider insight can now be considered legitimate and desirable
6 due to the potential for increased empathy with participants.⁴⁵ After reflection, it was felt that
7 researcher knowledge contributed positively to the interpretation of data through being able
8 to understand the particular scheme that participants were discussing.

9
10 For each participant, interviews took place on two occasions. Qualitative interviews are only
11 able to uncover what participants recall or are willing to reveal about their experiences at a
12 particular time, rather than realities. As such they may reflect recall bias or inaccuracies.
13 Participant knowledge of the researcher background may also have influenced what was
14 disclosed. Readers can make choices about whether the identified themes resonate with their
15 own intuitive understanding of such situations, which arguably can improve practice through
16 the process of naturalistic generalization.⁴⁶

17
18 It is not known whether the experiences of those who declined to participate or dropped out
19 of the study were different to those who took part. For example, we previously established
20 that those under 55 years of age were less likely to engage in the first instance and more
21 likely to dropout when they did.²⁴ However, only one participant from this demographic
22 completed a second interview. Additionally, this piece of work did not examine barriers to
23 scheme access for who did not attend the initial consultation. Understanding this group,
24 however, is critical for determining who current services are failing and why.

CONCLUSION

Overall, the data support arguments that ERSs can disproportionately engage with, and benefit, some disadvantaged groups. Importantly they can successfully engage those with non-communicable diseases, and positively affect health and wellbeing. The value of current ERSs appears to be for those with social confidence and previous positive experiences of PA. Conversely, such schemes may fail those who struggle to access social support due to varying health condition demands, or complex or impaired social circumstances. For those who are unable to adhere, feelings of ostracism and failure may further exacerbate outcome differentials. Ultimately, even programmes that target disadvantaged sub-groups (in the case of ERSs, those with non-communicable diseases) appear at risk of reinforcing inequalities. This study therefore highlights a need for services and systems that better provide for those with dynamic health and social circumstances.

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2 **Competing interests:** CLH is a former employee of Blyth Valley Arts and Leisure and

3 completed a PhD that was funded by the aforementioned company.

4

5 **Participant consent:** obtained

6

7 **Ethics approval:** Northumbria University Faculty of Health and Life Sciences Ethics

8 Committee (Ref: 15-03-131781)

9

10 **Provenance and peer review:** Not commissioned; externally peer reviewed.

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12 **Data sharing statement:** No additional data are available.

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Referral by healthcare professional
(Standardised referral form)



Personal contact from ERS

(Telephone call or postal contact to arrange initial one to one consultation)



Initial consultation

(All consultations based on Transtheoretical Model)

Assessment of stage of change, assessment of self-reported physical activity and discussion about physical activity levels / opportunities to exercise via the scheme (behaviour change techniques such as decisional balance incorporated as required)

Not ready to change or medically excluded



Brief physical activity advice notification to referrer of non-participation



Ready to change



Supervised ERS group physical activity sessions

12 weeks, 2 sessions per week

Options include gym usage, circuit classes, racquet sports and aqua aerobics

Individual non-ERS supervised physical activity options

Swimming, casual gym or fitness class attendance

Non-attenders return encouraged via telephone (3 attempts) / postal contact (if unable to contact by telephone)



12-week consultation

Assessment of stage of change, discussion about physical activity levels / opportunities to exercise via the scheme (behaviour change techniques incorporated as required)



Supervised ERS group physical activity sessions

12 weeks, 2 sessions per week

Options include gym usage, circuit classes, racquet sports and aqua aerobics

Individual non-ERS supervised physical activity options

Swimming, casual gym or fitness class attendance

Non-attenders return encouraged via telephone (3 attempts) / postal contact (if unable to contact by telephone)



24-week consultation

Assessment of stage of change, assessment of self-reported physical activity and discussion about physical activity levels / opportunities to exercise after completion of the scheme (behaviour change techniques incorporated as required)

Feedback to referrer

Exit routes (similar ERS supervised exit sessions, reduced cost fitness and/or swimming memberships) or **independent activity**

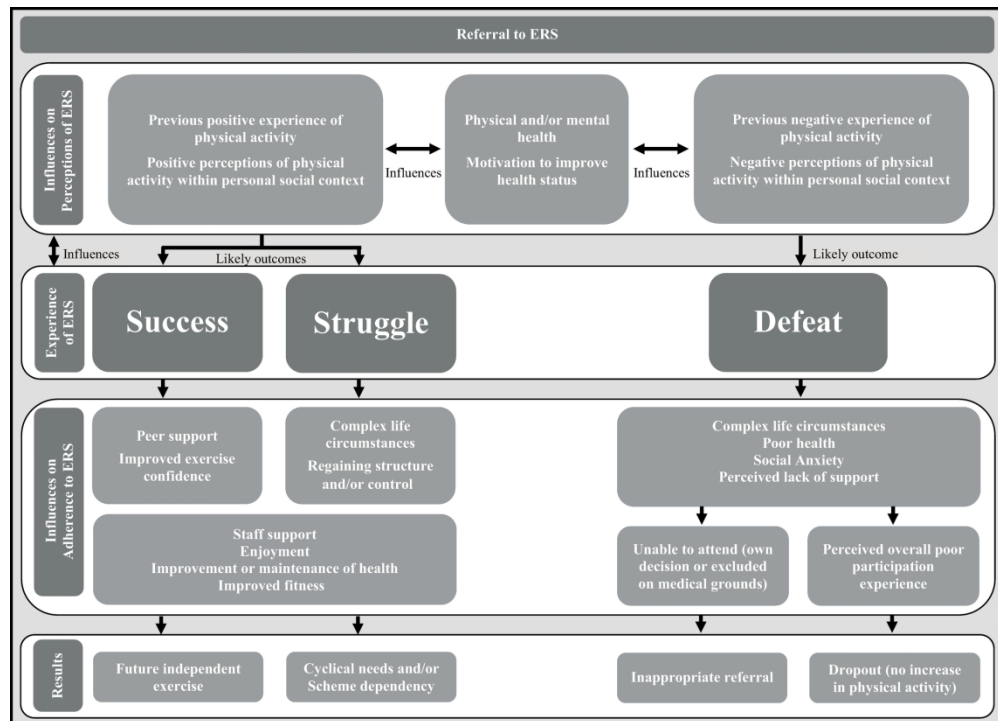


Figure 2: Thematic analysis of ERS experiences

206x148mm (300 x 300 DPI)

Expectations of participants in the Northumberland exercise on referral scheme.

Preface: Set the interviewee at rest; explain the purpose of the interview (to understand their expectations of the exercise on referral scheme) explain that the expected outcomes (that the study will give a better understanding of why the scheme works for some people, but not others); rules of confidentiality etc.

Record demographic / personal info to start:

- Gender
- Age
- Employment status

Question	Prompts
1. Tell me a bit about what sort of physical activity you have taken part in in the past.	<ul style="list-style-type: none"> • <i>What were your experiences of sport/physical activity at school/as a child</i> • <i>What influence have others had on the type of physical activity you have taken part in?</i> • <i>Do you have any particular likes / dislikes of sport/physical activity?</i> • <i>Tell me about any times in past where there has been a big change in your physical activity patterns</i> • <i>Has there been anything else that has influenced your participation in physical activity?</i>
2. How do you feel about taking part in physical activity now?	<ul style="list-style-type: none"> • <i>What type of physical activity (if any) do they take part in at the moment?</i> • <i>What type of physical activity would they like to take part in?</i> • <i>What do they think the important reasons for taking part in physical activity are?</i> • <i>Is there anything that particularly worries them about taking part in physical activity?</i>
3. So thinking about the exercise on referral scheme that you have been referred to, how did you find out about it?	<ul style="list-style-type: none"> • <i>Who/what has motivated you to attend?</i> • <i>What made you decide that this is the right time to take part in the scheme?</i>
4. Why were you referred to the scheme?	<ul style="list-style-type: none"> • <i>What did the referrer explain to you about the scheme?</i> • <i>What do you expect (if anything) when you start attending the scheme?</i>

	<ul style="list-style-type: none">What type of health professional referred you?
5. What do you hope to achieve by taking part in the scheme?	<ul style="list-style-type: none">What are the changes to your health that you expect will happen as a result of participation?How quickly do you expect to see these changes?How have you decided that these changes are realistic?
6. How do you feel about being referred?	<ul style="list-style-type: none">How confident do you feel about taking part in the scheme?What are you particularly looking forward to?What are you worried about?
7. What happened after you were referred?	<ul style="list-style-type: none">How long after referral did it take to be contacted about the scheme?What information has been given to you prior to the initial consultation?How comfortable do you feel coming to first consultation?
8. What are the things do you think will most influence you to attend sessions?	<ul style="list-style-type: none">How important do you think attendance in a group will be?What do you expect from the staff on the scheme?How important are changes in health?Why were the influences raised important?
9. What things do you think are most likely to prevent you from attending sessions?	<ul style="list-style-type: none">Tell me about any worries you might have about health issuesTell me about any other things such as other commitments that might stop you from attendingWhat ways might you overcome these issues if they arise?
10. Is there anything else that you would like to tell me about your expectations for participation in the scheme?	

Semi Structured Interview Questions:

Welcome interviewee back; explain the purpose of the interview (to hear about their experiences of the exercise referral scheme) explain that the expected outcomes (that the study will give a better understanding of why the scheme works for some people but not others); rules of confidentiality etc.

<p>1. First I would like to talk about the consultation that you had before you started the scheme – what you were asked about and what information you were given.</p>	<ul style="list-style-type: none"> • <i>What did the member of staff ask you about?(medical issues related to exercise past and current exercise, feelings about taking part in the scheme)</i> • <i>How did these questions make you feel?</i> • <i>What tests were carried out?</i> • <i>How did you feel about the different tests that you were asked to do (BP, BM, resting heart rate and Chester step test)?</i> • <i>What information were you given? (scheme information, times of sessions etc, results of tests that were carried out, other information about physical activity options outside the scheme, cost of attendance)</i> • <i>Did you agree to attend at the end of the consultation?(if no go on to question 2)</i> • <i>How did you feel about attending the scheme exercise sessions at the end of the consultation?</i> • <i>Was there anything that you were looking forward to?</i> • <i>Was there anything that you were concerned about</i>
<p>2. Why did you decide that the scheme was not right for you?</p>	<ul style="list-style-type: none"> • <i>How did you feel about being referred at the end of the consultation?</i> • <i>Did the consultation encourage you to take part in physical activity even though you did not attend any sessions? If so, in what way?</i> • <i>Have you been back to see the person who referred you to discuss your referral? If so, what did you discuss?</i> • <i>What could the scheme have offered you that would have encouraged you to attend?</i> • <i>Have you changed your levels of physical activity since you were referred? If yes, did the fact that you were referred influence this and in what way</i>
<p>How many scheme exercise sessions have you attended?</p>	

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3. Thinking about how first exercise session, how did you feel about the scheme before you attended this?	<ul style="list-style-type: none">• <i>How comfortable did you feel about coming into the centre to take part in a physical exercise session?</i>• <i>What happened during the first session?</i>• <i>What activities did you take part in?</i>• <i>How did you feel about the activities?</i>• <i>How did you find the other members of the group?</i>• <i>How did you feel after the first session?</i>
4. Are you still attending the scheme sessions? (if no, go to question 6)	<ul style="list-style-type: none">• <i>What are the things that you enjoy about attending the scheme?</i>• <i>How have you found the staff?</i>• <i>Have there been any weeks where you have not attended at all?</i>• <i>If yes, did anyone from the scheme contact you?</i>• <i>If yes, who, how and did it have any effect?</i>• <i>Do you have any suggestions for what the scheme might do differently? (go to Q6)</i>
5. When did you stop attending?	<ul style="list-style-type: none">• <i>Why did you stop attending?</i>• <i>Did anyone from the scheme contact you when you did not attend?</i>• <i>What happened?</i>• <i>How did you find the staff?</i>• <i>How did you find the sessions that you did attend?</i>• <i>What, if any, parts of the scheme did you enjoy?</i>• <i>Do you have any suggestions for what the scheme might do differently?</i>• <i>Compared to before you were referred to the scheme, have you changed the amount of physical activity that you do?</i>• <i>If yes, what do you do that is different?</i>• <i>What made you change your activity?</i>

	<ul style="list-style-type: none"> How important do you think that physical activity is in helping to maintain or improve your health? Has this view changed since you were referred?
6. At the first interview, you told me that you hoped to achieve.... Now you have taken part in the scheme for 12 weeks:	<ul style="list-style-type: none"> What changes to your health have you noticed? Were these changes what you expected? Have other factors outside the scheme had an effect on your health / lifestyle choices? How important are these changes in encouraging you to keep attending?
7. At the first interview, you told me that you are worried about....Now that you have taken part in the scheme for 12 weeks:	<ul style="list-style-type: none"> Were the concerns that you had justified? How were these concerns addressed when you attended? Is there anything that you can suggest that the scheme might do to help other people who feel the same way about attending as you did?
8. Have you increased the amount of activity you do overall?	<ul style="list-style-type: none"> Have you increased the amount of activity you are doing independently of the scheme sessions? If so, what you are doing that is different from before you started? Why have you changed your activity outside the scheme? How important do you think that physical activity is in maintaining or improving your health? Is this different to before you started?
9. What are you most looking forward to in the next 12 weeks of the scheme?	<ul style="list-style-type: none"> Is there anything in particular that you think will encourage you to keep attending? What are you hoping to achieve over the second part of the scheme?

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10. What things do you think are most likely to prevent you from attending sessions?	<ul style="list-style-type: none">• Tell me about any worries you might have about health issues and scheme attendance• Tell me about any other things such as other commitments that might stop you from attending• Have you thought about any ways that you might overcome these issues if they arise?
11. Is there anything else that you would like to tell me about your experience of participation in the scheme and your expectations for the rest of the scheme?	

COREQ GUIDELINES REPORTING CHECKLIST: How do participant experiences and characteristics influence engagement in exercise referral? A qualitative longitudinal study of a scheme in Northumberland, United Kingdom.

No	Item	Guide questions/description	Information	Reported in manuscript (Section, page no)
Domain 1: Research team and reflexivity				
Personal Characteristics				
1	Interviewer/facilitator:	Which author/s conducted the interview or focus group?	CLH	Data collection and analysis, page 9
2	Credentials	What were the researcher's credentials?	CLH PhD student and experienced in working in intervention studied. LJA experienced qualitative researcher	Data collection and analysis, page 9
3	Occupation	What was their occupation at the time of the study?	PhD student and strategic manager in the ERS provider organisation	Data collection and analysis, page 9
4	Gender	Was the researcher male or female?	Female (referred to as her)	Data collection and analysis, page 9
5	Experience and training	What experience or training did the researcher have?	CLH: Qualitative research training and support from experienced researcher (LJA)	Data collection and analysis, page 9
Relationship with participants				
6	Relationship established	Was a relationship established prior to study commencement?	No, participants were approached by ERS staff to explain the study and seek consent.	Sample, page 8
7	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	Participants were informed of researcher's employment status and that the research aimed to improved service delivery	Sample, page 8
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	Acknowledgement of potential bias due to insider knowledge. Interest in service improvement and employment status of interviewer disclosed in study invitation information.	Methodological Considerations, page 21-22 Sample, page 8
Domain 1: Study design				
Theoretical framework				
9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory,</i>	Thematic analysis using the framework approach	Data collection and analysis, page 9

		<i>discourse analysis, ethnography, phenomenology, content analysis</i>		
	Participant selection			
10	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	Initially convenience from a defined group, then purposive	Sample, page 8
11	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>	By telephone by scheme provider	Sample, page 8
12	Sample size	How many participants were in the study?	15 initially but only 11 completed both interviews	Results, page 10
13	Non-participation	How many people refused to participate or dropped out? Reasons?	Of initial invitees 13/25 refused. Of 15 initial participants, 4 dropped out. (no response n=2, too busy n=2)	Sample, page 8 Results, page 10
	Setting			
14	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	Leisure centre where ERS was attended	Data collection and analysis, page 9
15	Presence of non-participants	Was anyone else present besides the participants and researchers?	No, interviews were conducted in private	Data collection and analysis, page 9
16	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	Gender, age group, medical reason for referral, employment status and previous PA Date range for interviews reported	Results, Table 1 Data collection and analysis, page 9
	Data collection			
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Semi-structured interview guide used. Pilot tested. Guides provided as supplementary files	Data collection and analysis, page 9 Supplementary files 1 and 2
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	Yes, one further interview after 12-20 weeks	Data collection and analysis, page 9
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Yes, the interviews were audio recorded	Data collection and analysis, page 9
20	Field notes	Were field notes made during and/or after the interview or focus group?	Yes detailed field notes were made directly after interviews	Data collection and analysis, page 9
21	Duration	What was the duration of the interviews or focus groups?	Range and median length reported: 22-62 minutes (median 48 minutes)	Data collection and analysis, page 9
22	Data saturation	Was data saturation	Recruitment stopped	Sample, page 8

		discussed?	when no new themes overarching were emerging	
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Transcripts were checked by participants.	Data collection and analysis, page 9
Domain 3: analysis and findings				
Data analysis				
24	Number of data coders	How many data coders coded the data?	N=2 (CLH and LJA) independently N=4 in total at data workshops	Data collection and analysis, page 9
25	Description of the coding tree	Did authors provide a description of the coding tree?	Yes figure 2 visually describes the coding tree	Figure 2
26	Derivation of themes	Were themes identified in advance or derived from the data?	Identified from data	Data collection and analysis, page 9-10
27	Software	What software, if applicable, was used to manage the data?	No software used, data analysed manually using an excel spreadsheet	Data collection and analysis, page 9
28	Participant checking	Did participants provide feedback on the findings?	No, but themes were checked with ERS staff at a workshop.	Data collection and analysis, page 10
Reporting				
29	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	Yes, participants identified using a pseudonym	Results, page 10-17
30	Data and findings consistent	Was there consistency between the data presented and the findings?	Themes were illustrated by participant quotations	Results, page 10-17
31	Clarity of major themes	Were major themes clearly presented in the findings?	Three major experience themes were identified: success, struggle and defeat	Results, page 10-17
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Minor themes identified within each major theme: For success: improved health, increased PA, enjoyment and support For struggle: scheme dependency, multiple barriers and cyclical needs For defeat: inappropriate referral, poor participation experience, social anxiety.	Results, page 10-17

			Diverse cases discussed within themes	
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For peer review only