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The National Referral Database

An Initial Overview, Existing Work, And Future Plans

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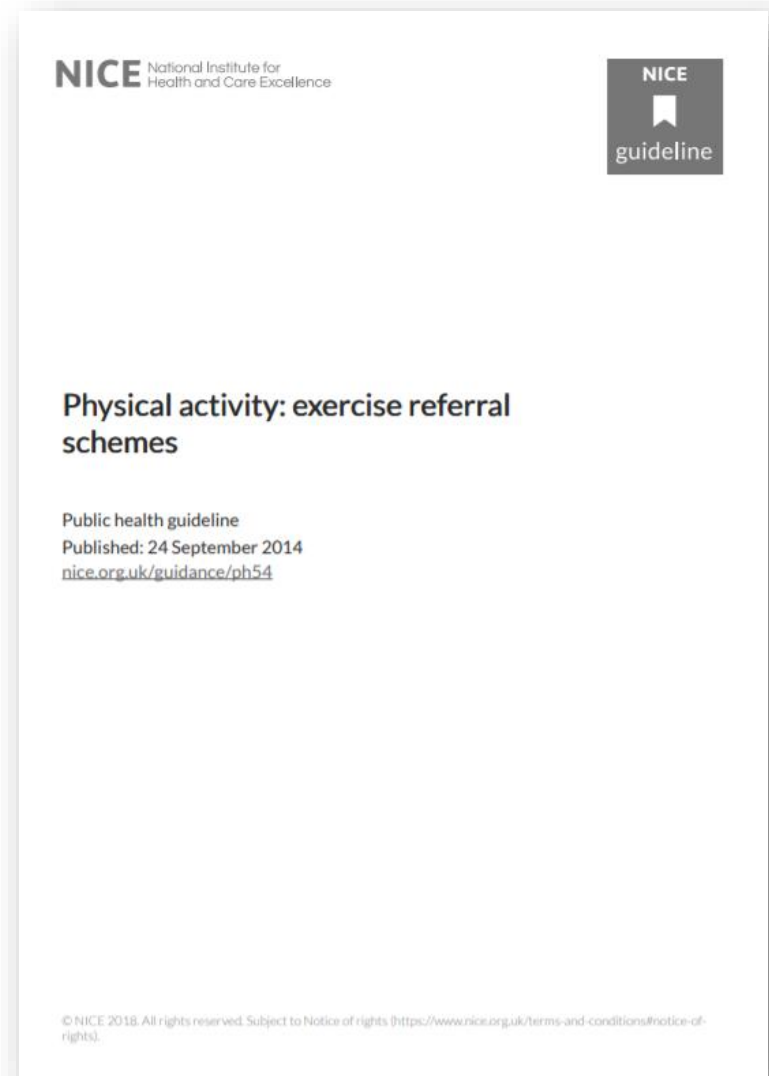
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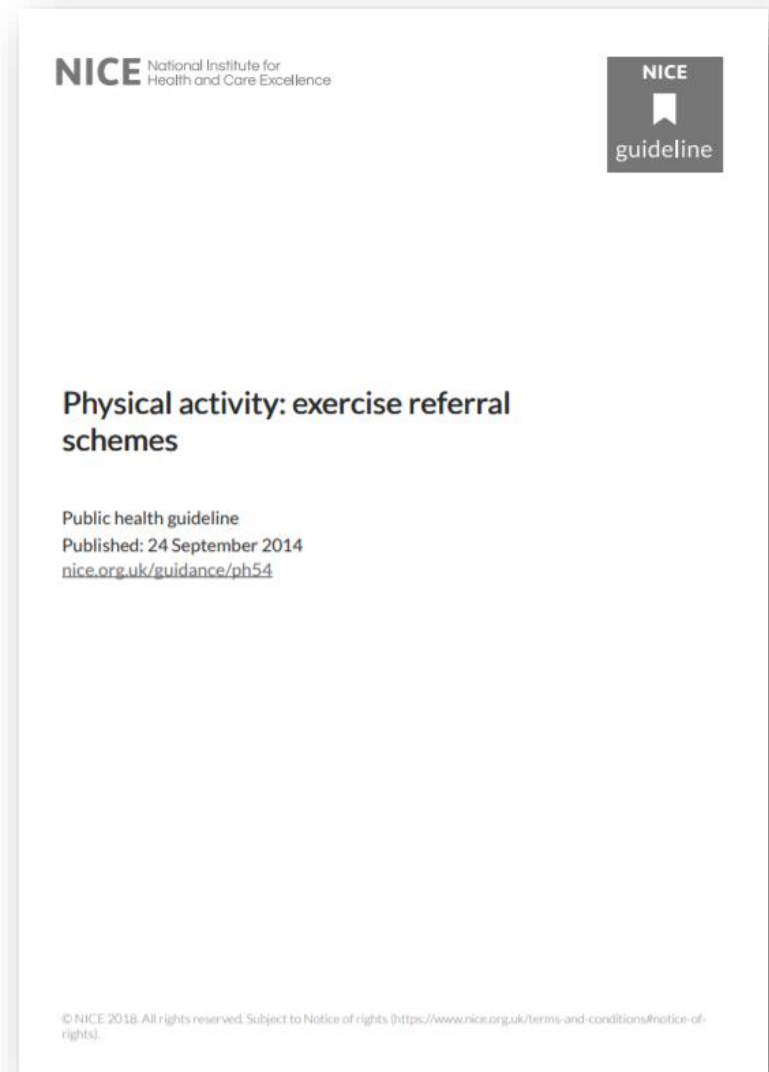
NICE Recommendations:

1. Policy makers/commissioners should **not** fund, and primary care practitioners should **not** refer people to, exercise referral schemes for people who are sedentary or inactive but otherwise healthy.
2. Policy makers/commissioners should fund, and primary care practitioners should refer people to exercise referral schemes incorporating recommendations 7-10 of *'Behaviour change: individual approaches'* (NICE public health guidance 49)
3. Public Health England should develop and manage a system to collate local data on exercise referral schemes



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Background

- In 2016 ukactive formed a partnership with ReferAll and the NCSEM Sheffield
- Work began in 2017 by ukactive Research Institute examining and analysing the initial database
- Development of plans to enhance the databases potential and enable continued evaluation of referral pathways at a national level
- Looking to positioned to support the NHS Long Term Plan, activation of link workers and social prescribing, and the current preventative agenda



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The National Referral Database: An initial overview

The National Referral Database: An initial overview

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SCIENTIFIC ABSTRACT

Background: In 2014 The National Institute for Health and Care Excellence (NICE) called for development of a system to collate local data on exercise referral schemes (ERS) to inform future practice. This database would be used to facilitate continued evaluation of ERS. 'Big data' analytics in a current trend to healthcare with the potential to influence decision making. Indeed, the use of health database data can spur scientific investigation and generation of evidence regarding healthcare practice. NICE's recommendation has not yet been met by public health bodies. However, through collaboration between ukactive, ReferAll, a specialist in software solutions for exercise referral, and the National Centre for Sport and Exercise Medicine, data has been collated from multiple UK-based ERS to generate one of the largest databases of its kind and move towards meeting NICE's recommendation. **Method:** This paper describes the formation of The National Referral Database, its structure including outcome measures, data cleaning processes, and in two accompanying manuscripts the first initial observational insights are presented from analysis of this data. **Results:** Collating data from 19 ERSs on 24,086 individuals, a database has been created containing pre and post referral data for metrics including: physical activity, blood pressure, BMI, resting heart rate, SWEMWBS scores, ERS scores, WHOS scores and EQoL scores. After data cleaning processes there were 14 ERSs remaining covering 23,782 participants with an average age of 51±15 years and 68% of whom were female. Further, the database contains demographic information, reason for referral, medical conditions, and information on the referrer. **Conclusion:** This database has now been created and the initial data is available for researchers to interrogate. The National Referral Database represents a potentially valuable resource for the wider research community, as well as policy makers and practitioners in this area, which will facilitate a better understanding of ERS and other physical activity related social prescribing pathways to help inform public health policy and practice. Longer term plans include establishment of the database as an open resource, continually updated with additional data and version controls, for researchers to access for further research and policy makers and practitioners to use to inform their policies/practices.

Key words: health database; exercise referral; physical activity; big data

INTRODUCTION

The National Institute for Health and Care Excellence (NICE) published guidelines regarding exercise referral schemes (ERS) in 2014 (NICE, 2014). The extant literature at the time regarding the impact of ERS was considered inadequate, with inconsistent and weak evidence regarding their effects upon health, wellbeing, and quality of life outcomes (Pavey et al., 2011; NICE, 2014; Duda et al., 2014; Duggill et al., 2005). A recent systematic review has highlighted that ERSs in the UK may be effective in increasing physical activity and that longer schemes (>20 weeks) may be more so than shorter schemes (<12 weeks; Rowley et al., 2018). However, it has been argued that physical activity promotion within primary care should extend beyond just ERS incorporating wider social prescribing of physical activity. Moreover, the impact of these programmes should be assessed

against outcomes beyond merely increasing physical activity levels to other health and wellbeing outcomes (Arvo et al., 2012). The world of ERSs has recently been described as 'wild and woolly' lacking clarity in the conceptualisation of 'exercise' and little stakeholder agreement in how to determine 'impact' (Henderson et al., 2018). Henderson et al. (2018) have argued that ERSs do not work *per se*, but that their effectiveness is determined by the interpretations of their participants and whether they 'improve' on an individual basis. Yet, while important to the person, change at the individual level does not facilitate understanding of whether an effect exists within a population, nor the size of that effect and the precision with which it can be estimated. These are important factors to consider when developing policies and commissioning programmes and interventions. Indeed, it has been argued (Beedie et al., 2016) that

The National Referral Database: Health and wellbeing outcomes

The effect of exercise referral schemes upon health and wellbeing: Initial observational insights using individual patient data meta-analysis from The National Referral Database

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SCIENTIFIC ABSTRACT

Background: Physical activity is widely considered to be effective in the prevention, management, and treatment of many chronic health disorders. Yet, population physical activity levels are relatively low and have changed little in recent years. Sufficient physical activity levels for health and wellbeing often do not arise as result of typical activities of daily living. As such, specific exercise has been argued to be necessary for many, and one approach to providing this has been through exercise referral schemes (ERS). Schemes are aimed at increasing physical activity levels in sedentary individuals with chronic disease, however, evidence is currently lacking as to whether ERSs are effective as currently implemented. Thus, it is of interest to consider broadly whether meaningful changes in health and wellbeing outcomes are observed in people undergoing and ERS. **Purpose:** To examine if ERSs are associated with meaningful changes in health and wellbeing in a large cohort of individuals throughout England, Scotland and Wales from The National Referral Database. **Method:** Data were obtained from 23731 participants from 13 different ERSs. Average age was 51±15 years and, 68% of participants were female. Health and wellbeing outcomes were examined including body mass index, blood pressure, resting heart rate, short Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS), World Health Organization Well-Being Index (WHO-5), Exercise Related Quality of Life scale (ERQoL), and Exercise Self-Efficacy Scale (ESES). Two stage individual patient data random effects meta-analysis was performed on the change scores, (i.e. post-minus pre-ERS scores) and interval estimates were compared to null intervals for meaningfulness. **Results:** Estimates and 95%CI revealed that statistically significant changes occurred when compared to point nulls of zero for body mass index (-0.55 kg.m² [-0.69 to -0.41]), systolic blood pressure (-2.95 mmHg [-3.97 to -1.92]), SWEMWBS (2.99 pts [1.61 to 4.36]), WHO-5 (8.78 pts [6.84 to 10.63]), ERQoL (15.26 pts [4.71 to 25.82]), ESES (2.58 pts [-1.76 to 3.40]), but not resting heart rate (0.22 f. [-1.57 to 1.12]), diastolic blood pressure (-0.93 mmHg [-1.51 to -0.35]). However, comparisons of estimates and intervals against null intervals for meaningfulness of changes suggested that the majority of outcomes may not improve meaningfully. **Conclusion:** The analysis performed here were with the intention of considering broadly, do we observe a meaningful effect in people who are undergoing ERSs? With respect to this broad question the present results demonstrate that, although many health and wellbeing outcomes are statistically significant when compared to point null estimates (i.e. they differ from a change of zero) our analysis revealed there may be a general lack of meaningful change over time in participants undergoing ERSs, though results varied widely across different schemes. These findings suggest the need to consider the implementation of ERSs more critically in order to discern how best to maximize their effectiveness such that it reflects the efficacy often evidence in the literature.

Key words: Exercise referral schemes; health and wellbeing; individual patient data meta-analysis; health database.

INTRODUCTION

Engagement in physical activity is widely considered to be effective in the prevention, management, and treatment of many chronic health disorders (Booth et al., 2012; Pedersen and Saltin, 2015). Despite this, in the United Kingdom (UK) a recent survey has shown that population levels of physical activity have remained unchanged in recent years, with a large proportion of the population still classed as inactive presenting potentially serious repercussions

for population health (Sport England, 2018). The costs of physical inactivity to the National Health Service (NHS) were estimated as £900 million in 2015 (Statistics Team, NHS Digital, 2017) which, despite relatively stable levels of physical activity, had risen to £1.2 billion in 2017 (British Heart Foundation, 2017). Though it is hoped that population wide increases in physical activity are possible they are difficult to achieve and thought to require complex interventions aimed at several socio-ecological levels (World

The National Referral Database: Physical activity

Are exercise referral schemes associated with an increase in physical activity? Observational findings using individual patient data meta-analysis from The National Referral Database

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SCIENTIFIC ABSTRACT

Background: Exercise referral schemes (ERSs) within clinical populations offer inactive individuals the opportunity to increase physical activity levels over the length of scheme. Schemes are also intended to support the treatment of specific health conditions of medically referred individuals through increased physical activity behaviours. The extant literature concerning the impact of exercise referral on physical activity levels is inconsistent. It is of interest researchers, policy makers, commissioners and practitioners to consider broadly whether meaningful change in physical activity levels are observed in people who undergo exercise referral, to identify potential effective policy actions in supporting active living. **Purpose:** To examine if ERSs increase physical activity levels in a large cohort of individuals throughout England, Scotland and Wales from The National Referral Database. **Method:** Data were obtained from 5246 participants from 12 different referral schemes. Average age was 53±15 years and, 68% of participants were female. Participants self-reported International Physical Activity Questionnaire (IPAQ) scores pre- and post- scheme, to determine if exercise referral had any impact on change in physical activity levels. Two stage individual patient data meta-analysis was performed on the pre-ERS, and change scores, (i.e. post-minus pre-ERS scores) for MET-minutes/week calculated from IPAQ. Analyses were conducted on the continuous data collected using the IPAQ. **Results:** For pre-ERS MET-minutes/week the estimate and 95%CI from random effects model was 676 MET-minutes/week [539 to 812 minutes]. For change in MET-minutes/week the estimate and 95%CI from random effects model for was an increase of 540 MET-minutes/week [396 to 684 minutes]. Significant heterogeneity was evident among the schemes ($I^2 > 80\%$). Changes in total PA levels occurred as a result of increases in vigorous activity of 17 minutes [95%CI 9 to 24 minutes], increases in moderate activity of 29 minutes [95%CI 22 to 36 minutes], and reductions in sitting of -61 minutes [95%CI -78 to -43 minutes], though little change in walking (<5 minutes [95%CI -14 to 5 minutes]). **Conclusion:** Observation of participants undergoing ERSs suggests that most are already 'moderately active' upon entering an ERS. Changes in physical activity behaviour associated with ERS participation were varied and primarily facilitated by increased moderate-to-vigorous physical activity and reduced sitting. However, this was not sufficient to result in IPAQ categorical change and participants were thus on average still classed as 'moderately active'. Further work is required to ensure ERSs are implemented to targeting the appropriate populations where they may result in the greatest benefit. **Key words:** Exercise referral schemes; physical activity; individual patient data meta-analysis; health database.

INTRODUCTION

Physical activity is widely considered an effective prevention and management tool for a wide range of chronic health disorders (Pavey, et al., 2011; Pedersen & Denollet 2003; Pedersen & Saltin 2015). Physical activity is considered as any bodily movement created by skeletal muscles that results in greater demand of energy expenditure than at would normally be required (World Health Organization 2015; 2018). Physical activity can be conducted in

many ways, including unstructured activities as part of an individual's daily living, leisure activities, or occupation, and is often performed without the explicitly desired goal of improving fitness. Improving health and fitness can be a by-product of these unstructured activities, although unstructured physical activity is decreasing within the modern era (Booth, et al., 2012).

Worldwide, one in four adults do not meet the current global recommendations for

Initial overview and findings

- Pre printed at [SportRxiv](https://www.sportrxiv.com/)

Summary so far...

- The first steps towards establishing a national database of exercise referral schemes have been taken.
 - The current database is available upon request for researchers to access for analysis
- The data we have analysed so far suggest that exercise referral schemes as currently delivered do not result in meaningful changes in:
 - Physical activity levels
 - Health and wellbeing outcomes
- So what are the next steps?
 - Stop there and forget about exercise referral because it doesn't seem to work?
 - Or, consider the limitations of current evidence and how we can generate better data to enable continued evaluation, elevation of standards, and translation of efficacy into real world effectiveness?



Overall Project Aim

To produce an open database of physical activity related referral schemes for researchers, practitioners, and decision makers to understand these schemes in greater detail

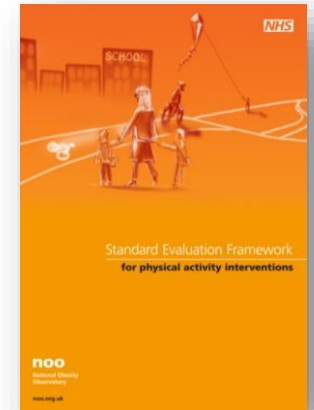
Current Aim

To source funding to support the overall project aim in terms of academic and technical development of the resource and platform

Future plans for development

To improve data quality:

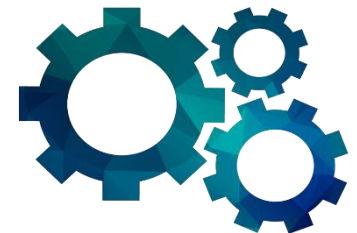
- Details of existing and new schemes
 - Using standardised reporting e.g.
 - CERT guidelines (Slade et al., 2016)
 - Existing fidelity frameworks (Borelli, 2011)
 - Incorporate wait-list control data capture where possible
 - Review appropriateness of current outcome measures
 - Standardise participant data capture
-
- This might facilitate conduct of large simple trials to:
 - Compare schemes, and understand what characteristics are optimal
 - Consider participant level predictors of outcomes
 - Causal modelling of scheme effects (Pearl & Mackenzie, 2018; Lederer et al., 2018)
 - Target trial emulation approaches (Hernan and Robins, 2016)



Future plans for development

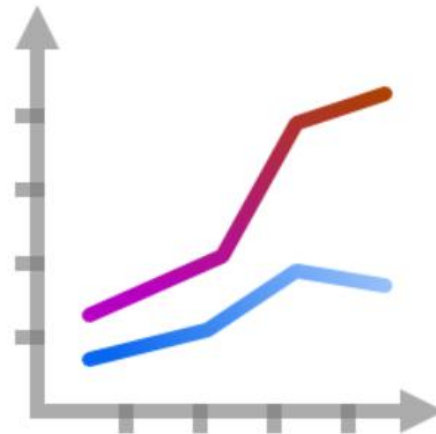
Establishment as an open resource with:

- Continually updated data with version controls – Direct integration to ReferAll system
- Schemes not using ReferAll provided with templates for contribution of data to the database
- Register requests for data with research questions and analysis plans specified
- Requests to be reviewed and publically pre-registered with an ‘in principle acceptance’ – in essence Registered Reports
- Hosting of any research reports using the database
- Directory of existing schemes, details, location etc.
- Dashboards and descriptive reporting to facilitate transmission of findings to practitioners and policy makers



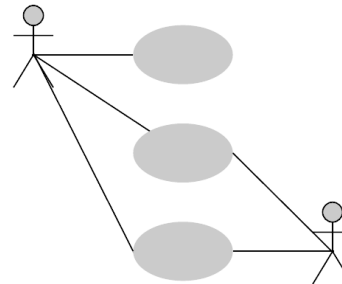
Future plans for development

- Over time, the database could incorporate new schemes and referral pathways (including wider social prescribing)
- Permit continued evaluation and refinement of policies and practice, thus setting and continually improving standards
- Novel schemes and pathways then compared against tried and tested standards



Use case...

- Presented at conference, and pre-printed with support and interest from the academic community
- Key stakeholders and organisations have expressed interest in the resource and findings it might generate
- Practitioners and providers wish to get involved to provide further data and to understand what the evidence suggests in terms of best practice



- Over to you!
 - What would you like to see in The National Referral Database?
 - What research questions would it help you to answer?
 - Any other questions?





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