A Toolkit for the Design, Implementation & Evaluation of Exercise Referral Schemes

Section 3: Exercise Referral Research

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The aim of this toolkit is to provide an easy-to-read, practical guide for all those professionals involved in the delivery, coordination, commissioning and evaluation of exercise referral schemes. These professionals include general practitioners, practice nurses, community nurses, allied health professionals (physiotherapists, dieticians etc), exercise professionals, health promotion/public health specialists, commissioners and researchers.

The toolkit has been developed in consultation and collaboration with a range of professionals involved with exercise referral schemes and key national stakeholders.

It draws upon current Government policy for the design and delivery of quality assured exercise referral schemes; it is NOT a replacement for such national policy. Furthermore it should NOT be used in isolation from the National Quality Assurance Framework for exercise referral schemes (NQAF).

It is a tool to aid the design, delivery and evaluation of exercise referral schemes, but is NOT POLICY. It uses the evidence base and local scheme practice to support schemes in meeting the guidelines set out within the National Quality Assurance Framework and to raise standards within schemes.
Using the toolkit

It is recognised that capacity, resources and funding vary across schemes and that some schemes are struggling to implement elements of the National Quality Assurance Framework and consequently may struggle to adopt some of the recommendations set out within the toolkit.

The toolkit is not designed as a ‘blueprint’ for how exercise referral schemes must be designed, implemented and evaluated; it offers some best practice principles for all those involved in the delivery, management and commissioning of exercise referral schemes. It is for individual schemes to consider whether the implementation of these principles will improve the design, delivery and effectiveness of their scheme, given the capacity and resources available.

Many schemes may already be meeting the recommendations outlined within the toolkit, in which case the toolkit can be used as a resource for professionals to take a fresh look at their scheme or as a guide for on-going reflection.

Some local health boards and primary care trusts may have developed an integrated system for the promotion of physical activity, which offers a range of physical activity opportunities for the local population, such as led-walks, green-exercise, exercise referral schemes and/or specialist condition specific whole exercise classes. This toolkit is predominantly concerned with exercise referral schemes designed for low to medium risk patients which involve the transfer of medical information from a healthcare practitioner to an appropriately qualified level 3, exercise professional.

Whilst it is recommended that, where appropriate, primary care professionals should advise patients to increase their physical activity it should be noted that recommending or sign-posting patients to local physical activity opportunities such as lay-led walking schemes is quite distinct from referring an individual to a dedicated service and transferring relevant medical information about this individual to this service.

Where schemes offer specialist condition specific whole exercise classes for patients/clients with any conditions covered by the level 4 national occupations standards these schemes should ensure they comply with the relevant governance arrangements and quality assurance guidelines.
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Executive Summary

The review of exercise referral research identified some key implications for practice, where appropriate, these have been used to develop some of the good practice guidelines and recommendations within the toolkit.

Research has shown that good quality evaluation is one of the key challenges for many existing exercise referral schemes and consistently highlighted that there should be more systematic gathering of quality data across exercise referral schemes using valid, reliable and comparable measures.

The evidence recommends that exercise referral schemes should offer a wider range of physical activity opportunities to meet the needs and preferences of different population sub-groups.
Section 3: Exercise Referral Research

The purpose of this section is to not to present a critique of the exercise referral research, rather it aims to extract information from key studies with a view to guiding and improving future service delivery.

3.1. Introduction

The benefits of a physically active lifestyle for health promotion and disease prevention are well documented. The Chief Medical Officer’s Report: ‘At least five a week’ stated that:

“Adults who are physically active have a 20-30% reduced risk of premature death and up to 50% reduced risk of developing the major chronic diseases such as coronary heart disease, stroke, diabetes and cancers.”


There is increasing recognition, both globally and in the UK, of the need to promote healthier lifestyles and improve physical activity levels in order to reduce premature mortality and morbidity from chronic diseases. The World Health Report (2002) estimated that 3% of all disease burden in developed countries was caused by physical inactivity. In the UK, there is a considerable public health burden due to physical inactivity, in 2003-2004 researchers found that physical inactivity was responsible for 3.1% morbidity and mortality.

Lord Darzi highlighted that the growth in the prevalence of many long-term conditions such as coronary heart disease, diabetes, hypertension, depression and chronic obstructive pulmonary disease, can be attributed not only to unhealthy lifestyle choices, but also to missed prevention opportunities. Many long-term conditions are commonly diagnosed, treated and monitored in primary care; however Darzi found that 54% of patients said that their GP had not provided advice on diet and exercise.

Primary care is recognised as a potentially important setting for the promotion of physical activity. Primary healthcare professionals come into frequent contact with the general public, about 85% of the population visit their GP surgery on an annual basis. Every consultation provides an opportunity to promote behaviour change or to refer patients to relevant support services.

In the UK exercise referral schemes are one of the most popular interventions used by primary care practitioners to encourage sedentary individuals and individuals with long-term medical conditions, such as diabetes, hypertension, asthma, arthritis, obesity etc. to become more physically active. The first exercise referral scheme was set up in the late 1980’s and over the past two decades there has been a significant and sustained growth in the number of exercise referral schemes operating across the United Kingdom.

Further Cochrane review level evidence on the therapeutic benefits of exercise with respect to several major chronic diseases can be found in section 4.2 of this toolkit.
3.2. Research Evidence

To date, most research surrounding exercise referral schemes has predominantly focused on assessing the effectiveness of schemes in increasing physical activity levels, with little attention being paid to the scheme characteristics and how these relate to access, uptake and adherence. The purpose of this section is to not to present a critique of the exercise referral research, rather it aims to extract information from key studies with a view to guiding and improving future service delivery.

The research design adopted in the included exercise referral studies can be grouped into three broad areas: controlled and randomised controlled trials; uncontrolled longitudinal cohort studies and qualitative research. Most of the evidence from the controlled and uncontrolled studies has been presented in systematic reviews. This section will consider the evidence from these collective studies and highlight considerations for practice.

3.2.1. Review Evidence

The first national review of exercise referral schemes was commissioned by the former Health Education Authority in 1994. The authors, Biddle, Fox and Edmunds found that exercise referral schemes were becoming increasingly widespread across England, with 121 schemes operating at the time of the review and a further 52 schemes planned. Biddle and colleagues identified two distinct types of scheme: first, practice-managed schemes where members of the primary care team retained responsibility for their patients’ physical activity programme and second, leisure-centre managed schemes where members of the primary care team passed on the responsibility for physical activity promotion to a local leisure facility by referring suitable patients. In their review Biddle and colleagues found that this latter type of scheme was the most common.

While the review identified the number and location of schemes, the authors acknowledged that it was much more difficult to estimate the number of patients either currently or previously engaged in these schemes. In spite of the limited of evidence on patient numbers, Biddle and colleagues presented a brief profile of the types of patients being referred to schemes: typically more women were involved in schemes than men; participants were predominantly middle-aged with relatively low CHD risk. The authors concluded that very few schemes had clear criteria for targeting patients and on the whole the selection of patients seemed ad hoc.

Biddle and colleagues also reported that the expertise and training of key personnel involved in schemes was variable, however they suggested the success of a scheme often depended on the qualities of the personnel in contact with patients. The authors highlighted that there was a need for appropriate training in health promotion techniques and counselling for exercise for key personnel in contact with patients. Finally, the national review found evidence that schemes were successful in that they were popular with patients, primary healthcare professionals and leisure facilities. However, the authors concluded that due to the absence of any rigorous evaluation it was difficult to assess whether schemes are effective in achieving sustained increases in physical activity.
Post the HEA review exercise referral scheme numbers continued to grow and with them emerged a number of published and unpublished, evaluations of individual schemes. Moreover, evaluations of some larger funded exercise referral studies and effectiveness trails started to appear in the research literature.

In 1998, Riddoch and colleagues undertook a review of the effectiveness of physical activity promotion schemes in primary care. The study involved a systematic review of the empirical data relating to the effectiveness of schemes and analysis of three case studies of existing schemes. Twenty-five UK empirical studies were identified and twelve of these met the inclusion criteria. These studies included a variety of outcome measures and assessment methods; and both physical activity and follow-up periods varied making it difficult to quantify results. The results were encouraging, in that the majority of studies reported small improvements in physical activity and other activity-related measures. Eight studies from outside the UK were also reviewed for comparative purposes, again small effects were observed. The adherence data was disappointing across nearly all studies,

Riddoch and colleagues also reviewed ‘grey literature’ from 45 existing schemes. Most of these schemes (93%) reported undertaking some form of ‘in-house’ evaluation, however the authors concluded that the evaluation design was consistently flawed and many schemes were selective in reporting positive findings. The data from these schemes suggested a much greater level of effect compared to the published studies.

As mentioned above, the authors included three cases studies in their review in order to assess the wider perceived effectiveness of the schemes and the overall level of impact for the key stakeholders, e.g. doctors, nurses, scheme organisers, leisure centre staff. Data collection lasted several days and included a range of methods, semi-structured interviews, informal discussions, observations and document searches. All three schemes were perceived as very successful and were perceived to have a positive impact on a range of parameters and a variety of people involved in such schemes. The main effects on patients were perceived to be social-psychological in nature. For patients who were initially anxious about exercise, the individually tailored exercise prescriptions and close supervision were seen as important factors. Riddoch and colleagues concluded that the case studies revealed that exercise referral schemes had other benefits, which the controlled trials of effectiveness had so far missed.

The two-stage review provided a valuable summary of the evidence on physical activity promotion schemes in primary care, taken together the evidence was generally positive. The experimental data suggested small, positive effects and the case studies suggested wider-ranging and more significant effects. However the authors highlighted a number of limitations with the existing research in this field: Very few UK studies of acceptable quality were available to form the basis of a systematic review; most studies had been conducted overseas thus their applicability to the UK context is uncertain. A wide range of outcome measures of physical activity had been used, resulting in contradictory findings in some cases. With regards to the research on existing GP exercise referral schemes in the UK, most evaluations had been conducted internally by scheme coordinators or providers with limited resources for robust evaluation, which tends to bias findings.
Riddoch and colleagues concluded that:

“Primary-care based exercise referral programmes, often involving referral of a patient by a General Practitioner to a local leisure facility, are not necessarily effective in increasing long-term physical activity.”

p.12, Riddoch et al., (1998)

Finally, Riddoch and colleagues highlighted a number of important considerations for exercise referral schemes in the UK, suggesting that:

- The design, delivery and evaluation of schemes should be theoretically based and they should use evidence-based strategies that are known to be successful.
- Closer working relationships between health and leisure need to be established and maintained.
- Both primary care and exercise referral staff should be trained in relevant theory-led behaviour change techniques.
- Appropriate criteria for referral should be developed, to take account of health status, activity status and readiness to change.
- Exercise referral instructors should undertake appropriate training, this is vital to the success and safety of the scheme.
- Schemes should offer a range of non-facility based exercise options, such as home-based and community based activity options which may promote longer-term adherence.
- Local exercise referral networks should be established to offer support and opportunities for interaction during and beyond the referral programme.
- Schemes should carefully select outcome measures and evaluation methodology to ensure data gathering is cost-effective and not too onerous.
- There should be more systematic gathering of quality data across the many schemes, using valid and comparable measures.

A further review of the evidence for the effectiveness of exercise referral schemes was conducted by Morgan. Morgan identified nine studies, based in a primary care setting which included interventions providing access to exercise activities and/or facilities. Four studies were from the UK, four from the USA and one from New Zealand. The UK studies evaluated interventions similar to those currently found in primary care, whereas the non-UK studies evaluated interventions which would be difficult to replicate in UK healthcare settings.

Consistent with the previous review, the author reported that both the UK and non-UK data suggested small effects on physical activity outcomes, however effects due to the initial intervention were reduced over time. Similar to Riddoch and colleagues, Morgan reported that the measurement of physical activity varied considerably between studies. Morgan highlighted that most studies had used self-report measures of physical activity and suggested that the contaminant bias associated with self-reported physical activity was one of the greatest weaknesses of the studies.

Morgan highlighted that the uptake of the exercise interventions were generally low in the UK studies, ranging from 33% – 87%. The recruitment in most of the non-UK studies was via media advertising or telephone surveys, which may have resulted in the recruitment of a highly select group of volunteers. The author reported that adherence to the exercise intervention appeared to be higher in participants who were slightly active at baseline, older and overweight.
Morgan concluded that:

“Exercise referral schemes appear to increase physical activity levels in certain populations, although the effect may wear off over time.”

p.369, Morgan (2005)

In 2005, the continued prominence of exercise referral schemes in policy and practice coupled with the uncertainty about their effectiveness led the Department of Health to commission the National Institute of Health and Clinical Excellence to review the evidence of the effectiveness for exercise referral schemes.

The NICE exercise referral review examined the evidence for the effectiveness of exercise referral schemes in increasing physical activity levels amongst adults. Studies were included in the review if they assessed the effect of an exercise referral scheme to increase physical activity in the adult population using a controlled research design and measured physical activity or physical fitness outcomes at baseline and from 6 weeks post intervention. Four randomised controlled trials satisfied the inclusion criteria. Three of the studies took place in the UK and the other took place in Australia.

The effectiveness of the interventions was examined over three timescales:

- The short term (6-12 weeks)
- The long term (over 12 weeks)
- Over the very long term (e.g. over 1 year)

Two of the trials examined the short-term effects of an exercise referral scheme on physical activity levels and both found a positive effect. Four studies assessed the effect of an exercise referral scheme on physical activity levels in the long term; overall the evidence indicated that exercise referral schemes were ineffective in increasing physical activity levels in the long term. Three trials examined the effects of an exercise referral scheme on physical activity levels over the very long term; two studies found no effect and the other study reported a positive effect.

NICE concluded that exercise referral schemes can have short-term positive effects on physical activity levels, but they are ineffective in increasing activity levels in the long term and over the very long term.

The two studies which had a positive short-term effect on physical activity were scrutinised in a bid to identify any aspects of these interventions that could be used to inform practice. The participants in both studies were recruited from GP practice lists; all received physical activity advice, written information and were referred for an individual consultation before commencing the scheme.

The study by Halbert showed short-term, long-term and very long term effects while the study by Taylor showed only short–term effects, based on this distinction it appeared that:

- Written information which included a personal physical activity plan and strategies to overcome barriers was more effective in increasing physical activity levels, particularly over the long and very long-term, than generic CHD prevention written information.
• Longer-term increases in physical activity were more likely to occur if the duration of the exercise referral programme was not limited by time.
• Individual advice from an exercise physiologist based in primary care had a longer-term effect on physical activity levels than an introductory assessment delivery by an exercise referral officer in a local leisure centre.

The feasibility of implementing a scheme similar to Halbert and colleagues\textsuperscript{16} is limited in the UK, as there are few if any, exercise physiologists based in primary care settings. Taylor and colleagues\textsuperscript{15} specifically targeted adults with CHD risk factors or on CHD risk registers within the general practice, given the move towards cardiovascular risk screening for adults over 40 years old, it would be viable to implement an exercise referral scheme which specifically targets particular ‘at risk’ groups.

Many of the previous reviews on exercise referral schemes have been commissioned in order to assess the effectiveness of schemes in improving physical activity behaviour. However, the lack of rigour in evaluations of exercise referral schemes has resulted in many studies failing to meet the strict inclusion criteria of systematic reviews, which often preclude studies that deviate from the randomised controlled trial (RCT) model.\textsuperscript{11,19} Although a certain level of rigour and methodological coherence is necessary to obtain meaningful results,\textsuperscript{19} it is important to recognise that exercise referral schemes and other physical activity promotion strategies should be guided by research that includes, but is not restricted to controlled trials.\textsuperscript{20} In order to understand an exercise referral scheme in its entirety it is argued that the research has to embrace and recognise the intervention complexity, rather than attempt to control the environment and strip away the layers, as an RCT would.\textsuperscript{21} James and colleagues\textsuperscript{22} suggested that exercise referral scheme effectiveness is likely to be influenced by the characteristics of the individual who gets referred and whether the exercise referral intervention is appropriate for them.

A systematic review by Gidlow and colleagues\textsuperscript{23} aimed to compare evaluations of existing schemes with randomised controlled trials in order to explore the characteristics of patients who attend exercise referral schemes in the UK and to identify why participants drop out of schemes. The review focused on attendance as the main outcome variable rather than changes in physical activity or other related variables. Given that most exercise referral schemes attempt to monitor attendance the authors felt their decision to focus on attendance as the outcome variable was justifiable. Studies were included in the review if they were investigating exercise referral interventions that were based in primary care in the UK, reported attendance related outcomes and were published in peer reviewed journals. Five evaluations of existing schemes and four randomised controlled trials satisfied the inclusion criteria.

The authors found that there were no marked differences in the design of the exercise interventions in the trials or existing schemes; they followed the typical model of delivery: the patient is referred by the healthcare professional for an initial assessment or consultation with an exercise professional. Where frequency was specified, patients were encouraged to attend two or three sessions per week for either 10, 12 or 14 weeks. One RCT lasted for two years, although only reported 10 month outcomes. All interventions were facility-based; however one evaluation study and one RCT reported the inclusion of home-based activities. Exercise sessions were either free of charge or offered at concessionary rates.
In the four evaluations patients were recruited through referral by GPs during routine consultations, the other evaluation used voluntary health screening visits at GP practices. One evaluation employed additional recruitment methods which included community screening and patient self-selection. In contrast patients in 3 RCTs were identified from practice registers and recruited by researchers, the other RCT approached patients during routine consultations and subsequent postal recruitment. Gidlow and colleagues suggested the differences between recruitment methods could have implications on exercise referral scheme uptake and attendance which must be considered. Patients are unlikely to respond to researcher and GPs in the same way. Some patients hold GPs in esteem and therefore may be more likely to act upon a referral. However, Graham and colleagues have reported some health professionals perceive barriers to referral and therefore may be more reluctant to promote schemes whereas researchers have a vested interest in recruiting study participants.

The authors suggested that the characteristics of scheme participants were generally not well reported and were limited to age and gender. In both evaluations and trials it appeared that men were harder to recruit, with women accounting for 60% of participants in two evaluations and 3 trials. Participants were mostly middle-aged and older, in RCTs this was the result of the inclusion criteria. Two RCTs performed baseline surveys to identify inactive patients and one targeted patients with modifiable CHD risk factors. Gidlow and colleagues found that no existing scheme evaluations reported specific patient targeting. Few studies provided details of the medical conditions for which patients were referred.

The authors commented that due to the retrospective nature of the evaluations it was unknown how many patients may have declined an offer of referral by their GP. Response rates to invitations were only available for the trials, these ranged from 15-70%, Gidlow and colleagues suggested these figures might provide insight into the proportion of people, if offered might accept a referral opportunity.

In practice referral is the entry point to exercise referral and according to Stevens and colleagues the most important component in terms of the financial viability of schemes, therefore it has several practical implications. Gidlow recommended that more thorough patient profiling is necessary at the point of referral; there is a need to better understand characteristics of those who decline the offer of a referral and why this might be so.

Following the referral by the health professional, the next step in an exercise referral scheme is ‘uptake’ of the referral. The authors found that referral uptake varied widely in both trials and existing evaluations. Gidlow and colleagues reported that differences in the way existing evaluations and RCTs defined referral uptake affected the levels recorded: referral uptake ranged from 23% to 60%. Scheme attendance levels in the evaluations were generally poor: three evaluations reported that between 12-18% of patients attended their final assessment. One trial reported 28% of patients attended based on the number who completed 75% of the exercise sessions, another reported similar attendance levels at the final assessment (25%). Attendance levels were most encouraging in the evaluation reported by Hammond and colleagues they reported improvements in attendance from 20 to 56% over a one-year period following several changes to their scheme. Given the relative ease with which attendance can be measured, Gidlow remarked that it was disappointing that only one trial and one evaluation study, in their review, used leisure centre records to objectively monitor the
number of sessions attended by scheme participants. The authors suggested that more systematic attendance monitoring is needed.

Characteristics of the patients who took up the referral or attended were even less well reported than for baseline, however based on the data available Gidlow and colleagues found that there appeared to be better uptake in women, but subsequent attendance was better in men. The fact that men are more likely to attend despite lower referral rates highlighted the importance of targeting men.

Gidlow and colleagues were critical about the content and quality of information available on attendees. They suggested there is a need for more detailed patient monitoring at the point of referral and at each stage of the scheme to determine the profile of who drops out; this should enable modifications to the scheme to reduce attrition. The authors also argued that schemes must recognise the importance of routinely collecting accurate and adequate data to enable quality evaluations. Relying on retrospective evaluations is not satisfactory and processes should be implemented at the design stage so that they are not necessary.

The majority of schemes still remain facility based, however the reasons patients cited for dropping out of the scheme highlight the need for schemes to diversify away from the facility based model, at least in part this may overcome several potential barriers such as transport, not wanting to attend alone, cost of attendance, disliking the gym environment and inconvenient session times.

Attrition from exercise referral schemes is reportedly very high, 80% of patients who take up a referral drop-out before the programme ends, which suggests that many patients may be inappropriately referred. The authors concluded that schemes are obliged to determine which members of the population are attending and why others miss out or are put off attending schemes, they suggest there is a need for more patient targeting in order that exercise referral schemes are effective for more than just a minority of the population.

The most recent systematic review by Williams, Hendry, France and colleagues aimed to assess whether exercise referral schemes are effective in improving exercise participation in sedentary adults, particularly in the long-term and to find reasons for non-adherence.

The review included a range of studies controlled trials (randomised or not), observational studies, process evaluations and qualitative studies. Study participants had to be adults, referred to an exercise referral schemes from primary care. The authors defined an exercise referral schemes as:

“Referral by a primary care clinician to a programme that encouraged increased physical activity or exercise, involving an initial assessment and a programme tailored to individual needs, as well as monitoring and supervision throughout the programme. Eligible participants could be recruited during routine consultations or after searching the primary care medical record database. The programme usually took place in a leisure centre, swimming pool or private gym, but could also involve gardening or walking.”

p.980, Williams (2007)
Eighteen studies met the inclusion criteria: these consisted of six randomised controlled trials (2 of which included a qualitative component); one non-randomised controlled trial; four observational studies; six process evaluations (2 of these included a qualitative component) and one qualitative study.

Three of the randomised controlled trials compared a gym-based exercise referral scheme with an intervention sheet; one compared community based exercise classes against no intervention, another compared walking with exercise advice and the other compared a gym-based scheme with a walking scheme and no advice. The non-randomised trial compared a walking programme for patients with type 2 diabetes with no programme. Patients in 4 RCTs were identified from practice registers and recruited by researchers, in the other 2 trials patients were recruited during routine consultations. The duration of the exercise intervention lasted between 12-16 weeks in 4 of the 6 RCTs and the controlled study. In one trial the intervention lasted for 2 years and in the other there appeared to be no time limit. Referral uptake varied 26-92% attended the initial exercise session and less than half completed the full intervention.

Five of the RCTs measured the proportion of individuals who were moderately active, defined as taking at least 90-150 minutes of moderate intensity exercise per week. Results of these trials were combined in a meta-analysis. There was a statistically significant, but small effect in the numbers of patients doing moderate intensity exercise with a combined relative risk of 1.20. This small effect was likely at least in part, a result of the poor uptake and adherence rates to the exercise intervention. Williams and colleagues calculated that 17 sedentary adults would need to be referred to a scheme for one to become moderately active.

Three of the RCTs and the non-randomised controlled study assessed a range of anthropometric, physiological and biochemical outcomes. The authors found that there were no statistically significant differences between the exercise groups and controls, the authors noted that:

“Any improvement in these outcomes in the exercise group, particularly in the subgroup which reached the exercise target, was mirrored by similar improvement in the control group.”

p.982, Williams (2007)

One other RCT measured skinfold thickness and found a statistically significant reduction (8%) in the exercise group compared to the control at 16 weeks.

Four trials measured a variety of psychological outcomes (stages of change, perceived intrinsic and extrinsic barriers to exercise) and used a range of assessment methods (Hospital Anxiety and Depression Scale, SF36), follow-up periods also varied, thus making it difficult to quantify results.

Williams and colleagues\(^27\) reviewed the evidence from one US and three UK observational studies, which provided data on the long-term effects of exercise referral schemes on physical activity levels. They reported that study qualities were moderate to poor. Results of the studies varied:

- One survey found no difference in activity levels of scheme adherers and non-adherers at 6 month intervals up to 3 years after completion.
One survey reported that two-thirds of respondents were more active than before the referral, 3-5 years later, however it wasn’t established whether this was a consequence of the scheme.

The US cohort study found that 33% of females referred to an exercise scheme were still attending after 1 year.

The other study found that 63% of frail older adults made the transition to a leisure centre-based exercise programme following a tailored exercise scheme.

It should be noted that these studies used self-report measures to assess physical activity which is a major weakness due to bias associated with self-reported physical activity.

The authors identified six process evaluations which provided data on typical exercise referral schemes. Consistent with previous reviews, the authors reported that uptake was low with around a third of referred patients not participating in schemes. Adherence to schemes was also poor with between 12-42% completing a 10-12 week programme; however sustained increases in physical activity levels were observed in those patients who completed the exercise programme. Studies reported improvements in aerobic fitness and stages of behaviour change and reductions in BP, resting heart rate, weight, BMI, anxiety and depression. Positive lifestyle changes were also reported. However it is interesting to note, that data from these process evaluations suggested a much greater level of effect compared to the controlled studies.

Williams and colleagues included one qualitative study in their review and examined the qualitative component of four of the previously reported studies. These studies used mixed methods: two used semi-structured interviews, two used focus groups and the other did not report study design. The review found that patient’s satisfaction with schemes was largely attributed to the professional, supportive, encouraging and friendly service provided by staff. Participants reported that they had derived physical, social and psychological benefits as a result of attending the schemes. The qualitative studies also identified barriers to participation. Williams and colleagues grouped these as personal barriers: such as lack of self-efficacy, poor body image, poor time management and lack of social support and scheme barriers: such as intimidating gym environment, inadequate supervision, poor organisation of the scheme, inconvenient operating hours and narrow range of activities.

Williams and colleagues concluded that their review was broadly in agreement with the NICE public health intervention guidance, exercise referral schemes have a small short-term effect on increasing physical activity in sedentary people, but it is not certain whether this small benefit is an efficient use of resources.

3.2.2. Longitudinal Cohort Studies

**Scheme reach:**

The systematic review undertaken by Gidlow and colleagues highlighted that there were several gaps in the evidence regarding which members of the population engage in exercise referral schemes. Several longitudinal cohort studies have attempted to examine data on scheme reach, i.e. who refers into schemes; which patients get referred; reasons for referral and who participates. It is necessary to consider the wider population impact of exercise referral schemes to determine whether schemes are reaching sedentary populations and whether schemes offer equitable access.
Five published studies\textsuperscript{21,22,28-30} were identified, which provided detailed information on the characteristics of patients accessing five existing exercise referral schemes in England. The scope and scale of the schemes varied from district-wide to county-wide and schemes were based in both urban and rural locations and in areas of social deprivation.

These studies reported data on patients who had been referred into schemes over a 2 to 5 year period. Uptake rates ranged from 65-79\% which is consistent with previous research.\textsuperscript{23} Data showed that a consistently higher number of females were referred into schemes than men (59-65\% vs 35-41\%). Referrals were most prevalent in the 40-70 year age category, accounting for approximately 60-70\% of all referrals and of all referred patients the average age was 51 years. Studies also found that younger patients were least likely to take up the referral opportunity. Data on the ethnic background of referred clients was not reported in any of the studies. Three studies\textsuperscript{28-30} examined the influence of socioeconomic deprivation on referral uptake: two studies\textsuperscript{29,30} found that patient deprivation status had no influence on the likelihood of attending the first exercise referral appointment. In contrast the other study\textsuperscript{28} reported that patients from more deprived areas were less likely to take up a referral. Sowden and colleagues\textsuperscript{30} also found that general practices in more deprived areas are more likely to refer patients, perhaps illustrating that exercise referral schemes do not follow the ‘inverse care law’, which has been reported for other preventive health care services.

Four studies\textsuperscript{21,22,29,30} reported data on the reasons for referral. Harrison and colleagues\textsuperscript{29} found that the two most common reasons for referral, in addition to sedentary behaviour, were musculoskeletal (32.8\%) and cardiovascular risk factors (29.9\%). Dugdill and colleagues\textsuperscript{21} reported data from two schemes: being overweight was the most popular reason for referral, followed by hypertension and mental ill-health in one scheme and having arthritis, low back pain and being overweight were the most common reasons for referral in the other scheme. James and colleagues\textsuperscript{22}, found that the most common reasons for referral were overweight or obesity (30.3\%), followed by musculoskeletal reasons (26.3\%) and cardiovascular disease (16\%). Harrison\textsuperscript{29} and James\textsuperscript{22} also examined whether the primary reason for referral was related to the likelihood of attending the first exercise referral appointment. Harrison and colleagues found that the reason for referral had some impact on the likelihood of attending the first appointment, patients referred for a specific reason were more likely to attend the first appointment compared with a referral with ‘no reason’ (other than sedentary behaviour), they found that those referred for mental health or fitness were most likely to attend. James and colleagues also found that the primary reason for referral was associated with referral uptake: patients referred for weight reasons; musculoskeletal health; mental health conditions and for ‘other’ reasons were less likely to take up a referral opportunity than patients with a referral for a cardiovascular condition. The inconsistent findings regarding the likelihood of patients with mental health problems attending the initial appointment needs further consideration, especially given that mental health conditions, such as stress, anxiety and depression account for some of the most commonly included conditions across existing schemes. Sowden and colleagues also reported data on relative likelihood of uptake by referral condition; they found that patients referred for musculoskeletal/neurological reasons were more likely to take up a referral than those who were referred for other reasons.\textsuperscript{30}

\textsuperscript{1} Data on the ethnic background of referred client is available in Sowden’s PhD thesis (2008) University of London.\textsuperscript{38}
Previous literature has reported the proportion of patients attending and completing referrals is low: one systematic review\textsuperscript{23} reported completion rates of between 12-56%; another\textsuperscript{27} reported completion rates of between of 12-42%. To date, there has been inadequate participant profiling of those patients who attend and complete schemes.

Four of the previous longitudinal cohort studies\textsuperscript{21,22,28,30} have attempted to profile those patients who complete schemes based on age, gender, socioeconomic status, reason for referral and referring practitioner. Consistent with previous literature\textsuperscript{15} these studies show that of those patients who took up the offer to join the scheme, between 31-46% completed the full referral programme. All of these studies observed that women were consistently more likely to be referred to a scheme than men and more likely to take up the referral than men. Three of these studies\textsuperscript{21,22,28} found the odds of completion were lower in women than men, again these observations concur with results of previous reviews.\textsuperscript{23}

Dugdill and colleagues\textsuperscript{21} reported that a larger number of patients in the older age categories (61-70; 71+) compared to younger category (18-30) completed the scheme, 23%, 42%, 48% respectively. Gidlow and colleagues\textsuperscript{28} reported similar results, of those who took up the referral the odds of completion increased with age; there was a 3-fold difference between the youngest (under thirty) and oldest age groups (over sixty). James\textsuperscript{22} and Sowden\textsuperscript{30} also found that increasing age was positively associated with scheme completion.

Two studies\textsuperscript{28,30} examined the influence of socioeconomic deprivation on the likelihood of programme completion. Gidlow and colleagues\textsuperscript{28} found that patients from more deprived and rural areas were more likely to remove themselves from the scheme at the earliest opportunity. However, Sowden and colleagues\textsuperscript{30} found that once given access to a scheme, patients living in areas of social deprivation were as likely as those from more socio-economically advantaged to take up and complete the scheme. Sowden and colleagues concluded that the results of their study suggest that concerns that leisure centre-based schemes are unlikely to recruit people from groups that are classified as deprived and that such people are unlikely to adhere to exercise programmes, may be unfounded. Gidlow and colleagues\textsuperscript{28} warned that exercise referral schemes may not be the solution to redressing inequalities; however the authors went on to suggest that this does not mean they should be dismissed completely.

Three of these longitudinal cohort studies\textsuperscript{21,22,30} examined whether there was a relationship between the reason for the referral and the likelihood of a patient completing the referral period. One study\textsuperscript{22} found no association whereas two studies\textsuperscript{21,30} found an association. Dugdill and colleagues found markedly higher adherence rates in those patients who were referred for established heart disease (61% adherence) compared to those referred for mental health problems (33% adherence). Sowden and colleagues found that patients referred for primary or secondary prevention of cardiovascular disease were more likely to complete the referral programme and patients referred for diabetes were less likely to complete the programme.\textsuperscript{30}

The evidence presented here on the characteristics of patients who take-up and complete an exercise referral scheme is limited as it relates only to a small number of studies, however it does support findings of previous reviews.\textsuperscript{23,27} It shows some
consistent age and gender patterns in exercise referral uptake and scheme completion, consequently there are a number of practical considerations that can be drawn for these studies.

The evidence that women are more likely to take up the opportunity to participate in an exercise referral scheme, but are less likely to complete the referral than men suggests there is a need for schemes to:

1. Adopt a more proactive strategy to engage men, the introduction of cardiovascular risk screening and NHS mid-life check may offer timely opportunities to make the case for this with primary care partners.
2. Offer a diverse range of activity opportunities that appeal to women and where possible introduce strategies to reduce drop-out (e.g. crèche, transport, opportunities to exercise with friends).

Exercise referral schemes seem to be much more appealing and effective with some segments of the population than others namely middle-aged patients (40-69 years).

Finally, Harrison and colleagues\textsuperscript{29} highlighted that few patients were referred relative to the percentage of the sedentary population residing in the scheme catchment area; they suggested that maybe exercise referral schemes should be reserved for those patients with medical conditions which require a safe and strictly supervised exercise environment.

**The nature of inappropriate referrals:**
While the above studies shed light on the characteristics of those patients who fail to attend the first consultation, they offer little explanation of why this might be the case. Johnston and colleagues\textsuperscript{31} highlighted that few studies have investigated the nature of inappropriate referrals to schemes or investigated why some patients are removed by the exercise professional at the initial appointment or why some patients choose to remove themselves from a scheme despite having agreed to a referral with their health professional. The next case study\textsuperscript{31} looks at this issue in more detail, however it must be borne in mind this is one study and further research is required is before any definitive conclusions can be made.

Following a scheme audit in 1998 Somerset physical activity advisory group introduced a Centralised Referral Mechanism (CRM) as way to address the problem of inappropriate referrals. The CRM system which involves an intermediary person (an accredited exercise scientist) between the referring health professional, the referred patient and the leisure provider, it adds an extra level of quality assurance to ensure unsuitable patients are removed from the scheme at the earliest opportunity. The CRM database records all referrals which are made regardless of the whether patients attend the initial appointment or not.

A review of the database between May 2000 and October 2002 found that 16% of patients were removed by the exercise scientist following the healthcare professional's referral as they were deemed inappropriate (207 males; 251 females). Further analysis of the CRM database revealed that 29% of these patients were removed for medical reasons (18% of these due to cardiac conditions). When this data was considered in relation to the original reason for referral it showed that the only medical conditions which were significantly more likely to be removed were established cardiac conditions. It is interesting to note that these patients were referred contrary to the guidelines issued to practitioners.
Forty-five percent of all inappropriate referrals were removed from the scheme because they were classified as not ready for exercise, sixteen percent were removed because they deemed themselves to be already active and the remaining nine percent cited a range of psychosocial reasons which prevented them from taking part (i.e. family ties, preference for alternative activities than a leisure centre, too young, too old, no transport). These inappropriate reasons for referral were classified as psychosocial reasons.

Johnston and colleagues reported that of all the inappropriate referrals significantly more patients were removed for psychosocial reasons (71%) compared to medical reasons (29%). Significantly more women were removed for psychosocial reasons than men (59% vs 41%) and although not statistically significant more men (56%) were represented in the medical condition group. The authors suggested there is a need to distinguish between those individuals who have no choice about being removed and those who essentially made some level of personal choice not to take part.

These observations show that of those patients removed from the scheme between the point of referral and the initial appointment, 5% were removed due to medical reasons. Within this group a high proportion were removed due to contraindications relating to heart disease such as unstable angina and unstable blood pressure, this was despite detailed referral guidelines with a list of contraindications being sent to all practice managers. Johnston and colleagues suggested it may be the case that the referral guidelines are not being disseminated effectively within practices or that referring health professionals require further training in this respect. It may be necessary to provide referring health professionals with access to appropriate risk stratification tools.

Referral guidelines predominantly include details of medical contraindications which are used to assess patient suitability for a scheme; the results of this study suggest that it might also be helpful if guidelines included guidance on assessment of patients’ readiness to change.

Given that almost a third of patients do not take up the referral opportunity James and colleagues recommend that health professionals may need additional training regarding the benefits of physical activity for health, so they are better informed about why the referral will benefit patients with a particular condition and make the referral more personalised to the patient. This might enable patients to make honest and more informed choices about whether they consider the scheme is appropriate for them.

### 3.2.3. Qualitative Research

**Patient experience:**
Current health policy emphasises the need for health services which genuinely focus on the needs of patients and empower patient choice, consequently patient feedback regarding healthcare provision and their experiences as service-users is essential in order to offer services which are ‘personal and responsive’.

Only one study was identified which focused on the views of exercise referral scheme participants themselves. Wormald and Ingle commented that issues such as participants’ views of the scheme, their opinions on its ability to increase physical activity and their perceptions of how schemes can be improved have rarely been the focus of investigations.
The authors conducted six focus groups which included thirty 30 white adults (10 men and 20 women, predominantly (77%) aged between 55-74 years (77% of study participants). All study participants had attended at least one session of the exercise referral scheme in one of the four scheme leisure-centres. Participants were categorised by leisure centre staff as either ‘completers’ (patients who attended the complete 10-week referral period) or ‘non-completers’ (patients who had not). Focus groups were chosen as the method of data collection, the authors selected this option as these are recommended as a suitable tool for exploring a range of opinions in health research. Focus groups lasted between 45-60 minutes and included between 2 to 8 participants in each group.

Three main themes emerged from the focus group data:

1. Role of primary care staff;
2. The exercise programme, environment & staff;
3. Perceived effects of the scheme.

Overall, patients reported positive experiences and had appreciated and enjoyed participating in the exercise referral scheme. Many patients felt the scheme had increased their physical activity levels, approximately half reported that they had gone on join a leisure facility and other patients reported they had intentions to do so. Even the non-completers had gone on to participate in other activities such walking or community based exercise classes, thus reinforcing the perceptions of some that non-completion may not always equate to a negative outcome. Patients perceived the scheme had improved their physical and mental health and general wellbeing.

Some patients felt that access to the scheme seemed to be restricted due to a lack of awareness of among primary care staff. On the whole patients reported positive experiences and were very satisfied with the level of service they had received from the exercise leaders. Patients reported that they were grateful for the supportive and personalised service they received and reported that the supervision had encouraged them to continue with the scheme. However, the authors reported that some respondents felt the scheme could be improved by ensuring appropriate and consistent supervision and support from exercise staff, broadening the scheme operating times and providing more opportunities to socialise, particularly with other referred patients.

It should be noted that the findings of this study are predominantly the views of patients who completed the scheme and may be subject to bias as these participants may hold more positive and enthusiastic opinions about the scheme.

The authors concluded that despite the current focus on the promotion of informal, unsupervised, non-facility based physical activity, for some individuals the supervision, support and structure provided by an exercise referral scheme may act as powerful motivator in maintaining exercise adherence. Exercise referral schemes should be seen as one approach to promoting physical activity and must be part of a broader strategy encompassing a diverse range of physical activity initiatives.
Wormald and Ingles identified several considerations for practice:
- Healthcare professionals need to be briefed more about the availability of exercise referral schemes and the benefits of the scheme to them and their patients;
- Where possible, scheme should ensure continuity of staff, a familiar face may improve patients’ confidence to attend the programme.
- Offer a wider range of activities.
- Increase opportunities to socialise with other participants e.g. exercise sessions exclusive to referred patients, group induction, buddy systems.
- Where possible, scheme should provide opportunities for family or friends to attend.

Health Professionals’ Perspective:
Wormald and Ingle’s study highlighted that access to the North Yorkshire scheme seemed to be restricted due to a lack of awareness among primary care staff. They suggested this might be due to a general lack of confidence in promoting physical activity in primary care or it may be a produce of the high workload and lack of time currently faced by primary care staff.

A recent qualitative study by Graham, Dugdill and Cable sought to gain an understanding of the key factors that affected scheme operation from the health professionals’ perspective. With the exception of two earlier studies examination of health professionals’ opinions and attitudes towards physical activity promotion in the context of an exercise referral scheme has not been investigated.

This study specifically aimed to gain an understanding of the perceived barriers to referral, priority given to an exercise referral scheme in general practice, perceived importance of their role in the process of behaviour change and referral practices to an exercise referral scheme. Uniquely an understanding of the referral process rather than patient outcome was sought.

The authors adopted a unique mixed-method approach which combined quantitative and qualitative data collection techniques and detailed content analysis in an attempt to gain a comprehensive understanding of health professionals’ opinions and practices towards physical activity promotion in relation to exercise referral schemes.

A questionnaire was sent to 144 General Practitioners in 52 practices which fell in the scheme’s catchment area. The questionnaire aimed to obtain the GPs perspectives and views on a range of issues: their referring practices; beliefs about the relative importance of physical activity; barriers to referral; feedback and training of health professionals within exercise referral schemes, partnership working and support for exercise referral schemes and perceived impact of the scheme with regard to other risk factors. Forty-nine percent of GPs from thirty-five of the targeted practices responded to the survey.

Semi-structured interviews were also carried out in order to gain a more in-depth understanding of how healthcare professionals relate to an exercise referral scheme. Ten GPs (6 male; 4 female) and two practice nurses volunteered to be interviewed, interviews lasted around 30 minutes. The interview script was developed on the basis of the responses to the postal questionnaire. Interviews were recorded and transcribed, the transcripts were then analysed by topic for key theme development using content analysis.
Graham and colleagues found four key themes emerged from the combined data analyses, there were:

1. Priority of physical activity promotion by health professionals in primary care,
2. Health professionals’ barriers to referral,
3. Health professionals’ perceived role in promoting physical activity behaviour change,
4. Methods for identifying patients for referral to an exercise referral scheme.

1. Priority of physical activity promotion
The results of this study suggested that physical activity was not a priority for the majority of primary care professionals. When compared to referrals for smoking cessation and dietetics, referrals for exercise were a lesser priority. Some health professionals perceived that their patients lacked the motivation to change their physical activity as it required a longer-term commitment, consequently health professionals did not prioritise physical activity in consultations as they perceived they would have limited effect. Health professionals expressed concerns about the medico-legal responsibility with respect to referring patients to an exercise referral scheme; they perceived the referral pathways for other services, such as dietetics and smoking cessation were much clearer. Due to the uncertainty regarding their clinical accountability, some health professionals were cautious about referring patients who exhibited symptoms of, or who had a history of heart disease.

2. Health professionals’ barriers to referral
In addition to the issues raised above, Graham and colleagues found there were a number of other barriers to referring patients to the scheme. Time limitations during routine consultations put pressures on health professionals to treat the primary reason for the patient’s visit, which meant physical was not a high priority in consultations. For some health professional a lack of feedback from the exercise referral scheme about their patient’s progress and the associated benefits was a concern, and barrier to referring.

3. Health professional’s role in promoting exercise behaviour change
Graham and colleagues reported that health professionals’ opinions differed as to their perceived role in patient behaviour change, some felt that their role was central whilst others did not.

4. Methods for identifying patients for referral to an exercise referral scheme
This study found that the way health professionals identified suitable patients for the scheme varied between practices. Although eligibility criteria exist for referral to the scheme, patients were often identified for referral to the scheme in an unsystematic way. Graham and colleagues stated that:

“Lack of feedback to health professionals with information as to what types of patients the exercise referral scheme works best for means that health professionals have a lack of evidence about who best to select for a referral”.

p.1420, Graham et.al, 2005
Graham and colleagues made several suggestions which have implications for practice.

- Closer partnership working is required between health professionals and exercise providers;
- Health professionals require training and practical resources to assist them in making a decision to refer a patient.
- In order to overcome some of the practical and perceived barriers to referral there needs to be greater feedback about the patient benefits;
- Alternative and more systematic mechanisms for identifying suitable patients for referral need to be in operation at the primary care level.

3.2.4. Evaluation

As previously noted there has been a rapid and uncontrolled expansion of exercise referral schemes throughout the UK in the past two decades, in spite of the fact that the evidence base regarding their effectiveness is ‘thin’. Dugdill, Graham and McNair\textsuperscript{21} argued that in the present climate of evidence-based practice and clinical effectiveness, it is no longer acceptable for agencies involved in the delivery of exercise referral to ignore the need to evaluate schemes.\textsuperscript{21} Furthermore, the NICE\textsuperscript{14} public health guidance on four commonly used methods for promoting physical activity called for ‘more rigorous and controlled evaluation of exercise referral schemes.’

Regardless of the NICE recommendations many PCTs and local authorities are unlikely to be in a financial position to be able to fund such rigorously designed and controlled evaluations. Moreover, Sowden and Raine\textsuperscript{35} have recently argued that evaluation of the effectiveness of exercise referral schemes in England in terms of improvements in health and reductions in health inequalities is now an unrealistic aim for several reasons. Firstly, they suggest the extent of exercise referral provision across England would make it difficult to identify a suitable site for a study; secondly it is doubtful that funding for a rigorously controlled exercise referral trial would be available. Finally they also suggested the results are unlikely to make a difference to provision as the consequences of disbanding ineffective schemes would have a much wider impact on local partnerships.\textsuperscript{35}

Besides some authors have pointed out that there is danger in regarding evidence from randomised controlled trials as the only evidence as counts.\textsuperscript{11,21,36} The arguments presented above do not, however give schemes complete freedom to ignore the need for more rigorous evaluation. Gidlow, Johnston and colleagues propose that those agencies involved in the delivery of exercise referral schemes must recognise and become attuned to evaluation as an integral part of practice; these authors suggest there is a need to develop an ‘evaluation culture’.\textsuperscript{37}

The National Quality Assurance Framework for exercise referral schemes moved some way towards developing a framework for evaluating exercise referral schemes, however Dugdill and colleagues argue that the NQAF guidance is limited and does not give practitioners a clear process to follow.\textsuperscript{21}

The mapping exercise reported in section two found that the evaluation practices of many existing schemes tend to be confined to the assessment of physical activity and physiological indicators at the start and end of the referral period. In addition, many schemes typically use data on the number of patients who pass through the scheme
on an annual basis as a means of evaluation. Often these evaluation practices are governed by commissioning arrangements and limited by resources and capacity for evaluation within schemes. Dugdill and colleagues highlight the limitations of this approach, suggesting that issues of quality (i.e. patient experiences) and sustainability (long-term physical activity adherence) are lost.\textsuperscript{21}

Dugdill and colleagues recommend:

\begin{quote}
"There is a need to move away from the ‘physiological measurement only’ model, which predominates in most ERS research currently and look for broader, more meaningful measurement of quality experience and health outcome from all stakeholder perspectives, which incorporates both quantitative and qualitative indicators."
\end{quote}

\textit{p.1398, Dugdill et al., (2005)}

Gidlow and colleagues\textsuperscript{37} endorse the importance of using qualitative methods in evaluating exercise referral schemes, they consider qualitative research may improve our understanding of exercise referral schemes and offer insight into why they work for some and not others. It is interesting to note that Dugdill and colleagues criticised the way schemes are often designed suggesting many are set up in an ‘off the shelf fashion.’ However, there is little qualitative evidence examining the exact nature of the intervention to determine whether certain characteristics are associated with programme completion and long-term behaviour change (i.e. the referral pathway and patients experiences through it, who refers, who gets referred, the length and nature of the referral period (number of sessions, exercise intensity, duration of sessions, or mode of activity)). Thus, until such evidence is available local schemes will continue to model the content and delivery of their localised scheme on programmes that are currently in existence.

Evaluation needs to be built into schemes from their inception, all stakeholders need to agree on the purpose of, and the methods for, evaluation and it is imperative that the resources (people, finances) necessary for systematic evaluation are made available. According to Gidlow and colleagues the overall data collection processes implemented at the design phase, with subsequent and regular evaluation and re-evaluation, should facilitate collation of sufficient good quality data that can explain scheme outcomes and as such inform and improve practice.\textsuperscript{37} This sentiment is echoed by Dugdill and colleagues who suggest that evaluation which goes beyond mere measurement should produce data and information which are meaningful and appropriate for the purpose of effecting change within a scheme.\textsuperscript{21}

Finally the research suggests that effective process and outcome evaluation strategies which are built into schemes at the planning stage should ultimately produce better quality data and if successful, this should negate the need for ‘one off’ experimental evaluations that employ complex and unsustainable research methods.
Summary:
Several consistent implications for practice have been identified from the research evidence considered in this section, some are more applicable to referring health professionals others are more pertinent to exercise professionals and exercise referral scheme coordinators. Many of these issues have been integrated as practical suggestions within the guidance sections of the toolkit.
3.3. References


