

# DEVELOPING BEHAVIOUR CHANGE INTERVENTIONS TO INCREASE LEVELS OF PHYSICAL ACTIVITY IN PATIENTS WITH CHRONIC KIDNEY DISEASE

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# Abstract

## **Developing Behaviour Change Interventions to Increase Levels of Physical Activity in Patients with Chronic Kidney Disease**

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This thesis aimed to develop an evidence based, theory driven behaviour change intervention to increase levels of physical activity (PA) in patients with chronic kidney disease (CKD). Using mixed-methods the following studies were conducted:

**Cross-sectional study of self-reported PA levels and PA correlates:** Survey of 1015 patients indicated a high prevalence of PA insufficiency (85.3%), but a readiness to change. Regression modelling indicated self-efficacy, physical function, older age and sex as independent predictors of PA.

**Observational study of walking and survival:** Walking behaviours were shown through Cox proportional hazard modelling to be independently associated with mortality in a 44-month median follow-up of 437 persons and 89 deaths.

**Qualitative study exploring patient factors influencing exercise:** Factors influencing exercise were captured via focus groups and semi-structured interviews with 36 patients. Analysed thematically findings were conceptualised within a social cognitive perspective and included: personal influences (co-morbidities, symptom burden, ageing, fear, previous experiences, and internal drive); behavioural influences (health and well-being, maintaining normality, and enjoyment); and environmental influences (organisation, physical, and social). Findings highlighted PA and disease information needs, and modifiable psychological targets for intervention.

**Person-Based Approach to the development of a PA intervention:** Expert consultations (n=9), examination of theory and evidence, observations of patient education programmes; Public Patient Involvement (n=9) to establish intervention guiding principles; user testing with patients (n=14) to refine the Physical Activity Changing Together (PACT) intervention, a structured group-based PA education programme.

**PACT feasibility study:** Recruitment, retention and engagement/acceptability were assessed using mixed methods in a 12-week study. Post intervention step counts indicated a mean increase of 2127 steps/day from baseline. PACT was feasible to implement, acceptable to patients and warrants further testing.

Original contributions to knowledge include: confirming a link between walking and health; identifying factors that influence PA; and the development/evaluation of a CKD specific PA intervention; all which can be framed within the Behavioural Epidemiology Framework.

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# Publications

## Peer-reviewed publications

**Clarke AC**, Smith AC, Gould DW, Hull KL, Yates T & Burton JO. Association of self-reported physical function with survival in patients with chronic kidney disease. *Clinical Kidney Journal*, 2017 (Submitted).

**Clarke AL**, Yates T, Smith AC, and Chilcot J. Patient's perceptions of chronic kidney disease and their association with psychosocial and clinical outcomes: a narrative review. *Clinical Kidney Journal* 2016: sfw014v1-sfw014.

**Clarke AL**, Young HM, Hull KL, Hudson N, Burton JO, Smith AC. Motivations and barriers to exercise in chronic kidney disease: A qualitative study. *Nephrol Dial Transplant*. 2015;30(11):1885-1892.

## Conference oral/poster presentations

**Clarke AL**, Yates T, Gould DW, Smith AC, Burton JO. Self-reported physical function predicts all-cause mortality in patients with chronic kidney disease. Poster presentation, European Renal Association-European Dialysis and Transplantation Association 54th Congress, Madrid June 2017.

**Clarke AL**, Savage J, Dibb M, Bishop NC, Young HML, Neale J & AC Smith. Sport and Exercise with a Kidney Transplant: A Hypothesis-Generating Patient Involvement Event. Poster presentation, UK Kidney Week, Birmingham, June 2016. (**Awarded best poster in group**).

**Clarke AL**, Developing behaviour change interventions to increase levels of physical activity in patients with CKD. Post graduate conference. April 2016.

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**Clarke AL**, MacKinnon HJ, T Yates & Smith AC. The “person-based approach” to developing a structured group education programme to increase physical activity in CKD: The PACT-Project. European Dialysis and Transplantation Association 2016, Vienna, Austria.

**Clarke AL**. Developing a programme to help kidney patients enjoy an active lifestyle. KRUK Fellows Day. York. September 2015. **Oral Presentation**.



**Clarke AL.** Increasing physical activity in chronic kidney disease: The patient perspective. British Renal Society. **Invited oral presentation.** Leeds. June 2015.

**Clarke AL,** Young HML, MacKinnon HJ, Hull KL, Hudson N, Burton JO, Smith AC. Exploring Physical Activity Levels in Chronic Kidney Disease: the role of Exercise Self-Efficacy and Stages of Behaviour Change. East Midlands Renal Showcase. Leicester, 2015. Poster Presentation (**Awarded best poster in group for clinical research**).

**Clarke AL & HJ MacKinnon.** Creating a SPARK. Kidney education conference. Coventry, 2015. **Oral presentation.**

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**Clarke, A.L.,** Young, H.M.L., Hull, K.L., Hudson, N., Burton J.O., & Smith A.C. Patient Perspectives and Readiness To Change In Chronic Kidney Disease: Exercise And Physical Activity Behaviours. Poster Presentation: *51<sup>st</sup> ERA-EDTA Congress*, Amsterdam, June 2014.

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**Clarke AL:** Exercise and Physical Activity habits of the UK Chronic Kidney Disease Population. Allied health professional research network conference, Leicester, February 2014.

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**Clarke AL,** Hull KL, Stone M, Hudson N, Burton JO & Smith AC. A survey of exercise and physical activity habits of Leicester's chronic kidney disease population. Oral presentation, East Midlands Renal Research Showcase, Loughborough, April 2013.

**Clarke AL**, Hull KL, Dungey M, Young HML, Burton JO & Smith AC. National Kidney Federation Roadshow 2012: Results of a Physical Activity Survey. Poster Presentation, East Midlands Renal Showcase, April 2013.

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# List of Key Abbreviations

ACSM	American College of Sports Medicine
ADL	Activities of Daily Living
AOR	Adjusted Odd Ratio
BCT	Behaviour Change Techniques
BIA	Bioelectrical Impedance Analysis
BMI	Body Mass Index
CI	Confidence Intervals
CKD	Chronic Kidney Disease
COPD	Chronic Obstructive Pulmonary Disease
CSM	Common Sense Model
CVD	Cardiovascular Disease
DASI	Duke Activity Status Index
DESMOND	Diabetes Education and Self-Management for Ongoing and Diagnosed
DOPPS	Dialysis Outcomes and Practice Patterns Study
ESRF	End Stage Renal Failure
ESSA	Exercise & Sports Science Australia
FITT	Frequency, Intensity, Type and Time
GFR	Glomerular Filtration Rate
GPPAQ	GP Physical Activity Questionnaire
HADS	Hospital Anxiety and Depression Scale
Hb	Haemoglobin
HR	Hazard Ratio
HTN	Hypertension
IMPAKT	Improving Patient Care and Awareness of Kidney Disease Progression
IPAQ-SF	International Physical Activity Questionnaire Short Form
IPQ-R	Illness Perceptions Questionnaire - Revised
ISWT	Incremental Shuttle Walking Test
KDIGO	Kidney Disease Improving Global Outcomes
KiKS	Kidney Knowledge Survey
MCAR	Missing Completely at Random
MCS	Mental Component Summary
MET	Metabolic Equivalent of Tasks
MOEES	Multi-Dimensional Outcome Expectancies for Exercise Scale
MPA	Moderate Physical Activity
MRC	Medical Research Council
MVPA	Moderate-Vigorous Physical Activity
NHANES	National Health and Nutrition Examination Survey
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
NRES	National Research Ethics Service
PA	Physical Activity
PACT	Physical Activity Changing Together
PAM-13	Patient Activation Measure
PCS	Physical Component Summary

PEARL	Programmes to Encourage Exercise and Activity Lifestyle in Kidney Disease
PPI	Public and Patient Involvement
PREPARE	Pre-diabetes Risk Education and Physical Activity Recommendation and Encouragement
QoL	Quality of Life
RCT	Randomised Controlled Trial
RPE	Rate of Perceived Exertion
RRT	Renal Replacement therapy
SCT	Social Cognitive Theory
SDT	Self-Determinism Theory
SPACE FOR COPD	Self-Management Programme of Activity, Coping and Education
SPARK	Self-Management Programme for Improving Health through Physical Activity in Chronic Kidney Disease
SOCQ	Stage of Change Questionnaire
SPBT	Short Performance Battery Test
STS60	Sit to Stand 60
STS5	Sit to Stand 5
TPB	Theory of Planned Behaviour
TTM	The Transtheoretical Model
TUAG	Timed Up and Go
VO <sub>2peak</sub>	Peak Oxygen Consumption
WHO	World Health Organisation
WSE	Walking Self-Efficacy

# **Chapter 1**

## **Thesis Introduction**

---

## **1.1 Introduction**

### **1.1.1 Physical inactivity a global pandemic**

Physical inactivity has been described as one of the most important threats to public health of the 21<sup>st</sup> century (Blair, 2009). The World Health Organisation (WHO) report physical inactivity to be a global pandemic, and the fourth leading cause of death worldwide (Kohl et al., 2012). Whilst the principle cause of mortality remains non-communicable diseases, physical inactivity is a key factor in the development of these diseases and a strong predictor of adverse outcomes. Lee et al. (2012) reported that approximately 6-10% of deaths relating to cardiovascular disease, diabetes mellitus, and certain cancers can be attributed to physical inactivity.

The WHO (2010) recommends that individuals participate in a minimum of 150 minutes of moderate physical activity or alternatively 75 minutes of vigorous physical activity a week. However, 31% of adults worldwide are not meeting these recommendations (Hallal et al., 2012). This figure may be even higher among adults living in the UK. The British Heart Foundation Physical Activity Statistics report 2015 indicated that 33% of men and 45% of women in England are not sufficiently active (Townsend et al., 2015). This data was collected via self-report, which can be subject to recall and social desirability biases leading to a potential overestimation of those deemed sufficiently active (Rhodes et al., 2017). Worryingly, if objective assessments were used it is likely that levels of physical inactivity would be even higher.

Health status is often correlated with levels of physical inactivity (Bauman et al., 2012), and these international activity guidelines are considered integral to the prevention and management of many long-term conditions (Dalal et al., 2015). However, physical inactivity has only more recently been implicated as a risk factor for the development of chronic kidney disease (CKD) (Bharakhada et al., 2012). Similarly, in regards to the management of CKD, no specific pathways of care exist to support patients to increase their level of physical activity, leaving provisions in this area seriously lacking in comparison to other long term conditions including cardiovascular disease (CVD),

diabetes mellitus and chronic obstructive pulmonary disease (COPD) (Smith and Burton, 2012).

## **1.2 Review aims:**

**1) To provide an overview of CKD and physical activity.**

**2) To provide a brief introduction to behaviour change.**

### **Clarification of terms that will be used throughout this thesis:**

**Physical function:** an individual's functional ability to perform activities of daily living (ADLs), instrumental activities and other discretionary activities (Painter and Marcus, 2013).

**Physical activity** is defined as “any bodily movement produced by the skeletal muscle that increases energy expenditure above a basal level” (Caspersen et al., 1985).

**Exercise** is a subcategory of physical activity that is “planned structured and repetitive with the purpose of improving fitness or health outcomes” (Caspersen et al., 1985).

Physical activity includes a whole host of movement which is required for daily activities, such as walking, gardening and housework. Exercise is one sub component of physical activity which is more structured. Both physical activity and exercise have the potential to improve fitness, but exercise is performed with the goal of doing so. However, the two are often synonymous when proposing a physical activity intervention. For example, an intervention aiming to improve an individual's health and fitness through physical activity e.g. more movement, may lead to a regular and structured exercise behaviour (i.e. initiating a structured daily walk to the shops).

## **1.3 Chronic kidney disease**

### **1.3.1 Classification**

CKD is a long-term progressive condition, which is defined as the presence of kidney damage or a decrease in kidney function (i.e. glomerular filtration rate (GFR)  $<60\text{mL/min/1.73m}^2$ ) for three months or more. GFR has traditionally been used to classify the disease into five stages:  $>90\text{ mL/min/1.73m}^2$  (stage 1);  $60\text{-}89\text{ mL/min/1.73m}^2$  (stage 2);  $30\text{-}59\text{ mL/min/1.73m}^2$  (stage 3);  $15\text{-}29\text{ mL/min/1.73m}^2$  (stage 4); and  $<15\text{ mL/min/1.73m}^2$  (stage 5) (National Kidney, 2002). CKD stages 1-2 require additional markers of kidney damage for a clinical diagnosis (National Kidney, 2002). End stage renal failure (ESRF) is defined by a GFR of  $<15\text{mL/min/1.73m}^2$  and generally requires a form of renal replacement therapy (dialysis or transplant) to support life.

### **1.3.2 Prevalence**

Current evidence estimates that CKD affects approximately 8-16% of the population worldwide and is an increasingly common cause of morbidity and mortality (Jha et al., 2013). The prevalence of CKD in England is slightly lower with an estimated prevalence of CKD (stages 3-5) of 6% for men and 7% for women (Roderick et al., 2011), increasing with age, in both men (29%) and women (35%) over the age of 75 years. The estimated cost of CKD for the English NHS was estimated at ~£1.45 billion between the years 2009-2010 (Kerr et al., 2012). Renal replacement therapy was responsible for more than half of this sum, yet represented only 2% of the CKD population. Furthermore, due to a growing elderly population and increases in prominent risk factors such as obesity, diabetes, and hypertension, future predictions indicate that the prevalence of long term conditions such as CKD will continue to rise.

### **1.3.3 Consequences and co-morbidities**

Optimal medical management of CKD often requires frequent routine monitoring of GFR and albumin creatinine ratio. Frequent monitoring allows for the identification of patients at high risk of progressing to ESRF (Webster et al., 2017). However, evidence

indicates that over a 5-year period as few as 2% of patients with CKD progress to requiring renal replacement therapy (RRT) (Keith et al., 2004). Furthermore, patients with CKD are 5 times more likely to die than progress to ESRF. Therefore, growing attention has been directed towards the management of co-morbidities. Co-morbidities pose an important problem for patients with CKD impacting on treatment, quality of life and survival (Abdel-Kader et al., 2009). A survey of 1741 CKD stage 3 patients indicated that 40% have at least two co-morbidities (Fraser et al., 2015). The most common co-morbidities identified included hypertension (87.8%), painful condition (30.4%), anaemia (24.0%), ischemic heart disease (22.9%), and diabetes (16.9%). Arguably, the most important is CVD which accounts for 46% of deaths among CKD patients not requiring RRT and is considered the leading cause of death (Shlipak et al., 2005). The high risk of CVD among CKD patients is a complex subject and is thought to be the result of both a higher prevalence of traditional risk factors and CKD specific non-traditional risk factors.

Patients with CKD are also at a higher risk of developing mental health problems than the general population (Hudson & Chilcot, 2018). Although, in contrast to physical co-morbidities, depression, whilst the most common psychological co-morbidity associated with CKD is less well recognised, particularly across earlier stages of the disease (Kimmel et al., 2002). One potential reason suggested for the under recognition of depression among the CKD population is the potential for uremic symptoms e.g. fatigue to confound the diagnosis of depression. Despite this, a recent systematic review indicated that depressive symptoms are highly prevalent within the CKD population, and depression is an area requiring further attention (Palmer et al., 2013). Assessments conducted by clinical interview indicated that 21.4% of CKD patients stages 1-5 and 22.8% of dialysis patients are depressed (Palmer et al., 2013). However, when assessed via questionnaire depression prevalence was higher with 26.5% and 39.3% of patients respectively meeting the criteria (Palmer et al., 2013). Furthermore, depression among non-dialysis CKD patients has been shown to be associated with increased risk of mortality, independent of age, sex and clinical predictors of survival (Kellerman et al., 2010).

Whilst some CKD patients are what is referred to as ‘asymptomatic’ and experience very few symptoms, others experience a high symptom burden. Symptoms are often



wide ranging, but some of the most commonly reported are excessive tiredness, sleep disturbance, pains in joints and bones, loss of muscle strength and shortness of breath (Brown et al., 2017). Symptom burden has been shown to have a profound negative effect on patient quality of life (QoL) (Senanayake et al., 2017). Perceived loss of muscle strength is likely due to the process of muscle wasting observed as a complication of CKD, which is often made worse by an inactive lifestyle. As such patients with CKD exhibit poor physical function (Painter and Roshanravan, 2013) and reduced exercise capacity (Leikis et al., 2006). Reduced physical function has been shown to be associated with adverse outcomes, hospitalisation and reduced QoL among patients requiring RRT (Painter and Marcus, 2013). However, evidence suggests that the onset of functional decline occurs earlier on in the disease process before RRT is required (Padilla et al., 2008, Johansen and Painter, 2012, Plantinga et al., 2011). Loss of functional independence in elderly adults has been shown to occur when cardiorespiratory fitness measured as peak oxygen consumption ( $VO_{2peak}$ ) falls <15 ml per min in women and <18 ml per min in men (Paterson et al., 1999). However, in CKD patients stages 3-4 this can occur 20 years earlier (Padilla et al., 2008). Similarly, in CKD patients' stages 2-4 objective assessments of physical function (via lower extremity measures e.g. gait speed and timed up and go test) have been shown to be associated with all-cause mortality (Roshanravan et al., 2013). In addition, self-reported measures of physical function in patients with CKD stages 3-5 have previously indicated physical function as a strong predictor of changes in health-related QoL (Mujais et al., 2009).

### **1.3.4 Management of chronic kidney disease**

The main stay of treatment for CKD is to prevent or delay progression, reduce or prevent the development of complications, and reduce the risk of CVD (Thomas et al., 2008). This requires complex pharmacotherapy treatment plans which often aim to improve blood pressure control, modify lipid profiles, improve arterial circulation and manage other complications such as bone disorders, anaemia, and acidosis (NICE, 2014). However, NICE guidelines also advocate non-pharmacological interventions directed at lifestyle. Essential to this is the recommendation that all CKD patients receive self-management advice ensuring that patients are: aware of their CKD

diagnosis; involved in the shared decisions of their treatment; provided with information regarding blood pressure control, smoking cessation, exercise, diet and medicines; and are given access to their medical data (NICE, 2014). Within the realm of self-management there is a large emphasis on patient education which is based on the premise that knowledge is linked to change; if patients lack the relevant knowledge about the impact of their lifestyle on their condition they have little reason to initiate health behaviour change (Bandura, 2004). A recent systematic review of patient education in CKD patients not requiring RRT indicated its potential to improve self-efficacy, QoL, self-management behaviours and clinical endpoints (Lopez-Vargas et al., 2016). However, whilst exercise is advised as part of the CKD management plan, few studies have targeted physical inactivity.

## **1.4 Physical activity and exercise in chronic kidney disease**

There is now irrefutable evidence supporting the importance of exercise and physical activity in the general healthy population and for the management of chronic disease. In healthy individuals, physical activity plays a crucial role in the prevention of non-communicable diseases such as: coronary heart disease (Berlin and Colditz, 1990), obesity (Lakka and Bouchard, 2005), type 2 diabetes (Laaksonen et al., 2005) and Alzheimer's disease (Rovio et al., 2005). Whereas, in the chronic disease population physical activity is essential to managing the primary disease, and preventing further deterioration (Climstein and Egger, 2017). However, the prescription of exercise and provisions provided for CKD patients is markedly less than other chronic diseases (Barcellos et al., 2015, Smith and Burton, 2012).

### **1.4.1 Benefits of regular physical activity and exercise in CKD**

#### **1.4.1.1 Physical activity benefits**

Observational studies have shown associations between higher levels of physical activity and better outcomes in non-dialysis CKD participants. In the first of two observational studies, Beddhu et al. (2009) reported improved survival amongst

physically active patients in comparison to a reference group of physically inactive patients based on self-reported frequency of physical activities, amongst a cohort of 906 non-dialysis CKD participants (eGFR<60ml/min/1.73m<sup>2</sup>). Following this, in a smaller cohort of non-dialysis CKD patients Beddhu et al. (2015) went on to report associations between objectively measured time spent doing light, moderate, and vigorous physical activity and mortality. The authors reported lower mortality amongst patients performing light intensity physical activity, however, moderate-to-vigorous activity conferred the greatest survival benefit. Further to improved survival, other observational studies have also reported associations between higher levels of leisure time physical activity and walking with slower decline in kidney function, and a reduced risk of RRT (Robinson-Cohen et al. 2014; Chen et al. 2014).

Whilst observational studies of habitual physical activity appear to be associated with better outcomes amongst CKD participants, evidence from experimental studies is lacking with few studies investigating the effects of increasing daily physical activity levels in non-dialysis CKD patients. However, of the limited published studies in this area, benefits have been indicated from simple cost effective home-based physical activity programmes such as regular walking. Indeed, Kosmadakis et al. (2012) conducted a prospective study to compare the benefits of regular walking in 40 CKD patients stages 4-5. Participants were allocated to intervention (n=20) or control (n=20), with the intervention group being instructed to walk 5 times a week for approximately 30 minutes for a 6-month period, whilst controls received normal care. The authors reported that 6-months of regular walking conferred benefits to exercise tolerance, weight loss, cardiovascular health, QoL, symptoms, and blood pressure control in comparison to the control participants. Benefits were evidenced within 1 month of walking and sustained for the remainder of the study. Moreover, a later analysis of samples collected from participants conducted by Viana et al. (2014) demonstrated further major cardio-protective benefits via the anti-inflammatory effect of walking.

#### **1.4.1.2 Exercise benefits**

In contrast, a number of small studies have investigated the use of exercise interventions in CKD populations. Whilst much of the research has been conducted exclusively in dialysis patients (Painter et al. 1986, Smart & Steele 2011, Cheema & Singh 2005),

more recently work has been undertaken to determine the benefits of exercise in CKD at an earlier stage. Indeed, there are now several systematic reviews and meta-analyses reporting significant beneficial effects of exercise on physical fitness, markers of cardiovascular risk including blood pressure and inflammation, depression, and patient QoL among non-dialysis CKD patients (Heiwe & Jacobson, 2011; Heiwe & Jacobson, 2014; Barcellos et al., 2015). Therefore, the potential of exercise to address a number of complications of CKD makes it an interesting and theoretically important treatment for patients with earlier stages of CKD (Gould et al., 2014; Clyne, 2004).

The majority of studies included in the aforementioned meta-analyses investigated supervised aerobic exercise of moderate to high intensity performed 3-4 times per week over relatively short periods (<12months). This is reflected in position statements published by the Swedish National Institute of Public Health (2012) and Exercise and Sport Science Australia (2013) advocating performing regular aerobic exercise (3-4x/week) at a moderate intensity ( $\geq 70\%$   $\text{VO}_{2\text{peak}}$ ) with the addition of resistance exercise to improve muscle strength and function. However, these recommendations are based on small scale randomised controlled trials (RCTs) that are at high risk of bias and are underpowered to detect important effects. Therefore, the optimal mode and dose of exercise to improve outcomes in CKD participants is currently unknown.

#### **1.4.1.3 Clinical guidelines**

Current national guidelines (NICE, 2014) for the management and treatment of CKD, state that patients should be encouraged to take exercise, whilst international guidelines by The Kidney Disease Improving Global Outcomes Guidelines (KDIGO) recommend, that CKD patients should engage in an exercise programme that is compatible with cardiovascular health for 30 minutes on 5 days of the week (Kidney Disease: Improving Global Outcomes Blood Pressure Work, 2012). However, these guidelines have been described as broad and lacking in sufficient detail to allow for the effective prescription of exercise in CKD populations (MacKinnon et al., 2015).

In comparison, no prescription guidelines exist for daily physical activity recommendations in patients with CKD and much of the evidence base for the safety and effectiveness of physical activity has in fact been derived from supervised exercise

trials (Zelle et al., 2017). Due to the nature of supervision, it is likely that patients work at a higher intensity in these trials, increasing our confidence that any increases in daily physical activity would be safe, but less is known regarding its effectiveness to produce benefits. Therefore, it is somewhat unsurprising that patients with CKD are regarded as one of the most inactive patient groups of all long-term conditions (Brawner et al., 2016). Current evidence suggests that only ~6% of patients receiving dialysis treatment are engaging in physical activity on 4-5 days of the week and approximately only 40% of non-dialysis CKD patients are sufficiently active (Zelle et al., 2017). However, to date much of this research has been conducted outside of the UK.

#### **1.4.2 Supervised vs self-directed physical activity**

Whilst there is clearly a need for a structured pathway to encourage levels of physical activity in patients with CKD, currently, this is not available within the UK. One option is to prescribe a course of supervised exercise as a short term intervention which is the basis of rehabilitation programmes in other chronic diseases e.g. COPD (British Thoracic Society Standards of Care Subcommittee on Pulmonary, 2001). Whilst attractive, the availability of such courses is inevitably limited to a set number of weeks per participant and improvements made during these programmes are often short lived with most losing the benefits within 6-24 months after discharge (Busby et al., 2014). Prescribed exercise training programmes have a number of limitations, including poor adherence after initial short lived engagement that decreases over time without supervision (Hewie and Jacobson, 2014). Exercise maintenance requires a high level of self-management and exercise self-efficacy (Bray et al., 2006), which centre-based programmes may fail to facilitate, making the transition to independent exercise challenging. However, encouraging an individual to engage in either supervised or self-directed physical activity requires the individual to make a behaviour change. Hewie & Jacobson (2014) stated that it would be of clinical importance to develop evidence based behavioural interventions that improve adherence and encourage exercise in patients with CKD.

## **1.5 Physical activity behaviour change and intervention development**

Behavioural interventions are usually multifaceted and inherently difficult to replicate, and as such are considered complex interventions. However, such interventions are now recognised in the prevention and management of many chronic diseases (Conn et al., 2008), and have the ability to improve health outcome with relatively little cost (Lindgren et al., 2007, Greaves et al., 2011). Physical activity and exercise is one such target of lifestyle intervention. However, despite there being a range of effective behaviour change interventions for the promotion of physical activity in other chronic diseases, CKD has been somewhat omitted from this research. Thus, there is little in the way of systematic evidence or guidance available to inform the development of a CKD specific intervention designed to increase levels of physical activity, something which is required but not yet commissioned in the UK.

There is now a growing appreciation for the use of theory within the development of behavioural interventions. Theories can be used to explain and predict aspects of behaviour change and further our understanding with regards to mechanisms of action (the processes through which a behaviour change technique affects behaviour) (Michie et al., 2009). Behaviour change techniques refer to the content of the intervention, and recent advancements have allowed for clearer reporting of diet and physical activity interventional content via the use of taxonomies (Michie et al., 2011). Furthermore, intervention development requires a systematic approach, which can be aided by the use of frameworks. One of the most influential includes the Medical Research Council (MRC) Framework for the Development and Evaluation of Complex Interventions (Craig et al., 2008, Craig et al., 2013), which provides a systematic approach to the development, testing, evaluation and implementation of complex interventions. The MRC Framework is considered useful for the development of behaviour change interventions, and clearly emphasises the importance of theory as does the NICE guidelines for behaviour change (NICE, 2014b). However, whilst the MRC Framework advocates the use of theory, it provides little guidance with regards to how to select a suitable theory to base the intervention on.

Behavioural epidemiology states that understanding the key influences on behaviour is a vital step to undertake prior to intervention development (Sallis et al., 2000). The Behavioural Epidemiology Framework applied to physical activity proposes a five-stage process which includes: 1) establishing links between physical activity and health, 2) developing methods for accurately assessing physical activity, 3) identifying factors that influence levels of physical activity, 4) evaluating interventions to increase physical activity and 5) translating research into practice (Sallis et al., 2000). Understanding the associations between health and physical activity and determining current physical activity levels, is an essential first step in demonstrating a patient need for an intervention. Correlates of physical activity then build upon this and can help to identify potentially modifiable factors that can then be targeted via suitable interventions (Owen et al., 2005).

This area is under researched among CKD patients not requiring RRT. Although, this is undeniably a step that has been taken in other long term conditions that now have clear commissioned pathways to helping patients increase their levels of physical activity. For example within the type 2 diabetes literature common correlates of physical activity include: biological (body mass index, age, gender, and disease status); psychological (self-efficacy, perceived barriers and perceived behavioural control) and environmental factors (social support, availability of facilities and weather) (Heiss and Petosa, 2014). While there may be some overlap between correlates of physical activity among long term conditions, there is also clear difference between the conditions which may confound the findings. The most prominent being the mechanistic effect of physical activity on the primary causes of disease which may influence how patients view exercise and physical activity as a treatment. Evidence suggests that in the majority (82%) of patients with coronary heart disease, effects of the disease can be regressed through lifestyle changes (Ornish et al., 1990). Similarly, intensive lifestyle interventions have been shown to lead to partial remission for obese patients with type 2 diabetes (Gregg et al., 2012). Furthermore, exercise adherence has been shown to be associated with perceptions that it could improve diabetes and prevent heart problems (Broadbent et al., 2011). In contrast, only a small minority of studies have linked exercise to improved eGFR in CKD, and the evidence remains ambiguous (Gould et al., 2014). However, as described above regular exercise and physical activity has many benefits for patients with CKD. Therefore, further research is required to determine

potential correlates of physical activity and develop an understanding of the patient perspective of exercise, prior to the development of a physical activity intervention.

## **1.6 Conclusions**

- CKD is associated with many complications including CVD, muscle wasting, poor physical function and mental health disorders such as anxiety and depression.
- Physical activity has the potential to positively impact on many of these complications, however, no structured pathways exist to encourage CKD patients to be active, and as such the majority lead insufficiently active lifestyles.
- Supervised exercise is the cornerstone to many successful rehabilitations programmes in other chronic diseases, however, programmes are limited to a set number of weeks, require many resources to run and patients often lose the benefits after completion due to no maintenance plan.
- On the other hand, a lifestyle programme encouraging physical activity may provide a low-cost alternative, whereby patients are equipped with the required knowledge and skills to be able to increase levels of physical activity in their own environment.
- Whilst this type of programme has been shown to be beneficial in other patient groups, little is known about the best way to encourage physical activity in patients with CKD.



## **1.7 Thesis objectives**

The overall aim of this thesis is to report the development of a theory driven, evidence based and self-directed behaviour change intervention designed to increase levels of physical activity in patients with CKD not requiring RRT. My intention is to present a detailed account of intervention development, from identifying an evidence base (Chapters 2 & 3), exploring patient perspectives of exercise (Chapter 4), developing a physical activity behaviour change intervention (Chapters 5) and finally assessing the feasibility of the proposed intervention and study trial (Chapter 6). This thesis applied a mixed methods approach to the development of the intervention and aimed to highlight the importance of co-design through collaborations with Public and Patient Involvement (PPI) groups and the necessity of qualitative research at all stages of development to ensure that the users voice is central and kept at the heart of the development process.

Below I outline the intentions of each chapter:

Chapter 2: Details a cross-sectional study, designed to explore self-reported levels of physical activity in patients with CKD stages 1-5 not requiring RRT living in the UK. The prevalence of physical inactivity is reported in relation to demographics, health and clinical status, physical function, stage of change and self-efficacy. Further analysis investigated correlates of meeting physical activity recommendations.

Chapter 3: Reports follow-up data from the cross-sectional study reported in Chapter 2, and investigated the association between walking behaviours and survival among CKD patients stages 1-5 not requiring RRT.

Chapter 4: Explored the beliefs, motivations, and barriers held by patients with CKD towards exercise. Furthermore, this study sought to elicit the patient perspective regarding a future physical activity behaviour change intervention, highlighting motivational strategies and suggested resources to be incorporated.

Chapter 5: Details the rationale and development of an intervention designed to increase levels of physical activity in patients with CKD stages 1-5. This work was informed by the MRC Framework for the Development of Complex Interventions and the Person-Based Approach. Qualitative methods were utilised in the planning (Chapter 4), design and development of the intervention to produce a working model. In line with the Person-Based Approach, the intervention was designed using psychological theory and proven behaviour change techniques, in collaboration with a PPI group and expert panel. The structured group based education part of the intervention was then taken through a number of user testing rounds, with the sessions being iteratively updated based on patient feedback.

Chapter 6: Reports a before and after trial designed to examine the feasibility of Physical Activity Changing Together (PACT), a structured group education programme designed to increase levels of physical activity in patient with CKD. The final study consists of measures of physical activity, physical function, quality of life, anthropometrics, knowledge and psychological measures targeted within the intervention. Participants were then re-assessed after 8 weeks of home-based physical activity and invited to attend a semi-structured interview to explore their experience of the intervention in greater depth.

Chapter 7: This final chapter concludes the thesis with a summary of the main findings of each of the studies presented, a discussion of the limitations, consideration of the implications and future directions.

# Chapter 2

## Prevalence and Correlates of Physical Activity in CKD

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This chapter reports the results of the QCKD study: Physical activity opinions in kidney patients (Trial registry number: DOI 10.1186/ISRCTN87066351), a mixed methods cross-sectional study of habitual levels of physical activity in patients with CKD. The current chapter investigates levels of habitual physical activity and correlates associated with meeting physical activity guidelines among CKD patients not requiring RRT.

### **Statement of originality**

Data collection by the candidate preceded this PhD. However, after PhD enrolment data collection was expanded to multiple centres in the UK, for which the candidate provided on-going support and advice for all centres involved. The candidate undertook collation of the databases and all subsequent analysis.

## **1.2 Introduction**

### **2.1.1 Prevalence of physical inactivity in chronic kidney disease**

The promotion of physical activity has received much attention within the realm of chronic disease and is now considered integral to the prevention and management of many long-term conditions (Bauman et al., 2012). However, in contrast to many chronic diseases, physical inactivity has only more recently been implicated as a risk factor for the development of CKD (Bharakhada et al., 2012) and acknowledged as an indicator of adverse outcomes (Beddhu et al., 2009). Currently, no specific pathways of care exist to support CKD patients to increase their level of physical activity, leaving provisions in this area lacking in comparison to other long term conditions including CVD and COPD (Smith and Burton, 2012). However, despite the slow integration of physical activity into routine care, it is recommended in international guidelines that CKD patients engage in physical activity that is compatible with cardiovascular health on most days of the week (Kidney Disease: Improving Global Outcomes Blood Pressure Work, 2012). Regular physical activity has been shown to have numerous benefits including cardio protection (Viana et al., 2014), improved exercise tolerance and QoL (Kosmadakis et al., 2012), and increased survival in patients with CKD (Beddhu et al., 2009). Despite the benefits and guideline recommendations, the current evidence suggests that only 5.7% of CKD patients receiving dialysis treatment are engaging in physical activity on 4-5 days of the week (Tentori et al., 2010). Similarly, it is widely assumed that patients with CKD not requiring RRT also lead insufficiently active lifestyles, however, the evidence is somewhat variable with studies reporting between 6.5-50% of patients achieving recommended levels of physical activity (Beddhu et al., 2009, Robinson-Cohen et al., 2013, Fassett et al., 2009). Much of this work to date has been conducted internationally, and far less is known regarding habitual physical activity levels of non-dialysis CKD patients residing in the UK.

### **2.1.2 Predictors of physical inactivity**

Moreover, understanding correlates of physical activity is essential to ensuring a strong evidence base to inform the planning, design, and development of behavioural interventions, as indicated by the MRC Framework for the Development and Evaluation of Complex Interventions (Craig et al., 2013). Bauman et al. (2012) identified nine systematic reviews which aimed to explore correlates and determinants of physical activity among non-clinical adult cohorts. Correlates were defined as associations identified between variables of interest and behaviour and are often identified from cross-sectional or longitudinal studies and used to generate hypotheses for future research or intervention. Whereas, determinants were classified as causal factors of the behaviour identified from the manipulation of a variable within a quasi-experimental or randomised controlled trial (RCT) study design. The most consistent correlates of physical activity identified were health status and self-efficacy, which were reported as correlates in four of seven systematic reviews, and determinants in one of two reviews (Bauman et al., 2012). Personal history of exercise and intention to exercise were also relatively consistent predictors of physical activity and were identified as correlates in two systematic reviews and determinants in one. Stage of change was identified as a correlate in one review and a determinant in another. Other personal and demographic factors such as older age, sex (male), weight, ethnic origin, education level, perceived effort and social support were correlates but not determinants of physical activity.

In contrast, the exact correlates of physical activity among patients with CKD are not fully understood. A number of studies have explored factors associated with physical activity in CKD patients requiring RRT (haemodialysis treatment or kidney transplant), with the most commonly reported correlates including age (Avesani et al., 2012, Bossola et al., 2014, Cobo et al., 2015, Johansen et al., 2000, Plantinga et al., 2011, Panaye et al., 2015, Patterson et al., 2014), body mass index (BMI) (Avesani et al., 2012, Bossola et al., 2014, Johansen et al., 2000), haemoglobin (Cobo et al., 2015, Zamojska et al., 2006), physical function (Tentori et al., 2010, Gordon et al., 2010) co-morbidities (Tentori et al., 2010, Avesani et al., 2012, Panaye et al., 2015), previous history of physical activity (Pakpour et al., 2011, Rosa et al., 2015) and self-efficacy (Gordon et al., 2010, Patterson et al., 2014). However, the studies indicated above differed with regards to the definition of “active”, and the assessment of physical

activity making it difficult to determine the most consistent correlates associated with meeting physical activity guidelines. Further work is now required in the form of a high-quality systematic review. Very little is known regarding the correlates of physical activity in non-dialysis CKD patients. This is an area which deserves attention due to the potential benefits of physical activity to improve or preserve the health and QoL of patients with CKD, via early intervention.

The aim of this study was to provide further evidence about the magnitude of physical inactivity in non-dialysis CKD patients, adding a large UK cohort to the literature; and to investigate potential correlates of meeting physical activity guidelines.

## **2.2 Methods**

The work described in this chapter emerges from a large multi-centre cross-sectional study titled “Physical Activity Opinions in Kidney Patients” which is registered with the ISCRTN (trial number: ISRCTN87066351). The larger study involves the exploration of habitual physical activity, leisure time exercise and psychological determinants of exercise in CKD patients across all stages of the disease trajectory including CKD stages 1-5 not requiring RRT, dialysis patients and patients with a renal transplant. The work presented in this chapter describes the findings for patients with CKD stages 1-5 not requiring RRT.

### **2.2.1 Cross-sectional study**

A cross-sectional study design was used to explore the prevalence of physical inactivity in patients with CKD stages 1-5 not requiring RRT. This design allowed for a measure of self-reported physical activity at a single time point, whereby this information could then be explored in relation to other factors and potential correlates of physical activity including demographics, health status, physical function and psychological predictors of exercise.

### **2.2.2 Ethics**

This study REC 12/EM/0184 received a favourable opinion by the National Research Ethics Service (NRES) Committee East Midlands—Northampton on 13 June 2012. Local approval for this study CSP:105209 was authorised on the 31/07/2012.

### **2.2.3 Setting**

Participants were recruited from a total of seven secondary or tertiary National Health Service (NHS) nephrology outpatient clinics from across the East Midlands and Greater Manchester renal networks in the United Kingdom. Recruitment took place between September 2012 and December 2015.

### **2.2.4 Participants**

Adult patients ( $\geq 18$  years) who were under the care of a nephrologist and attending a nephrology outpatient clinic appointment, with CKD stages 1-5 not requiring RRT were eligible for inclusion.

### **2.2.5 Recruitment**

Participants were approached in the waiting room by a researcher and provided with a patient information sheet. The researcher went through the information sheet in detail with the participant. If happy to continue participants were asked to provide written informed consent to allow the researcher to access medical records and to extract relevant clinical information. Participants were also provided with the option to complete the survey anonymously.

### **2.2.6 Variables**

Participants were asked to complete the Leicester Kidney Patient – Physical Activity Questionnaire (LKP-PAQ), which included a demographics sections, physical activity measure, self-reported physical function and psychological predictors of physical activity. The survey pack took approximately 10 minutes to complete. Where possible participants were encouraged to complete the survey pack by themselves. However, if this was not possible the researcher or an accompanying relative or friend delivered the questionnaire as an interview. When delivering the questionnaire as an interview relatives were asked to remain neutral when delivering the questions.

#### **2.2.6.1 Self-reported physical activity**

The General Practice Physical Activity Questionnaire (GPPAQ) was used to assess if participants were meeting the current recommendation for 30 minutes of moderate activity on 5 days of the week (National Collaborating Centre for Nursing and Supportive Care UK, 2008). The measure provides a simple 4 – level physical activity index ranging from “inactive” to “active”, which can be mapped to relevant codes that then offer an insight into what physical activity intervention may be most appropriate. Individuals categorised as less than “active”, should receive advice pertaining to government recommendations of 30 minutes of moderate physical activity on 5 days of the week. Therefore, participant’s physical activity was deemed sufficient if they were considered active as defined by the GPPAQ. Participants who were classified by the GPPAQ as: moderately active, moderately inactive or inactive were defined as insufficiently active. The GPPAQ questionnaire is scored as follows: inactive = sedentary job and no physical exercise or cycling; moderately inactive = sedentary job and some but <1 hour of physical exercise or cycling or standing job and no physical exercise or cycling; moderately active = sedentary job and 1-2.9 hours of physical exercise and or cycling, standing job but <1 hour of physical exercise and or cycling, physical job and no physical exercise or cycling; and active = sedentary job and at least 3 hours of physical exercise/ cycling, standing job and 1-2.9 hours of physical exercise or cycling or physical job and some but <1 hour of physical exercise and or cycling or heavy manual job.



The GPPAQ scoring protocol is based on employments status, physical exercise and cycling, which was deemed a potential limitation for assessing physical activity levels. To overcome this all questionnaires were re-coded to include walking in the scoring protocol of physical activity level (GP-WALK). The GP-WALK differed from the original GPPAQ score in that participants who self-reported  $\geq 3$  hours of walking per week, and self-reported a walking speed of  $\geq 3$ mph (steady, brisk or fast) were re-coded as active. The cut-offs were informed by the physical activity compendium, where walking at a pace of 3mph is reported as moderate intensity (Ainsworth et al., 2011). Therefore, walking for 3 or more hours (180 minutes) per week is more than that required to meet the government recommendation of 150 minutes of moderate intensity physical activity per week.

#### **2.2.6.2 Self-reported physical function**

Self-reported physical function was measured by the Duke Activity Status Index (DASI) a brief 12-item self-administered questionnaire used to assess the participant's ability to perform a number of activities of daily living (ADLs) (Hlatky et al., 1989). Participants were asked to respond either "yes" or "no" to their perceived capability of partaking in ADLs. A "no" is assigned a value of 0, whereas a "yes" response is assigned a metabolic equivalent of task (MET) value which is weighted to the amount of energy expended to perform the activity. The scores are then summed to produce a continuous measure ranging from 0–58.2 indicating a total of summed MET scores. The DASI has been validated in many chronic disease populations including CKD (Ravani et al., 2012).

#### **2.2.6.3 Exercise self-efficacy**

The exercise self-efficacy questionnaire developed by Marcus et al. (1992) was used to assess an individual's confidence to regulate their exercise behaviour even in the face of potential barriers (weather, time, mood, tiredness and vacation). Self-efficacy is rated on a 5-point Likert Scale, 1 indicating "not confident at all" to 5 indicating "very confident". The mean score is then used as a measure of exercise self-efficacy. The exercise self-efficacy questionnaire has been used previously in other chronic disease

populations and has been shown to have a good reliability of 0.90 (Marcus et al., 1992) and internal consistency scores of 0.85 (Marcus and Owen, 1992).

#### **2.2.6.4 Stage of change**

The Stage of Change Questionnaire (SOCQ) consists of 5 items representing the Stages of Change model (pre-contemplation, contemplation, preparation, action, and maintenance) proposed by Prochaska and DiClemente (1982) as part of the Transtheoretical Model (TTM). The pre-contemplation stage refers to an individual who is not currently engaging in exercise behaviour and has no intention to do so. Contemplation describes an individual who currently is not exercising but may have intentions to do so in the future. Preparation refers to someone who is thinking about exercise and has started to perform limited amounts of activity not on a regular basis. Action describes someone who is currently meeting physical activity recommendations as described by the American College of Sports Medicine (ACSM) guidelines (Marcus et al., 1992, Pate et al., 1995). Maintenance describes an individual who has been meeting the physical activity guidelines for 6 months or more. Participants were classified as either being in a receptive stage of change (contemplation, preparation, action or maintenance) or a non-receptive stage of change (pre-contemplation).

#### **2.2.6.5 Demographic, clinical parameters and co-morbidities**

Demographics included questions about: sex, age, smoking status, and ethnicity. The information recorded about ethnic categories was obtained by asking the patients using the ethnic category default codes provided by the NHS Information Standards Board. With written consent obtained researchers extracted laboratory results including estimated Glomerular Filtration Rate (eGFR) and haemoglobin from electronic hospital records. Kidney function was measured using the “Modification of Diet in Renal Disease Formula” which provides an estimation of kidney function based on age, sex, race and serum creatinine (Levey et al., 1999). Co-morbidities were recorded based on a composite of patient self-report and medical notes.

### 2.2.7 Statistical analysis

All statistical analyses were performed using the statistical package IBM SPSS statistics for Windows, version 22 (IBM Corp., Armonk, N.Y., USA). Statistical significance was accepted as a p-value of  $<0.05$ . Descriptive statistics were used to describe patient characteristics (see Table 2.1). Dichotomous and categorical variables were presented as percentages and continuous variables were presented as median (25<sup>th</sup>-75<sup>th</sup> interquartile range [IQR]) for non-normally distributed data. Participant characteristics were expressed separately for participants deemed to be meeting physical activity recommendations versus those who were insufficiently active as defined by the GPPAQ.

Univariate and multiple regression analyses (logistic or binomial) were conducted to explore individual (crude) associations between physical activity status and demographics (age, sex, ethnicity, smoking status), clinical parameters (eGFR and haemoglobin), co-morbidities (diabetes mellitus, hypertension and cardiovascular disease), physical function, exercise self-efficacy and receptive stage of change. Physical activity status was coded as a dichotomous variable, insufficient physical activity was coded as 0 and sufficient physical activity was coded as 1. The SOCQ and exercise self-efficacy were also coded as dichotomous variables. Stages of change was coded as 0=non-receptive (pre-contemplation) or 1=receptive (contemplation, preparation, action and maintenance). Self-efficacy was coded as 0=low and 1=high self-efficacy as determined by the median. Variables associated with physical activity status were then entered (forced entry) into a multiple logistic regression to identify independent correlates associated with partaking in sufficient weekly physical activity. The model was adjusted for all variables that were significantly associated with physical activity status. Results are expressed as odds ratio (OR) and 95% confidence intervals; and adjusted odds ratio (AOR) and 95% confidence intervals for the multiple regression. The GPPAQ was then re-coded into a GP-WALK score to classify participants walking for 3 or more hours per week at a pace of  $\geq 3$ mph as sufficiently active. This new scoring protocol was introduced to address the potential limitations of the current GPPAQ scoring, which is confounded for older adults by retirement status and the predominate focus being on gym work and cycling modes of exercise. Within the logistic regression models, an odds ratio of less than 1 represents a reduced

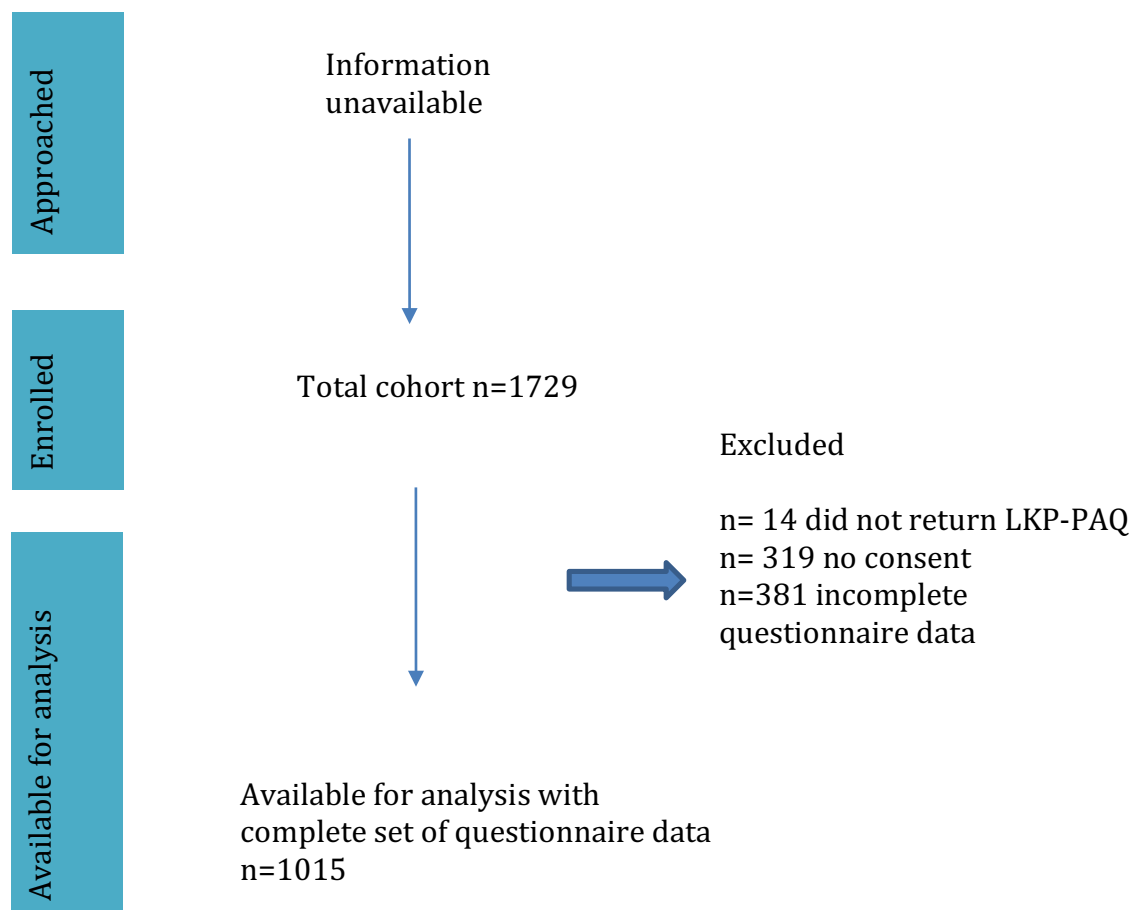
likelihood of being classified as meeting the recommended level of physical activity. For continuous variables, odds are reported per 1 unit change. An odds ratio of greater than 1 indicates increased odds of being classified as sufficiently active. Participants without completed survey packs were excluded from the analysis and missing data for other variables were analysed list wise. Missing data is discussed in the results section. No data imputations were performed and the number of participants included in each analysis is reported.

## 2.3 Results

### 2.3.1 Study Sample

A total of 1715 participants returned the LKP-PAQ survey, and of those 1396 (81.4%) gave written consent for the researchers to access their medical records to extract relevant clinical information. Non-consenting participants were significantly ( $P<0.05$ ): older median (IQR) age (years): 73 (56-80) vs 67 (56-80); and reported significantly lower levels of physical function (summed METs): 23.45 (12.45 – 39.45) vs 29.45 (15.95 – 50.20). Non-consenting participants were excluded from further analyses.

**Figure 2.1 Consort diagram showing participant flow through study**



### **2.3.2 Missing data analysis**

Of the consenting patients, the LKP-PAQ was fully completed by 1015 (73%) of participants, of which are included in all further analyses. Participants with a full data set were significantly ( $p < 0.05$ ): younger median (IQR) age (years): 65 (49-76) vs 71 (56-79); of a predominantly white ethnic background (92% vs 86%), and had lower levels of comorbidity including diabetes (29% vs 36%) and cardiovascular disease (22% vs 29%). No differences were observed between sex, eGFR, hypertension or smoking status. Missing values for co-variables were  $< 5\%$ , except for ethnicity, which had 8.5% missing data. Little's missing completely at random (MCAR) test was conducted for all co-variables to determine the type of missing data. The test was non-significant ( $p = 0.255$ ) indicating that there is evidence for the data to be missing completely at random, meaning that missing data should not influence the data results. Therefore, no missing data were imputed.

### **2.3.3 Patient characteristics**

Patient characteristics are described in full and by physical activity status in Table 2.1. Participants were regarded as meeting physical activity guidelines if they were deemed as active by the GPPAQ, whereas participants classified as inactive, moderately inactive or moderately active were not deemed to be meeting physical activity guidelines. For the total population ( $n = 1015$ ), the median (IQR) age was 65 (49-76) years, with over half (55.8%) of participants being male. The median (IQR) eGFR was 31 (21-52) ml/min/1.73 m<sup>2</sup> indicating that most participants were between CKD stages 3-4.

**Table 2.1 Patient characteristics**

Patient Characteristics	Available for analysis	Total population n=1015	Not meeting PA guidelines n=870	Meeting PA guidelines n =145
Age (y)	n=1014	65(49-76)	67 (53-78)	47(38-58)
Sex	n=1015			
Males, n (%)		564 (56)	459 (81)	105 (19)
Females, n (%)		451 (44)	411 (91)	40(9)
Ethnicity, n (%)	n=929			
White,		851 (92)	734 (86)	117 (14)
Non-white		78 (8)	61 (78)	17 (22)
Smoking Status, n (%)	n=975			
Never smoked		406 (42)	337 (83)	69(17)
Ex- smoker		443 (45)	391 (88)	52(12)
Current		126 (13)	107 (85)	19(15)
*eGFR [mL/min/1.73m <sup>2</sup>	n=979	31 (21-52)	29 (21-46)	47 (23-75)
*CKD stage, n (%)	n=979			
1		80 (8)	59(74)	21 (26)
2		125(13)	90(72)	35 (28)
3		308 (32)	267(87)	41 (13)
4		368 (38)	334(91)	34 (9)
5		98 (10)	88(90)	10 (10)
*Hb [g/dl]	n=976	124 (18)	122(17)	131(18)
Diabetes, n (%)	n=966			
No		691 (72)	564 (82)	127 (18)
Yes		275 (28)	260 (95)	15 (5)
CVD, n %				
No	n=964	748 (78)	616 (82)	132 (18)
Yes		216 (22)	206 (95)	10 (5)
Hypertension, n (%)				
No	n=972	291 (30)	232 (80)	59 (20)
Yes		681 (70)	597 (88)	84 (12)
*DASI	n=1015	32.2 (18.95-50.20)	27.2 (15.95-44.7)	58.2 (50.7-58.2)
*SOCQ, n (%)	n=1015			
Pre-contemplation		346 (34.1)	340(98)	6(2)
Contemplation		199 (19.6)	188(94)	11 (6)
Preparation		191 (18.8)	166(87)	25 (13)
Action		50 (4.9)	36(72)	14(28)
Maintenance		229 (22.6)	140 (61)	89(39)
*SEQ	n=1015	2.6 (1.6-3.4)	2.4(1.4-3.2)	3.4(2.6-3.8)

\*Abbreviations: eGFR (estimated glomerular filtration rate [mL/min/1.73m<sup>2</sup>]); Hb (haemoglobin [g/dl]); DASI (Duke Activity Status Index [DASI score 0-58.2]); SOCQ (Stages of change questionnaire); SEQ (self-efficacy questionnaire, [average score across 5 barriers questions on a Likert scale of 1-5). Percentages for categorical variables denote percentage of total population for each patient characteristic across sufficient and insufficient physical activity status.

### 2.3.4 Prevalence of physical inactivity

The GPPAQ was used to classify participants to 1 of 4 physical activity indexes: inactive (n=675, 66.5%); moderately inactive (n=87, 8.6%); moderately active (n=108, 10.7%) and active (n=145, 14.3%). Table 2.2 reports the number of participants participating in the differing physical activities as indicated within the GPPAQ. Walking was the most frequently reported type of physical activity, with 58.5% of participants walking for at least 1 hour a week. In contrast, gym work and cycling were the least frequently reported types of physical activity, with only 15.8% and 4.8% of participants engaging in these activities for at least 1 hour per week respectively. The prevalence of physical inactivity was high, with 85.7% of participants not meeting the recommended minimum level of physical activity.

**Table 2.2 Frequency of activities performed in non-dialysis CKD patients**

	Number of participants	None	<1 h	1-3 h	>3h
Gym, n (%)	1000	775 (78)	67(7)	98(10)	60(6.0)
Cycling, n (%)	990	902 (91)	40 (4)	32 (3)	16 (2)
Walking, n (%)	1004	176 (18)	241 (24)	270 (27)	318(32)
House, n (%)	1004	223(22)	231(23)	248(25)	302(30)
Gardening, n (%)	999	559(56)	155(16)	150(16)	135(14)

Abbreviations: h= hours per week



### **2.3.5 Correlates of physical activity**

#### **2.3.5.1 GPPAQ classification**

Logistic regression analysis was undertaken to identify correlates of achieving sufficient levels of physical activity as classified by the GPPAQ (see Table 2.3). Increasing age, the presence of co-morbidities including CVD, hypertension and diabetes mellitus were all associated with lower odds of achieving sufficient levels of physical activity. Whereas, male sex, better clinical parameters including eGFR and haemoglobin; better physical function, higher self-efficacy and being in a receptive stage of change were associated with increased odds of being classified as sufficiently active. Ethnicity (white vs non-white) and smoking status (smoker vs non-smoker) were not associated with physical activity classification ( $p=0.06$ ,  $p=0.81$ ).

A multiple logistic regression was performed to determine which correlates may be independently associated with meeting the physical activity guideline recommendations. Adjusted odd ratios for physical activity are shown in Table 2.2. The multiple logistic regression model was statistically significant,  $\chi^2(10)=250.93$ ,  $p < 0.001$ , explaining 42% (Nagelkerke  $R^2$ ) of the variance in meeting or not meeting physical activity guidelines, and correctly classified 86.2% of cases. Increasing age was associated with a reduced likelihood of exhibiting sufficient physical activity; but male sex, better physical function and higher levels of self-efficacy were associated with an increased likelihood of sufficient physical activity.

#### **2.3.5.2 GPPAQ Walk (GP-WALK) classification**

A further investigation was carried out to identify correlates associated with meeting physical activity recommendations through walking only. For this scoring protocol, self-reported walking of at least 3 hours at a walking speed of  $\geq 3$  mph was considered as meeting physical activity guideline recommendations. The inclusion of walking allowed for a further 184 participants to be classified as meeting physical activity guideline recommendations. Classification of physical activity by walking reduced the prevalence of physical inactivity from 85.3% (original GPPAQ scoring) to 67.6% (GP-WALK scoring).

Participants (n=62) meeting physical activity recommendations through other exercise modes only e.g. gym work or cycling; and (n=6) participants with missing walking data were excluded from the GP-WALK analysis. Data were available for 947 participants. Overall, 267 participants (28.2%) were meeting physical activity guidelines through walking, whereas 680 participants (71.8%) were classified as insufficiently active. Participants meeting the physical activity guidelines through walking had a median (IQR) age of 53 (38-68), and a median (IQR) eGFR 27 (23-73).

Logistic regression analysis was performed to identify individual (crude) predictors associated with meeting physical activity recommendations as classified by the GP-WALK (Table 2.3). Increasing age and the presence of co-morbidities were associated with a reduced likelihood of meeting physical activity recommendations. However, better physical function and clinical parameters; higher levels of self-efficacy and receptive stage of change were associated with an increased likelihood of being classified as physically active. Smoking status, sex, and ethnicity were not associated with the GP-WALK classification of physical activity. The multiple logistic regression model using the GP-WALK classification was significant  $\chi^2(9) = 356.68, p < 0.001$ , and explained 50% (Nagelkerke  $R^2$ ) of the variance in the meeting or not meeting physical activity guidelines, and correctly identified 81% of cases. Associations between meeting physical activity guidelines and the following predictor variables: age, physical function, and self-efficacy, remained stable in the GP-WALK analysis (Table 2.3).

**Table 2.3 Crude and multiple logistic regression for meeting physical activity for GPPAQ classification and re-coded GP-WALK classification.**

Predictor variables (Reference group)	Meeting PA recommendations GPPAQ (Crude Logistic Regression)			Meeting PA recommendations GPPAQ <sup>a</sup> (Multiple Logistic Regression)			Meeting PA recommendations Walking (Crude Logistic Regression)			Meeting PA recommendations Walking <sup>b</sup> (Multiple Logistics Regression)		
	OR (95% CI)	P-Value	AOR (95% CI)	P-Value	OR (95% CI)	P-Value	AOR (95% CI)	P-Value	AOR (95% CI)	P-Value	AOR (95% CI)	P-Value
Age (years)	0.95 (0.94-0.96)	p<0.001**	0.98 (0.96, 0.99)	0.02*	0.95(0.95,0.96)	p<0.001**	1.00 (0.99,1.01)	0.86				
Sex (Female)	2.35 (1.60-3.46)	p<0.001**	2.81 (1.68, 4.71)	0.001**	1.32(0.99,1.76)	0.06	-	-				
Ethnicity (Non-white)	1.75 (0.99,3.10)	0.056	-	-	1.07 (0.62,1.86)	0.80	-	-				
Smoking (Smoker)	1.07(0.63, 1.81)	0.81	-	-	0.72(0.45,1.14)	0.16	-	-				
DASI [Summed METs, 0-58.2]	1.12 (1.09-1.14)	p<0.001**	1.08 (1.05,1.11)	P<0.001**	1.10(1.09,1.12)	p<0.001**	1.09(1.07,1.11)	P<0.001**				
SEQ (Low self-efficacy)	1.72 (1.48-2.00)	p<0.001**	1.98 (1.23, 3.20)	0.005*	4.81 (3.54, 6.55)	p<0.001**	2.16 (1.46,3.20)	P<0.001**				
SOCQ (Non -receptive stage)	14.86 (6.49-34.03)	p<0.001**	2.26 (0.90,5.63)	0.081	6.34 (4.24,9.49)	p<0.001**	1.24(0.73,2.10)	0.43				
eGFR (mL/min/1.73 m <sup>2</sup> )	1.02 (1.01-1.03)	p<0.001**	0.99 (0.99,1.01)	0.829	1.02(1.02,1.03)	p<0.001**	0.99 (0.99, 1.00)	0.20				
Hb (g/dl)	1.03 (1.02-1.04)	p<0.001**	1.002 (0.99, 1.02)	0.736	1.03(1.02,1.04)	p<0.001**	1.00(0.99, 1.02)	0.53				
DM (No)	0.26 (0.15,0.45)	p<0.001**	0.68 (0.34, 1.34)	0.302	0.32 (0.22, 0.47)	p<0.001**	0.86(0.52,1.42)	0.56				
HTN (No)	0.55 (0.38,0.80)	0.002*	1.005 (0.62, 1.63)	0.982	0.54(0.40,0.74)	p<0.001**	0.77(0.50,1.17)	0.22				
CVD (No)	0.23 (0.12, 0.44)	p<0.001**	0.40 (0.33, 1.56)	0.397	0.35(0.23,0.53)	p<0.001**	1.08 (0.62,1.87)	0.80				

Abbreviations: DASI (Duke activity status index); SEQ (Self-efficacy questionnaire); SOCQ (stage of change questionnaire [respective stage vs non-receptive stage]); eGFR (estimated glomerular filtration rate); Hb (haemoglobin); DM (Diabetes mellitus); HTN (hypertension); CVD (Cardiovascular disease).

<sup>a</sup> Continuous variables: age, eGFR and Hb show odds ratio per unit increase.

<sup>b</sup> Model adjusted for age, sex, DASI, SEQ, SOCQ, eGFR, Hb, DM, HTN, CVD

<sup>c</sup> Model adjusted for age, DASI, SEQ, SOCQ, eGFR, Hb, DM, HTN, CVD

\*p<0.05

\*\*p<0.001

## 2.4 Discussion

This study aimed to explore habitual levels of physical activity in non-dialysis CKD patients living in the UK. Overall, we found a high prevalence of physical activity insufficiency among this cohort, with 85.3% of participants not meeting physical activity guideline recommendations. This finding corroborates the low level of physical activity previously reported among non-dialysis CKD patients (Beddhu et al., 2009, Robinson-Cohen et al., 2013).

Interestingly, the findings of this study showed that kidney function assessed by eGFR was not associated with meeting physical activity guidelines through the original scoring of the GPPAQ or GP-WALK after full adjustment. However, this finding supports that of a recent investigation into the association of daily activity and eGFR, which found no association between disease severity and physical activity levels in 110 CKD patients stages 3-5 when using objective measures (West et al., 2017). Furthermore, a recent prospective 5 year follow-up study reported no association between lower eGFR and reduced physical activity using the self-report Cambridge Physical Activity Index (Herber-Gast et al., 2015). However, in contrast, several cross-sectional studies have previously reported a positive relationship between eGFR and physical activity (Bharakhada et al., 2012, Hallan et al., 2006, Finkelstein et al., 2006). Similarly, Robinson-Cohen and colleagues (2013b) reported a 28% reduction in risk of eGFR decline among the two higher physical activity groups identified using the Four Week Physical Activity Questionnaire when compared to the lowest PA groups, in 5888 older adults participating in a study of cardiovascular health. As it stands it is difficult to draw a consensus regarding the relationship between eGFR and physical activity due to differences in activity monitoring and kidney function assessment. This area requires further interrogation; however, this is beyond the scope of this thesis.

This study did not include a healthy control group and because of this, any direct comparisons between a CKD cohort and aged matched controls are not possible. Similarly, any conjecture is hindered by the non-existent use of the GPPAQ in healthy adults in the UK. However, previous investigations undertaken in primary care have reported similar levels of insufficient physical activity (84%) when using the GPPAQ

(Ahmad et al., 2015). However, the reason for consultation was not made explicit and this population may represent patients with acute illnesses or those also managing long term conditions. Either way assessments of patient physical activity when using the GPPAQ are higher than previously reported population level data of healthy older adults (49-74 years of age) living in the UK (Townsend & Rayner, 2015). In the present study when walking was included as part of the scoring protocol (GP-WALK) results were more compatible with that of the general population. However, whilst the level of physical inactivity identified in primary care and the general population is also high, there remains a necessity to target physical inactivity among non-dialysis CKD patients. CKD has been shown to be associated with an increased risk of morbidity and mortality after adjustment for confounding variables such as age and co-morbidities (Tonelli et al., 2006, Zelle et al., 2017). Furthermore, non-dialysis CKD patients that are active have a 56% reduced risk of mortality compared to inactive patients (Beddhu et al., 2009). Therefore, irrespective of age or disease severity patients with CKD may benefit greatly from a lifestyle intervention. Furthermore, despite the low levels of physical activity indicated, the majority (65.9%) of participants were in a receptive stage of change indicating intentions to change their current level of physical activity or current attempts to do this. This is vital information for the consideration of a behaviour change intervention, as it demonstrates both a patient need and desire to become more active, and suggests that CKD patients would be receptive to a suitable physical activity intervention. However, as described in Chapter 1 this type of programme is not currently available for CKD patients in the UK.

Of those participants who did indicate some level of physical activity walking was the most frequently reported. Overall, 58.5% of participants reported walking for at least 1 hour per week. This is below the level of physical activity recommended, but it does signify walking to be a suitable type of physical activity for most patients with CKD. This finding is in line with that of the general population and other chronic disease groups, where walking is often reported as the most acceptable type of physical activity (Morris and Hardman, 1997). This is likely due to the perceived safety and high level of accessibility that walking offers. Furthermore, although not reported here, data from the DASI indicated that 85.3% of patients reported feeling functionally capable of “walking a block or two on a ground level”. Walking has previously been demonstrated to be safe and beneficial for patients with CKD (Viana et al., 2014, Kosmadakis et al., 2012), and

is often the exercise of choice advocated in self-management programmes for other chronic diseases. This includes Self-management Programmes of Activity, Coping and Education (SPACE FOR COPD) (Apps et al., 2013) and Walking Away from Diabetes (Yates et al., 2012, Yates et al., 2017).

Physical activity is regarded as a complex phenomenon, with biological, psychological, behavioural, social and environmental factors influencing an individual's behaviour (Bauman et al., 2012). The present study indicated via a multiple logistic regression several potentially important correlates of meeting physical activity guidelines in non-dialysis CKD patients, which included age, sex, physical function, receptive stage of change and self-efficacy. Whilst age and gender cannot be modified, previous work has indicated that perceptions of older age can be a barrier to engaging in physical activity among dialysis patients (Fiaccadori et al., 2014). Therefore, patients of an older age may benefit from counselling to elicit perceptions around age and physical activity, or specifically targeted information to address safe and appropriate physical activity for persons of an older age (Fiaccadori et al., 2014). However, age and sex may not be as important when considering walking activity only, as sex was not associated with meeting physical activity recommendation through walking, and age was not significant after adjustment for physical function, clinical parameters, psychological variables and the presence of co-morbidities. Furthermore, the relationship between physical function and physical activity demonstrated in both the GPPAQ and GP-WALK multiple regressions is likely bi-directional. Supervised exercise interventions have successfully demonstrated exercise to be a safe and effective treatment for increasing physical function in CKD patients not requiring RRT (Heiwe and Jacobson, 2011, Rossi et al., 2014, Gould et al., 2014). Further exploration of how these correlates of physical activity may influence patient perceptions and barriers to exercise is required to gain insight into how best to help patients overcome barriers to lead a more active lifestyle.

Of relevance when considering the development of a behavioural intervention are the psychological modifiable correlates associated with physical activity. Higher levels of exercise self-efficacy were significantly correlated with meeting physical activity guidelines via the original GPPAQ and GP-WALK classifications. Self-efficacy has previously been shown to be one of the most consistent correlates of physical activity among healthy adults (Bauman et al., 2012) and CKD patients requiring RRT (Gordon

et al., 2010, Patterson et al., 2014, Zelle et al., 2016). A recent study showed that a brief intervention consisting of a theory-led semi-structured discussion increased levels of self-efficacy and intention to exercise in patients with ESRF (Meyer et al., 2016). However, further research is now required to see if targeting self-efficacy and other social cognitive constructs may lead to an actual increase in physical activity within the CKD non-dialysis population. Exercise self-efficacy is important as the more confident one feels to overcome barriers to exercise the more likely one is to engage in the behaviour (Bandura, 2004). As physical activity or exercise needs to be performed on a regular basis to experience the benefits, the relationship between exercise self-efficacy and physical activity is likely reciprocal, whereby efficacy cognitions are influenced by both successful and failed exercise experiences (McAuley et al., 1993). Greater exercise exposure may facilitate efficacy cognitions via performance accomplishment, helping individuals to persist with their exercise even in the face of barriers (McAuley et al., 1993). Therefore, the findings of this current study in which exercise self-efficacy levels were significantly greater among participants who were sufficiently active is consistent with the Social Cognitive Theory (SCT) and the literature. SCT describes four processes to enhance self-efficacy that can be operationalised within behavioural interventions; these include mastery, vicarious experiences, verbal persuasion and perceptions of emotional and physiological response (Bandura, 2004, Lee et al., 2008). Mastery is regarded as the most influential process in changing behaviour as efficacy beliefs are influenced by both successes and failures. Therefore, exercise should initially be graded to help patients achieve small goals and feel a sense of accomplishment, whilst avoiding feelings of disappointment (Lee et al., 2008).

#### **2.4.1 Limitations**

To our knowledge this is the largest study of habitual levels of physical activity in non-dialysis CKD patients in the UK. However, it does have several limitations. Whilst the GPPAQ was developed for general clinical practice and was suitable for collecting data from a large sample population due to its simplicity and quickness to complete, it is not without its flaws. The GPPAQ is currently not validated for its use in adults over the age of 74 and has been heavily criticised for its use in primary care (Ahmad et al., 2015). When compared to objective measures of physical activity the GPPAQ showed

poor agreement and low sensitivity for identifying active patients (Ahmad et al., 2015). Furthermore, the GPPAQ scoring protocol is limited to employment status, physical exercise and cycling. With most participants being of retirement age, individuals would have had to perform at least 3 hours of physical exercise e.g. gym work or cycling to be classified as active. As walking, housework, and gardening were the most commonly reported types of physical activity, these aspects of the questionnaire may have been particularly relevant to this population. The present study looked at a walking only scoring protocol (GP-WALK) as an attempt to overcome this shortcoming of the questionnaire. However, a previous study that included walking as part of the original scoring protocol found that this modification increased the questionnaires ability to identify active participants (sensitivity), but it reduced its ability to correctly identify inactive patients (specificity) (Ahmad et al., 2015). The current study was limited with regards to its sole reliance on self-reported measures of physical activity, which are prone to recall bias, the misinterpretation of questions, and difficulties quantifying levels of energy expenditure (Painter and Marcus, 2013). The GPPAQ does not quantify energy expenditure and instead provides a 4-level physical activity index that can be dichotomised into sufficient vs non-sufficient physical activity. Therefore, a more objective assessment of physical activity e.g. 7-day accelerometry in combination with an activity diary may have enhanced the quality of this research fulfilling all the requirements for physical activity assessment including frequency, intensity, time (duration) and type. However, the purpose of this work was to identify a need for a physical activity behaviour change intervention in patients with CKD. Therefore, this work fulfilled its purpose in defining a high prevalence of physical inactivity among non-dialysis CKD patients living in the UK.

## **2.5 Conclusion**

In conclusion, few CKD patients stages 1-5 not requiring RRT are meeting the recommended level of physical activity. Despite this, the majority of participants reported being in a receptive stage of change, indicating that appropriate interventions aimed at increasing physical activity in this population may be well received and feasible to deliver. With regards to physical activity type, walking was most commonly reported. However, walking is not traditionally included in the scoring protocol of the



GPPAQ, and further work is required to determine if self-reported walking is associated with better outcomes in the context of a UK CKD population. As expected, increasing age and reduced physical function were associated with lower levels of physical activity. Although interestingly, kidney function was not an independent correlate of physical activity, and further work is required to better understand barriers to physical activity in CKD. However, as a starting point this work does highlight the potential importance of exercise self-efficacy, which was demonstrated to be an independent correlate of meeting activity guidelines. This suggests that self-efficacy may be a suitable target for intervention when promoting physical activity for patients with CKD.

The following chapter extends this work by investigating the association between walking behaviours and survival in a subset of participants recruited to the QCKD study.

# Chapter 3

## **Associations between self-reported walking behaviours and survival in patients with CKD**

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The previous chapter reported a high prevalence of physical inactivity among patients with CKD not requiring RRT. Walking was demonstrated to be the most common form of physical activity. However, the evidence regarding self-reported walking and health outcomes is limited within this population. This chapter follows on directly from the previous and sought to investigate the association between walking behaviours and survival in a subset of patients who participated in the QCKD trial.

### 3.1 Introduction

Walking has previously been defined as a “dynamic, rhythmical, aerobic activity of large skeletal muscles”, and is often cited as the most common form of exercise for men and women alike (Morris and Hardman, 1997). The Health Survey for England 2012 reported that walking was the most common form of exercise, with men reporting on average 2.7 hours of walking per week and women 2.5 hours (Townsend & Rayner, 2015). Walking likely appeals due to its high level of accessibility, with no special skills, equipment or high membership fees required. Furthermore, walking has been demonstrated to have a multitude of benefits related to reducing cardiovascular disease (Murtagh et al., 2010). A systematic review of 24 walking programmes in previously sedentary adults demonstrated that walking had a positive effect on exercise capacity, body composition (body weight, BMI and body fat) and blood pressure (Murphy et al., 2007). However, other studies have found that walking may not be sufficient to produce health benefits (Bell et al., 2010). In addition, walking has been omitted (without further integration), from the scoring protocols of questionnaires designed to assess levels of physical activity in the general UK population such as the GPPAQ (National Collaborating Centre for Nursing and Supportive Care UK, 2008). This is due to concerns over the intensity of walking and whether it is sufficient to count towards the “moderate” intensity required for health benefits as described within physical activity guidelines. The beneficial effects of walking are likely influenced by walking pace, with the ACSM recommending that individuals walk at a moderate pace to confer the greatest benefits to health (American College of Sports, 2013). This is supported by a meta-analysis that confirmed that walking pace is a better predictor of all-cause mortality than walking volume (Hamer and Chida, 2008).

The previous chapter demonstrated that walking was the most frequently performed physical activity reported by non-dialysis CKD patients living in the UK. However, whilst the benefits of regular exercise in the form of supervised aerobic gym sessions are well established (Heiwe and Jacobson, 2014, Heiwe and Jacobson, 2011, Gould et al., 2014), but walking has received less attention with few studies exploring the benefits of walking for patients with CKD. Walking can be performed for leisure, transport, as part of an individual’s occupation or exercise regime, therefore, with such

a wide spectrum; it is easy to see how walking intensity may differ depending on the purpose of the behaviour. Therefore, walking may be somewhat less intuitive to the study of exercise and its potential therapeutic role in CKD. Nevertheless, the few published studies in this area have found benefits from simple cost effective home-based walking programmes. Kosmadakis et al. (2012) conducted a prospective study to compare the benefits of walking in 40 CKD patients' stages 4-5. The intervention group was instructed to walk 5 times a week for approximately 30 minutes for a 6-month period. Improvements to exercise tolerance, weight loss, cardiovascular health, quality of life, symptoms and blood pressure medication control were made within 1 month of walking and sustained for the remainder of the study. A later analysis conducted by Viana et al. (2014) demonstrated further major cardio-protective benefits via the systemic anti-inflammatory effect of walking. Furthermore, walking duration and frequency has also been associated with increased survival and an extended time to dialysis in patients with CKD stages 3-5 not requiring RRT (Chen et al., 2014). However, this study was conducted in Taiwan, which has a higher burden of CKD than that of the UK, and the highest prevalence of patients with ESRF globally (Wen et al., 2008). Whilst some risk factors are consistent across countries such as type 2 diabetes and hypertension (Kuo et al., 2007), others such as non-prescribed Chinese herbal medicine (Hsieh et al., 2012) would not be considered a major risk factor for a UK population. Therefore, the potential differences between Taiwan and UK cohorts warranted a further examination of self-reported walking behaviours and mortality in a UK CKD population.

Furthermore, walking pace has also been shown to be a predictor of survival among older adults (Studenski et al., 2011), and patients with CKD (Kutner et al., 2015, Roshanravan et al., 2013). Walking speed is representative of multiple organ systems including neurological, musculoskeletal and cardiopulmonary (Studenski et al., 2011). Therefore, a decline in walking speed may indicate a global reduction in overall health status (Roshanravan, 2015). However, the association between self-reported walking pace and survival has not been explored previously in a non-dialysis CKD population.

The aim of this study was to investigate whether self-reported walking behaviours are associated with survival among CKD patients not requiring RRT.

## **3.2 Methods**

Follow-up data were analysed from the QCKD trial (Physical activity opinions in kidney patients: ISRCTN 87066351), a prospective observational mixed methods study of physical activity in patients with CKD, reported in Chapter 2. However, due to access limitations for other participating sites, follow-up data were only available from one single centre. Participants were enrolled at this site between September 2012 and June 2013.

### **3.2.1 Recruitment and inclusion**

Recruitment procedures including inclusion and exclusion criteria are reported in Chapter 2.

### **3.2.2 Procedures**

Upon entry to the study, participants were asked to complete a survey pack, which included questionnaires assessing self-reported levels of physical activity. Demographic and clinical data including age, gender, ethnicity, eGFR ml/min per 1.73m<sup>2</sup> (MDRD equation) (Levey et al., 1999), haemoglobin (g/L), and comorbidities were obtained from patient medical records. The extraction of clinical data was performed in temporal proximity to questionnaire completion. Written consent was obtained prior to accessing medical records.

### **3.2.3 Self-reported walking behaviours**

As described in the previous chapter the GPPAQ is a screening tool used to classify individuals to one of four physical activity indexes (inactive, moderately inactive, moderately active or active) (National Collaborating Centre for Nursing and Supportive Care UK, 2008). However, certain subcategories within the questionnaire such as walking, gardening, housework and walking pace are not included in the classification system. Instead, this relies upon employment status, hours of physical exercise e.g. gym

work and cycling. As the majority of participants in the QCKD study were of retirement age, and walking was reported as the most common form of physical activity, we extracted hours of walking and walking pace from the GPPAQ. As part of the GPPAQ participants were asked to report number of hours spent walking per week, including walking to work, shopping and walking for pleasure. Responses were recorded categorically: none, some but less than 1 hour, 1-3 hours or 3 hours or more. In addition, participants were asked to self-report their walking pace as slow <3mph; steady; brisk or fast >4mph.

### **3.2.4 Outcome assessment**

All-cause mortality data were extracted from the PROTON system (an electronic patient medical record used for renal patients) in September 2016. Patient records are accessed and updated by the clinical team routinely. Time zero in the survival models was taken at the point where patients were consented to the study and completed the survey questions. Patients were right censored if they had not experienced the event (death) at the time of data extraction (the end of study). Time to event data is subsequently incomplete for these participants, but survival time is assumed to be at least as long as the duration of the study follow-up.

### **3.2.5 Statistical Analysis**

Descriptive statistics were summarised as median (interquartile range [IQR 25<sup>th</sup>-75<sup>th</sup> percentile]) for continuous variables and percentages for categorical variables. Categorical variables including hours of walking (0 hours, <1 hour, 1-3 hours and >3 hours) and self-reported walking pace (slow <3mph, steady, brisk and fast) were extracted from the GPPAQ. Due to the small number of participants reporting brisk or fast paced walking, categories were merged for analysis to create 2 walking pace groups: <3mph and >3mph. A walking pace of 3mph is considered a moderate pace in the 2011 Compendium of Physical Activities (Ainsworth et al., 2011).

The main outcome of interest was all-cause mortality after study enrolment. Kaplan-Meier survival curves and log-rank tests were used to estimate survival proportions for

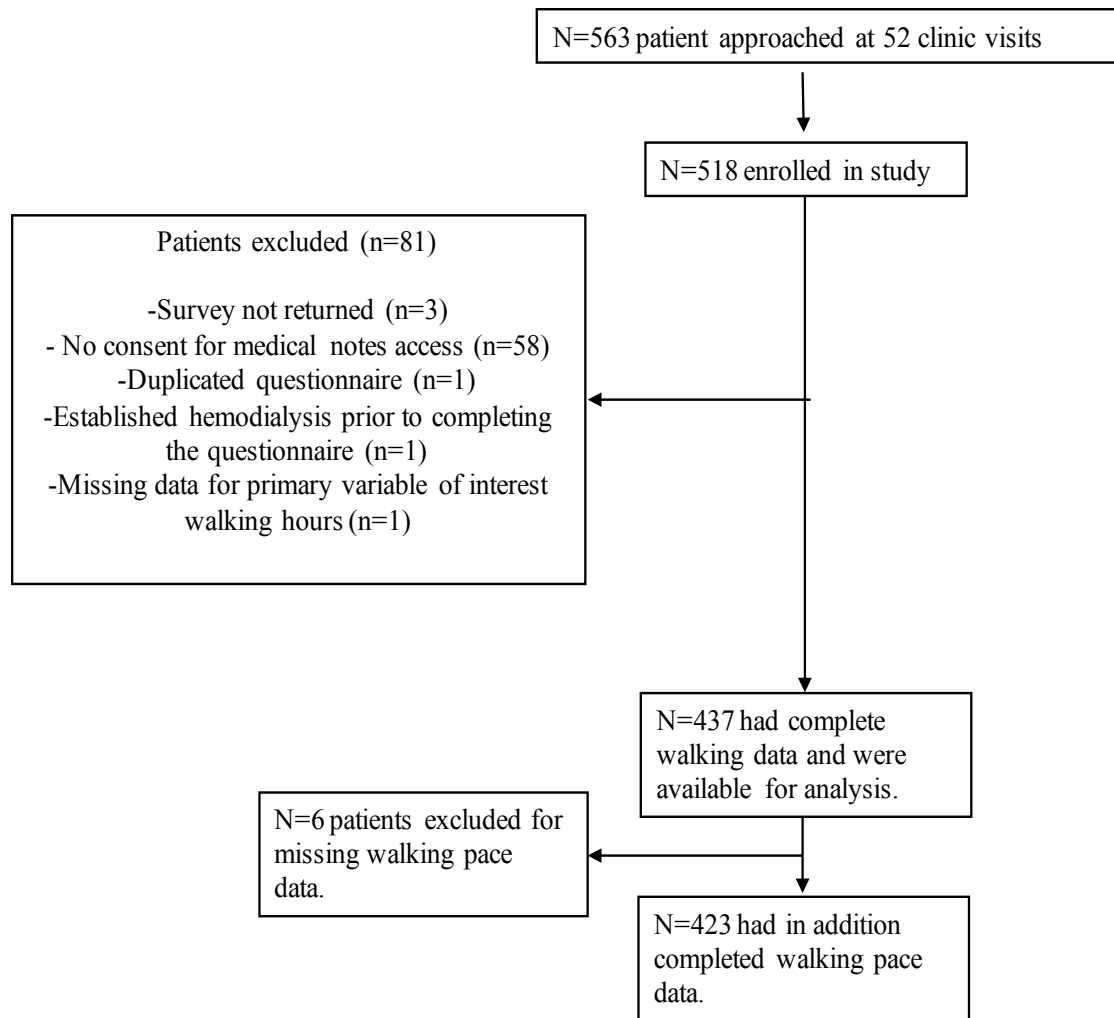
categorical variables of interest. Cox proportional hazard models were constructed to examine the association between hours of walking per week, walking pace, and all-cause mortality in both unadjusted and adjusted models. The proportional hazards assumption was tested using a graphical approach to determine the extent to which the survival curves were parallel for each covariate. The models were then adjusted to control for the following co-variables: age, gender, ethnicity, eGFR, haemoglobin, diabetes mellitus, hypertension and ischemic heart disease. In addition, two sensitivity analyses were conducted using a modified inclusion criteria of CKD including only participants with an eGFR of  $<60$  ml/min per  $1.73\text{m}^2$ . The second sensitivity analysis was performed to reduce the potential of reverse causation by excluding participants who died within 6 months of enrolment.

All statistical analyses were performed using the statistical package IBM SPSS Statistics for Windows, version 22 (IBM Corp., Armonk, N.Y., USA). Statistical significance was accepted as a p-value  $<0.05$ .

### **3.3 Results**

Data from 437 participants were available for analysis (see Figure 3.1 for the flow of participants through study). Follow-up data were obtained covering a median of 44 (IQR 42-45) months. There were 89 deaths (20.4%) during this follow-up period. Of the remaining 348 participants, none were lost to follow-up. Missing data for all variables of interest were  $<5\%$ . Participant characteristics are detailed in Table 3.1.

**Figure 3.1 Consort diagram to show participant flow through study**





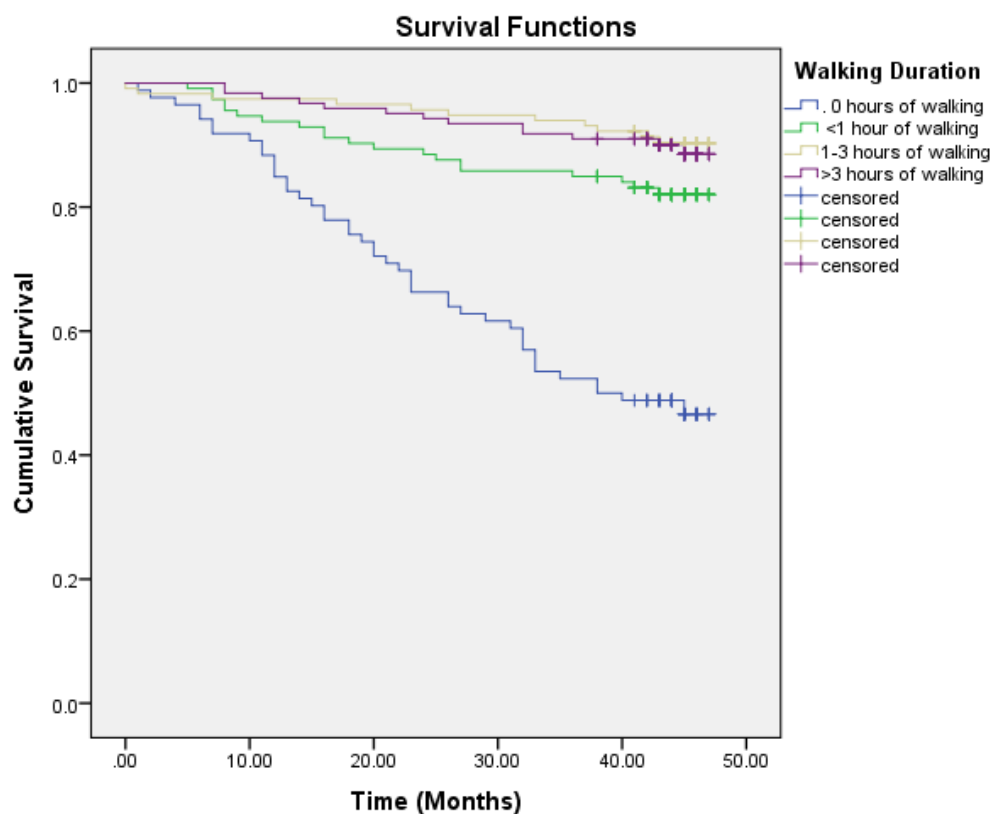
**Table 3.1 Baseline patient characteristics**

<b>Characteristic</b>	<b>Total N=437</b>	<b>Survival N=348</b>	<b>Non-survival N=89</b>
<b>Age [years], median (IQR)</b>	62(48-75)	58(45-71)	77(67-81)
<b>Sex [male], n (%)</b>	250 (57.2)	190 (54.6)	60 (67.4)
<b>Ethnicity [white], n (%)</b>	350 (80.1)	268 (77.0)	82 (92.1)
<b>eGFR [ml/min/1.73m<sup>2</sup>]. median (IQR)</b>	30 (19-54)	34(20-66)	21(16-32)
<b>Haemoglobin [g/L], median (IQR)</b>	122 (108-135)	125(112-136)	111(100-124)
<b>Diabetes, n (%)</b>	115(26.4)	83 (23.9)	32 (36.4)
<b>Hypertension, n (%)</b>	238(54.6)	185(53.2)	53(60.2)
<b>Cardiovascular disease, n (%)</b>	80(18.3)	45 (12.9)	35(39.8)
<b>Walking weekly hours, n (%)</b>			
<b>0</b>	86(19.7)	41(11.8)	45(50.6)
<b>&lt;1</b>	113(25.9)	93(26.7)	20(22.5)
<b>1-3</b>	116(26.5)	105(30.2)	11(12.4)
<b>&gt;3</b>	122(27.9)	109(31.3)	13(14.6)
<b>Walking pace, n (%)</b>			
<b>Slow &lt;3mph</b>	186(42.6)	116(33.3)	70(78.7)
<b>Steady</b>	175(40.0)	163(46.8)	12(13.5)
<b>Brisk/Fast</b>	62(14.2)	57(16.4)	6(5.6)
<b>Missing</b>	14(3.2)	12(3.4)	2(2.2)

### 3.3.1 Associations between hours of walking and survival

Estimated survival proportions varied across reported hours of walking ( $P=<0.001$ ); (see Figure 3.2). Of the 86 participants reporting 0 hours of walking, the proportion surviving was 46.6%, compared to 82.0% of the 113 who reported <1 hour per week, 90.3% of the 116 who reported 1-3 hours per week and 90.1% of the 112 who reported >3 hours of walking per week. Table 3.2 shows the hazard ratios for the associations between hours of walking and all-cause mortality. After adjustment for co-variates (age, sex, ethnicity, eGFR, haemoglobin, diabetes mellitus, hypertension and CVD) all categories of walking were associated with reduced mortality (see Table 3.2).

**Figure 3. 2 Using hours of walking per week survival estimates**

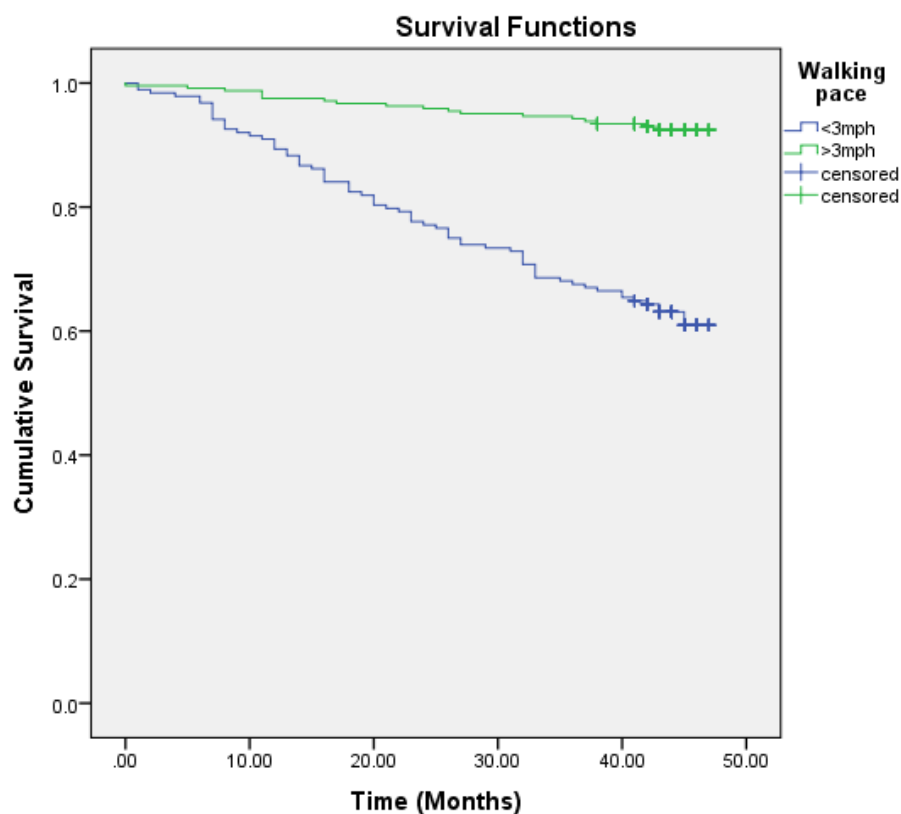


**Legend for figure 3.2:** Kaplan-Meier analyses of 437 patients stratified by hours walked per week. Estimated survival proportions for participants reporting 0 hours, <1 hour, 1-3 hours and >3 hours per week were 46.6%, 82.0%, 90.3% and 90.1% respectively ( $X^2=82.803$ ,  $df=3$ ,  $p=<0.001$ )

### 3.3.2 Associations between walking pace and survival

Self-reported walking pace data were available for 431 participants, including the 89 participants who died during the follow-up period. The estimated survival proportions differed within self-reported walking pace categories. Of the 188 participants who reported walking at a pace <3mph, estimated survival proportions were 61.0%, compared with 92.5% of participants who reported walking >3mph ( $P<0.001$ ); (see Figure 3.3). Walking at a pace >3mph conferred a reduced risk in all-cause mortality when compared to the reference group <3mph (see Table 3.2). After adjustment for the aforementioned covariates, a pace of >3mph was associated with a reduced risk of all-cause mortality (HR 0.38, 95 % CI 0.22-0.67,  $P=0.01$ ) (see Table 3.2).

**Figure 3.3** Using walking pace survival estimates



**Legend for figure 3.3:** Kaplan-Meier analysis of 431 patients stratified by walking pace. Estimated survival proportions for participants reporting a walking pace of <3mph was 61.0% compared with 92.5% reporting a walking pace of >3mph ( $X^2=61.29$ ,  $df=1$ ,  $P<0.001$ ).

**Table 3.2 Cox proportional hazard analysis for all-cause mortality**

Measures	Crude HR (95% CI)	P-Value	Adjusted HR (95% , CI)	P-Value
<b>Walking</b>				
<b>(h per week)</b>				
<b>Walking some but &lt;1 h*</b>	0.27 (0.16-0.46)	<0.001	0.48 (0.28-0.83)	0.008
<b>Walking 1-3 h*</b>	0.14 (0.07-0.26)	<0.001	0.27 (0.13-0.54)	<0.001
<b>Walking &gt;3 h*</b>	0.15 (0.08-0.28)	<0.001	0.41 (0.21-0.80)	0.009
<b>Walking Pace</b>				
<b>&gt;3mph *</b>	0.16 (0.10-0.28)	<0.001	0.38 (0.22-0.67)	0.001

Adjusted for: age, sex, ethnicity, eGFR, haemoglobin, diabetes mellitus, hypertension and ischemic heart disease.

\*Reference category is 0 hours of walking a week.

\*Reference category is <3mph.

### 3.3.3 Sensitivity Analysis

99 patients with an eGFR >60 ml/min/1.73m<sup>2</sup> were excluded from the analyses. 338 participants were available for analysis and 85 deaths occurred over the follow-up. The results remained stable across all variables of interest after adjustment for aforementioned co-variates (Sensitivity Analysis 1; Table 3.3). A further sensitivity analysis excluded participants who died within 6 months of enrolment. 429 participants were available for analysis and 81 deaths occurred over the follow-up. Similarly, the results remained stable across all variables after adjustment (Sensitivity Analysis 2; Table 3.3).

**Table 3.3 Cox proportional hazard analysis for sensitivity analyses for all-cause mortality**

<b>Measures</b>	<b>Sensitivity Analysis 1</b>		<b>Sensitivity Analysis 2</b>	
	<b>Adjusted HR (95% CI)</b>	<b>P-Value</b>	<b>Adjusted HR (95%, CI)</b>	<b>P-Value</b>
<b>Walking (h per week)</b>				
<b>Walking some but &lt;1 h*</b>	0.44 (0.25-0.78)	0.005	0.52 (0.29-0.91)	0.03
<b>Walking 1-3 h*</b>	0.27 (0.13-0.54)	<0.001	0.24 (0.12-0.54)	<0.001
<b>Walking &gt;3 h *</b>	0.38 (0.19-0.76)	0.006	0.47 (0.24-0.94)	0.03
<b>Walking Pace</b>				
<b>&gt;3mph *</b>	0.38 (0.21-0.68)	0.001	0.37 (0.20-0.68)	0.001

Adjusted for: age, sex, ethnicity, eGFR, haemoglobin, diabetes mellitus, hypertension and ischemic heart disease.

\*Reference category is 0 hours of walking a week.

\*Reference category is <3mph.

Sensitivity analysis 1: Cox proportional hazard analysis was conducted for all-cause mortality after excluding patients with an eGFR>60 ml/min/1.73m<sup>2</sup>.

Sensitivity analysis 2: Cox proportional hazard analysis was conducted for all-cause mortality after excluding patients who died within the first 6 months after enrolment to the study.

### 3.4 Discussion

This chapter aimed to explore if self-reported measures of walking behaviour were associated with survival among a CKD cohort not requiring RRT. Walking has previously been shown to have numerous benefits for patients with CKD (Kosmadakis et al., 2012). However, to our knowledge, this is the first study to report the association between walking behaviours and survival in a UK non-dialysis CKD population. The results of this study indicate that walking is associated with a reduction in risk of all-cause mortality among CKD patients not requiring RRT.

Previous research from a large observational study conducted in Taiwan indicated that walking frequency was associated with survival among patients with CKD stages 3-5 (Chen et al., 2014), independent of age, eGFR and comorbidities. The authors reported a clear dose response between walking frequency and better outcomes. However, in the present study all reported walking activity durations were associated with a reduction in mortality when compared to 0 hours of walking per week, with no clear evidence of a dose-response relationship. There is increasing evidence now to suggest that the dose-response relationship between moderate physical activity and all cause-mortality may not be linear (Kelly et al., 2014). A meta-analysis including 22 studies showed how walking 2.5 hours per week was associated with a 19% reduction in all-cause mortality risk, whereas walking 7 hours per week was associated with a reduction in risk of 24% (Woodcock et al., 2011). This indicated that the greatest benefits to health may be found when encouraging patients to move from sedentary to low levels of activity, although further health benefits were still accrued from additional activity in patients reporting greater levels of physical activity (Woodcock et al., 2011). Further work is required to explore the walking frequency, duration, and intensity, to inform the relationship between dose-response and improved outcomes in patients with CKD.

Gait speed is known to be associated with survival in older adults (Studenski et al., 2011) and patients with CKD (Roshanravan et al., 2013). However, objective measures of gait speed are not readily available in a UK nephrology clinical setting. Therefore, self-reported measures of walking pace may offer an alternative that is quick and simple to complete, and could be easily implemented into the routine clinical assessment.

Recent evidence has suggested that self-reported walking pace may provide a good surrogate measure of walking speed when direct measurement is unavailable (Syddall et al., 2015). Our results suggest that patients who reported a walking speed of >3mph had a reduced risk of all-cause mortality, suggesting a simple self-reported walking pace question could be used to predict future mortality risk in CKD patients.

To our knowledge, this is the largest UK CKD cohort utilised to investigate the association between self-reported walking behaviour and survival. However, this study is not without its limitations. Due to the observational study design, caution should be taken when assigning a causal relationship between walking behaviours and increased risk of all-cause mortality. Data regarding a cause of death was not obtainable; this coupled with a small sample size limited our ability to perform additional analyses regarding cardiovascular mortalities, which would have been of interest. However, a previous large observational study demonstrated the relationship between walking and cardiovascular event risk in 9,306 individuals with impaired glucose tolerance (Yates et al., 2014). This study indicated that an increase of 2,000 steps (approximately 20 minutes of walking) was associated with an 8% reduction in cardiovascular events. Furthermore, whilst an attempt was made in the present study to control for reverse causation by excluding participants who had died within 6 months of enrolment, the follow-up length of this study is short and remains a limitation. Moreover, it is still unclear from this study and the literature if positive changes to walking behaviour would be associated with improved rates of survival. Preliminary evidence demonstrates that physical activity in patients with CKD can be successfully targeted via a behavioural intervention (Kao et al., 2012). Therefore, further longitudinal and interventional studies are required to investigate the effect of increasing walking behaviours on adverse events and; determine the optimal dose-response for walking with regards to frequency, duration and intensity associated with survival. In addition, as with all self-reported data, there may be tendencies for participants to over or underestimate physical capabilities and level of physical activity. However, in the absence of objective assessment, we have shown that self-reported measures of walking behaviours could be incorporated into routine clinical assessment and help to identify patients at risk of adverse events.

### **3.5 Conclusion**

Self-reported hours of walking, and walking pace are independent predictors of all-cause mortality in CKD patients not requiring RRT. This suggests that measures of walking behaviour, when used alongside clinical information, may be useful in identifying participants at risk of adverse events.



# Chapter 4

## **Motivations and Barriers to Exercise in Patients with CKD: A Qualitative Study**

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The previous chapters have reported Part 1 results of the QCKD trial. However, this trial was a mixed-methods design and included a qualitative study. Mixed methods are often associated with the pragmatism epistemology, whereby moving away from paradigm debates and taking advantages of both qualitative and quantitative methods used in collaboration to explore a phenomenon in a deep and meaningful way. Furthermore, the MRC provides a Framework for the Development and Evaluation of Complex Interventions, in which both quantitative and qualitative methodology is advocated. Complex interventions are defined as having multiple interacting components that work in a synergistic manner to affect behaviour. Therefore, whilst the quantitative cross-sectional study reported in Chapter 2 was appropriately designed to confirm the prevalence of behaviour and identify correlates associated with meeting physical activity guidelines, it was not sufficient to explore in a greater depth the perceptions that patients with CKD hold towards exercise. This is important as a number of the correlates identified are also associated with physical activity in the general population. Therefore, in its simplest form, this chapter reports an exploration of the barriers to being active that CKD patients face day to day, whilst aiming to understand what might help patients to overcome these barriers to lead a more active lifestyle.

\* A version of this chapter is published in Nephrology Dialysis Transplantation (Clarke et al., 2015). The version reported in this chapter includes CKD patients stages 1-5. Patients with CKD stages 1-2 were removed from the analysis for publication after undergoing review. However, lifestyle interventions may be beneficial to all CKD

patients and part of this work is to determine the most appropriate time for an intervention.

As an Oxford University Press academic author, one maintains: “The right to include the article in full or in part in a thesis or dissertation, provided that this not be published commercially” [https://academic.oup.com/journals/pages/access\\_purchase/rights\\_and\\_permissions/publication\\_rights](https://academic.oup.com/journals/pages/access_purchase/rights_and_permissions/publication_rights)

## **4.1 Introduction**

Identifying barriers and asking participants to strategize ways to overcome them is a popular technique used in behaviour change interventions (Michie et al., 2011). However, little is known about the barriers and motivators CKD patients have towards exercise participation, though these have been explored more extensively in other target populations (Sanchez et al., 2007, Wilcox et al., 2006, Goodman and Ballou, 2004). Commonly reported barriers from other cohorts include: a lack of time, fear of pain/injury, health problems, and poor weather. Nearly all of these studies identified enjoyment as a motivator for exercise participation, an intrinsic motivator associated with sustained exercise behaviours (Buckworth et al., 2007). Understanding the barriers, motivators, and beliefs towards physical activity may allow us to tailor interventions and inform the delivery and development of CKD specific behaviour change programmes designed to promote physical activity. Recent preliminary data in the form of a pilot study conducted in Taiwan indicated that behaviour modification in CKD patients is feasible and efficacious at increasing levels of exercise (Kao et al., 2012). However, this work lacks sufficient intervention development transparency and detail, meaning that it would be difficult to replicate and may not yield the same result if conducted in a UK CKD population.

Furthermore, qualitative research is gaining much recognition for its utility to inform intervention development. Assessing patients’ needs and perspectives is a fundamental first step in optimising acceptability and engagement with a behaviour change intervention. The “Person-Based Approach” uses iterative qualitative research to inform the planning, design, and development of an intervention (Yardley et al., 2015a).

Exploratory research at the early stages of intervention conceptualisation may help to identify important novel components that have not previously been identified and are therefore not yet evidence-based. Whilst drawing on previous qualitative work is important, currently, no studies have sought to understand the needs and perspectives of patients with CKD not requiring RRT with regards to a physical activity intervention.

This qualitative study had two main objectives. The first was to explore attitudes and perceptions towards exercise in patients with CKD not requiring RRT, in order to identify factors that act as barriers (to be addressed) and motivators (to be utilised) in future interventions. SCT was used as a conceptual framework to organise the findings and to highlight the ways in which this work could be used in the design of an appropriate intervention for this patient group. Secondly, by understanding the participants' perspectives on exercise, it was intended that contextual elements that would aid intervention development and inform delivery, could be exposed.

## **4.2 Methods**

### **4.2.1 Study Design**

This study was conducted within the constructivist paradigm, enabling the researchers to theorise meaning and form assumptions around what was articulated within the data (Braun and Clarke, 2006). Data were elicited through a qualitative design utilising focus groups and semi-structured interviews (Lambert and Loiselle, 2008). Focus groups were used to initially explore perceptions of exercise amongst this patient group in a dynamic and collaborative context as well as to identify topics for inclusion in the one to one interviews which followed (Sparkes and Smith, 2013). Focus groups have been indicated as a useful method within exploratory qualitative research as they promote group discussion, which can elicit new topics of interest and bolster the confidence of the group. In addition to focus groups, individual face-to-face interviews were conducted to explore patient accounts of exercise in more detail. Participants filled in a brief demographics questionnaire and the GPPAQ prior to attending a focus group or interview as part of an earlier stage of this research.

#### **4.2.2 Sample and setting**

A convenience sampling method was used to recruit participants who had previously expressed an interest and completed a contact form during recruitment to Part 1 of the QCKD study (Chapter 2). All interviews and focus groups were conducted away from clinical areas within a UK hospital setting. An independent multilingual facilitator was used to conduct interviews with participants whose first language was not English to gain more diverse opinions. All participants gave informed consent. Patient recruitment details are illustrated in Figure 4.1.

#### **4.2.3 Ethics**

This study REC 12/EM/0184 was given a favourable opinion by the NRES Committee East Midlands – Northampton on 13/06/2012.

#### **4.2.4 Data Collection**

A PPI group convened for the study assisted with the development of the data collection tools. Focus groups and semi-structured interviews covered the following topics: the meaning of exercise; perceived benefits, advantages and disadvantages of exercise; sources of information about exercise; experiences of exercise; factors that influence personal decisions about exercise; focusing on group level perceptions and individual experiences respectively. Interview questions were informed by the early focus group data. Focus groups were conducted with 4-6 participants and lasted between 60-80 minutes. Individual interviews lasted between 30-85 minutes. All focus groups and interviews were digitally recorded, professionally transcribed verbatim, anonymised and translated where necessary. Transcripts were then entered into Nvivo 10.

#### **4.2.5 Analytical Approach**

Data were analysed using inductive thematic analysis, identifying themes at a semantic level (Braun and Clarke, 2006). This approach is consistent with the applied objectives of health services research, whilst maintaining the potential to provide a rich and

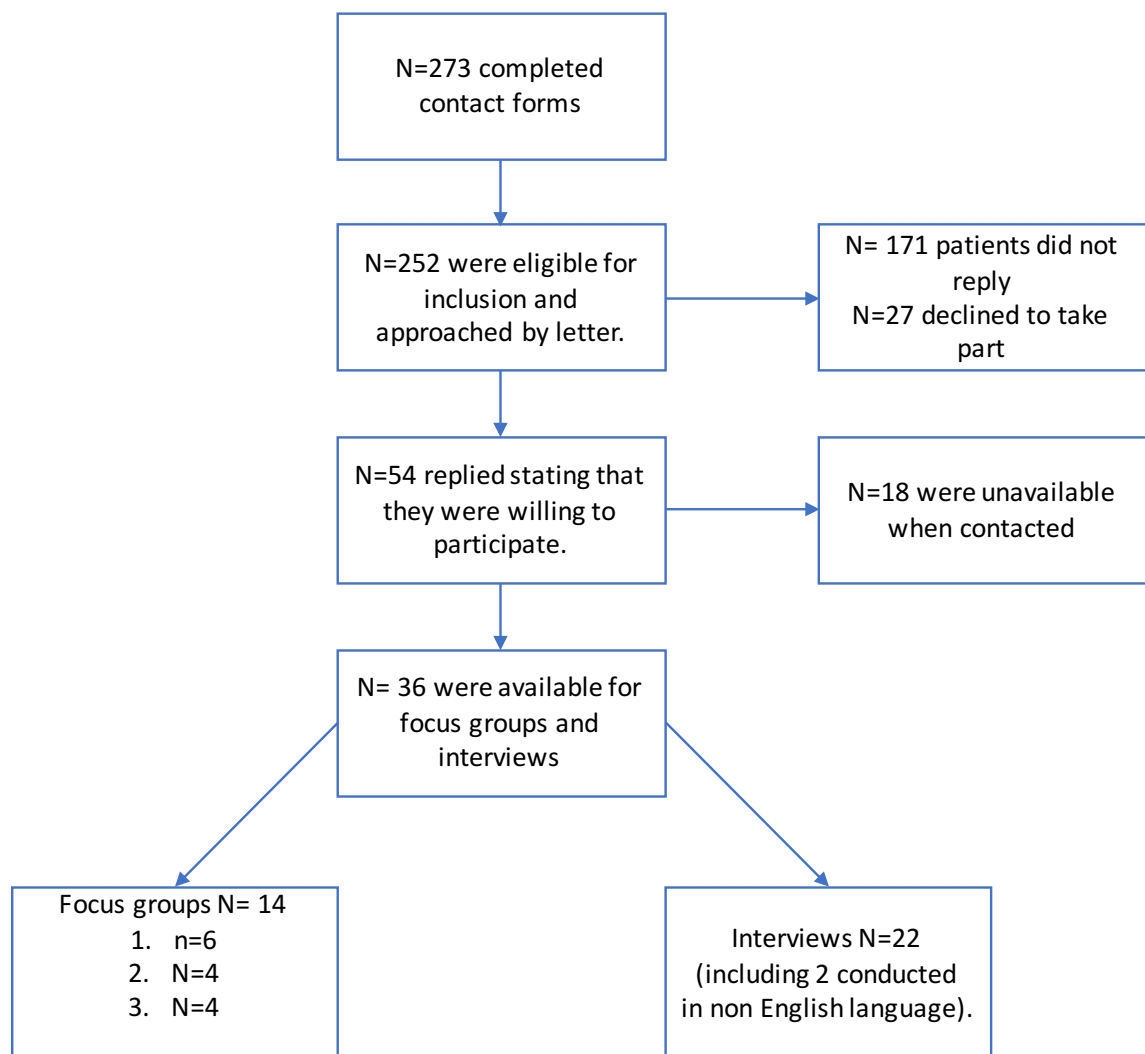
complex account of the studied phenomenon (Braun and Clarke, 2006). Analysis followed the steps provided by Braun & Clarke (2006): familiarisation with all data; initial coding; searching for themes; reviewing themes using the constant comparison method and finally defining themes for the final part of the analysis.

The analysis identified a number of themes compatible with health promotion from a SCT perspective. SCT provides a framework to understand how personal, behavioural and environmental factors interact to influence behaviour (Bandura, 1986) and has been used to inform the analytical framework within this report. Themes were categorised according to: personal (e.g. biological state, cognitive and affective); behavioural (e.g. self-regulation, enlisted incentives for making a personal change) and environment (e.g. social and physical environment). These themes are presented below and featured in this account as both motivators and barriers to exercise. Steps of analysis were repeated to define themes relevant to future intervention conceptualisation from the patients' perspective.

### 4.3 Results

These results describe the beliefs, motivations, and barriers to exercise held by patients with CKD. Patient flow through study is shown in Figure 4.1 and patient characteristics are detailed in Table 4.1.

**Figure 4.1 Consort diagram to show participant flow through study.**



**Table 4.1 Patient characteristics**

<b>Characteristics</b>	<b>Focus Group N=14</b>	<b>Interviews N=22</b>	<b>Total Cohort N=36</b>
<b>Sex</b>			
<b>Male: Female</b>	7: 7	13: 9	20:16
<b>Age (Years)</b>	68 (48-83)	61 (26-78)	66 (56-74)
<b>Ethnicity (n)</b>			
<b>White British</b>	12	17	29
<b>Other White Background</b>	1	1	2
<b>Other Black Background</b>	1	0	1
<b>Asian or Asian British Indian</b>	0	4	4
<b>CKD Stage (n)</b>			
<b>1</b>	1	1	2
<b>2</b>	0	4	4
<b>3</b>	3	8	11
<b>4</b>	10	7	17
<b>5</b>	0	2	2
<b>Co-morbidities (n)</b>			
<b>Hypertension</b>	7	10	17
<b>CVD/ Stroke</b>	7	6	13
<b>Diabetes Type 11</b>	5	3	8
<b>Musculoskeletal</b>	5	3	8
<b>Asthma/ COPD</b>	2	2	4
<b>Mental Health Illness</b>	2	2	4
<b>Physical Activity Index (n)</b>			
<b>Inactive</b>	3	10	13
<b>Moderately Inactive</b>	2	3	5
<b>Moderately Active</b>	3	2	5
<b>Active</b>	1	3	4
<b>Incomplete</b>	5	4	9

**Table 4.2 Individual patient characteristics for interview participants**

<b>Interview</b>	<b>Sex</b>	<b>Age (years)</b>	<b>Ethnicity</b>	<b>CKD stage</b>	<b>Number of self-reported co-morbidities</b>	<b>PAI</b>
<b>1</b>	Female	64	A	4	1	Inactive
<b>2</b>	Male	56	A	5	4	Moderately active
<b>3</b>	Male	67	A	4	3	Inactive
<b>4</b>	Male	74	A	4	2	Moderately inactive
<b>5</b>	Female	55	H	4	3	Inactive
<b>6</b>	Female	68	A	4	0	Moderately active
<b>7</b>	Male	66	H	5	2	Inactive
<b>8</b>	Female	78	A	4	2	Inactive
<b>9</b>	Male	73	C	4	1	Missing
<b>10</b>	Female	58	A	3	2	Missing
<b>11</b>	Male	69	H	3	3	Missing
<b>12</b>	Male	69	A	3	3	Active
<b>13</b>	Female	48	A	2	1	Inactive
<b>14</b>	Female	39	A	2	1	Moderately inactive
<b>15</b>	Male	26	A	3	0	Active
<b>16</b>	Female	63	A	2	2	Inactive
<b>17</b>	Male	43	A	2	0	Inactive
<b>18</b>	Male	56	A	3	0	Missing
<b>19</b>	Female	76	A	3	2	Inactive
<b>20</b>	Male	58	H	3	2	Active
<b>21</b>	Male	55	A	1	2	Inactive
<b>22</b>	Male	77	A	3	1	Moderately inactive

**Abbreviations:** Ethnicity NHS codes (A = White British, C= Other White Background and H= Asian or Asian British Indian); PAI = Physical activity index (self-reported via GPPAQ from previous study described in Chapter 2).

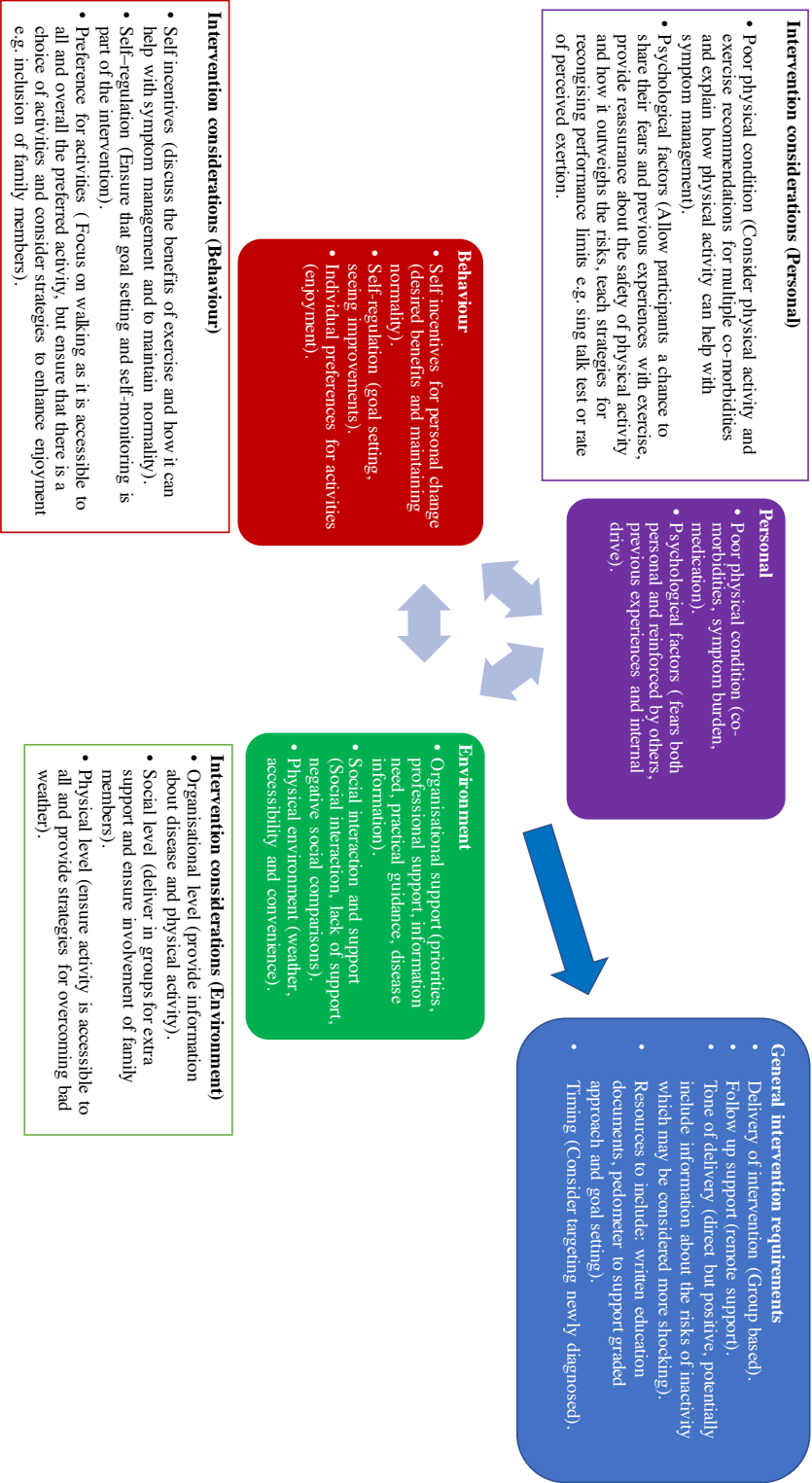


**Table 4.3 Individual patient characteristics for focus group participants**

<b>Focus Group</b>	<b>Sex</b>	<b>Age (years)</b>	<b>Ethnicity</b>	<b>CKD stage</b>	<b>Number of self-reported co-morbidities</b>	<b>PAI</b>
<b>1</b>	Male	74	A	4	1	Missing
	Male	76	A	5	3	Missing
	Female	50	A	4	1	Moderately inactive
	Male	81	A	4	2	Moderately active
	Female	61	A	4	0	Inactive
	Male	73	A	4	3	Inactive
<b>2</b>	Female	73	A	4	5	Missing
	Male	83	A	4	4	Missing
	Male	77	A	4	1	Moderately inactive
	Female	58	A	4	3	Inactive
<b>3</b>	Female	45	P	3	0	Missing
	Female	61	A	1	1	Moderately active
	Female	75	A	3	3	Active
	Male	66	C	3	3	Moderately active

**Abbreviations:** Ethnicity NHS codes (A = White British, C= Other White Background and P= Other Black Background); PAI = Physical activity index (self-reported via GPPAQ from previous study described in Chapter 2).

**Figure 4.2 Shows a graphical representation of psychosocial factors that may influence physical activity and exercise behaviours in patients with CKD, and considerations for intervention development based on these.**



### 4.3.1 Personal Factors

#### 4.3.1.1 Poor physical and/or mental health and exercise related concerns.

**Co-morbidities:** Co-morbid conditions and symptom burden were described as the most prevalent barriers to exercise. Conditions included: CVD; hypertension, respiratory disease; diabetes mellitus; musculoskeletal and mental health illnesses.

*“I have got this respiratory problem that has probably changed my activity... more than the kidney” (Interview 10).*

*“...we could go for mile [walking] but then I started getting trouble with my back and they don’t know whether that is to do with my kidneys but I just get a lot of pain now in my legs and back” (Interview 14).*

*“I have to be careful because I have got two replacement knees so I can’t do things like the rowing machine...there is a danger of dislocation” (Interview 22).*

*“I am not a big exercise [fan] but walking was a big thing for me, I did four miles a day which I thought was reasonable but then I got rheumatoid arthritis, whatever it is means a new knee, and I can’t walk very far at all” (Focus group 1).*

*“I used to do a lot of walking...but since I had this flare up its knocked me down a bit...I don’t know if it’s kidneys or heart, I think in my case it might be heart” (Focus group 1).*

**Symptoms:** Participants perceived a number of symptoms to be functionally limiting at all stages of disease progression and most commonly included: fatigue; pain in joints and back; and shortness of breath. Fatigue was described as the most prominent barrier and made performing functional tasks such as walking around the house a challenge.

*“...you just feel like you are trying to walk through treacle... walking from one side of the house to the other...you think phew made it” (Male, Age 56).*

*“Before I was ill...I was quite active so I don’t know if this is an excuse but I do get really tired quite quickly...I think that sometimes it is an excuse that I use for myself rather than it’s actually stopping me...but whether that is because I am a bit scared I don’t know” (Interview 13).*

*“I notice that I am getting more pain and I am really tired now which is a new thing...I start getting really tearful, really emotional, really washed out, really overwhelmed” (Interview 14).*

*“I know it sounds like an excuse...but it really isn’t at the moment...there is nothing in the tank...I feel like I am chopping at the bit mentally to do some exercise but physically I just haven’t got it in me to do it” (Interview 17).*

**Perceptions of ageing:** Symptoms were often linked to the negative effects of medication or normalised as part of the aging process with some participants accepting functional decline and fatigue with increasing age. In contrast, some participants felt that *“people get to a certain age and think I have got to do this”*, and so used their age as an incentive to remain active (Interview 13). Furthermore, some participants described a relationship between symptoms and their medical management. For example, symptoms of fatigue and shortness of breath were reported to have improved after receiving Erythropoietin, which they perceived impacted positively on their level of activity.

*“I probably don’t swim as long as I used to because I am tired but I don’t know if that’s the kidney or ...just my age as well” (Interview 10).*

*“...I think you become capable of doing less, I don’t think it’s a question of doing less I think you physically [can’t]...” (Interview 22).*

*“...since I’ve been on these injections which [raise] the blood oxygen, I have got more energy and I’ve got more stamina” (Interview 4).*

*“I needed to do some exercise I was on these steroid pills...and my legs felt like ton weights, my arms, I could hardly lift my arms, I felt bloated pretty awful...I had got no energy and I felt I have got to do something to try and get some life back in me” (Interview 22).*

*“It annoys me that I can’t do as much as I did, like the pace of walking is much slower than five years ago, I get breathless, and with the kidney, I think a lot of it is medication, I tire quicker” (Interview 10).*

**Fears (personal and reinforced by others):** Over half of participants expressed concerns about injury and aggravating their physical condition through exercise. Fears were often related to a lack of exercise knowledge, or previous bad experiences. Participants described a lack of confidence in recognising performance limits and felt that *“too much exercise could inhibit [them]”* (Interview 9). Patients with diabetes mellitus reported anxiety regarding exercise-induced hypoglycaemia: *“... if I start walking... after about half a mile I can’t guarantee what my sugar level will be... it is very dangerous to go on my own...”* (Interview 11).

*“I think it’s probably since I have been ill I am a bit scared to do it...so just having someone tell me I can do that or I can’t do that...”* (Interview 13).

*“When I am digging [gardening] my back tends to ache a little, but I don’t know if it’s my back aching or my kidneys might be hurting...I can’t tell the different between the two. I tend to step back a little when that starts to happen, because I think if it’s my kidneys I don’t want to push them as they are not brilliant”* (Interview 15).

Participants also described how family members and health care professionals occasionally projected their fears onto them, with such communication often deemed

unsupportive. However, participants who had supportive family members encouraging them to exercise helped them to overcome their fears.

*“No, she [wife] wanted me to pack up playing squash when I was in my early sixties... she said it’s bad...you will die on court” (Interview 22).*

*“He [dad] always says don’t push yourself too far...think of your kidneys are stuff like that. He always says that as I am leaving, jumping on my bike” (Interview 15).*

*“Some of the doctors were a bit reticent, especially when I wanted to join this Gym-a-Phobics...he was just saying you really don’t want to overdo it” (Interview 16).*

*“I think it’s just that extra encouragement...he [husband] doesn’t push it too far...because he knows deep down that it’s probably because I am a bit unsure or a bit frightened. He has always been a motivator...we are doing the Sky Ride in August so he has signed us up for that so we have got to keep going” (Interview 13).*

**Previous experiences:** Some participants recalled times when they had injured themselves through exercise, or had negative experiences at school, of which both impacted on their current view of exercise. Conversely, some participants described their previous exercise experiences more positively, focusing on how exercise had improved certain health conditions.

*“I have tried going to Zumba, but that was a disaster, it was too much to quickly and I tore my calf muscle” (Interview 16).*

*“I have never been interested...I had to do it at school but I am not really a gym person. I never learnt to swim and I am not a runner, not really a sports person, I used to have trouble when I was younger in physical education” (Interview 3).*

*“...I consciously joined the Pilates because; I had done a bit of it in Loughborough and thought this is good for my back...” (Interview 6).*

*“ ..my knee problem more or less stopped through doing exercise. I do notice if I don’t do so much then I get the aches and pains back in my knees” (Interview 1).*

*“My diabetes and blood pressure is normal and kidney stable because of regular yoga” (Interview 7).*

**Internal drive:** Participants who appeared most confident in their ability to exercise regularly described how they felt motivated by an ‘internal drive’. This motivation was described to be based on knowledge of the benefits and/or feelings of guilt over missed exercise sessions.

*“It’s just something that is there and I think if you have got that then you will do what you have to do” (Interview 22).*

*“..I will feel guilty if I don’t go to the [exercise] class!” (Interview 20).*

#### **4.3.2 Behavioural Factors**

##### **4.3.2.1 Self-regulation and goal setting**

**Goal setting:** Nearly all participants described setting specific goals relating to their functional aspirations. Participants expressed greater confidence in achieving exercise goals, which they perceived helped to sustain their motivation. Autonomy was reported to be an important factor in goal setting, but most participants wanted goals to be reviewed by professionals.

*“Yes it just makes you feel better...indirectly you achieve little goals...which builds up your confidence” (Interview 20).*

*“...a target distance every day you want to do it because somebody is keeping tabs on you, big brother is watching you” (Interview 3).*

**Seeing improvements:** Seeing clinical and functional improvements were perceived as motivation for sustained exercise participation and participants described self-monitoring devices such as pedometers as useful.

*“If you can see an improvement every say two or three weeks that gives you an incentive to go on” (Interview 18).*

*“Pedometer will make a difference...you will be eager to do more steps...” (Interview 7).*

*“...you know the little step monitor [pedometer], even I find them motivating” (Interview 1).*

*“...for men, I think it [pedometer] would bring out the competitive element...if you give a man a target they will want to reach it and go over the target and even for women I think it’s confidence building” (Interview 6).*

**Task orientated:** Planning and identifying targets allowed participants to incorporate exercise into their daily routine so that their exercise was more task orientated as opposed to *“just wandering aimlessly around”* (Interview 1). Participants who felt they lacked a target or exercise purpose described difficulties in staying motivated which for some appeared to coincide with life transitions such as retirement and ageing. Such participants described a desire for a more structured approach to exercise.

*“When...for no reason I don’t hit my target then I get cheesed off and then I am back the next day and then I will hit the target” (Interview 18).*

*“...a target distance every day you want to do it because somebody is keeping tabs on you, big brother is watching you” (Interview 3).*

*“Since I retired I haven’t had the need to walk if you know what I mean...I think a task to do, if you have got to go to work you have got to go to work...retirement is*



*more sitting...the most difficult [thing] is no target” (Interview 3).*

*“...I would be able to kick a ball further than before, or miss two steps instead of going up each one. Only little things but they mean so much as you get older ..I just wish we could all be pushed into it..I wish there was something...like compulsory”*  
(Focus group 2).

#### **4.3.2.2 Self-incentives for personal change**

**Desired benefits of exercise on health and well-being:** Similarly, the majority of participants felt that exercise had the potential to make them “*feel a lot better*” (Focus Group) and could help to maintain health and promote longevity by protecting against complications associated with older age and disease.

*“It’s just about getting up and getting out..I will be 66 next [year] and you have not got that much longer left when you think about it, so you want to keep going...you don’t want to be like an old 66-year-old”* (Interview 1).

*“If you do exercise it will benefit your kidneys, benefit your liver, benefit your weight management, it will take the pressure off your kidneys and liver and therefore the likelihood is that you will live longer and you won’t need dialysis”* (Interview 21).

*“Well exercise comes into that doesn’t it...I know a lot of people that are kidney patients that have diabetes as well, so I try really hard not to get that”* (Interview 19).

Exercise was also described as useful in pain management and regarded as a way of preserving mobility, muscle strength, and cognitive function.

*“Well it [exercise] keeps me able to move about well and the more you do the more you are able to do I think. It keeps you going, do it in small doses to begin with and the more you can do the better”* (Interview 19).

*“...I think it keeps the mind going. If you were just sat down in the chair of an afternoon you would nod off, whereas if you are out your mind is going and you talk about things”* (Interview 1).

Participants also specifically acknowledged the role of exercise in reducing health risks, with the desire to manage weight, blood pressure and cholesterol levels being an incentive to become active.

*“...I have got to keep my blood pressure in check, because blood pressure affects the kidneys and exercise does keep your blood pressure down...I have seen it with older people they rely more and more on pills and I don’t want to”* (Interview 1).

*“You want to keep fit don’t you because as soon as you put weight on it destroys your body...so if you keep piling on the pounds you can’t move so well, it destroys your life”* (Focus group 3).

*“I am desperate to get the weight off; I think if I didn’t do anything the weight would probably creep on”* (Interview 10).

Exercise was also perceived to positively impact mental wellbeing by helping patients to feel “*happier*” and “*more confident*” (Male, Age 58).

*“...I started exercising as frequently as I did because I felt so much better for doing it and that was mentally as well as physically”* (Interview 17).

*“My wife says you come back far brighter than when you go out and there isn’t a mental answer to it, it’s just you feel better”* (Focus group 1).

**Maintaining normality:** Exercise was also viewed with a sense of optimism, where participants described how they used it as a way of fighting their condition in order to maintain normality in their lives. For some participants achieving normality meant remaining in employment, but for others this was about maintaining independence and

the ability to walk: “...as long as I can keep going on my legs, that’s the part that worries me really I never want to get so I can’t walk about” (Interview 1).

*“...I have not had any time off work with my condition and that’s why I think I can exercise because I won’t let myself have time off work, I don’t think it’s a valid disease...it’s something I have got but it’s something that I have got that I have to manage” (Interview 13).*

*“...I am aware that this kidney problem is not going to go away...I need to exercise to keep things going” (Interview 10).*

These participants desired more health benefits from exercise, reported fewer environmental barriers, stronger family support and perceived inactivity to be “...a state of mind resulting from a general lack of motivation for exercise as well as other aspects of life” (Interview 4).

#### **4.3.2.3 Individual preferences for activities**

**Enjoyment:** Participants believed that levels of participation in exercise could be enhanced if they “enjoyed doing it” (Interview 10). The enjoyment of specific activities was a strong determinant of perceived exercise maintenance, with the majority favouring walking. Gym based exercise was described less positively, with one participant describing it as “soul destroying” (Focus group 3) but exercise that was outdoors or in groups was viewed as more rewarding.

*“Running, cycling and swimming I enjoyed them, and they are the three that I maintained, so I think that is proof in the pudding if you want” (Interview 15).*

*“I have tried everything and I found that walking is the best form of exercise...plus twice a week I look after my granddaughter so she loves to be out” (Interview 1).*

*“I get really fed up with myself if I am sat in, and then I start getting stressed...we just put our boots on, we will go out and have a walk around the fields for an hour...it’s for him as well as me, we both really enjoy it (Interview 14).*

### **4.3.3 Environmental Factors**

#### **4.3.3.1 Social interaction and support**

**Social interaction:** Enjoyment was regularly linked with social interaction; having someone to exercise with was encouraging and family support was highly valued. Exercise was also seen as a way of spending quality time with loved ones and making new friends, which added a perceived responsibility to not let others down.

*“...I am lucky really because my husband is a bit of a motivator; he will motivate me, come on then let’s go [walking]” (Interview 1).*

*“...if I promise you I am going to meet you there then I will make the effort to come out” (Interview 20).*

*“If we go walking with some friends I will perhaps ring and say oh we haven’t had a nice walk this month...so yes I think we encourage each other” (Interview 10).*

*“I am lazy. If [my] doctor says I have to walk every day, I won’t do that as pain will start in my body but if my friend comes and says let’s go out for a bit then I will go with her but if somebody tells me or forces me for a walk then I won’t go” (Interview 5).*

**Lack of support:** However, a lack of social support was linked to periods of perceived inactivity.

*“I didn’t do so much exercise then, for lack of somebody to do it with really” (Interview 6).*

**Negative social comparisons:** Participants described social support as encouraging but there was still a sense that “...a lot of people don’t understand anything about it [CKD], you can’t see it so nobody takes much notice” (Interview 19). This perception appeared to incite amplified negative social comparisons when participants exercised with healthier or younger members of the community, which lead to a reduction in perceived competence.

*“I couldn’t go into an aerobics class with a lot of teenage, early twenty, girls; because I knew I wouldn’t be able to keep up with them”* (Interview 10).

*“...my kidneys are really growing and I have got loads of bulk around here and its embarrassing...you go to gyms and the exercise classes and they are all like stick insects, they don’t need to be there always”* (Interview 1).

*“It’s more difficult the older you get...when I go down the gym and see the young ladies pounding away on the machines...a poor old chap like me gets on the running machine and walks, that makes you think”* (Interview 22).

#### **4.3.3.2 Informational support**

**Organisational priorities:** Participants did not perceive exercise for CKD patients to be a priority of the health service. This lead to some drawing distinctions between seeing the doctor for “the medical side of things” and lifestyle advice e.g. exercise (Interview 18).

*“Here you come to see your specialist and the nurses maybe take your blood and take your urine sample, that’s all...I don’t think they have the time...they have not spoken to me about exercise or anything like that...”* (Interview 11).

**Professional support:** Health care professionals were viewed as important in supporting and encouraging exercise behaviours, although who ultimately delivered the information did not appear to be a key factor in influencing exercise attitudes.

*“If [my] doctor said to me yesterday right you have got a bit weak, your muscles are blah, blah, blah, I want you to build yourself up. I would probably take a bit of notice...” (Interview 12).*

*“...if you have got the confidence in anybody that is advising you no matter what it is, but particularly a doctor, it makes a massive difference” (Interview 22).*

*“...he [consultant] is always busy if there are new people then I think that is what they should spend their time on. Not saying to me you need to do this, this and this, because that [exercise] isn’t really his speciality. But he would know the level of my illness as to what would best suit that illness but then given that information to someone else that is qualified...” (Interview 13).*

*“I think it’s that advice thing, from a personal point of view, someone that I can think well is that normal, just knowing the difference between normal physical exercise pain and should I be doing that with my body, and what to do, the best thing to do for me” (Interview 13).*

*“I think perhaps when you are first ill they could mention gentle exercise” (Interview 16).*

**Information needs:** Participants desired individualised information, which would allow them to self-manage their condition through exercise. Specifically, participants wanted a greater understanding of the benefits of exercise, and the principles of exercise that are safe and appropriate for renal patients.

*“...if a person has not done much physical exercise it’s important someone explains to them the benefits ...” (Interview 10).*

*“It would be interesting if somebody said to me you have got this kidney disease this exercise is particularly good for you” (Interview 10).*

*“I don’t know if people do realise how important it is to exercise” (Interview 19).*

*“I did more exercise would my creatinine level go up and down...There is no guidance on that or if there is I haven’t [seen it], most information about kidney disease says keep active, but almost all the health advice throughout your life says keep active so it’s not specific to kidney disease...”* (Interview 6).

**Practical guidance:** Some participants felt that exercising initially in a hospital environment would help them to build confidence and feel safe, but they also wanted “*practical guidance*” to help them access their local facilities (Interview 12). However, others felt that exercising at home would be fine, they were just in need of motivation and support.

*“...find out what are the facilities they have to do exercises and help in that way”* (Interview 11).

*“I tried to get into a group, but I think it was for heart and stroke patients...when I rang Charnwood they said I didn’t fit the criteria. So, I was a bit disappointed really”* (Interview 16).

**Disease information:** However, the extent to which patients demonstrated the need for informational support reached beyond that of physical activity. Participants expressed a need for greater disease information.

*“I think looking back it would have been handy to... maybe just a basic leaflet saying this is what renal failure is, how severe or un-severe it can be, the symptoms to be expected and then maybe a bit of activity, keep active, and give examples of what activity you can do”* (Interview 15).

*“When I first went to the consultant 7 years ago ignorant of what could help the kidneys I said do I need to drink more water, knowing that it flushes out kidneys, and she said no that won’t help but she didn’t tell me what would help”* (Focus group 1).

#### 4.3.3.3 Physical environment

**Weather:** Some participants described how bad weather interrupted planned outdoor exercise sessions, lowered motivation and exacerbated symptoms such as joint stiffness.

*“It’s just sometimes you know if it’s raining or something and its normally the time you would go for a walk you think oh I can’t be bothered it’s raining”* (Interview 10).

*“At the minute, I think it’s getting to that season where you feel a bit more, everyone is the same though winter, you need that extra motivation...”* (Interview 13).

*“In the cold I get arthritis anyway so that never helps”* (Interview 2).

**Accessibility and convenience:** Local exercise facilities were often unknown and many participants were discouraged by high membership costs. In general, local access to facilities was important so that exercise was convenient and could be incorporated into daily routines. This was essential for employed participants, as long working hours were perceived to make finding time and energy to exercise difficult. On the other hand, some participants were motivated to exercise because they were sedentary at work.

*“Well, I suppose it’s accessibility, something which is there that I can get to”* (Interview 4).

*“It’s convenient, it’s on the way to work so you go there in the morning, work out...no hassle”* (Interview 20).

*“...the fact that I am sat at a desk all day...I almost feel guilty ... it can’t be good for me ...So it is more the fact that I feel need it than any other reason”* (Interview 15).

*“I think classes would be another option, out in Market Harborough I wouldn’t want to come into Leicester just for an exercise class in the evening...”* (Interview 2).



#### **4.3.4 Requirements for a physical activity intervention**

##### **4.3.4.1 Delivery of intervention**

**Group delivery:** Participants described how a group delivery in which they would be surrounded by peers of similar capabilities would be mutually supportive, educational and a way of improving confidence. Participants felt that if the intervention was to include a practical exercise element, classes should be stratified by age or fitness level, however, if the session was purely educational it was better to have a mixed group.

*“I will have a chance to know about other patient’s problems... share my problem with others [and] understand more about what helps me in the future” (Interview 7).*

*“...it becomes social thing as well then, you are competing against each other and see who has lost most weight or got most fit, who has picked up the best habits and who has done nothing” (Interview 20).*

*“If we were interacting as a group from a health perspective that is different because the common denominator is health and exercise...” (Interview 21).*

**Face to face:** Participants also stated that education was better delivered face-to-face as it provided a more personal approach.

*“I think people react better with a face to face encounter, but that might just be me” (Interview 2).*

*“I think initially it would be nice to see someone and then maybe if there were hints and tips” (Interview 13).*

##### **Follow-up support**

Continued follow-up support was deemed important for any physical activity intervention and sessions should review progress and goal attainments. Participants

acknowledged that remote follow-up was needed as travelling to the hospital on a regular basis may prove difficult for some. Suggestions included telephone calls, web cameras, and an interactive website.

*“Even like if you could log in somewhere and have a chat with someone or if not a chat leave a message for someone and for them to get back to you” (Interview 13).*

*“I think it would be nice to have a review of someone, or you could say to someone I have been going and nothing is happening, or I feel worse, but not have to go to the doctor” (Interview 13).*

*“Also, I think keeping in contact with the person ..from time to time just to see how they are...probably phoning them or sending them a letter or an email just to give them some re-assurance...” (Focus group 3).*

### **Tone of Delivery**

Participants stated that it was important to use a direct approach when delivering health and lifestyle education.

**Shock tactics:** Some participants suggested using “*shock tactics*” to motivate patients to become active and referenced smoking campaigns. This suggestion tended to be made by male participants who regarded themselves as regularly active.

*“Tell them if ...they don’t get some decent regular exercise they are going to end up with more kidney failure, maybe diabetes, stroke, heart attack...and tell them straight forward, don’t beat about” (Interview 18).*

*“If somebody is going to tell me something don’t mess about tell it straight. At least then you accept what you have been told and you do something about it” (Interview 18).*

*“I am not a medical person but I know what I’d do, I would frighten the life out of them, I would tell them if they didn’t do this, this and this it could affect their kidneys...”* (Interview 22).

**Positivity:** Other participants favoured a more positive approach to information giving which included mutual discussions to identify what was right for the individual. The concept of prescribed exercise was not viewed favourably, with the view that it might lead to resentment. Alternatively, participants described a preference for collaborative goal setting and review.

*“Yes, information in a very positive matter, they have got to be fed positivity. And encouragement as well, a lot of encouragement...I would have it in the form of counselling to get to know the person a bit more and to try and feed in”* (Focus group 3).

*“...you have got to make it a positive thing...it’s not a negative. If you don’t do anything then your kidney is going to deteriorate, if you do something you have got the chance for another few years, the choice is yours...”* (Interview 20).

*“...not just come down and say right we are going to talk about exercise [and] sport, [but] more of less weave it into a form of counselling...”* (Focus group 3).

#### **4.3.4.2 Resources to facilitate learning**

**Written resources:** Participants felt provisions of written materials were important and should include information about CKD in addition to specific advice regarding exercise that is safe and effective for renal patients. Written resources were described as a way of allowing family members to learn more about exercise and CKD.

*“I think looking back it would have been handy to...maybe just a basic leaflet saying this is what renal failure is, how severe or un-severe it can be, the symptoms to be*

*expected and then maybe a bit of activity, keep active, and give examples of what activity you can do” (Interview 15).*

*“...maybe even after 3 months [post diagnosis] an interim [exercise] information leaflet...because the spouse is usually more aware of what needs to be done than the patient” (Interview 21).*

Participants described how exercise should be graded, with supported progression from an initial gentle level. As indicated above, tracking progress was important and pedometers were suggested as a cheap and simple way to motivate individuals and increase their self-confidence.

*“If they have never done exercise obviously, they will have to start off very light, and that would mean just tell them to go out for a two mile walk after tea... Walk to the park, walk around it once and then walk home, once they start doing it they will feel the benefits after a couple of weeks they will think I can do more...” (Interview 18).*

*“I think [pedometers are] a good idea, for the men I think it would bring out the competitive element ... and even for women, I think it is confidence building” (Interview 6).*

#### **4.3.4.3 Timing of education delivery.**

**Early intervention:** The majority of participants felt that education should be offered at the point of diagnosis.

*“...sell it [exercise] straight away...if you have been told a negative, you have probably got all these questions like I did. So, if you are saying...you have got kidney failure but you can still do all this exercise...then I think it makes them all think that it is actually not as bad as it sounds” (Interview 15).*

*“Certainly, for the patient who is newly diagnosed the importance of regular moderate exercise should be made aware” (Interview 21).*

However, participants also described feeling “*shocked*” at diagnosis and described how people may “*need time to come to terms with it [CKD]*” before thinking about physical activity (Interview 10). Participants remembered having questions such as: “*Why me, how will it affect my lifestyle, what should I do, what shouldn’t I do?*” and felt that “*exercise [was] probably further down the list in terms of priorities*” (Interview 15).

## **4.4 Discussion**

CKD patients experience impaired physical performance which is associated with an increased risk of all-cause mortality (Painter and Roshanravan, 2013). Despite the potential of exercise to positively impact upon this, Chapter 2 demonstrated that 85% of non-dialysis CKD patients are not meeting recommended physical activity levels. Currently, little research is available to inform the development of a CKD-specific exercise behaviour change intervention. This study identified perceived barriers towards exercise held by patients with CKD and provided a greater understanding of the motivational processes required to increase levels of activity. SCT was used to inform the analytical framework, offering broader categories to aid understanding of the influences that impede or promote exercise behaviour in this patient group.

### **Personal influences**

Conceptualised in a framework of reciprocal determinism, this study identified several potential characteristics of engagement with exercise. Data suggests that personal characteristics influencing exercise include: 1) co-morbidities, 2) symptom burden, 3) negative perceptions of ageing, 4) fear of injury, 5) previous experiences of exercise, and 6) internal drive. Poor physical condition resulting from co-morbid conditions and CKD-related symptoms (fatigue, joint pain, and shortness of breath) were felt by participants to be the predominant barrier to exercise. These symptoms have been shown to be common in patients with CKD (Abdel-Kader et al., 2009). Advancing age

was linked to symptom experience, but as seen in other studies it was not clear if this barrier was a physiological or psychological limiting factor for exercise (Thorpe et al., 2014), as perceptions tended not to reflect biological age.

Perceived psychological barriers to exercise included fear of injury, and concerns about CKD aggravation because of over-doing exercise. Fears tended to be more pronounced in patients who had either had negative experiences of exercise, acute bouts of serious illness or those managing multiple co-morbidities. Participants described how exercising with someone and the support of friends or family helped them to feel more confident. However, participants wanted more concrete advice regarding what they can and cannot do in terms of exercise, and support and guidance in recognising their own performance limits. Similar fears have been described in dialysis patients and kidney transplant recipients, as well as a number of other chronic diseases (Wilcox et al., 2006, Goodman and Ballou, 2004, Painter, 1999). Painter et al. (1999) proposed that fear of exercise in transplant patients is partly due to the lack of information patients receive about the benefits of exercise from health care professionals. Patients form both emotional and cognitive representations of health and illness, including treatment perceptions (Leventhal et al., 1980). Perceiving exercise as a threat to health is likely reinforced by physiological experiences such as shortness of breath on exertion, and may lead to reduced exercise self-efficacy and the formation of negative treatment perceptions. Coping strategies to deal with emotional reactions may lead to threat avoidance (Zelle et al., 2016).

In contrast, participants who viewed their past experiences of exercise positively, described how they had re-engaged with exercise to experience the benefits again, indicating a high self-efficacy in their ability to perform the behaviour. Self-efficacy to perform physical activity is essential to engaging in regular exercise, and mastery experiences are often deemed as the most influential source of efficacy (Bandura, 2004). These participants also described their motivation as being innate to the self and reported how they used exercise as a way of fighting their condition. For some participants, this appeared to be driven by their perceptions of being an “active” person their whole lives, and previous positive experiences of exercise. However, for most participants this theme appeared to capture a survival instinct where exercise could be used to fight the condition, and giving up would lead to unthinkable consequences. This

is consistent with theories of self-regulation that propose that individuals will actively choose to engage in activities that are consistent with reducing a health threat (Leventhal et al., 1980). However, SCT posits that behaviour is not driven solely by inner forces, but an interaction between personal, behavioural and environmental factors. This is supported by a recent study where self-determined motivation was enhanced and maintained in patients who took part in structured exercise (Fortier et al., 2007). This suggests that extrinsic motivations for exercise can over time become more internalized, prompting maintenance. The Basic Needs Theory (a sub-theory within SDT) (Deci and Ryan, 2000) suggests that if basic psychological needs, e.g. autonomy, competency, and relatedness, are fulfilled, then individuals are more likely to exhibit autonomous motivational profiles, which are related to sustained exercise (Stewart et al., 2014). However, this could also be explained by the self-efficacy construct of SCT, where engaging in exercise or physical activity provides experiences of mastery, influencing levels of self-efficacy. Stronger efficacy beliefs ensure greater persistence in the face of barriers, which allows an individual to extend more control over their physical activity and exercise behaviours (Bandura, 2004).

### **Environmental influences**

Perceived environmental influences on exercise arose from number of different environmental sources including: 1) organisational, 2) physical, and 3) social. As described above participants expressed a need for tailored advice and support from their health care professionals regarding the specific principles of exercise which are safe and appropriate for renal patients. Participants also desired greater information relating to their disease and the management of symptoms. This need for improved education and lifestyle self-management advice has recently been demonstrated in the “Kidney Health: Delivering Excellence” report (The Kidney Health Advisory, 2013). However, patients in this current study thought that exercise for patients with CKD is not prioritised by the health service, highlighting the need for health care professionals to ensure they regularly consult with patients about exercise habits.

Furthermore, physical environmental factors such as bad weather and a lack of facilities were perceived to hinder exercise participation, as documented in the general population (Humpel et al., 2002) and other chronic disease populations. This is even

more important for the CKD population as exercise provisions and facilities are markedly less defined and less accessible in comparison to the services provided for cardiac and pulmonary patients (Smith and Burton, 2012). As a result patients with CKD lack the opportunity to develop peer support networks, which can significantly improve exercise adherence (Fraser and Spink, 2002).

Social environment appeared to be one of the key influences on participants attitudes towards exercise. Family support was highly valued and provided great motivation for engagement. Exercising with friends had the added incentive to not let others down. Participants described how they had joined gyms in the past and left due to feeling that the environment was not supportive enough. As such gym based exercise was often described with negative connotations, and as an environment that would foster feelings of inadequacy due to negative social comparisons between themselves and other exercisers. However, the majority of participants felt they would benefit from the opportunity to attend a CKD specific education and/or exercise class. This would provide a safe environment with other patients experiencing similar difficulties and allow people to feel more comfortable and confident. Exercise that is socially supported or performed in an environment that offers a sense of belonging is fundamental to a number of psychological theories, including SCT (Bandura, 2004), Self-Determinism Theory (SDT) (Ryan and Deci., 2000), and Theory of Planned Behaviour (TPB) (Ajzen, 1991).

### **Behavioural influences**

Participants perceived that participating in exercise had the potential to influence several aspects of their lives mainly: 1) health and well-being, 2) maintaining normality, 3) enjoyment and 4) influencing their social environment. Participants described how engaging in exercise had the potential to make them feel better, positively impacting on symptoms (particularly fatigue and pain) and improving mental health. This would indicate that patients with CKD have the potential to hold positive treatment perceptions towards exercise, which have been suggested to influence adherence (Leventhal et al., 1999). Some participants described how they used physical activity as a treatment to help control their disease and maintain normality in their lives. Perceptions of normality varied between participants and included staying fit for work, being able to keep



walking and being able to play with grandchildren. Controllability refers to the level to which an individual believes their condition can be controlled or cured by themselves or their treatment (Clarke et al., 2016). From the data presented in this chapter cognitions of controllability may be influenced by previous experiences of exercise and efficacy beliefs. Both may be influential in helping patients to overcome barriers to exercise such as fatigue, ageing and fear. Future interventions should consider ways to foster positive outcome expectancies and enhance feelings of efficacy to help CKD patients overcome barriers and engage in physical activity. Mechanisms to target self-efficacy are described in Chapter 5.

Desired social benefits were often described as one of the main reasons for engaging in the behaviour, be it making new friends or spending time with loved ones. However, the type of physical activity or exercise performed, and enjoyment seemed fundamental to participation. Participants described a love for certain activities, with many feeling that they gained the most physical and psychological benefits from walking. Enjoyment, inherently linked to social interaction in this study, enhanced motivation for exercise and is regarded in SDT as “intrinsic motivation”; the most internalized and self-determined form of motivation (Deci and Ryan., 2002). Desired benefits are also consistent with the construct of outcome expectancies within SCT, whereby motivation to engage in the behaviour is weighted against the pros and cons to which it can bring about positive changes to physical, social and self-evaluative outcomes (Bandura, 2004).

Participants also described a greater motivation to engage in exercise if it was purposeful or task orientated. Some participants noted difficulty in finding the motivation to exercise after experiencing life transitions such as retirement. However, others appeared to cope with this by setting themselves goals or including exercise as part of a routine in everyday activities e.g. walking to the shops. Self-monitoring behaviours were described as particularly important by participants who were more task orientated, as opposed to those who established exercise or physical activity routines. Self-regulation strategies have previously been shown to influence adherence (McAuley et al., 2011); and allow an individual greater control in influencing their own motivations for change and selecting behaviours that align with their preferences and competencies. Self-monitoring and goal setting operationalise self-regulation practices.

Participants tended to set goals that they felt could be achieved through exercise, which has previously been described in other patient groups (Thorpe et al., 2014). Goals are most effective when feedback is given regarding progress, something that should be considered when developing a physical activity intervention as participants desired the opportunity to discuss and alter goals with an exercise professional. However, participants felt that feedback could be delivered in a number of ways. Pedometers or step counters were described as a way of providing instant feedback and most felt this would be very motivating. Evidence shows that simple self-monitoring tools such as pedometers are effective at increasing levels of physical activity (Bravata et al., 2007), however, tools should be combined with a theory based intervention to be most effective. Monitoring progress provides the opportunity to react and change behaviour respectively. Goal commitment is enhanced by greater self-efficacy (Locke and Latham, 2002) and seeing improvements can increase feelings of competence. This was described in the current study where perceptions of positive exercise experiences increased motivation to engage in the behaviour. SCT posits that self-efficacy can be enhanced by seeing others which you consider similar to yourself accomplish something through what is termed as vicarious learning (Bandura, 2004). Therefore, asking individuals to share positive experiences of exercise may help to enhance the self-efficacy of others within a group setting, as well as reinforcing their own efficacy beliefs through memories of mastery.

#### **4.4.1 Implications for implementation**

Based on the findings of this study hospital-affiliated group-based rehabilitation programmes similar to those offered to UK cardiology and pulmonary patients could be an attractive option for CKD. This type of programme provides the opportunity for peer support and supervision, which could potentially reduce fears and concerns and increase exercise self-efficacy. A structured hospital-affiliated programme would most likely benefit patients with little exercise experience, fewer personal commitments, those requiring greater levels of support and those who are struggling to find purpose through life transitions such as retirement.

Alternatively, group based interventions that foster self-management skills and promote free living physical activity via education and behaviour change theory may offer greater flexibility than traditional rehabilitation, whilst still offering a supportive environment. The majority of patients felt that group based interventions would be beneficial and provide the opportunity for peer interaction and learning. Group based interventions utilising SCT components: self-regulation, self-efficacy, and barrier management have successfully increased physical activity levels in other cohorts (Yates et al., 2011). Incorporating group dynamic strategies e.g. group goal setting, interaction, and friendly competition, has been shown to increase self-directed exercise in a clinical setting (Estabrooks et al., 2011) and may help to improve adherence and reduce attrition rates. Participants in the current study desired greater information regarding their disease and exercise. Health information was deemed to be more acceptable if delivered in a group for extra support. Participants felt that all sessions should be supported with written education materials which would help to involve family members in the self-management of their condition. Furthermore, as described above participants thought that intervention resources such as pedometers would enable them to set goals, track their progress and help them to feel as though their exercise had more of a purpose. Based on the findings of this study participants should be asked about what types of physical activity they enjoy the most, and any exercise or physical activity prescription would benefit from a graded structure to enable participants to build confidence and fitness at their own pace.

Walking was the activity favoured by the majority of participants, as acknowledged in Chapter 2, as well as previous studies conducted in CKD (Chen et al., 2014) and the general population (Darker et al., 2010). Walking is particularly suited to engaging inactive participants of all competencies as it is deemed acceptable and accessible (Morris and Hardman, 1997). Evidence shows that just 30 minutes of walking, 5 times a week has major cardio-protective benefits (Kosmadakis et al., 2012) as well as positively impacting immune function and inflammation (Viana et al., 2014) in patients with CKD stages 4-5. Furthermore, Chapter 3 demonstrated an association between walking and a reduced risk of mortality. However, it is important to ensure that other activities are available as one size does not fit all.

This work also highlighted additional priorities for intervention development, which included gaining an understanding of the optimal timing for education and tone in which it should be delivered. The majority of patients felt that basic disease and physical activity lifestyle advice should be provided at the point of diagnosis or within the first 6 months to allow the patient time for personal adjustment, but few participants recalled receiving any lifestyle advice at all. Health care professionals can play an important role in promoting physical activity in patients with CKD, but may experience barriers in delivering early education such as a reluctance to induce emotional distress (Narva et al., 2015). The impact of this is that many patients do not receive disease education until eligible for information regarding the initiation of RRT following a progressive decline of kidney function. However, this approach is in stark contrast to diabetes mellitus, whereby intensive lifestyle education is offered to patients prior to the onset of type 2 diabetes (Yates et al., 2011). Therefore, whilst the content and delivery of lifestyle education may need further investigation, the present study reports a clear patient need and desire for early education, which is also recommended by the KHA-CARI guidelines (Johnson et al., 2013).

Participants displayed individual preferences when describing the tone in which education should be delivered to be most effective at changing behaviour. One suggested approach focused on the use of “shock tactics” with patients referencing smoking campaigns, as what they perceived would be the most beneficial approach to encouraging physical activity behaviour change. This concept is regarded in the literature as fear-inducing health messages and describes messages that induce both an emotional (fear) and cognitive (threat evaluation) response (Witte and Allen, 2000). The use of such messages tends to evoke strong opinions among researchers and healthcare professionals regarding the success and potential for backfire. However, a recent meta-analysis indicated that fear appeals are successful at changing attitudes, intentions and behaviours (Tannenbaum et al., 2015). The findings suggested that fear inducing health messages may be most effective when including statements of severity, susceptibility, and efficacy, and when targeting female audiences and promoting one time only behaviours. In addition, the review also showed that fear may have a maximum effect value, beyond which no further effect is achieved from depicting additional fear. Patients in the current study reported fears regarding potential injury and disease exasperation through exercise, and a recent narrative review reported that patients with

CKD experience worries about their condition, compatible with that of ESRF patients requiring dialysis therapy (Clarke et al., 2016). The effect of fear messages to promote physical activity in patients with CKD is unknown but may represent an interesting area for future consideration. However, it is important to note that this approach would not be suitable for all and some patients also desired a more person-centred approach, wanting information to be tailored and delivered in a very positive way. A greater understanding of both effective and acceptable methods for delivering education to promote physical activity is required.

#### **4.4.2 Limitations**

This study had a relatively low response rate to invitations sent out, and due to the voluntary nature of participation, it is possible that this was a self-selecting group that had an interest in exercise greater than that of the general CKD population. The low response rate may be partially explained by the length of time from expression of interest to being contacted for Part 2, in which participants may have forgotten about the study or lost interest. One way to maintain engagement would have been to send out regular study updates from QCKD Part 1. Another reason for the low consent rate when compared to initial expression of interest could be that participants had not had time to fully read the patient information sheet and consider the implications of participating in the study at this initial point. Instead participants were simply consenting to hearing more information and being invited to participate in QCKD Part 2. Patient information sheets were then sent as part of a postal invitation, which may have seemed less personal than face-to-face recruitment in clinic. However, participants may have also felt more obliged to express an interest when approached by a researcher in clinic for reasons related to social desirability, but felt less obliged to participate when contacted via post. Although the study is somewhat limited due to the potentially biased sample, findings of the GPPAQ suggest that of those interviewed 60% would be eligible for a brief intervention in physical activity.

This study was designed to broadly explore psychosocial factors that influence CKD patients' engagement or willingness to engage with exercise or physical activity. Also, to identify potential intervention features that might help to encourage patients to be more active. Therefore, whilst participants may have completed a physical activity

survey as part of an earlier stage of this work, the study was not set up to explore differences in the perceptions of active or inactive participants. In recognition of this limitation, thick descriptions for each theme have been provided, enabling inferences to be drawn from the data. Despite the limitations, this study offers a unique detailed account of patient perceptions and attitudes towards exercise.

## **4.5 Conclusion**

CKD patients reported more motivators than barriers to exercise. They described a positive attitude to exercise and would therefore potentially be receptive to a CKD-specific exercise behaviour change intervention. Such interventions need to be designed to accommodate multiple and complex psycho-social and environmental influences. This should include information and content that meets the needs of individual patients as well as considering the wider social and structural context. Health services need to actively support exercise for CKD patients, offering routine exercise counselling, and providing accessible services and facilities.

# Chapter 5

## **Rationale and Development of a Structured Group Based Education Programme Designed to Increase Levels of Physical Activity in Patients with CKD.**

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Previous chapters have identified high levels of physical inactivity among CKD patients stages 1-5 not requiring RRT. This chapter details how the Person-Based Approach was used to inform the development of the Physical Activity Changing Together (PACT) programme, a behaviour change intervention designed to increase levels of physical activity in non-dialysis CKD patients. The rationale and development for PACT is presented and qualitative enquiry is used to refine the intervention based on patient responses and feedback.

### **Statement of originality**

The work contained in this chapter was completed by the candidate and is her own work. H.J.M supported the delivery of the intervention within the user testing phase, and senior research nurse S.B identified the Nottingham participants for the study.

## 5.1 Introduction

Patients with CKD are at high risk for cardiovascular complications, which is the leading cause of mortality (Drey et al., 2003). Risk factors for CVD are often classified into modifiable and non-modifiable risk factors. Modifiable factors related to an increased risk of CVD include poor diet, high blood cholesterol, high blood pressure, insufficient physical activity, overweight/obesity, diabetes, psychosocial stress, excess alcohol consumption and smoking/tobacco (NICE, 2010). Addressing these factors is essential to the medical management of CKD, along with behaviours such as medication adherence. However, patient-level CKD awareness referring to general CKD knowledge, risk factors, associated complications and individual risk continues to be low (Plantinga et al., 2010). Health literacy is defined by the WHO as the “cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (Kickbusch and Nutbeam, 1998). Health literacy has been shown to be low among patients with CKD and has been associated with lower eGFR, less favourable cardiovascular profiles (Ricardo et al., 2013) and increased risk of mortality (Cavanaugh et al., 2010).

Knowledge has been shown to be associated with self-care behaviours, and interventions that target both knowledge and confidence may result in positive behavioural changes (Kaleth et al., 2014). Patient education is based on the premise that knowledge is linked to change, if patients lack the relevant knowledge about the impact of their lifestyle on their condition they have little reason to initiate health behaviour change (Bandura, 2004). Patient education aims to increase knowledge and empower patients in disease management. The importance of patient education to increase levels of physical activity in patients with chronic disease is of growing interest with promising results (Conn et al., 2008), but few studies have examined the use of such programmes in CKD. Still, patient education has the potential to encourage individuals to take a more active role in their health, and self-management programmes are becoming increasingly important within the CKD care context (Curtin et al., 2008). Furthermore, education regarding self-management has been shown to be a patient priority (Ormandy and Hulme, 2013), and as demonstrated in Chapter 4 CKD patients

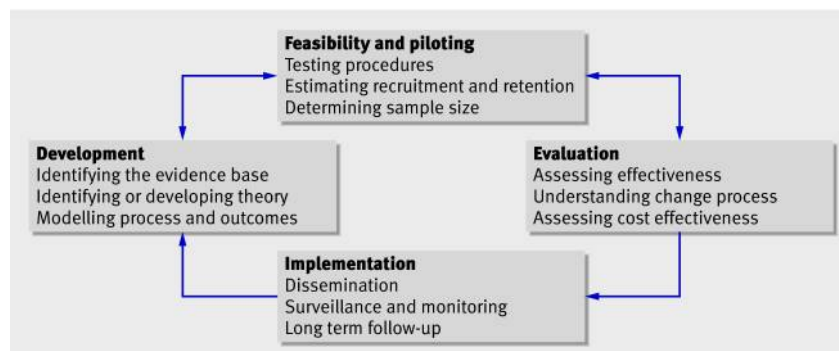


desire greater information about safe and effective exercise. Structured group based education has been used effectively within other patient cohorts to increase levels of physical activity (Yates et al., 2011). However, no theory driven, evidence based, structured education programmes exist within the UK to target levels of physical inactivity among non-dialysis CKD patients. Byrne et al. (2011) called for more robust pilot work to ensure the acceptability of CKD education programmes prior to effectiveness testing. Intervention development frameworks can be used to ensure a systematic approach to development and are explained below.

### 5.1.1 Intervention development frameworks

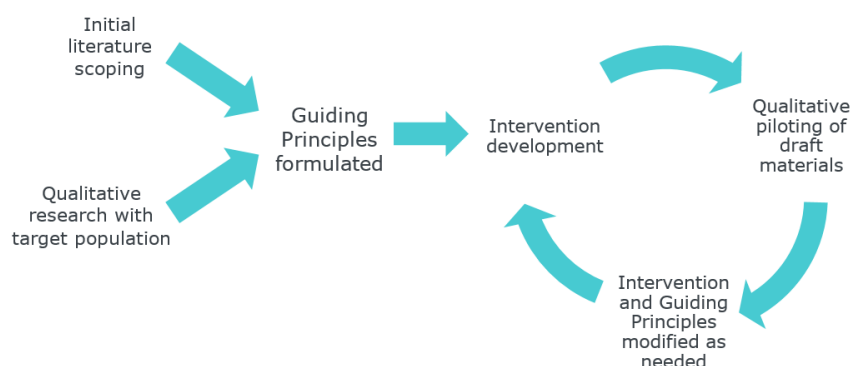
Encouraging an individual to engage in either a supervised exercise programme or a lifestyle intervention requires them to make a behavioural change. Behaviour interventions are usually multifaceted and inherently difficult to replicate, and as such are considered complex interventions (Michie et al., 2009). NICE guidelines recommend the use of evidence based principles including proven behaviour change techniques, and to ensure that the behaviour change intervention is underpinned by theory. Furthermore, the MRC provides guidance for developing complex interventions, which is considered a useful approach in developing, testing, implementing and evaluating behaviour change interventions (Figure 5.1). The MRC recommend that evidence be reviewed systematically and suitable theory be identified for the development of a complex intervention.

**Figure 5.1 Developing and Evaluating Complex Interventions: The New Medical Research Council Guidance.**



However, as argued by Band et al. (2017), an in-depth understanding of the user and context in which the intervention is to be delivered is vital to ensure patient acceptability. Thus, enhancing the likelihood of effectiveness. Qualitative enquiry, therefore, plays an important role in the development of complex interventions and whilst it is recommended within the MRC Framework, no guidance is offered with regards to how to maximise the use of qualitative research for intervention development. As discussed in the previous chapter, qualitative research is fundamental to understanding the needs and perspectives of patients. This is recognised by the Person-Based Approach, which has evolved from the successful development of digital interventions to help patients manage health and illness (Yardley et al., 2015a). This systematic approach to the development of behavioural interventions has also been applied by the expert Diabetes Research Centre, who have developed a number of structured group based education programmes for the prevention and treatment of type 2 diabetes (Morton et al., 2015, Troughton et al., 2016). This approach has led to the successful award of a recent NIHR grant to translate evidence into primary care (Davies et al., 2017). Central to the development of these types of interventions is the use of qualitative research providing a tool to explore the users' perspectives (Yardley et al., 2015a). This approach compliments the broader category of “development” described within the MRC Framework, and provides guidance for the use of iterative qualitative research to inform the planning, development, and implementation of an intervention (Yardley et al., 2015a).

**Figure 5.2 The Person-Based Approach.**



\* Diagram copied from Yardley & Weal (2016).

### **5.1.2 Aim**

The aim of this chapter is to describe transparently the processes undertaken to develop the PACT intervention. This includes a review of the evidence, theory and the application of the Person-Based Approach.

## **5.2 Methods**

The Person-Based Approach was used as a framework to guide the development of a structured group based education programme to increase levels of physical activity in patients with CKD. This approach focuses on the patients' needs and perspectives and has been used to develop several successful behaviour change interventions in patients with other chronic diseases. The study was split into three main phases including:

**Phase 1) Intervention Planning**

**Phase 2) Intervention Design**

**Phase 3) Intervention Development**

### **5.2.1 Ethics**

Table 5.1 outlines research activity in each of these stages and the following sections details the methods and results for each stage. The development of this intervention was part of the Self-Management Programme for Improving Health through Physical Activity in Chronic Kidney Disease (SPARK) study (ISRCTN 12942806). A favourable opinion was obtained from NRES committee West Midlands–Solihull on the 21/10/2014. Methods are detailed in greater depth for each phase within the results section.

**Table 5.1 Reports the methods and research activity undertaken during planning, design, and development of PACT.**

<b>Stage of intervention development and design</b>	<b>Specific person-based activity conducted at each stage</b>	<b>Other activities relevant to the Person-Based Approach</b>
<b>Phase 1</b> <b>Intervention Planning</b>	<p>A literature review of patient education and self-management programmes in patients with CKD with a focus on exercise and physical activity.</p> <p>Qualitative data analysis to explore perceptions towards physical activity and elicit users views of specific design objectives and features of a physical activity intervention. (Presented in Chapter 4).</p>	<p>Consulted with experts in the field.</p> <p>Observed education and behaviour change programmes that are currently running as part of the NHS.</p> <p>Examined relevant literature around behaviour change theory and BCT for changing physical activity behaviour.</p>
<b>Phase 2</b> <b>Intervention Design</b>	<p>Convened a PPI group as a steering committee on this research programme.</p> <p>Used themes from the planning phase to identify key guiding principles for intervention.</p>	<p>Readability assessments of written materials.</p> <p>Mapping of behaviour change determinants to the theoretical constructs of SCT using the CALO-RE taxonomy (Michie et al., 2011).</p>
<b>Phase 3</b> <b>Intervention Development and Evaluation of Acceptability and Feasibility</b>	<p>Focus groups to observe users' reactions and gain feedback to intervention. The Intervention was iteratively modified to enhance acceptability and engagement.</p>	<p>Developed detailed instructions for intervention delivery including an educator's manual.</p> <p>The feasibility study will involve a mixed methods approach to evaluate acceptability, feasibility and assess intervention efficacy to target physical activity behaviours (Chapter 6).</p>

## 5.3 Results

### 5.3.1 Phase 1 Planning

#### 5.3.1.1 Literature review

**Purpose:** To conduct a rapid review of the literature to explore the effectiveness of patient education or behaviour change interventions for increasing levels of physical activity in patients with CKD not requiring RRT. The MRC Framework states that this evidence should ideally be presented in the context of an up to date systematic review, therefore, literature searches were conducted to identify relevant systematic reviews only.

**Methods:** Due to the anticipated small evidence base, no restrictions were made regarding patient characteristics or study design. Search terms included: “educat\*” or “self-manag\*” or “self manag\*” or “self-car\*” or “self car\*” or “train\*” or “instruct\*” or “patient cent\*” or “patient-cent\*” or “patient focus\*” or “patient focus\*” or “behaviour change” or “patient-education” or “patient education” or “management plan\*” or “management program\*” and “physical activity” or “exercise” or “lifestyle” and several variations of “CKD”. The following databases were searched: AMED, BNI, CINAHL, EMBASE, Health Business Elite, HMIC, Medline, PsycINFO and Google Scholar (April 2016).

**Results:** The search identified two comprehensive systematic reviews evaluating the use of educational interventions in patients with CKD. However, only one of these high-quality reviews included lifestyle based education programmes in non-dialysis CKD patients (Lopez-Vargas et al., 2016). Three studies aiming to increase levels of exercise or physical activity via lifestyle-based education were reported (Table 5.2). Identified studies were conducted in either Taiwan or the Netherlands between years 2012 -2013. Two of the studies were RCTs and the other was a pilot quasi-experimental study design. All three studies provided some form of education. Two of the identified studies aimed to target multiple health behaviours, but were unsuccessful at changing physical activity or exercise behaviour. In comparison, the pilot study by Kao et al. (2012) only aimed to target exercise behaviour, and demonstrated improvements in this outcome.

This suggests that interventions targeting a specific behaviour may be more successful than interventions that target multiple behaviours (Bull et al., 2014).

With regards to psychological theory, two of the identified studies used the TTM (Prochaska and DiClemente, 1982), and the other study used a cycle of change adopted from one of the pillars of motivational interviewing, to design the intervention. The role and selection of psychological theory for intervention development is given greater discussion later.

With regards to delivery, the promising pilot study conducted by Kao et al. (2012) supports the use of group based education in CKD patients, which has been highlighted as an area for further research (Mason et al., 2008). Group-based interventions have been shown to be more effective than individually targeted interventions at increasing physical activity (Burke et al., 2006), and nationally commissioned programmes such as Diabetes Education and Self-management for Ongoing and Newly Diagnosed (DESMOND) have been shown to be financially viable (Gillett et al., 2010). Furthermore, group education has positively impacted on QoL and health outcomes in other patient groups (Yates et al., 2011, Estabrooks et al., 2011) and is typically more cost-effective (Beauchamp and Eys, 2014). As seen in the Chapter 4 participants strongly favoured the idea of a group delivery, describing how groups foster enjoyment and would provide them with much needed peer support.

Furthermore, the successful intervention also included the provision of an exercise diary to allow participants to self-monitor their physical activity. Setting goals and monitoring progress towards them were also described as important intervention features by patients in Chapter 4. Self-monitoring is considered an essential behaviour change technique for changing physical activity behaviour (Michie et al., 2011).

Based on the limited evidence presented in Table 5.2, interventions for changing physical activity may be more successful if including proven behaviour change techniques and targeting only one behaviour. The pilot study conducted by Kao et al. (2012) demonstrated a potential for increasing levels of physical activity in the target population. However, the reporting of the intervention lacked sufficient detail to be able to replicate it for a UK CKD population.

Therefore, the candidate sought to identify a physical activity group-based education programme that utilised self-monitoring, that could be readily adapted for patients with CKD. Leicester hosts the leading Leicester Diabetes Centre, which has a number of self-management and behaviour change interventions running as clinical research studies and within the clinical service. Of interest was the Walking Away from Diabetes programme, an established low resource, group based education programme that utilises pedometers to increase levels of physical activity (Yates et al. 2012). Walking Away from Diabetes is an adaption of the successful DESMOND programme and at the time of developing the PACT intervention was being trialled in patients with glucose intolerance. Similar programmes were also being adapted for patients with schizophrenia (Gossage-Worrall et al., 2016) and polycystic ovaries syndrome (Mani et al., 2015). As such, Desmond informed trials such as Walking Away from Diabetes (Yates et al. 2012) appeared to provide a format that could be readily adapted to different populations. The running of this programme was observed by the candidate, and general impressions of its suitability for fulfilling CKD patient requirements are indicated in section 5.3.1.4.

**Table 5.2 Studies examining the role of patient education to target levels of physical activity or exercise in non-dialysis CKD patients.**

Author	Objective	Study Design/ duration	Participants	Intervention	Physical activity outcome measures	Physical Results	Activity/Exercise
<b>Kao (2012), Taiwan</b>	Investigate the effects of an exercise education intervention on depression, fatigue status and exercise behaviour of CKD patients.	Pilot study (quasi-experimental)  4 months	CKD eGFR >15 ml/min/1.73m  n=45 intervention n=49 control arm	TTM theory driven exercise education intervention utilising: educational lectures; written material, self-monitoring (exercise diaries) and telephone follow-up. The intervention group received an initial tailored report based on their readiness to change and telephone counselling was also tailored to this. Participants were advised to exercise within their own load capacity using the “sing talk” test, doing an activity they enjoyed for 30 minutes 5 times a week.	Past Year Regular Exercise Questionnaire	Increased self-reported weekly activity (11.9 – 13.04 MET)	
<b>Teng (2013), Taiwan</b>	The purpose of the study was to test the ability of targeted interventions, matched to the TTM stage of change, to modify the diet and exercise behaviours of patients with early CKD.	RCT  12 months	CKD diagnosed by nephrologist early – moderate stages.  n=80 intervention n=80 control arm	Patients received counselling based on their readiness to change. The intervention consisted of 5 appointments: baseline, 3, 6, 9, and 12 months. Readiness to change was assessed at each visit to ensure participants received the appropriate intervention targeted to their stage of change. The control group received standardised face to face education on the benefits of healthy eating and physical activity and were given an educational booklet.	Exercise Stage of Change Questionnaire Assessments were undertaken at 3, 6, 9 and 12 months	The intervention group showed a significant change in diet behaviour in comparison to control group over the 12-month period. However, neither the intervention nor control group made significant behavioural changes for exercise (transition from an earlier stage of change to action or maintenance).	
<b>van Zuilen (2012), Netherlands</b>	Assess the strict implementation of current guidelines with emphasis on lifestyle change, to improve cardiovascular outcomes.	RCT  4.6 years	CKD stages 2-4 N=788	Multifactorial risk factor management by nurse practitioners, supervised by nephrologist, provided lifestyle intervention (physical exercise, nutritional counselling, weight reduction and smoking cessation), the use of specified cardio protective medication and the implementation of current guidelines. Nurses goal attainment and adjusted treatment to achieve target values. Control arm received ‘usual care’.	Self-report achieving Dutch PA guidelines	The intervention group increased from 57-60% meeting recommended guidelines, this was not significantly different	



### **5.3.1.2 Qualitative research with target population**

Chapter 4 detailed the findings of a qualitative study conducted with the target population CKD patients' stages 1-5 not requiring RRT. The study was designed to explore patients' perceptions to exercise and highlight key design objectives and features that could be utilised in the development of a physical activity intervention. To summarise, patients reported several barriers to physical activity including poor physical health; fears related to injury and disease progression; lack of support and guidance and a lack of facilities. However, overall patients demonstrated a high level of enthusiasm for physical activity. Some participants described how they had experienced the benefits of exercise for themselves, whereas others wished to engage in exercise to experience desired benefits to help them manage their condition. Motivators included the enjoyment of exercise, goal setting, and support. More specifically with regards to intervention development, participants desired the opportunity to meet other patients, some form of supported follow-up contact, the information presented in a direct but positive light tailored to themselves, information supported by written documents and a physical activity monitoring device. Finally, the majority described how they wished to receive this information soon after diagnosis.

### **5.3.1.3 Expert consultations**

**Purpose:** This phase of the research aimed to understand experts' perceptions of potential intervention concepts and their feasibility.

**Methods:** A purposive sampling method was used to recruit expert panel members with relative expertise in the areas of CKD, patient education, physical activity and behaviour change. Experts were contacted via email inviting them to take part as an advisor for the development of the PACT study. Researchers (A.L.C & H.J.M) met with panel members on an individual basis. The expert panel consisted of nephrology consultants n=2, dieticians n=2, health scientists n=2, health psychologists n=2, physical activity expert n=1 and national director of the highly-regarded DESMOND programme n=1. All experts approached agreed to participate as part of the expert panel. Meeting agendas were tailored to the participants' area of expertise, but broadly covered: current or previous work undertaken by the participant that may provide useful insight for the

development of a physical activity intervention; education or health behaviour change theories; suitable outcome measures; skills required to facilitate a group; and engaging patients with health information.

**Results:** Following consultations with experts in the field of CKD, physical activity, patient education and behaviour change; field notes were reviewed and suggestions were organised into themes including: 1) outcome measures, 2) patient acceptability, 3) fostering a supportive environment, 4) importance of theory and 5) intervention fidelity. Themes are presented below with information on how suggestions were incorporated into the design of the PACT intervention.

**Outcome measures:** Experts emphasised the importance of choosing the right outcome assessments to evaluate the PACT programme. Discussions tended to be focused on choosing either a behavioural outcome e.g. steps or a clinical outcome. To undertake limited efficacy testing of the physical activity intervention it was decided that steps would be a suitable measure. Based on their own experience one expert recommended a target of 2,000 steps. However, the target was increased to 3,000 steps after discussions with the PPI group and to be in line with the government physical activity recommendation. Experts advised that secondary outcomes should include measures of illness perceptions, self-efficacy and patient activation.

**Patient acceptability:** Experts emphasised the importance of PPI in developing the intervention. It was advised that a PPI group should be consulted on factors that may influence engagement and acceptability e.g. length of session and the chance to review intervention materials. Specific techniques such as the use of a “Think Aloud Protocol” (Jääskeläinen, 2010) was also recommended to ensure the acceptability of intervention content. Based on this advice a PPI group was convened to co-develop and provide feedback on all education resources. Think aloud protocols were utilised successfully in the development phase.

**Fostering a supportive environment:** Experts described the importance of professional, peer and family support for promoting health behaviour change and physical activity maintenance. Recommendations for support included regular text messages and engaging consultants with the research so they could act as a source of support for

physical activity maintenance during routine appointments. This was implemented by organising several individual meetings with clinicians to describe the PACT intervention and explain the importance of regularly engaging in supportive discussions with patients about their level of physical activity after the programme.

Social media was described as a useful tool to help patients feel more supported by peers. However, this idea was not implemented into the intervention due to concerns related to safe guarding and social inequality. However, other ideas to foster group dynamics such as having small groups between 4-6 participants and inviting participants to bring a partner were all successfully implemented into the PACT intervention. Other suggestions such as scheduling long coffee breaks to help participants build relationships was also included in the intervention session.

***Importance of theory:*** Experts all agreed that behaviour change interventions should be theory driven. The most common theories recommended included the Common-Sense Model (CSM) and SCT. A review by Clarke et al. (2016) was undertaken to synthesize the existing literature on the CSM and illness perceptions, to understand more about how patients with CKD think and feel towards their illness, and identify negative illness perceptions that could be targeted within the intervention. Constructs of illness and treatment perceptions such as identity, perceived consequences, timeline and controllability were all targeted within the PACT group session and written resources

The behaviour change taxonomy was recommended as an important tool in defining the “active ingredients” of the intervention. Specific recommendations to include self-monitoring and action planning were also given. The CALO-RE taxonomy (Michie et al., 2011) was utilised to inform behaviour change techniques for the intervention (see section 5.3.1.5). The Yamax SW200 was recommended as a suitable tool to encourage self-monitoring of steps.

***Intervention fidelity:*** Expert members also emphasised the importance of standardising the delivery of the education session and content; as well as undertaking fidelity checks and ensuring that any external patient sources recommended were safe and accurate. In response to these recommendations a standardised education manual was developed and

reviewed by 3 clinicians to ensure that the information was both accurate and appropriate for patients with CKD (see Appendix 1).

**Conclusions:** The expert panel provided essential guidance with regards to psychological theory; the practicalities in delivering an intervention, study design, and outcome measures. Following our discussions with some of the expert panel members (A.L.C & H.J.M) were invited to observe interventions running in a real-life context which is detailed below.

#### **5.3.1.4 Programme observations**

**Purpose:** To gain a greater understanding of how structured group based education programmes are delivered in practice two programmes were observed that are currently running as part of either a clinical pathway or service. This step was undertaken to further our understanding of patient education content and delivery, and help to develop ideas for the development of a CKD specific behaviour change programme.

**Methods:** Two programme running as part of a clinical service were observed. The first programme observed was “Walking Away From Diabetes” a structured group based education programme (Yates et al., 2012) designed to increase ambulatory behaviours in those who are at high risk of developing type two diabetes. The second was a structured patient education programme designed to increase knowledge and self-efficacy in CKD patients approaching RRT delivered as part of the clinical service at University Hospital Coventry (McCarthy, 2014). Notes reflecting my first impressions, general observations and discussions with the facilitators were made after both sessions.

**Results:** Anecdotally, participants appeared to engage more when the session was interactive and used props e.g. picture to facilitate discussions as opposed to lecture-based education. Didactic teaching via structured slides and question/answer sessions seen in one programme appeared to accompany an atmosphere of separation between the expert (educators) and the user (patient). Whilst, acknowledging the difficulties of patient education, it was clear that utilising open-ended questions prompted most discussion among participants. I was also particularly impressed with the reflection of questions, to encourage group discussion.

**Conclusions:** After seeing these programmes in practice, it appeared that an adapted format of the “Walking Away from Diabetes” programme offering a combination of disease knowledge and physical activity/self-monitoring guidance may be a suitable avenue to explore among patients with CKD.

#### **5.3.1.5 Examination of behaviour change theory**

**Purpose:** Theory provides a framework to guide intervention development and allows for evidence to be collated determining the successful mechanisms of change. However, multiple theories exist and difficulty comes in choosing the most suitable theory for the behaviour and context an intervention will be delivered in. The purpose of this mini narrative review is to provide an overview of behaviour change theories most commonly applied to physical activity, and identify a suitable theory to guide the development of a CKD specific physical activity behaviour change programme.

**Methods:** A literature search revealed a recent systematic review detailing the most commonly applied psychological theories to physical activity behaviour change interventions in the general population (Gourlan et al., 2016). The most dominant theoretical perspectives applied to physical activity behaviour change are social cognitive theories. These conceptualise physical activity as a deliberate and conscious behaviour. Such theories include the Transtheoretical model (TTM) (Prochaska and DiClemente, 1982), Theory of Planned behaviour (TPB) (Ajzen, 1991) and Social Cognitive Theory (SCT) (Bandura, 1986). In addition to these models, whilst less commonly applied to physical inactivity in the general population, we also identified a growing interest in models of self-regulation among individuals with chronic disease, and how perceptions of illness may influence health behaviours. Therefore, this section will also consider the Common Sense Model (CSM) for Health and Illness (Leventhal et al., 1980).

## **Overview of theories**

### **Transtheoretical Model**

The TTM assesses an individual's readiness to change a health related behaviour and describes a number of processes and decisions which may influence change (Prochaska and DiClemente, 1982). The stages of change part of the TTM suggests that individual's progress through five stages of change. These stages include: pre-contemplation, contemplation, preparation, action, and maintenance. This part of the model describes a time frame of when the changes take place; however, the TTM also includes a number of additional constructs. The other part of the model describes processes of change which involve cognitive and behavioural strategies that influence the behaviour change process. Identifying the consequences of behaviour change (decisional balance) is a fundamental part of the theory, it is expected that those in the later stages of change will anticipate greater benefits. Self-efficacy has also been shown to change as individual's progress through the stages of change (Marshall and Biddle, 2001). However, whilst commonly applied to physical activity interventions it has been shown to have mixed effectiveness at producing changes in physical activity behaviour and has recently been described as outdated, with a call for theories that recognise the triggers and potential suddenness of change to take its place (West, 2005). Furthermore, Bandura (2004) has provided extensive critique for the Stage of Change model, stating that it violates all three assumptions (qualitative transformation across discrete stages, an invariant sequence of change and non-reversibility) of a genuine stage theory. For example, the transition from action to maintenance requires no specific qualitative changes only the passing of time; an individual that quits smoking abruptly may not pass through all stages and finally in a true stage model one cannot revert to an earlier phase. Bandura (2004) suggests that individuals do not progress or regress through stages. Instead they fluctuate in their ability to exercise control over their behaviour, which is influenced by personal, behavioural and environmental factors, as well as facilitators and impediments.

## **Theory of planned behaviour**

The TPB is based on influences of attitudes (instrumental/ affective), subjective normative (descriptive/ injunctive) and perceived behaviour control (self-efficacy/ controllability), on intentions to perform the behaviour (Ajzen, 1991). Intention has been shown to be a strong predictor of behaviour change, but there is still what is known as an “intention- behaviour gap”. Controversy surrounds the TPB as it does not explain how cognitions change, which has led to queries regarding the model being used as a theory of behaviour change as opposed to simply a model to explain behaviour (Sniehotta et al., 2014). The TPB has recently been expanded to include a more comprehensive integrated model of behaviour change including 10 psychological constructs applied to physical activity, but it still requires confirmation of effectiveness through empirical testing (Hagger and Chatzisarantis, 2014). Furthermore, although this new theory has addressed the intention-behaviour gap of the TPB, it appears complex and still provides little guidance with regards to how each construct should be manipulated to bring about positive changes in physical activity.

## **Social Cognitive Theory**

SCT was founded on the model of causation favouring the reciprocal determinism triad in explaining behaviour (Bandura, 1986). This describes how personal factors (cognitive, affective and biological states), environmental factors (physical and social environment) and current behavioural factors interact to influence human behaviour. For instance, our expectations, how we think and feel, and the goals we have, influence our behaviour and what we do. In turn, our actions influence our affective reactions and thought processes. Whereas, the beliefs we hold are shaped by our environment and the people around us through modelling, instruction, and verbal persuasion. Individuals are then able to impact on their environment through their conveyed social role. What we do can alter our environment; however, most environments need to be activated by a specific behaviour before they can impact upon us (Bandura, 1986).

SCT is a broad theory that assumes knowledge as a pre-condition to change, but recognises that it takes more than knowledge to overcome impediments to changing behaviour. Individuals may have to alter personal motivations, thought processes,

affective states, and in some cases, restructure their environments to facilitate change. The concept of self-efficacy is central to the theory and describes an individual's efficacy beliefs to regulate their own behaviour including motivations, personal goals and level of commitment to them, and determine the outcomes expected from performing the behaviour (Bandura, 2004).

Beliefs regarding one's ability to obtain a desired outcome influences perseverance in the face of barriers. Barriers to change are categorised into two groups, these include personal/situational (e.g. fatigue or perceived lack of time) and socio-structural (e.g. a lack of exercise facilities). Therefore, individuals with high self-efficacy are more likely to view barriers as something they can overcome. Self-efficacy can be influenced by four main processes including mastery, verbal persuasion, vicarious learning /modelling, and relying on interpretations of somatic and emotional states (Bandura, 2004). The main constructs of SCT for changing behaviour include knowledge (only as a pre-condition to change); outcome expectancies, self-efficacy, goal setting and facilitators and impediments to change. However, SCT is often criticised for being perceived as a one construct theory which is centred on self-efficacy. Whilst self-efficacy is an important predictor of physical activity, other constructs of interest such as outcome expectations should be given consideration.

### **Self-regulation**

Self-regulation is considered essential to changing health behaviours and has been a large part of the success of physical activity programmes such as PREPARE (Yates et al., 2011). Self-regulation allows an individual to exercise control over their behaviour and motivations and is operationalised by self-monitoring the behaviour, enlisting personal incentives for change, and goal setting (Bandura, 1997). Goals are most effective, when feedback is given regarding progress as it provides the opportunity to react and change behaviour respectively (Bandura, 2005). Goal commitment is enhanced by greater self-efficacy (Locke and Latham, 2002) as seeing improvements can increase feelings of competence. Encouraging individuals to self-monitor using pedometers has been shown to be effective at increasing levels of physical activity (Bravata et al., 2007), and was a key component in the PREPARE programme (Yates et al., 2011). Gollwitzer's Implementation Intentions (Gollwitzer, 1999) is a self-



regulatory model that has been found to be useful in helping individuals to initiate behaviours and was also included in the Integrated Theory of Behaviour (Hagger and Chatzisarantis, 2014). Implementation intentions specify where, when and how the performance of the behaviour will take place. This describes action planning, defined as taking an individual's intentions and motivations to a volitional stage where they can action their behaviour (Michie et al., 2011).

### **Common Sense Model**

When applied specifically to health and illness self-regulation theories propose that individuals are “active problem seekers” who will undertake behaviours that are consistent with reducing a health threat. Illness perceptions are organised patterns of thought that are generated in response to a threat and are theorized within Leventhal's Common Sense Model (CSM) of self-regulation (Leventhal et al., 1980). These illness schemas may inform an individual's coping strategy including their willingness to engage in self-management behaviours e.g. regular physical activity. CSM suggests individuals perceive an illness based on the following principles: Identity (the name and symptoms that go with it); Cause (the perceived cause of the condition); Timeline (whether they believe it to be chronic or not); Consequences (how the illness will impact on them physically and socially) and Curability/Controllability (the degree to which the illness can be cured or managed and the role the individual plays in making this happen) (Hale et al., 2007). In addition to the cognitive appraisal of symptoms and illness, individuals form parallel emotional responses to health threats such as feelings of fear or distress (Leventhal et al., 1980). CKD patients who hold a better understanding of the relationship between CKD and lifestyle factors (illness coherence) have been shown to describe stronger intentions to adopt a healthier lifestyle (Wu et al., 2015). Furthermore, evidence from other chronic diseases has shown that illness perception based interventions are successful at increasing levels of physical activity (Broadbent et al., 2009).

### **Results**

SCT was identified as the most appropriate theory of behaviour change for the development of this physical activity intervention. Not only has SCT been the basis of

many successful PA interventions in other non-communicable diseases (Short et al., 2014, Yates et al., 2011), but it also includes self-efficacy a construct shown to be associated with physical activity in patients with CKD (Chapter 2) and a clear guidance for targeting it. Furthermore, in Chapter 4 participants described how goal setting and self-monitoring may be useful motivational tools. Therefore, Gollwitzer's Implementation Intentions theory was identified as a suitable concept to inform the action plan and goal setting part of the intervention (Gollwitzer, 1999). Finally, participants described a desire to understand more about their disease and physical activity, therefore, the Common-Sense Model (Leventhal et al., 1980) was identified as a suitable theory to help patients to develop positive disease management strategies through the promotion of physical activity.

### **5.3.1.6 Examination of Behaviour Change Techniques**

**Purpose:** Behaviour change interventions are inherently known for their inexplicit reporting, making interventions difficult to replicate and identify the active ingredient responsible for facilitating change. In recent years, there has been a push to use Behaviour Change Taxonomies to describe and standardise the intervention content based on the behaviour change techniques (BCTs) used. BCTs are the “observable, replicable and irreducible component of an intervention designed to alter or re-direct causal processes that regulate behaviour” (Michie et al., 2011). However, linking BCTs to theory is more complex. This examination aimed to identify which BCTs can be enlisted to effectively target constructs of SCT to produce positive changes in physical activity.

**Methods:** The CALO-RE Behaviour Change Taxonomy developed by Michie et al. (2011) detailing behaviour change techniques useful for changing physical activity and/or dietary behaviours, was reviewed. Furthermore, a systematic review was identified that identified the most effective BCTs at increasing self-efficacy and physical activity (Williams and French, 2011).

**Results:** The systematic review identified a number of BCTs including action planning, time management, prompt-self-monitoring and plan social support/social change, that were associated with positive changes in both self-efficacy and physical activity

(Williams and French, 2011). These will be considered for inclusion in the PACT intervention.

#### **5.3.1.7 Summary of planning phase**

The planning phases identified that education delivered within a group format may be both acceptable and feasible to implement in a non-dialysis CKD population. SCT may be a suitable theory on which to base the physical activity programme, with its main construct self-efficacy being a consistent correlate of physical activity as reported in Chapter 2. Behaviour change techniques that target both self-efficacy and physical activity should be considered. Furthermore, an intervention informed by the CSM may help to elicit illness perceptions and reduce negative representations of illness.

### **5.3.2 Phase 2 Design**

#### **5.3.2.1 Co-creation of guiding principles with PPI**

**Purpose:** To identify guiding principles to inform the design and development of the physical activity intervention in collaboration with a PPI group (Morris et al., 2014), specifically convened for this study.

**Method:** A total of 10 CKD patients who had previously demonstrated an interest in the exercise research were approached via letter and asked to join a steering panel as PPI members. Eligibility criteria for the PPI included:

- CKD stage 1-5
- Capacity to partake in physical activity
- Ability to read and write in English

The PPI group consisted of 9 members, including 6 patient representatives (3 males and 3 females) and 3 spouses. PPI meetings were facilitated by the candidate who was responsible for guiding the discussions. Individual meetings and group meetings were organised as required. In total the candidate facilitated 7 individual meetings and 2 group meetings. All participants were sent an agenda via email or post, prior to the

meeting. Participants were briefed at the start of each meeting about the overall aim of the research. Informed by the planning phase (rapid review, qualitative research, expert consultations, programme observations, examination of behaviour change theory and techniques) initial ideas were built upon in collaboration with the PPI group to refine objectives and relevant intervention features. Discussions focused on intervention content, delivery, and resources. Written notes were taken by the candidate at all meetings. Key themes were extracted from the notes and then discussed with the PPI group to decide on the final guiding principles.

## **Results**

In collaboration with the PPI group guiding principles for the intervention development were decided upon and are shown in Figure 5.3. These include, physical activity education including written materials, opportunities for peer learning and sharing of CKD and exercise experiences, short term and long term goals with a tool for self-monitoring and follow-up support. Each principle was carefully selected to broadly cover discussions held with the PPI group, including ways to help engage patients with physical activity.

**Education:** The PPI group proposed that the intervention should help patients to understand the benefits of physical activity for CKD, provide information regarding how to participate in physical activity safely, and how patients should expect to feel if engaging in more activity. The group suggested that the intervention include educational materials covering both disease and physical activity. Terminology and framing of exercise was described to be key. All PPI members emphasised the importance of promoting “home-based physical activity” as opposed to “exercise” which was deemed to carry negative connotations relating to gym work. Instead physical activity was described as a more accessible and less intimidating term. The PPI group provided key motivational phrases which could be used in the education session such as: “You don’t have to join a gym” and “No matter what your starting point everyone can get fitter”. Symptoms were considered an important barrier to address. The PPI group stated that patients require a better understanding of common symptoms in CKD and the role that physical activity can play in symptom management.

Supporting the education session with written resources was described as important. All written resources were developed in collaboration with the PPI group, and based on their feedback substantial changes were made to the presentation of these documents. This included splitting one larger A4 educational resource into three smaller A5 booklets (kidneys, physical activity and action plan); and making changes to the size and colour of the font to ensure acceptability for patients with visual impairment. PPI members also recommended that a short video might be useful for describing the functions of the kidneys.

The PPI group were key to informing the length of the session, stating that the 3.5-hour time frame suggested by the candidate would be acceptable. Any longer and it was advised that attending patients might lose focus.

***Peer sharing and learning:*** During both the individual and group meetings PPI members expressed the importance of family and peer support, stating how beneficial it was to spend time with other kidney patients, which supported the findings from Chapter 4. Whilst, the PPI members recommended a group delivery, they suggested a focused and structured approach to the session, allowing each participant the chance to tell their story within a 5-minute timeframe. The PPI group felt that it was important to explain session timings e.g. “we are now going to listen to (patient name) tell their story for a few minutes before we move onto the (next patient)”. Furthermore, in line with SCT it was suggested that videos of people exercising would encourage confidence among the group, as described within the process of vicarious learning. The PPI members suggested using videos as a way of demonstrating various physical activities and recommended recruiting a diverse range of models that participants could relate to.

***Self-monitoring:*** Members of the PPI group were asked to guide us on the best possible intervention resources and outcome measures. Self-monitoring devices were described by the PPI group as an essential element to any intervention aiming to encourage physical activity. Some members of the PPI group trialled the PAM device and Yamax SW200 pedometer (which was recommended by a member the expert panel) over a few weeks. Feedback favoured the pedometer, with users describing how the step counting function was more accurate and easier to interpret than the PAM points. Some members described difficulty in opening the device and suggested that a demonstration be

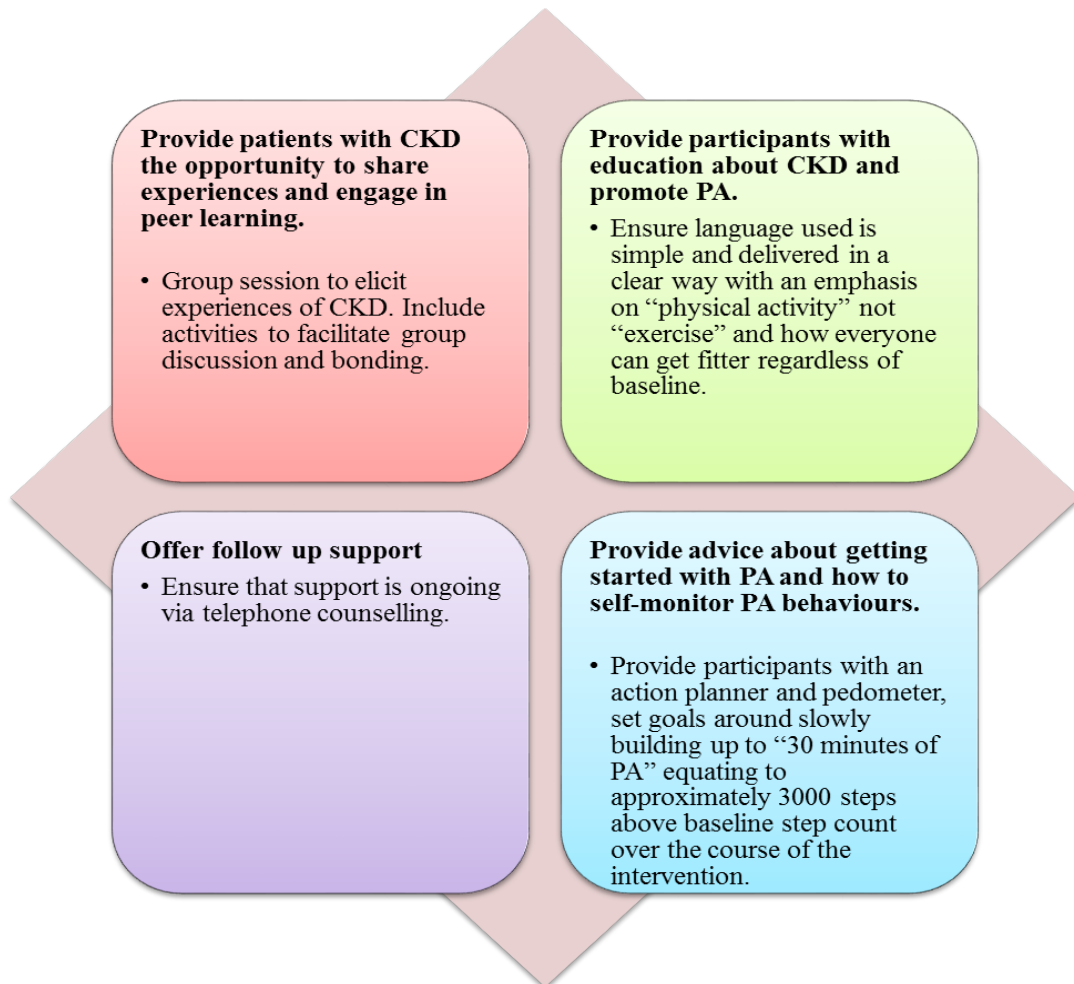
included in the programme to ensure participants felt competent to use it. PPI members also guided us on the use of questionnaires as outcome measures e.g. what was interesting, easy to complete and how many questionnaires would be acceptable to participants.

***Follow-up support:*** The PPI group stated that follow-up could be delivered by either email or telephone. However, the consensus was that telephone may feel more personal and supportive. Therefore, it was decided that the first telephone call would take place after 1 week of physical activity. However, participants suggested that patients be encouraged to act as their own support and motivation. For example, noting down why making the change was important to them and then reflecting on this at a later point.

## **Discussion**

The use of PPI in the development of the PACT intervention was useful in helping to identify key patient concerns regarding the proposed intervention. This collaborative approach was useful for both designing, developing and refining the delivery and content of the programme. However, the approach described does have its limitations. Participants invited to participate were known to the researcher and had previously expressed an interest in physical activity, therefore, the PPI group may not have been representative of the intended more sedentary CKD target population.

**Figure 5.3 Guiding principles developed in collaboration with the PPI group and key intervention features relevant to intervention design and development**



### **5.3.2.2 Readability of written materials**

**Purpose:** The readability of written information is likely to impact on patient comprehension and engagement. Health literacy has previously been shown to be low among patients with CKD (Morony et al., 2015). Guidelines recommend that CKD patient information should be written at a reading level of grade 5 (age 10 – 11 years) (Morony et al., 2015). In collaboration with the PPI group, three booklets were designed. These provided information about CKD and physical activity, as well as an exercise diary to provide a space for recording action plans and steps. The booklets

were informed by the CSM and topics covered included the identity, timeline, consequences and curability/controllability of CKD. The CSM can also be applied to treatment perceptions. Therefore, the second booklet was devised around these constructs for physical activity as a treatment of CKD. For example, the illness perception identity was targeted by including physiological symptoms of moderate to vigorous physical activity e.g. feeling warm and slightly out of breath. The aim of this section was to subject all written materials developed in collaboration with the PPI group to readability testing to ensure their suitability for a wider patient audience.

**Methods:** An online version of the Flesch reading ease and Flesch-Kincaid Grade Level formula was used to assess the readability of the supportive written materials. The readability tests produce a reading score ranging from 0 to 100 with a higher score indicating easier reading materials, and a US grade level score respectively (Morony et al., 2015).

**Results:** The booklet designed to support knowledge about CKD was scored as 69.1 and graded as reading level 5.8. The estimated time taken to read the document was 5 minutes 46 seconds. Similarly, the booklet designed to increase levels of physical activity was scored as 71.8 and graded at reading level 5.7. The estimated time taken to read this was 6 minutes 25 seconds. The final booklet (action planner/ diary) was not assessed as it mainly consisted of a calendar and step recording sheet.

### **5.3.2.3 Mapping of Behaviour Change Techniques**

As described within the planning phase the PACT intervention was informed by several complementary theories including SCT (Bandura, 1991) and the CSM (Leventhal et al., 1980). Behaviour change techniques were mapped to theory to address the guiding principles of the PACT intervention shown in Figure 5.3. BCTs were enlisted from the CALO-RE taxonomy, developed to target individual motivation for changing diet and physical behaviours (Michie et al., 2011). Additional techniques not described in the taxonomy were also employed to elicit illness perceptions and provide education on CKD and associated risk factors (Table 5.3).



#### **5.3.2.4 Design Phase Summary**

This phase detailed the work undertaken in collaboration with a PPI group to design an evidence based, theory driven, structured group education programme designed to increase physical activity in patients with CKD, by utilising proven behaviour change techniques. In addition, three booklets were developed including one self-monitoring diary and two booklets to support disease education and physical activity advice. The readability of the booklets was assessed to ensure they would be suitable for a wide range of participants.

**Table 5.3 Outline of the PACT intervention showing behaviour changed techniques mapped to guiding principles and theory.**

<b>Aim:</b> The PACT intervention will aim to increase physical activity by an increase of 3,000 steps from baseline through theory driven structured group based education and proven behaviour change techniques.						
<b>Guiding Principles designed in collaboration with the PPI group.</b>	<b>Session plan</b>	<b>Personal, behavioural and environmental influences identified from qualitative work (Chapter 4) to target within the intervention.</b>	<b>Theory</b>	<b>How will this be achieved?</b>	<b>Example activities</b>	<b>BCTs</b>
	Welcome introductions		N/A	Completion of the sign in sheet and short introduction regarding the session plan and housekeeping information.	Short slides presentation by the educator.	N/A
Provide the opportunity to share experiences	Participants story (20 minutes)	<b>Environment:</b> Addresses the need for group based delivery to foster support and facilitate peer learning. <b>Personal:</b> Target the barrier fear, by allowing participants to share positive experiences of physical activity.	CSM	Structured group discussions to elicit current beliefs about illness and treatment. Participants asked to consider the controllability of the disease and share personal experiences of physical activity.	Sharing and recording of experience by laminated card prompts around: symptoms, illness coherence, emotional response, controllability.	N/A
Provide participants with education about CKD and promote physical activity.	Chronic kidney disease (20 minutes)	<b>Environment:</b> Address perceived lack of organisational support in providing clear disease based information.	CSM	Structured group discussion to impart knowledge regarding the roles of the kidney, knowledge of symptoms, chronic nature of CKD, possible causes and consequences of the illness.	Short video developed using video scribe showing kidney function. Question and answer session for kidney roles, CKD basic information e.g. identity, cause, timeline. Followed by a symptom card vs symptom word matching task.	N/A

Provide participants with education about CKD and promote physical activity.	Changing factors (15 minutes)	<b>Behavioural:</b> Address outcome expectations (risks and benefits) of engaging in physical activity and other healthy lifestyles.	CSM SCT	Introduce health risk associated with CKD. Concept of personal responsibility for health focusing on modifiable and non-modifiable CVD risk factors	Laminated human body with image cards representing problems with the heart and blood vessels that are common to the general population. Tray demonstration adapted from Walking Away from Diabetes representing everyday build-up of risks when making a cup of tea. Laminated cards of modifiable and non-modifiable risk factors stuck up on the relevant boards.	Provide information on consequences of behaviour Provide feedback on performance Instruction on how to perform behaviour Demonstrating behaviour Facilitate social comparison
Provide participants with education about CKD and promote physical activity.	Physical activity (25 minutes)	<b>Environmental:</b> Address lack of organisational support in providing physical activity guidelines. <b>Personal:</b> Guidelines and advice on what is safe and appropriate may help to reduce fears related to recognising performance limitations. <b>Behavioural:</b> Address the benefits of engaging in physical activity and how it can help to support symptom management e.g. fatigue and help individuals stay independent, re-enforcing innate desires and outcome expectancies for physical activity.	SCT	Highlight the benefits of physical activity both physical and psychological. Address knowledge regarding PA guidelines e.g. Frequency, Intensity, Type and Time (FITT principle) Address factors related to health concerns, physiological responses to exercise and pacing. Discuss activity preferences utilizing positive past experiences.	Picture cards representing benefits of physical activity. Laminated cards showing RPE (Rate of perceived exertion) scale, with participants asking to relate the scale to activities they are shown on videos. Picture cards showing light – vigorous physical activities. Participants as a group asked to rank the cards.	

Provide advice about getting started with PA and how to self-monitor PA behaviours.	Self-regulation “make things happen” (20 minutes)	<b>Behavioural:</b> Target physical activity motivations by including self-regulation strategies which were deemed useful e.g. goal setting and self-monitoring.  <b>Personal:</b> Target innate drives for physical activity by asking participants to consider why physical activity may be important to them and how it would specifically benefit them in their lives.	SCT GII	Encourage participants to set short term and long term walking goals.  Encourage participants to develop action plans.  Encourage the use of the step counters (pedometer) and logging PA behaviours.	Participants asked to rank step counts that could be obtained through 15 minutes of various activities e.g. swimming or walking.  Participants provided with diary and given step counts taken off the accelerometers.	Goal setting behaviour Set graded task Action planning Prompt self-monitoring of behaviour Plan social support/social change Demonstrating behaviour
Follow-up	Telephone calls (10 minutes)	<b>Environmental:</b> Address the need for organisational support with regards to routine follow-up about physical activity, troubleshooting and goal review.	SCT	Encourage participants to review progress and discuss achievements and identify problems with a focus on how to cope with these and plan for the next coming weeks. Provide encouragement and prompt the continued use of the pedometer and diary.	A prompt sheet is used to ensure fidelity of telephone calls.	Prompt self-monitoring of behaviour Problem solving

Abbreviations: Common Sense Model (CSM); Social Cognitive Theory (SCT); Gollwitzer's Implementations Intentions (GII)

### **5.3.3 Phase 3 Development**

This section outlines the processes of conceptual refinement undertaken to ensure the PACT intervention was ready to progress into feasibility testing (Chapter 6).

#### **5.3.3.1 The PACT intervention**

Based on the findings of the planning and design stages, PACT, a 3 ½ hour structured group based education programme was designed. This duration was informed by both the patient and expert recommendations presented in this chapter. The intervention consists of 6 modules: 1) Welcoming and Housekeeping; 2) Patient Story; 3) Chronic Kidney Disease; 4) Changing Risk Factors; 5) Physical Activity and 6) Self-regulation. The session was also supported by a pedometer and three booklets, including: The Kidneys, Becoming More Active and an Action Planner. An overview of the content was provided in the design phase see Table 5.3, but each element will now be described in detail. For the educator manual and written resources see Appendix 1. This intervention was adapted from previous programmes including PREPARE (Yates et al., 2011) and Walking Away from Diabetes (Yates et al., 2012). However, unlike these programmes diet was not a target of the PACT intervention. This decision was made after consulting a renal dietitian within the planning phase, which highlighted how individual the renal diet is and the lack of general information available to provide within a group session. Telephone counselling was also designed to be more intensive in the PACT intervention with participants being contacted twice during the 8-week walking period. Follow-up intensity was advised by the expert panel, and the choice of follow-up contact determined by the PPI group.

The PACT intervention was designed to increase physical activity via structured education and the use of self-monitoring strategies. Participants are encouraged to slowly built up to an increase of 3000 steps per day, and these additional steps should be performed at a moderate pace over the 8 week period. Walking at a cadence of approximately 100 steps per minute, these 3000 steps would be equivalent to the 30 minutes of moderate intensity physical activity guideline recommendation (Tudor-Locke et al., 2011). Participants are asked to think about their own capabilities and decide on how many steps to add per day, and are encouraged to progress their goals

during follow-up telephone counselling. For individuals who are already achieving the recommended 10,000 steps a day, strategies for maintenance and changes in intensity are discussed. Participants complete an action plan as part of the group session, which is provided in one of the resources booklets (Appendix 1). The action plan is based on Gollwitzer's Implementation Intentions theory and details where, when and how physical activity will be performed to reach a specified goal (Gollwitzer, 1999). As part of the action plan participants were also encouraged to consider potential barriers to goal achievement, solutions, and rate their confidence on a scale of (1-10) that they can execute their plan as described. Participants were also asked to consider where they could seek social support or others to exercise with. However, this was omitted from the booklet as some participants may prefer to increase their physical activity independently.

Based on the feedback from both the expert panel and PPI group, it was important that the intervention delivery be interactive. As such video resources were included to teach participants about the roles of the kidney and different types of physical activities. The PPI group recommended that models and activities portrayed be diverse to allow participants to view individuals they perceive as similar to themselves engaging in physical activity. These videos were used to specifically help target fears around not being able to recognize performance limits. Participants were provided with a Rate of Perceived Exertion (RPE) scale (Borg, 1982) and asked to estimate the intensity of the physical activity performed in the videos by looking for signs of visual exertion such as breathlessness or sweating. This was followed by a focused discussion on how physical activity intensity is different for everyone and it is about listening to your own body and recognising the signs of working at a moderate intensity.

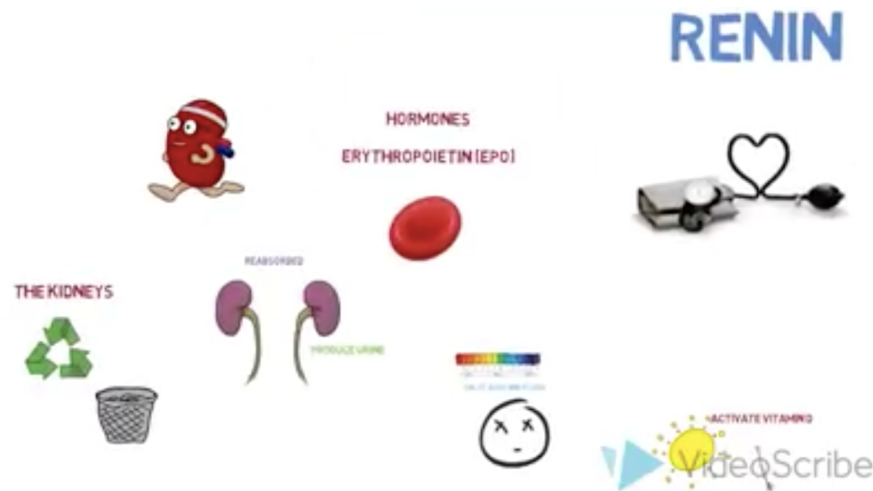
**Welcoming and housekeeping:** On arrival, participants are welcomed to the PACT session and asked to sign a register. Once settled, educators provide information and a general introduction to the session. This includes detailing the proposed content and timetable, as well as housekeeping information such as toilets, fire alarms, and refreshment breaks. At this point, participants are re-assured about the friendly and relaxed intentions of the group setting and advised to only provide content that they feel comfortable sharing.

**Patient Story:** This session is designed to give participants the opportunity to introduce themselves to the group and share their personal perceptions and experience of CKD. Educators aim to elicit cognitive and emotional representations that participants may have about their disease. Questions are informed by the CSM and cover the following illness perceptions:

- Illness coherence: How well do you feel that you understand your kidney condition?
- Illness identity: Have you experienced any symptoms that you think are linked to your kidney condition?
- Consequences/Emotional: How does your kidney condition make you feel or impact your life?
- Control/Cure: Is there anything you do to help manage your kidney condition e.g. physical activity?
- Cause of CKD and timeline were not asked directly due to the heterogeneous nature of the illness but were discussed if guided by the participants' interests.
- Key questions board: Answers are documented by the educator on laminated sheets.

**Chronic Kidney Disease:** This module is designed to give participants an opportunity to try to make sense of their experiences by learning more about CKD including: the role of the kidneys; the meaning of chronic; common causes of CKD; how kidney function is measured and staged; symptoms of CKD and confidence to communicate symptoms to healthcare professionals. The module was designed to increase basic understanding of CKD, targeting the illness coherence representation of the CSM. As a starting point participants are shown a short Video Scribe (developed by the candidate), which introduces the many roles of the kidneys. A discussion is then facilitated around what happens when the kidneys are less able to perform these functions, with regards to the timeline of CKD (meaning of chronic, the chronic nature of CKD and stages); cause (most common cause of CKD) and illness identify (symptoms associated with CKD). Symptom awareness and communication are important for self-management; as such a symptom picture/word-matching task is used to facilitate discussion.

**Figure 5.4** Screen shot of the Video Scribe developed to increase awareness of the functions of the kidneys.

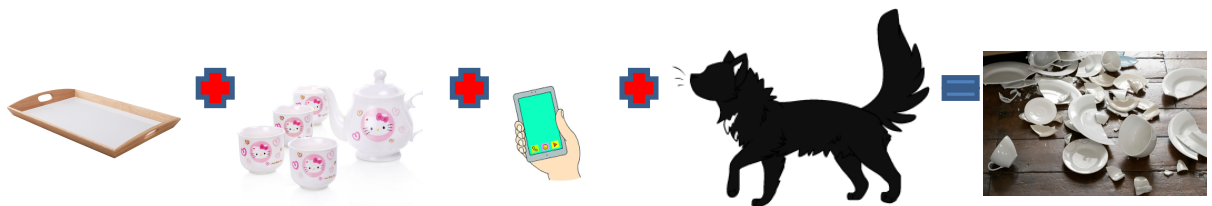


**Changing risk factors:** This module was designed to introduce health complications associated with CKD. The focus is on reducing the risk of CVD, and highlighting personal responsibility for health. Through a variety of tasks, participants learn about the meaning of risk, as well as modifiable and non-modifiable risk factors, which they can consider in the context of their own lives. Participants view a demonstration of risk, which was adapted with the help of the PPI group from the Walking Away from Diabetes programme (Yates et al., 2012). The demonstration illustrates how adding multiple items to a tray increases the risk of it becoming unbalanced (Figure 5.5) and was designed to increase awareness of everyday risk. The demonstration is shown twice, firstly in the form of a simple run through asking participants to consider the general narrative presented, and then secondly how the narrative might relate to CKD. Participants are asked to contemplate CKD as the teapot, and the phone and cat as risk factors, then asked to visualise the teapot getting heavier as a symbol for disease progression. The heavier the teapot, the more unstable the tray, and the greater the level of care needed to avoid other risk factors to prevent an ill health event e.g. heart attack symbolized by dropping the tray. Participants are also asked to correctly place pictures of risk factors (e.g. physical inactivity, poor diet) on cards labelled as either modifiable or non-modifiable. Vignettes are used to encourage participants to consider differing situations related to lifestyle and kidney function decline, and allow participants to recommended advice from what they have learnt regarding how to reduce risk. Participants are then advised that the following modules will focus on the importance of



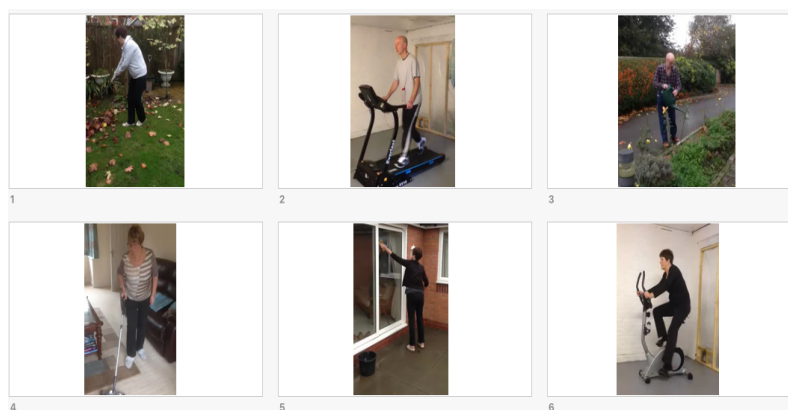
modifying physical inactivity, but are promoted to consider where they could access relevant information related to other modifiable risk factors e.g. diet, emotional management and medication adherence.

**Figure 5.5 Shows the demonstration narrative adapted from the walking away from diabetes programme designed to increase risk awareness.**



**Physical Activity:** The previous module provides an opportunity for participants to learn more about physical inactivity and risk. This session was designed to facilitate discussion around the benefits of physical activity, guidelines recommendations using the FITT principle (frequency, intensity, time and type), and how to stay safe when exercising. Specific attention is given to physical activity intensity and participants are encouraged to consider differing ways of measuring intensity, and taught how to use the RPE illustrated in their green booklet (Borg, 1982). Participants are then shown 6 videos of individuals participating in differing activities and asked to rate the intensity of the activity (Figure 5.6). This task was designed to highlight that intensity needs to be considered on an individual basis. Participants are then invited to take part in another task where they can sort pictures of various activities into the light, moderate or vigorous intensities. Finally, participants are encouraged to work together to consider how they could build up a physical activity programme to accommodate the 30 minutes of daily physical activity recommendation.

**Figure 5.6 Physical activity videos used to promote awareness of physical activity intensity.**



**Self-regulation:** This final module encourages participants to consider the physical activity recommendations they have learnt in terms of steps per day. As part of the trial, participants will wear an accelerometer for 7-days prior to attending the session and are then given feedback regarding their baseline average daily steps. Participants are asked to consider both long term (an increase of 3,000 steps from baseline) and short term goals that can be slowly built up over the 8-week intervention period. Whilst, the PACT programme focuses on walking, information is provided regarding step equivalents for other physical activities e.g. swimming and cycling. Participants are then given some time to complete the action planner in their diaries and given a demonstration on how to use the pedometer. Discussions are then facilitated around how to increase steps in everyday environments e.g. home, work, and shopping, and participants along with educators are invited to share a meaningful reason for why increasing/maintaining their level of physical activity is important to them.

**Follow-up telephone:** The PPI group in the design phase of the intervention felt that follow-up support was essential to changing physical activity behaviour. As such the PACT intervention was designed to include 2 x 10-minute follow-up telephone-counselling sessions, which are delivered after 1 week and between 3-4 weeks of walking. Telephone calls follow a scripted prompt sheet (Appendix 1) which are designed to encourage discussion around progress towards goals or goal attainment, use

of self-monitoring tools e.g. pedometer and diary, problem solving regarding any barriers to reaching the goals and progression/ revision of goals.

### **5.3.3.2 Concept refinement**

**Purpose:** User testing allows the researchers to observe and elicit participants' reactions to intervention content in order to refine the concept for future feasibility testing.

**Methods:** User testing of the PACT intervention was conducted in 4 group sessions (n=14 participants aged 21-77 years, CKD stages 2-5). Participants were recruited by mail shot through a database held by the Leicester Kidney Exercise Team of patients interested in research and from a nephrology outpatient clinic from Nottingham University Hospitals NHS trust.

The user-testing sessions were delivered by the candidate and a senior renal physiotherapist (H.J.M). This qualitative work included focus group methods and think aloud techniques (Jääskeläinen, 2010). Think aloud was applied to various interactive activities such as symptom card sort; risk demonstration; RPE physical activity videos and physical activity intensity card ordering task. Participants were asked to explain their thought processes whilst undertaking each task.

Topics for user testing included: first impressions of the session, quality of resources including written materials, perceptions of content and group activities. Additional observations related to patient engagement and acceptability were noted by the researcher. User testing was conducted with 3-5 patients in each group and lasted between 3.5 to 4 hours. Participant interaction and involvement in the education session was recorded using a digital audio recorder and then professionally transcribed verbatim and analysed using inductive thematic analysis (Braun and Clarke, 2006).

Modifications were made to the education module following each session to increase patient acceptability and engagement. After each session field notes, audio files and transcripts were reviewed by the candidate. Problems relating mainly to acceptability, engagement and understanding of educational content were identified as a first step. The transcripts were searched again to see if participants had made suggestions for

improvement. Modifications based on suggestions where appropriate were then made to the programme prior to delivering the next session. An example of this method is presented in Table 5.4.

**Table 5.4 Example of iterative concept refinement process for the theme of risk awareness.**

Session	Communication	Themes	Patients quotations	Modifications
1	Health messages were communicated using visual aids and a systematic model of information processing e.g. “What are some of the health problems linked to having chronic kidney disease?”	<ul style="list-style-type: none"> <li>Increased anxiety towards health risks</li> <li>Humour and sarcastic verbalisations</li> <li>Negative emotions e.g. helplessness</li> <li>Lack of risk awareness.</li> </ul>	<p><i>“This is really going to cheer us up! I was going to say I didn't know that. Oh gosh what else are we going to get” (Male).</i></p> <p><i>“This might sound daft but would you be at risk of say having a stroke or getting depressed if your kidneys were AI?” (Male).</i></p>	Earlier emphasis on modifiable risk factors using a “gain” not “loss” framework and communicating risk at the population level.
2	Health messages were communicated using a didactic approach and at population level e.g. “CVD is a big problem for the general population, having CKD is a risk factor for these conditions but there are many things that can be done to reduce risk.”	<ul style="list-style-type: none"> <li>Sensitive material,</li> <li>Lack of risk awareness,</li> <li>Risk awareness appreciation</li> <li>Desire for further education.</li> </ul>	<p><i>What I am trying to say is that hasn't scared me but I never thought about strokes or limbs, legs” (Female).</i></p> <p><i>“It's useful, it is awareness” (Female).</i></p> <p><i>“...it's important to tie all the things in together ... a lot of people wouldn't understand it initially having a kidney problem. They think that's what I have got not realising that it is related to so many other possibilities” (Male).</i></p>	Provide further information for why kidney disease may be linked to an increased cardiovascular risk.
3	Health information was communicated with a greater focus on empowerment e.g. “Everyone has risk factors for CVD including myself, but knowing about the risk factors puts you in control and it means that you can do something about it.” Information needs from session 2 regarding the complex relationship between CKD and CVD were addressed and participants were encouraged to speak to their doctor for further information.	<ul style="list-style-type: none"> <li>Increased perceived control</li> <li>Enhanced understanding</li> <li>Risk awareness appreciation.</li> </ul>	<p><i>Difficult as it might be sometimes for some people you have got to let them know, they have got to understand the severity of it” (Female).</i></p> <p><i>“If you have just got your teapot to look after, your underlying condition is going to affect everything else” (Female).</i></p> <p><i>“You spin it round don't you to your advantage” (Female).</i></p>	No changes recommended.
4	No changes were made prior to the delivery of Session 4			

## **Results**

The results below report key observations from the concept refinement stage and provides consideration for the PACT intervention and future trial protocol.

### **Education Delivery**

Exemplars for this theme are presented in Table 5.5.

**Target audience and timing of education:** Participants described the importance of ensuring that members of the group could relate to one another. Specifically, participants suggested that those attending should have been diagnosed around the same time and have similar levels of baseline knowledge. When asked about the best time to deliver education participants stated that it would be most useful if delivered at the point of diagnosis.

**Group dynamics and interaction:** Participants described how the education session successfully encouraged discussion and participation amongst the group. Being around other patients with CKD was described as beneficial and participants emphasised how only someone with the condition could really understand their experience. Participants could draw comparisons between each other's experiences and their own which they described to be an important part of the learning process.

**Session timings:** Participants felt that the time given to each module was appropriate. Participants indicated that having flexible sessions to accommodate participants with other commitments was important and may impact on attendance. Suggestions included offering sessions in the evening or on a Saturday.

**Table 5.5 Exemplar quotations from kidney patients: Delivery**

Major theme	Minor theme	Exemplar quotations from kidney patients
<b>Delivery of education session</b>	Target audience	<i>“...it’s about ..making sure the people feel they are included and not excluded because they know too much or not excluded because they know too little” (Focus group 1).</i>
	Timing of education	<i>“And all the things like we are doing here, activities and everything helps. When I was seen by the [Nephrologist]... exercise didn’t even come into the equation ..I said what can I do to improve things, [they] never really came forward with anything” (Focus group 2).</i>  <i>“I wish this was here [education programme] when I was newly diagnosed” (Focus group 1).</i>
	Group dynamics	<i>“The best part of it [PACT intervention] is to spend time with people the same as you because you learn from each other and only you can understand me and only I can understand you” (Focus group 4).</i>  <i>“I like having ..support groups on the internet, that’s brilliant, but you can’t beat the face to face sat round a table talking like this...” (Focus group 4).</i>
	Session timings	<i>“...what I am saying is make it on a Saturday or you could do it 6 pm at night..I have got no issues with attending something like this a couple of times a month” (Focus group 4).</i>

## Education content

Exemplars for this theme are presented in Table 5.6.

**The framing of risk information:** As detailed in Table 5.4 participants showed a lack of awareness regarding CKD as a risk factor for other health conditions e.g. CVD. Observations suggested that open-ended questions incited distress, and increased anxiety towards health risks, and were not acceptable. During the subsequent user testing sessions, the topic of CVD risk was addressed at the population level. Framed in this way, participants responded more positively and were appreciative of their newly gained awareness.

**Lifestyle education:** Participants in the first two user testing sessions desired further information regarding the association between CKD and health risks, as well more information about the renal diet and their medication. Subsequently, modifications were made to the programme to add greater detail regarding the link between the heart and kidneys. Whilst, some participants suggested the use of statistics to explain risk within the session, the PPI group felt that this information may be viewed as threatening to some patients. As such, statistics of health events e.g. myocardial infarction were not added to the following sessions. More detailed health risk information was not a theme within following sessions, indicating that the information added to the programme was satisfactory. The other health behaviours were addressed by adding sign-posting information to later sessions about accessing the renal pharmacists and dieticians.

**Simple language and short open questions:** The educator re-phrased a number of open-ended questions during the earlier user testing sessions due to participant misunderstandings or need for clarification. On review of the audio files and transcripts, re-phrasing was most common in the: Kidney Education, Modifying Risks and Physical Activity sessions. Modifications were made to the script to ensure that it used simple language and short questions. However, participants also described in some instances that they felt answers occasionally were too obvious. An additional sentence was added to the programme to re-assure participants that there were no trick questions. In the

sessions to follow the simplicity of the programme was described as a positive and something that would be accessible for all.

**Table 5.6 Exemplar quotations from kidney patients: Education content**

Major theme	Minor theme	Exemplar quotations from kidney patients
Content of education session	The framing of health and risk information	<p><i>“This is really going to cheer us up! I was going to say I didn't know that. Oh gosh what else are we going to get” (Focus Group 1).</i></p> <p><i>“This might sound daft but would you be at risk of say having a stroke or getting depressed if your kidneys were AI?” Researcher: Yes “You would still have that risk, I think it is worthwhile saying that, it’s not all down to kidneys” (Focus Group 1).</i></p> <p><i>“You spin it around don’t you to your advantage. I could be sitting next to somebody that has got something going on in and they have got no symptoms, it doesn’t mean there is nothing wrong with them all the time. I think that’s the only way you can look at it” (Focus Group 2).</i></p>
	Lifestyle education needs	<p><i>“What is a healthy diet actually? Because there are some foods which normally are healthy but you can’t eat them because, I don’t know which they are now. Some fruits and vegetables like grapefruit they are causing high blood pressure” (Focus Group 4).</i></p>
	Simplifying content	<p><i>“You don’t want to say it because it seems obvious” (Focus group 2).</i></p> <p><i>“I think sometimes as you said you feel as if you are giving a silly answer, you are looking for harder answers when there is no need to” (Focus group 2).</i></p> <p><i>“I think it was simplistic and that just makes it easy because it’s as simple as that. It needs to be simplistic, don’t over complicate it” (Focus group 3).</i></p>



## Session resources

Exemplar quotations for this theme are presented in Table 5.7.

**Videos:** A video extracted from the internet detailing the roles of the kidney was described as “... a bit of a garbled 45 seconds...” with participants stating that it could be clearer and twice as long. Using a video scribe software, a new video was created with these comments in mind. Participants in the following sessions described the new video as a “*nice introduction*”, which could be used to facilitate further discussions around each of the points. Modifications were also made to the physical activity videos. Participants in focus group 1 desired more variety with regards to representative models and home based physical activities. Additional videos incorporating these recommendations were included in later sessions.

**Booklets:** The written resources were well received. Participants described the overall layout as “*very good*” and said that the content was “...*really comprehensive*” (Focus group 3). The booklets were designed to be colourful which the majority of participants appreciated. However, some participants described difficulties in reading lighter text colours. Participants were asked to annotate problem sections and colours were modified.

**Activities:** Participants described enjoying the activities as they provided “...*a different way of thinking about things*” (Focus group 2). In addition, participants thought that the activity sessions were a good way to build individual confidence within a group setting. No changes were made to the delivery of the interactive tasks.

**Pedometers:** Participants described finding step counting with the pedometer interesting. Some participants reported difficulties in operating the device and one participant felt it was uncomfortable to wear. A demonstration was added to the following sessions showing participants the easiest way to open the device.

Participants from session 1 were sent an action planning booklet along with the pedometer prior to the session. This was to allow the participants a chance to use the pedometers, whilst trialling the collection of baseline step outcome data. However, the

booklet mentioned setting a goal for week 1, which caused confusion. Instead, a standardised goal was set for this period: “Your goal for week one is to learn how to use the pedometer and get used to tracking your steps”. This was later removed from the booklet as it was decided that the PACT trial protocol would use accelerometers to gain physical activity outcome data, and the pedometer would only be used as a self-monitoring intervention tool.

**Table 5.7 Exemplar quotations from kidney patients: Session resources**

Major theme	Minor theme	Exemplar quotations from kidney patients
<b>Problems with media, activities and self-monitoring devices.</b>	Videos	<i>“For developing your own workshop session, you could have another video alongside that with someone who is really not as mobile going for a walk just around a garden and they might be really struggling”</i> (Focus group 1).
	Written booklets	<i>“And I think with all these booklets are good as well, good colours and everything, got enough information”</i> (Focus group 3).
	Group activities	<p>Researcher: And was it quite fun to get up and play with the pictures and cards?</p> <p><i>“Yes it gets over your inhibitions doesn’t it because not everyone is used to doing that, I am used to doing it with the job I used to have so it doesn’t bother me, but some people are not used to speaking out and doing stuff. And it gets you into a comfort zone doesn’t it to be able to do that sort of thing”</i> (Focus group 3).</p>
	Pedometers	<p><i>“It was good and I thought it made you more aware but I just found it difficult to wear”</i> (Focus group 3).</p> <p><i>“Very well I enjoyed it... but my sheet said set your goal and I couldn’t because I hadn’t got a clue. But now I have done it for a week and listening to what you have just said I could set goals more realistically”</i> (Focus group 1).</p>

### **5.3.3.3 Development Phase Summary**

This phase detailed the work undertaken to develop a working model of the intervention and conduct user testing to refine the concept. A lack of awareness regarding cardiovascular risk was highlighted, and the use of open-ended questions were inappropriate to explore this topic with participants. Instead, the module was adapted to provide a general overview of risk at the population level and then focus on modifiable risk factors and the importance of these in a CKD context. Participants also suggested refinements to some of the session resources including additional and more appropriate videos, and wording changes to the activity diary. Refinements were also made to the educator manual to shorten some of the questions and simplify language. User testing at this stage allowed for refinements to be made before establishing the feasibility of the intervention.

## **5.4 Discussion**

The Person-Based Approach (Yardley et al., 2015b) provided a systematic framework to aid the development of the PACT intervention. The planning phase helped to conceptualise what would be required from a physical activity intervention and determine what may be feasible to deliver in the current context of care. The systematic review identified in the initial planning phase suggested that patient education had the potential to increase levels of physical activity in patients with CKD (Lopez-Vargas et al., 2016). Certain intervention education intervention elements were shown to be associated with improved outcomes in patients with CKD. These included group delivery, family involvement, interactive studies, workshops that include the teaching of practical skills, negotiated goal setting and frequent contact between participants and facilitators. These findings were supported by the qualitative study presented in Chapter 4 and were then discussed with the PPI group when designing the guiding principles in Phase 2. The PPI group were essential to the development of the supportive written materials and drafting of the education programme.

Whilst, the systematic review by Lopez-Vargas and colleagues (2016) identified the most successful elements of CKD patient education, it also highlighted the lack of

psychological interventions targeting physical inactivity in this population. The review identified only one intervention of this type that had successfully increased physical activity levels, however, this was poorly reported and lacked the sufficient detail required to replicate the intervention in a UK CKD population. Instead, after programme observations carried out by the candidate, adaptations were made to an existing programme (Walking Away from Diabetes) in collaboration with a PPI group and expert panel to ensure its suitability for patients with CKD. The content and delivery of the PACT programme was also designed to overcome barriers and target potential enablers identified in Chapter 4.

Qualitative enquiry was vital to inform how best to engage patients with CKD in education and what would be most acceptable to them. The user-testing groups highlighted several modifications to the content and use of resources. The initial testing group described a lack of awareness regarding the consequences of CKD and associated CVD risk which has previously been reported in this population (Plantinga et al., 2010). However, there is little guidance to communicate risk to patients with CKD. Other programmes including “Walking Away from Diabetes” (Yates et al., 2012) which was observed in Phase 1, promoted discussion via open-ended questions to facilitate learning about consequence and risk. However, in this instance due to a lack of awareness, the open-ended questions led to guessing and appeared to incite distress among the group, indicated by negative comments about the future and sarcastic humour. Increased knowledge has been shown to be negatively associated with patient acceptability of provider communication in patients with CKD (Nunes et al., 2011). Therefore, understanding how best to tailor education in a way that is acceptable to patients is important. This session was designed to promote risk awareness but more importantly to allow participants to experience a sense of empowerment in knowing that they themselves can modify their behaviour to reduce their risk of adverse events. Without, testing this part of the intervention we would have risked developing an intervention that was not acceptable to patients. Participant feedback was essential to understanding how to deliver sensitive information. Delivering risk at a population level and within a gain-framed perspective (Gallagher and Updegraff, 2012) (e.g. following the risk information with the benefits of physical activity), emphasising control and empowerment were deemed most acceptable. When delivered in the revised way participants were grateful for their newly gained awareness. However, this work

highlighted a need to better understand the best ways to communicate risk to patients with CKD. Overall, making iterative changes based on patient recommendations and then trialling these in subsequent groups provided a robust method for gaining an insight into the best methods of delivery.

#### **5.4.1 Limitations**

This chapter documents a systematic approach undertaken to produce a theory driven, evidence based, structured group based education programme designed specifically to target physical inactivity in patients with non-dialysis CKD. However, this work is not without its limitations. The qualitative work undertaken to explore user-testing employed a variety of methods including focus groups, think aloud techniques and observation. However, whilst user-testing is common for digital interventions, there was no guidance available for the use of it in testing an education programme, and certain techniques applied such as ‘think aloud’ may not have been entirely appropriate in this instance. Encouraging participants to engage in “think aloud” whilst under considerable cognitive load from participating in the session may have made it difficult for participants to divulge their thought processes. Furthermore, focus group discussions were conducted throughout the intervention delivery, meaning there was a lot of stopping and starting that may have broken the flow of the session in comparison to how it was intended to be run. However, care was taken to ensure that the user testing sessions were all objectively recorded and transcribed verbatim, which helps to enhance the validity and rigour of qualitative research (Seale and Silverman, 1997). This allowed for further interrogation into the interactions between members of the group and educators; and identified problem areas for refinement such as the educator re-phrasing questions if patients demonstrated a lack of understanding. Overall, whilst methods employed were not fully appropriate, this qualitative work adds to knowledge, and was useful in highlighting important areas for refinement. Future consideration should be given with regards to how best to undertake user-testing of educational interventions.

Furthermore, behaviour change interventions are often poorly reported with regards to content and delivery, making it difficult for others to identify successful or non-successful elements that lead to change (Abraham and Michie, 2008). Due to the

complex nature of these types of interventions, the development process of PACT underwent many iterative design phases, and processes were not always linear as indicated. Instead refinements consisted of back and forth discussions with patients, experts panel members, and supervisors. However, whilst intervention transparency has been central to this chapter, and care was taken to document each process there may be some level of bias with regards to what is reported. For example, the PPI group recommended some type of online network to encourage peer support after the group session, however, this was deemed unfeasible due to time and resource limitations and was not included. As such, decisions were made in how to organise the development process to provide a succinct and fluid piece of work that documented steps undertaken.

## **5.5 Conclusion**

In conclusion, it has been achievable to develop a structured group based education programme designed to increase levels of physical activity in CKD patients, using theory, evidence and the Person-Based Approach. Furthermore, it has been possible to document the planning, design, and development phases, fulfilling the requirement of transparency for intervention development. A feasibility trial is now required to assess engagement and acceptability of the PACT intervention, and implementation of the trial protocol.

# Chapter 6

## **“It’s Opened Up My Eyes to How Much I Can Actually Do”: A Mixed Methods Study Exploring the Feasibility of a Physical Activity Education Programme in CKD.**

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The previous chapter described the development of the PACT intervention. This chapter presents a feasibility study that was conducted to explore recruitment, retention, and engagement as well as the acceptability of the programme and outcome measures. The results of the study are presented in this chapter and implications for future development are discussed.

### **Statement of originality**

The work presented in Chapter 6 was undertaken by the candidate. The delivery of the PACT intervention was supported by H.J.M.

## 6.1 Introduction

Slowing the progressive nature of CKD and the prevention or management of other complications such as CVD is central to the CKD treatment plan. Clinical management includes improving blood pressure and glycemic control as well as dietary and lifestyle changes (Kidney Disease: Improving Global Outcomes Blood Pressure Work, 2012). However, whilst patient-centred care actively encourages patient involvement with the management of their own health, most patients show limited disease knowledge (Plantinga et al., 2010); and a lack of awareness of the risk factors associated with physical inactivity for persons with CKD (Chapter 5).

Earlier phases of this work determined existing preliminary evidence for the use of patient education to increase levels of physical activity in patients with CKD not requiring RRT (Chapter 5). However, such interventions are not readily available in the UK. Therefore, the previous chapters have aimed to investigate the evidence base for a patient education programme designed to increase levels of physical activity, and systematically report its development. Chapter 2 identified widespread physical inactivity among non-dialysis CKD patients in the UK. In addition, Chapter 2 also highlighted the association between physical activity and self-efficacy, signifying the potential importance of targeting self-efficacy to increase levels of physical activity in this population. Chapter 4 indicated a deeper patient need for informational support regarding the benefits of physical activity, as well as basic disease education, and emphasised potentially useful interventional strategies such as goal setting and self-monitoring that could be used as the active ingredients within the intervention. Patients also reported walking as their most commonly undertaken and preferred mode of physical activity, indicating a suitable activity for promotion (Chapters 2 & 4). Furthermore, Chapter 3 demonstrated an association between walking and survival in patients with CKD, which is in line with the evidence (Chen et al., 2014). Whilst, this evidence is solely observational at this time, previous work has reported many short-term benefits obtained from increasing levels of walking in CKD patients stages 4-5 (Kosmadakis et al., 2012).



This detailed preliminary work identified a definite need for a physical activity programme to support patients with non-dialysis CKD to increase their level of physical activity. In response to this need, a structured group based education programme PACT (detailed in Chapter 5) was developed from evidence presented in Chapter 4, and in co-creation with patient partners and an expert panel. The content and delivery of the PACT intervention was influenced heavily by detailed qualitative enquiry of patient preferences, and informed by complementary psychological theories of behaviour change, and existing evidence. Having developed a working model of the intervention the next step was to explore its feasibility with regards to patient acceptability and engagement with both the intervention and trial.

## **6.2 Aims**

The aim of this study was to explore the feasibility of a structure group based education programme (PACT), designed to increase levels of physical activity in patients with CKD not requiring RRT.

### **6.2.1 Objectives:**

- Explore the feasibility of the intervention with regards to recruitment and retention.
- Explore the feasibility of implementing the trial protocol including outcome assessments.
- Explore patient engagement with the intervention.
- Conduct limited efficacy testing to highlight potential positive mean changes, indicating outcome measures that might be sensitive and useful for use in a future trial.
- Assess the feasibility of the PACT intervention by employing qualitative methods to capture participant's experience.

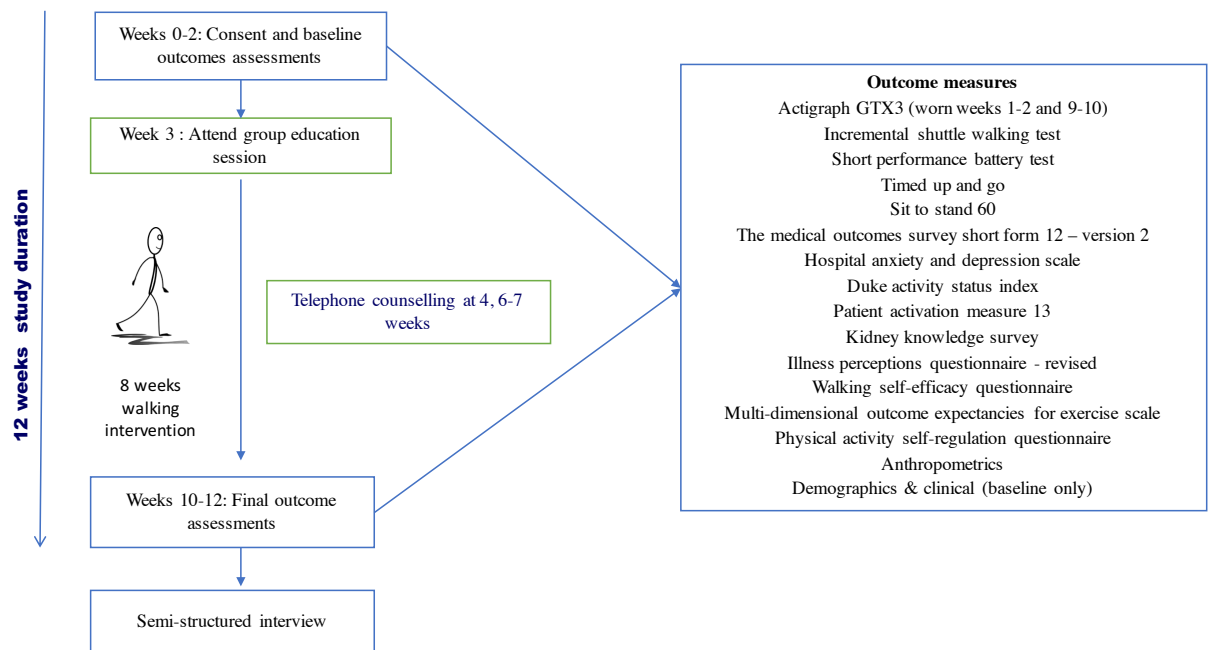
## **6.3 Methods**

### **6.3.1 Study design**

The aim of this study was to determine whether the PACT intervention was appropriate to move forward into more rigorous efficacy testing by examining the trial and intervention feasibility. The study was designed to adhere to the feasibility/piloting phase of the MRC Framework for the Development and Evaluation of Complex Interventions. Feasibility studies are proposed as an essential step prior to conducting a full evaluation of the intervention within a RCT and are often determined by 8 general areas including acceptability, demand, implementation, practicality, adaption, integration, expansion and limited efficacy testing (Bowen et al., 2009). This study addresses acceptability, implementation and limited efficacy testing.

The study utilised a mixed methods approach with a one study group, pre-and post-intervention design. The study duration was 12 weeks which included an 8 week walking intervention period (see Figure 6.1). This allowed for a 2-week window either side of the group intervention to conduct assessments. Outcome measures included: physical activity, physical function, psychological constructs of behaviour change, and parameters associated with quality of life at baseline and then after 8 weeks of home based physical activity. In addition, participants participated in a semi-structured interview at the end of the study to explore aspects of feasibility in more depth, with a focus on patient acceptability.

**Figure 6.1 Diagram to show study design**



### 6.3.2 Sample size

This feasibility trial was not powered. A sample size of 12 was originally selected pragmatically on the premise that 2 testing groups incorporating 6 participants in each would be assessed. However, this was modified to 4 testing groups after only 4 participants were recruited to the first round of testing.

### 6.3.3 Participants

Participants were recruited from a single centre site in Leicester and were either recruited directly from routine nephrology outpatient clinics, or from a database held by the Leicester Kidney Exercise Team of patients willing to be contacted about current research projects. All participants approached were screened for their eligibility to safely participate in the study by one of the renal consultants. Participants were either sent a patient information sheet and invitation in the post. Or approached by a trained researcher whilst awaiting their clinic appointment and given a patient information sheet. If participants expressed an interest, contact details were recorded and

participants were given at least 48 hours before being contacted by a researcher. At this point of contact

participants were given the chance to ask any questions. With regards to the mailshot recruitment, a reply slip was included along with a free post envelope for participants to establish contact and express an interest.

#### **6.3.4 Inclusion/ Exclusion criteria**

The study was designed to be pragmatic, as such attempts were made to be as inclusive as possible with the inclusion/exclusion criteria. Participants were not eligible if they were:

- <18 years old,
- $eGFR > 90 \text{ mL/min/1.73m}^2$ ,
- Pregnant ,
- Unable to speak English.

Or had any of the following:

- Unstable angina or myocardial infarction during past 6 weeks
- Severe heart failure
- Severe COPD
- Severe lower limb orthopedic problems
- Severe neuromuscular disease
- Considered unfit by own consultant due to physical impairment, co-morbidity or any other reason for any element of the protocol.

#### **6.3.5 Setting**

The study was coordinated from the University Hospitals of Leicester NHS Trust and all education sessions and outcomes measures were conducted on site. Participants were reimbursed for travel expenses or provided with transport if necessary.

### **6.3.6 Ethics**

This study 15/EM/0208 was given a favorable opinion by East Midlands–Nottingham Research Ethics Committee on the 13/04/2016.

### **6.3.7 Intervention**

Participants received the PACT intervention, a structured group based education programme that was described in full in Chapter 5. The intervention was designed to be delivered to 3–10 individuals and was delivered by the candidate (a health and behavioural psychology PhD student) and a senior renal physiotherapist (H.J.M). In brief the PACT intervention consisted of a 3 ½ hour structured group based education session and two follow-up telephone counselling sessions delivered in week 4 and 6-7 of the study. The PACT programme was designed to provide patients with the opportunity to share their experiences, learn more about CKD and the importance of physical activity in the management of their condition.

Specifically the intervention aimed to:

- Elicit participants cognitive and emotional representations of CKD;
- Enhance disease knowledge;
- Increase awareness of associated health problems e.g. CVD and modifiable risk factors;
- Discuss the benefits of PA whilst targeting exercise self-efficacy;
- Offer self-regulation strategies such as goal setting, action planning, social change and relapse prevention to encourage PA.

All participants were given a step counter in the form of the Yamax SW2000 Digi-Walker pedometer to self-monitor their physical activity behaviour. Pedometers have been shown to be an effective tool at increasing levels of physical activity (Bravata et al., 2007) and were described by patients in Chapter 4 as “*simple yet motivating*”. Goals were based on the recommendations of Tudor-Locke et al. (2011) and were described in Chapter 5.

The programme content and written resources were underpinned by several complementary theories of health behaviour change. These included: CSM (Leventhal et al., 1980), SCT (Bandura, 1977) and Gollwitzer’s Implementation Intentions (Gollwitzer, 1999). Theory choice was informed by the literature; a previous survey that looked at psychological correlates of exercise (Chapter 2), and a qualitative study, which explored motivations and barriers to exercise (Chapter 4) and existing interventions running in other disease populations. The choice of theory and detailed development of the PACT intervention is reported in Chapter 5.

### **6.3.8 Outcome measures**

A number of outcome measures were used as part of this protocol, assessing physical activity, physical performance, domains of quality of life, and psychological constructs. At this stage of testing it was important to use a wide range of outcome measures to determine which outcome assessments may be sensitive to change, the most relevant, and acceptable to the patients. Outcome assessments were performed in the same order at baseline and follow-up assessments.

#### **6.3.8.1 Physical activity**

Physical activity was measured objectively using the ActiGraph GTX3 accelerometer, which measured free-living activity in epochs of 10 seconds. The accelerometer was given to participants at two time points, between weeks 1-2 which was prior to attending the group session at week 3, and weeks 7-8 the final week of home-based physical activity undertaken as part of the intervention. Accelerometers were attached to an elastic waist belt and participants were asked to wear it on their right hip during

waking hours. The accelerometers were used to capture number of steps taken and number of minutes spent in moderate-vigorous physical activity (MVPA). The ActiGraph GTX3 has previously been validated against indirect calorimetry and been shown to yield accurate energy expenditure estimations (Santos-Lozano et al., 2013). ActiLife (version 6.13.3 Actigraph, US) software was used for processing the data from GTX3 accelerometers. The default protocol by Troiano et al. (2008), was applied to the data. Optional screening parameters were altered to consider an acceptable wear time to be a minimum of 10 hours per day for 4 days. Non-wear time was defined as a time interval of 60 consecutive minutes of no movement, with the allowance of 1-2 minutes of movement between 0 and 100 counts/minute. Time spent in MVPA was determined by using a cut point value of  $\geq 2020$  counts (Troiano et al., 2008).

Physical activity was also measured via self-report using the International Physical Activity Short Form Questionnaire (Craig et al., 2003). IPAQ-SF is a validated questionnaire that has been developed to give internationally comparable data regarding physical activity and inactivity. Three specific types of physical activity are assessed including walking, moderate intensity and vigorous intensity, whereby participants specify duration (minutes performed) and frequency (how many times the activity was performed in the last 7 days). Each physical activity is weighted with a MET value of 3.3, 4.0 and 8.0 respectively. The MET score is then multiplied by duration and frequency for each activity and then summed to produce a total score of MET mins/per week. Scores can also be classified into categorical indexes of low(no activity or not enough to meet the other categories), moderate (3 or more days of vigorous for at least 20 minutes per day; 5 or more days of moderate and/or walking for at least 30 minutes per day or any combination of walking, moderate or vigorous calculating at least 600 MET mins/per week), and high (vigorous undertaken at least 3 days of the week calculated as at least 1500 MET mins/per week or a combination of walking, moderate and vigorous calculated as at least 3000 MET mins/per week).

#### **6.3.8.2 Physical performance**

The assessment of physical function is an important clinical measure for the prediction of poor outcomes in patients with CKD. Currently, there is little consensus with regards to the most appropriate tests to use clinically and within research for measures of

physical function. Therefore, a number of widely used tests were adopted to assess this outcome.

#### **6.3.8.2.1 The Incremental Shuttle Walk Test**

The Incremental Shuttle Walk Test (ISWT) is a symptom limited maximal performance test that requires participants to walk around a 10m course at a speed controlled by an external audio signal (Singh et al., 1992). Walking speed is set to increase consistently at one minute intervals. The maximum distance that can be achieved on the ISWT is 1020m. Upon the first visit, participants were asked to repeat this test twice with at least a 30-minute rest period in-between, with the first test acting as a familiarisation. The ISWT was designed to assess physical function and disability in patients with COPD. However, has since been widely used within the CKD population as a measure of exercise capacity (Greenwood et al., 2012).

#### **6.3.8.2.2 Short Physical Performance Battery**

The Short Physical Performance Battery (SPPB) is a simple measure of lower extremity function and measures three areas that are essential to independent living including static balance, gait speed and getting out of a chair. Each subscale is scored from 0-4 with a zero score indicating an inability to complete the task, and a score of four indicating the highest level of physical functioning (Puthoff, 2008). The SPPB has been used previously to assess physical functioning within a CKD cohort, where renal function was associated with a graded response against the SPPB (Reese et al., 2013).

#### **6.3.8.2.3 Timed up and go**

Timed up and go (TUAG) is another test of lower extremity function as well as assessing static and dynamic balance (Podsiadlo and Richardson, 1991). Participants were asked to stand from a chair, walk 3 metres, turn around, walk back to the chair and sit down. This test has been shown to be significantly associated with all-cause mortality in CKD patient's stages 2-4. Specifically, a 1 second longer TUAG score has been found to be associated with an 8% increase in death among this population (Roshanravan et al., 2013).



#### **6.3.8.2.4 Sit to stand 60**

The sit to stand 60 (STS-60) is similar to the chair standing test from the SPPB, but it measures how many times the participant can stand from a chair in 60 seconds and is a surrogate measure of muscular endurance. This test has also been shown to be a good measure of functional ability and has been used extensively in CKD patients (Abramowitz et al., 2013).

#### **6.3.8.3 Patient reported outcome measures.**

QoL including psychological and physical domains of health, patient activation, and knowledge were assessed to determine the suitability and acceptability of these measures, and to perform limited efficacy testing to see whether measures were sensitive to change during the PACT intervention.

##### **6.3.8.3.1 The Medical Outcomes Survey Short Form-12 version 2 (SF-12v2)**

Health related quality of life data was assessed using The Medical Outcomes Survey Short Form-12 version 2 (SF-12v2) (Ware et al., 1996), which is a 12 item questionnaire reflecting general health, physical functioning, physical role, emotional role, bodily pain, vitality, mental health, and social functioning. The 12 items of the SF-12v2 are rated on a 5 point Likert scale ranging from 1 (totally disagree) to 5 (totally agree), and then summarised using a scoring algorithm to two domains: Physical Component Summary (PCS), and Mental Component Summary (MCS). The SF-12v2 is designed to assess everyday functioning in both physical and mental domains, with lower scores indicating greater impairment. This measure is commonly used to measure QoL in patients with CKD (Krishnasamy, 2015).

##### **6.3.8.3.2 Hospital Anxiety and Depression Scale**

The Hospital Anxiety and Depression Scale (HADS) has been shown to be a valid tool in patients with ESRF for the diagnosis of depression and anxiety (Loosman et al., 2010), which is highly prevalent in patients with CKD (Hedayati et al., 2012). This tool is suitable for this population as it assesses non-physical symptoms of depression, where

an overlap is often seen between symptoms of uraemia and depression e.g. changes in appetite and fatigue. The HADS comprises of 14 statements, which relate to anxiety or depression. Questions are scored on a Likert scale which ranges from 0-4, and then each subscale is added separately (Zigmond and Snaith, 1983). Higher scores indicate greater levels of anxiety and/or depression. Cut-off scores are available for both subsets, whereby a score of 8 or more for anxiety has a specificity of 0.78 and a sensitivity of 0.90, and for depression a specificity of 0.79 and a sensitivity of 0.83 (Zigmond and Snaith, 1983)<sup>22</sup>.

#### **6.3.8.3.3 Duke Activity Status Index**

The Duke Activity Status Index (DASI) (Hlatky et al., 1989) is a validated and widely-used measure of self-reported physical capability and is detailed in Chapter 2.

#### **6.3.8.3.4 Patient Activation Measure -13**

The Patient Activation Measure-13 (PAM-13) was used to assess an individual's willingness or ability to take independent action to engage with one's health and clinical care. The questionnaire has 13 items that generate a score between 0-100. Responses range from: 1 strongly disagree to 4 strongly agree, scores are then scaled using an established scoring spreadsheet. The scores correspond to differing stages of activation which range from: Stage 1—does not yet understand an active role is important (score  $\leq 47.0$ ); Stage 2—lacks knowledge and confidence to take action (score  $\geq 47.1$  and  $\leq 55.1$ ); Stage 3—beginning to take action (score  $\geq 55.2$  and  $\leq 67.0$ ); and Stage 4—maintaining behaviours over time (score  $\geq 67.1$ ) (Mosen et al., 2007). Patient activation has been shown to be a changeable characteristic and linked to improved self-management behaviours including regular exercise (Hibbard et al., 2007).

#### **6.3.8.3.5 Kidney Knowledge Survey (KiKS).**

The KiKS is a short 28 item validated questionnaire used to measure the participant's knowledge of CKD, covering topics such as kidney function, RRT options, symptoms, blood pressure targets, the role of the kidney and medication (Wright et al., 2011). Questions consist of a mixture of yes/no answers and multiple questions, with scores

ranging from 0-28. The questionnaire has previously been shown to have a good level of reliability Kuder-Richardson -20 coefficient = 0.72.

#### **6.3.8.4 Psychological constructs**

Questionnaires were selected to assess the psychological constructs targeted within the PACT intervention. These included an assessment of illness perceptions addressing constructs of the CSM; and self-efficacy, outcome expectations, and self-regulation were used to address the constructs of SCT.

##### **6.3.8.4.1 Illness Perceptions Questionnaire – Revised**

The Illness Perceptions Questionnaire-Revised (IPQ-R) is an 84 item questionnaire which is used to assess the principal components of illness representations (Moss-Morris et al., 2002). The authors advise adapting the questionnaire to the specific requirements of the research. Therefore, this questionnaire has been tailored for patients with CKD and was used to assess their perceptions of physical activity as a treatment. The IPQ-R is categorised into three main sections: identity; seven subscales (consequences, timeline acute/chronic/cyclical, personal and treatment control/cure, illness coherence, and emotional representations); and causal factors related to the disease. The identify subscale consists of 14 symptoms, of which an individual is asked to rate whether they experience the symptom “yes” or “no” and whether they relate it to their condition. A “yes” is assigned a value of 1, whereas a “no” is assigned a value of 0. Scores are then summed to produce a total score representing an individual’s illness identity, higher scores are associated with a stronger illness identity. In the remaining sections, each question is appointed a 5-point Likert- style scale (strongly disagree, disagree, neither agree or disagree, agree, strongly agree). Strongly disagree is given a score of 1 while strongly agree is given a score of 5. Higher scores are indicative of stronger beliefs on the given construct. High scores on identity, consequences, timeline acute/chronic/cyclical and emotional subscales represent negative illness beliefs. Whereas high scores on illness coherence and personal and treatment control indicate positive illness beliefs.

#### **6.3.8.4.2 Walking Self-Efficacy Questionnaire.**

The PACT intervention was predominately designed to encourage walking behaviour, therefore a walking specific self-efficacy questionnaire was adopted. The walking self-efficacy questionnaire (WSE) was used to determine an individual's belief in their physical capability to successfully complete incremental 5-minute intervals of walking at a moderately fast pace (McAuley et al., 2000). The intervals range from 5-40 minute of walking, and self-efficacy to execute the behaviour is recorded on a percentage scale ranging from 0 – 100%. Higher scores indicate higher levels of self-efficacy. Total self-efficacy for walking is then calculated by summing the confidence rating and dividing it by the total number of items on the scale, resulting in a maximum possible score of 100. The questionnaire was originally developed for use in older adults and demonstrated excellent internal consistency  $\alpha=.95$ .

#### **6.3.8.4.3 Multi-dimensional Outcome Expectancies for Exercise Scale.**

The Multi-dimensional Outcomes Expectancies For Exercise Scale (MOEES) is a validated questionnaire used to assess an individual's perspectives on what will change if they engage in a new behaviour (outcome expectations) (Wójcicki et al., 2009). The MOEES consists of 31 questions that reflect three categories of outcome expectations including physical, self-evaluative and social outcome of physical activity. Each item is rated on a 5-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, and 5 = strongly agree). Summing the rating for the corresponding questions then scores each dimension. Higher scores reflect higher outcome expectations. All three outcome expectations scales have been shown to have good internal consistency: physical ( $\alpha = .82$ ), self-evaluative ( $\alpha = .84$ ), and social ( $\alpha = .81$ ).

#### **6.3.8.4.4 The Physical Activity Self-Regulation Questionnaire**

This is a 6-item questionnaire developed by the researchers to assess the self-regulation behaviours of the participant at the end of the intervention. Each item is rated individually on a 4 point Likert scale: 1= never, 2 = some of the time, 3= most of the time, and 4 = all of the time.

### **6.3.8.5 Anthropometrics**

Anthropometrics were assessed at both assessment points. In addition, Bioelectrical Impedance Analysis (BIA) (In Body) was used to provide an overview of body composition, capturing this by applying a small current to the body. The underlying principle is that resistance to the current changes depending on the amount of water in the body, with water content differing among properties such as muscle, fat, and bone. BIA has been shown to correlate highly with DEXA which is a gold standard measure of body composition.

### **6.3.8.6 Demographics and clinical data**

Baseline demographics and clinical data including eGFR, the cause of CKD and other-comorbidities were extracted from a composite of the questionnaire and computerised medical records.

### **6.3.9 Programme evaluation**

#### **6.3.9.1 Statistical Analysis**

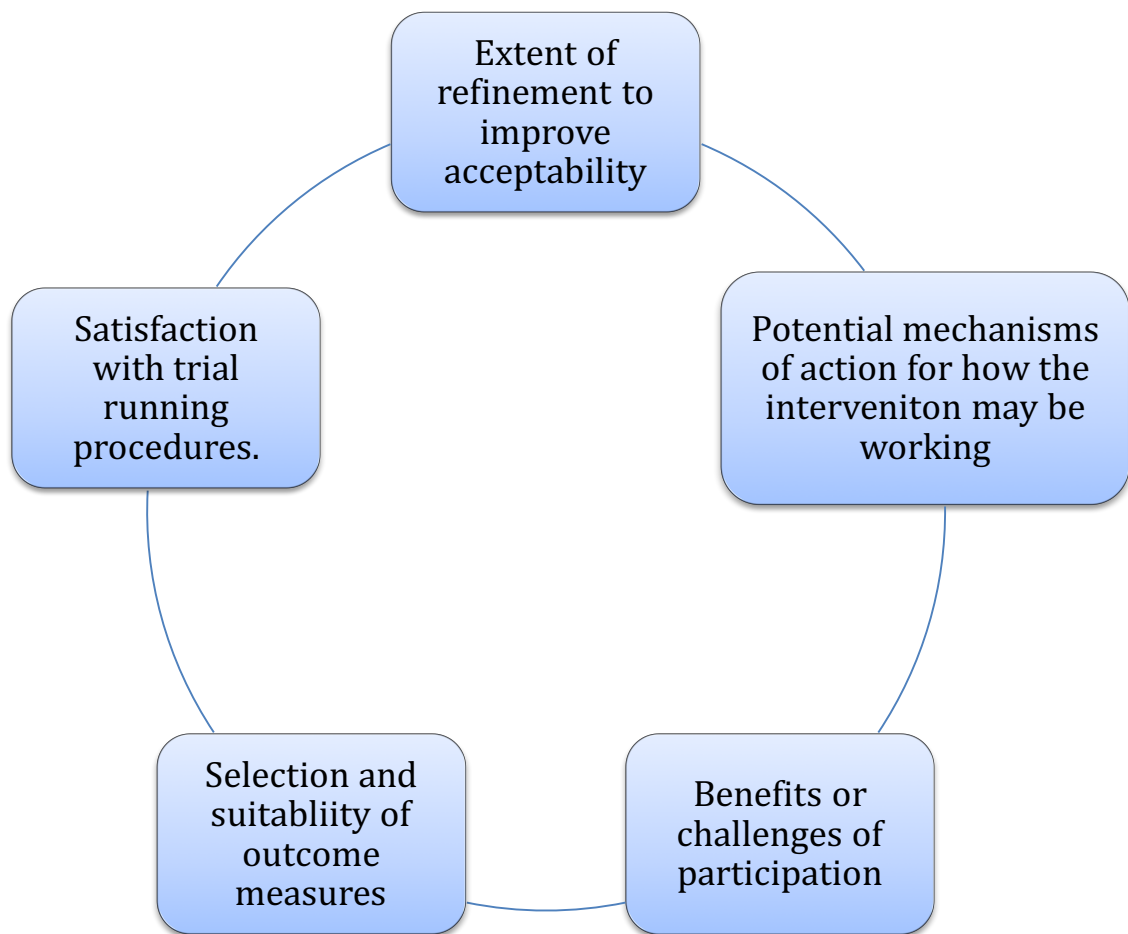
Data were transferred from the CFR to a Microsoft Excel spreadsheet for storage and then exported into SPSS for analysis. Data were analysed using descriptive statistics for demographic and all outcomes measures collected at baseline and 12 weeks, as well as changes in outcome measures. Continuous variables were described as mean (SD) or median (IQR 25<sup>th</sup>-75<sup>th</sup> percentile) and categorical variables were described by percentages. Non-normally distributed data were log-transformed to reduce skewness prior to statistical analyse, then back-transformed to report the mean difference and 95% CI. Exploratory t-tests were conducted to determine differences pre-and post-intervention, a p-value of <0.05 was considered a finding that might be worth another look in a future trial. However, t-tests results should be interpreted with caution as this study was not sufficiently powered. Effect sizes for the difference between pre-and post-scores were also calculated using Cohen's *d* effect size using the mean and standard deviation of each time point. A small effect is regarded as 0.2, medium effect 0.5 and a large effect is 0.8. Positive changes in outcome measures will be highlighted

for discussion purposes, to suggest potentially suitable measures that are sensitive to change.

#### **6.3.9.2 Qualitative Analysis**

Semi-structured interviews were conducted to explore the patients experience of participating in the PACT intervention and assess the acceptability of outcome measures used in the trial. Interviews were carried out by H.J.M and D.C, both of whom are researchers in the department and have experience in conducting semi-structured interviews. A convenience sampling method was employed whereby all participants who completed the intervention were invited to participate. All 13 participants were approached and 12 attended a semi-structured interview. One participant did not attend due to relocation for work. All interviews took place at the Leicester General Hospital in a comfortable room away from any usual clinical service. Interviewers were provided with a topic guide which was developed by the candidate, and designed to explore more about participant experience and acceptability of the PACT intervention. All semi-structured interviews were audio recorded and professionally transcribed verbatim. Transcripts were then imported into Nvivo 10 to help facilitate data analysis. Data were analysed using the 6 phases of thematic analysis as described by Braun and Clark (Braun and Clarke, 2006) also described in Chapter 4. However, themes were organised to reflect the categories of questions inferred by O’Cathain et al. (2015), for the use of qualitative research in feasibility studies for RCTs. Figure 6.2 shows a conceptual framework used to organise emergent themes.

**Figure 6.2 Conceptual diagram of feasibility themes**



## **6.4 Results**

Overall, 75 non-dialysis CKD patients were approached and 19 (25%) consented. 17 (90%) attended one of the 4 group sessions, and 4 participants were withdrawn due to unrelated reasons, resulting in a completion rate of 68%. Participant flow through study is shown in Figure 6.3, and participant characteristics are shown in Table 6.1.

**Figure 6.3** Consort diagram showing participant flow through study.

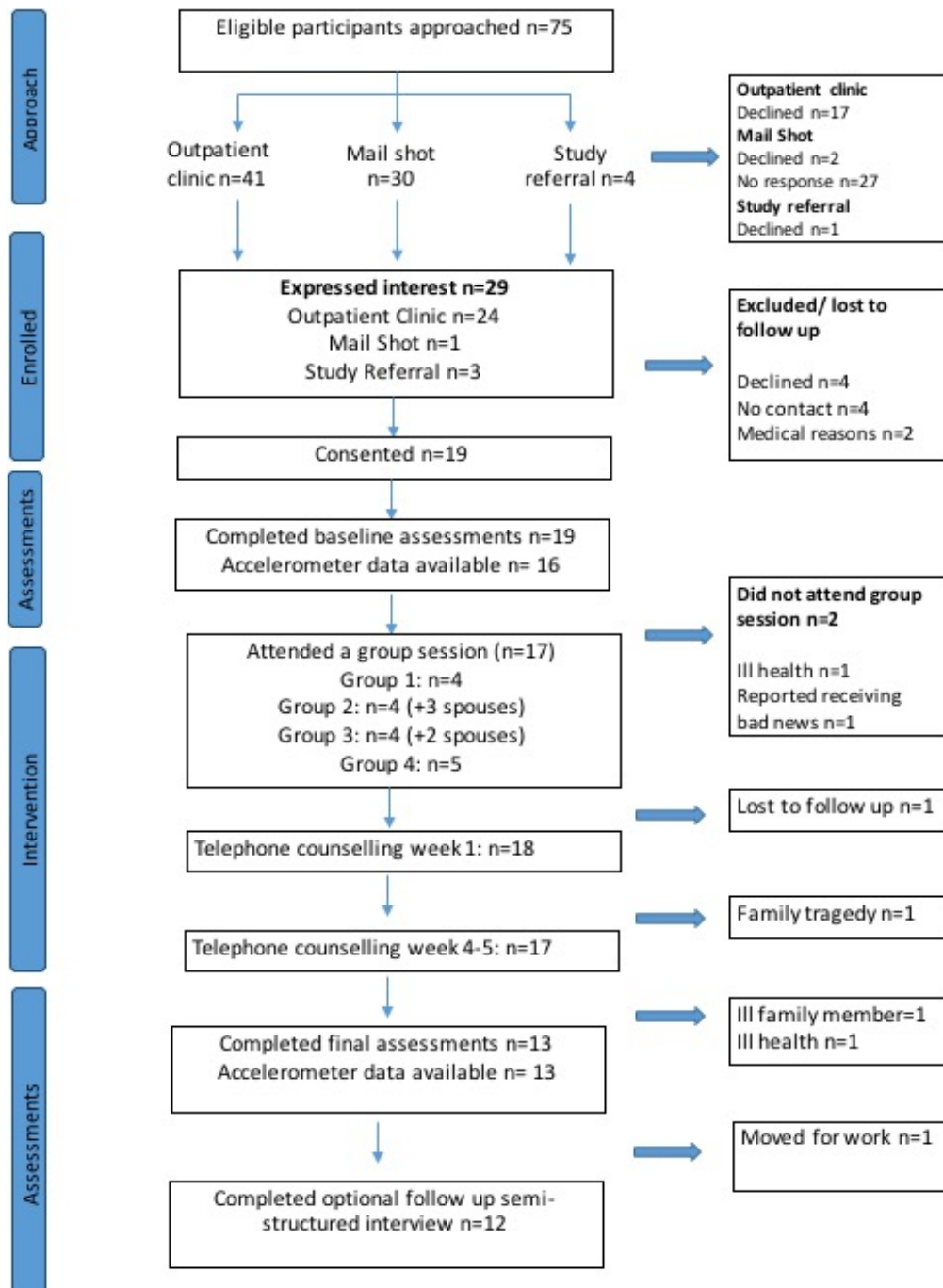




Table 6. 1 Patient characteristics at baseline

Baseline characteristics	N=13
Age, years	54.15 (14.50)
Gender M: F	9:4
Ethnicity	
White	10
South Asian	3
Black	1
eGFR, ml/min/1.73m <sup>2</sup>	43 (15)
Cause	
IgA Nephropathy	3
AKI (Sepsis)	1
FSGS	1
Tubulointerstitial nephritis	1
Membranous nephropathy	2
Granulomatosis with polyangiitis	1
Cancer	1
Unknown	3
History of cardiovascular disease	3
Diabetes	4
Hypertension	5
Systolic blood pressure at rest, mmHg	133(19)
Diastolic blood pressure at rest, mmHg	84(8)
Weight, kg	90 (35)
BMI, kg /m <sup>2</sup>	31(8)

Categorical data presented as N.

Continuous data presented as mean  $\pm$  SD

### 6.4.1 Implementation

Implementation refers to the degree to which an intervention can be implemented as proposed (Bowen et al., 2009), therefore questioning the extent to which the protocol was successfully executed as intended within the current pre–post uncontrolled design. This study was designed to be delivered within a 12-week time frame, providing a two-week window for pre-and post-intervention assessments and an 8-week home-based walking intervention period. The intervention implementation profile for participants who completed the study are illustrated in Table 6.2.

**Table 6.2 Implementation profiles for n=13 participants.**

Implementation profile	Range
Duration of PACT in weeks	9-13
Number of outcome visits (per participant)	2
Time taken to complete outcome assessments (minutes)	
Assessments 1	90-180
Assessments 2	50-120
Length of group session (minutes)	120-225
Length of telephone calls (minutes)	5-30
Total number of visits to the hospital (per participant)	3-4

On average participants took a mean of 10.5 weeks to complete the full study protocol (not including the optional semi-structured interview). The cohort attended a total of 51 hospital visits between them which consisted of: 2 outcome assessments visits, 1 group session, and 1 semi-structured interview of which 12 participants were available to participate in. Group sessions were designed to be conducted within a 3.5-hour timeframe, but the first session was much shorter lasting only 120 minutes. Educators realised when comparing the first session to previous development sessions (Chapter 5) that refreshment breaks were crucial to building rapport within the group, but these were declined in this afternoon session. Therefore, subsequent sessions were conducted between the hours of 10 am to 1.30 pm to allow for a lunch, which was provided by the candidate.

All participants received two follow-up counselling telephone calls. Telephone calls lasted between 5-30 minutes. Whilst telephone calls were structured with prompt sheets used for fidelity, participants varied regarding enthusiasm to discuss activity levels, time available to talk, and level of support required. All participants had access to the candidate's telephone number; however, contact was only made by one participant to discuss issues around the accelerometer. One participant contacted the candidate via hospital email at one time point to describe how they had proudly reached their target.

#### **6.4.2 Acceptability**

Acceptability refers to how the intended target audience reacts to the intervention and trial procedures. The main aim of the PACT intervention was to increase levels of physical activity. Physical activity was assessed objectively using the ActiGraph GTX3 accelerometer. To assess the acceptability of this outcome measure we looked at wear time and compliance. A valid wear time was defined as a minimum of 10 hours per day and a minimum of 4 valid days. Using these thresholds 11 participants had full valid wear time data for both pre-and post-intervention. Two participants failed to reach this minimum for post intervention wear time and as such was excluded from the analysis. The average wear time for valid days among patients achieving the minimum threshold was 14 hours 22 minutes. Numbers of valid wear time days ranged from 4-7.

Secondary outcomes including assessments of physical performance and questionnaires had a completion rate of 100%; except for 1 incomplete IPQ-R questionnaire, 1 missing PAM-13 questionnaire, and 3 missing IPAQ-SF questionnaires. Baseline IPAQ-SF questionnaires were intended to be completed at the start of the group session. However, with late arrivals, some questionnaires were not completed, and anecdotally for future consideration completing questionnaires within the group session was a distraction as opposed to a session icebreaker as intended.

Physical activity was encouraged by providing the opportunity to learn about behavioural goal setting and physical activity self-monitoring. Engagement with self-regulation strategies was assessed using a specifically developed questionnaire

(Physical Activity Self-Regulation Questionnaire) delivered post intervention of which results are shown in Table 6.3.

**Table 6.3 Participants self-regulation practices were assessed post-intervention.**

	Never	Some of the time	Most of the time	All of the time
Goal setting (n)	0	0	3	9
Walking plan (n)	0	1	4	8
Worn pedometer (n)	0	0	1	12
Kept a step log (n)	0	0	1	12
Been aware of physical activity (n)	0	0	3	10
Increased physical activity (n)	0	0	4	9

#### **6.4.2.1 Step monitoring / diary engagement**

Engagement with step monitoring was good during the 8 weeks of walking. 11 participants returned physical activity diaries, which were completed at a rate of 61-100%. Participants were considered to have engaged with the booklet and monitoring process if they had noted down either steps or reasons for not monitoring their steps for that day. Days with missing steps ranged from 0-21 days. Weeks were classed as missing if they had no valid step days entered. From the data, it appears that engagement with step monitoring was better during the first 6 weeks of walking. Weekly averaged steps counts are shown for individual participants in Table 6.4. Additional measures of acceptability are explored within the qualitative data.

**Table 6.4 Averaged daily step counts recorded over 8-week self-directed physical activity.**

Participant	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7	Week 8	Diary entry days missing (N)	Diary engagement, % of days
<b>P1</b>	16351*	19439*	19340*	17681*	18748*	21164*	21240*	23405*	0	100%
<b>P5</b>	10197*	11442*	9081	10961*	10867*	9600	7933	x	8	85%
<b>P6</b>	8183*	7959*	6914*	8377*	8653*	10570*	9780*	9927*	10	82%
<b>P7</b>	3310	3346	3639	2837	3168	3017	3777	4359	0	100%
<b>P8</b>	8598	6987	9987	8922	9292	8615	x	x	12	78%
<b>P9</b>	3858	2439	3444	3025	2939	4484	4949	4971	1	100%
<b>P12</b>	x	x	x	x	x	x	x	x	x	0
<b>P13</b>	6767	7610*	7126*	6557	7587*	7298*	5324	6119	2	100%
<b>P14</b>	x	x	x	x	x	x	x	x	x	0
<b>P15</b>	8814	8115	8331	9254*	5231	5328	6725	11158*	2	100%
<b>P16</b>	6560	6907	8151	7412	7298	7696	8062	7842	0	100%
<b>P18</b>	7243	5936	7827	10112	9053	x	x	x	21	61%
<b>P19</b>	5090	4070	3080	1539	3284	2341	3798	4720	8	100%

**X=missing data, \*=long-term goal achieved (baseline + 3000 steps)**

### **6.4.3 Limited efficacy testing**

Outcome scores at pre-intervention, post intervention and changes in scores for all outcome measures are shown in Tables 6.6, 6.7, 6.8 and 6.9. These include data for the 13 participants who completed the intervention. Data for the participants who withdrew were removed prior to the analysis. This study was not designed to evaluate changes in outcome measures and was not powered to do so. Therefore, preliminary data analyses are indicated for discussion purposes and to guide potential future investigations only.

Objectively measured baseline and follow-up physical activity data were available for all 13 participants and results are detailed in Table 6.6. Post intervention step counts indicated a mean (95 % CI) increase of 2127 (-774, 5029) steps per day from baseline,  $p=0.08$ ,  $d=-0.96$ . Whilst, not statistically significant, this indicates a change in the direction of improvement. Similarly, time spent in moderate to vigorous physical activity showed the same pattern of improvement of a group mean (95% CI) increase of 13.83 (-6.74, 34.40) minutes per day. However, 3 participants recorded an increase in steps, but a decrease in MVPA, indicating that these steps may not have been performed at the intended moderate intensity. In addition to physical activity, all physical performance measures showed a change in the direction of improvement (Table 6.7).

Moreover, all measures of patient QoL including both mental and physical domains showed a change for improvement (Table 6.8), as did measures of patient activation and knowledge. Changes denoting improvement were also identified for certain psychological constructs targeted within the intervention including walking self-efficacy, illness coherence, timeline cyclical and perceived consequences of disease (Table 6.9). Due to the variability in the group, changes of improvement were not indicated for weight (kg) and body mass index (BMI) as some participants wanted to put weight on after periods of ill health and others had weight loss goals. However, results indicated a change in the direction of improvement for skeletal muscle mass (kg) and body fat percentage (Table 6.10).

**Table 6.5 Individual objective physical activity data at baseline and post intervention (n=13)**

Study ID	Steps (per/day)				MVPA (minutes per/day)				Average wear time (hours: minutes per/day)		
	Participant	Baseline	Post Intervention	Difference	% Change	Baseline	Post Intervention	Differences	% Change	Baseline	Post Intervention
PACT01		10140	23702**	13562**	134	86	193	107	124**	11H 13M	13H 54M
PACT05		7531	-	-	-	51	-	-	-	11H 23M	-
PACT06		3167	9323**	6159**	194	18	57	39	217**	12H 41M	12H 16M
PACT07		2826	3445**	629**	22	6	5	-1	-17	8H 21M	11H 58M
PACT08		7323	6404	-918	-13	49	41	-8	-16	10H 11M	8H 9M 45S
PACT09		2285	-	-	15	8	-	-	-	12H 21M	-
PACT12		7615	5995	-1620	-21	51	41	-10	-20	8H 18M	7H 22M
PACT13		3941	4908**	967**	25	13	25	12	92**	8H 21M	9H 46M
PACT14		5168	4849	-319	-6	20	19	-1.15	-5	9H 13M	10H 29M
PACT15		6836	8871**	2007**	29	77	96	19	25**	10H 6M	8H 37M
PACT16		6116	7373**	1257**	21	47	47	0	0	9H 34M	9H 2M
PACT18		5341	7304**	1963**	37	25	38	13	52	8H 29M	11H 18M
PACT19		3887	3604	-283	-7	28	24	-4	-14	8H 31M	7H 36M

Baseline and post intervention individual scores for steps per day and moderate to vigorous physical activity (MVPA) minutes per day.  
\*\* denotes a change in the direction of improvement.

**Table 6. 6 Outcome measures pertaining to physical activity and physical performance**

<b>Outcome measure</b>	<b>N</b>	<b>Baseline</b>	<b>Post-intervention</b>	<b>Mean change (95% CI)</b>	<b>P-value</b>	<b>Effect size Cohen's d</b>
<sup>1</sup> Steps per/day	11	5672(2214)	7799(5617)	2127 (-774, 5028) <sup>**</sup>	0.08	-0.96
Time spent in MVPA (Minutes)	11	35.67 (26.41)	49.5(51.33)	13.83 (6.74,34.40) <sup>**</sup>	0.14	-0.34
ISWT (m)*	13	409.23(192.64)	460.77 (208.98)	51.54(21.75,81.33) <sup>**</sup>	0.03	-0.26
STS60 (reps)*	13	23.16(10.77)	29 (12.82)	5.85 (2.51,9.18) <sup>**</sup>	0.004	-0.51
STS5 (sec)*	13	13.91(5.74)	11.23 (3.69)	-2.69(-5.05, -0.32) <sup>**</sup>	0.029	0.56
TUAG (sec)	13	8.82 (1.78)	8.15(1.91)	-0.67(-1.42,0.08) <sup>**</sup>	0.075	0.36
Gait speed (m/s)	13	1.11(0.18)	1.15(0.20)	0.03 (-0.04-0.11) <sup>**</sup>	<0.01	-0.21
SPBT	13	10.00(1.83)	10.69(1.25)	0.69(0.02-1.36) <sup>**</sup>	0.044	-0.44

Baseline, post-intervention and mean change with 95% confidence intervals (CIs) and effect size for physical activity measures including steps, time spent in MVPA; and objective physical performance measures and physical function including: incremental shuttle walking test (ISWT), sit to stand 60 (STS60), sit to stand 5 (STS5), timed up and go (TUAG), gait speed, short performance battery test (SPBT). <sup>\*\*</sup>Denotes a change in the direction of improvement.

\* Unpublished work by the Leicester Kidney Exercise Team has found that the minimally clinically important difference based on patients' self-report of "feeling better" is: +45 for the ISWT; +5 for the STS60 and -4.2 for the STS5.

<sup>1</sup> T-test was repeated to remove the effects of statistical outlier (PACT 01). Steps per/day mean change (95% CI) for n=10 participants were 984 (-574, 2541), p=0.17, D = -0.52.



**Table 6. 7 Outcome measures pertaining to domains of quality of life, knowledge and patient activation**

<b>Outcome measures</b>	<b>N</b>	<b>Pre-Intervention</b>	<b>Post- Intervention</b>	<b>Mean change (95% CI)</b>	<b>p-value</b>	<b>Effect size Cohen's <i>d</i></b>
HADS Anxiety	13	5.38(3.15)	4.69(2.21)	-0.69 (-2.10,0.71)**	0.30	0.25
Depression		4.00(3.16)	3.00(2.68)	-1 (0.21, -1.80)**	0.10	0.14
SF-12-V2	13					
PHC		42.60(8.78)	44.88(7.70)	2.28(-0.91,5.48)**	0.15	-0.28
MHC		49.10(5.55)	53.35(7.34)	4.2 (0.59,7.91)**	0.03	-0.65
DASI	13	41.97(14.0)	46.52(13.24)	4.55 (-0.01,9.11**	0.05	-0.33
KiKs	13	18.30(3.52)	20.0(2.82)	1.69(0.03,3.35)**	0.047	-0.53
PAM-13	12	54.16(10.80)	58.18(9.05)	4.02(-0.81-8.85)**	0.09	-0.40

Baseline, post-intervention and mean change with 95% confidence intervals (CIs) and effect size for The 12-Item Short Form Health Survey (SF-12-v2), and Hospital Anxiety Depression Scale (HADS), Duke Activity Status Index (DASI), Kidney Disease Knowledge Survey (KiKs) and Patient Activation Measure (PAM-13).

\*\* Denotes a change in direction of improvement

**Table 6.8 Outcome measures pertaining to psychological constructs**

<b>Outcome measures</b>	<b>N</b>	<b>Pre-Intervention</b>	<b>Post-Intervention</b>	<b>Mean change (95% CI)</b>	<b>p-value</b>	<b>Effect size Cohen's <i>d</i></b>
WSE	13	53(42.43)	65.87(29.94)	12.87 (-1.42,27.15)**	0.07	-0.35
MOEES	13					
Physical		26.3(2.10)	26.0(1.73)	-0.31 (-1.84,1.22)	0.67	0.16
Social		13.31(1.97)	12.85(2.15)	-0.46 (-1.61,0.69)	0.40	0.22
Self-evaluative		20.08(2.78)	21.15(2.03)	1.08 (-0.57, 2.72)**	0.18	-0.44
IPQ-R	12					
Identity		3.31 (2.53)	4.38(3.25)	1.08(-0.26,2.42)	0.12	-0.37
Timeline		22.75(5.58)	25.25(3.44)	2.5(-0.63,5.63)	0.11	-0.54
Consequences		17.83 (4.49)	17.75(3.84)	-0.08 (-3.17,3.00)**	0.95	0.02
Personal control		20 (4.63)	19.67(3.50)	-0.33 (-2.46, 1.79)	0.74	0.08
Treatment control		15.83 (2.18)	15.41 (2.31)	-0.41 (-2.51,1.67)	0.67	0.19
Illness coherence		15.42 (4.42)	18.25 (4.45)	2.83 (0.69, 4.98)**	0.01*	-0.64
Timeline cyclical		12(3.05)	10.92 (3.53)	-1.08 (-3.0,84)**	0.24	0.34
Emotional		15.33 (4.54)	15.58 (4.93)	0.25 (-1.42,1.92)	0.75	-0.05

Baseline, post-intervention and mean change with 95% confidence intervals (CIs) and effect size for walking self-efficacy (WSE), Multi-dimensional outcome expectancies for exercise scale (MOEES) and Illness perceptions questionnaire – revised (IPQ-R).

\*\* Denotes a change in direction of improvement

Table 6.9 Outcome measures pertaining to anthropometric measures

Outcome measures	N	Pre-Intervention	Post-Intervention	Mean change (95% CI)	P-value	Effect size Cohen's <i>d</i>
Weight (kg)	13	85.15(14.62)	85.32(14.32)	0.18 (-1.48, 1.84)	0.82	-0.01
Body Mass Index (BMI)	13	31.10(7.81)	31.12(7.97)	0.02 (-0.62, 0.65)	0.96	-03
Skeletal Muscle Mass (kg)	13	30.14(6.24)	30.30(6.64)	0.16 (-1.06, 1.38) **	0.78	-0.02
Body Fat (%)	13	35.73(10.95)	35.26(10.93)	-0.47 (-2.36, 1.42) **	0.60	0.04

Baseline, post intervention and mean change with 95% confidence intervals (Cis) and effect size for weight (kg), Body mass index (BMI); skeletal muscle mass (kg) and body fat percentage (%).

\*\* Denotes a change in direction of improvement  
Changes in improvement have not been highlighted for weight (kg) and body mass index as participants had differing goals with regards to weight gain/loss.

#### 6.4.4 Qualitative results

Twelve participants were interviewed. Themes derived following thematic analysis of semi-structured interviews were organised to answer questions related to intervention feasibility.

##### 6.4.4.1 Extent of refinement to improve acceptability

Exemplar patient quotations are shown in Table 6.10.

The dimension of acceptability in this context relates to the extent to which the PACT intervention content, delivery or resources may need to be refined to ensure the programme is most acceptable to the patients.

***Acceptability and refinement of content:*** The group education session was deemed to be comprehensive, informative and was described as “*really interesting*” (PACT 13 male, aged 68). Participants described how they had “*...particularly liked the bit about the function of the kidneys... [and] the bit ..about exercise ..but the positive things like mood as well as the things about cardiovascular health and reducing risks*” (PACT 01 male, aged 55). The session was said to be pitched correctly and accessible for a wide range of patients. However, some participants felt that additional information to address a wider range of lifestyle factors including diet and emotional management in CKD would be beneficial. Furthermore, participants desired advice regarding strengthening exercises, with some feeling that walking alone was not enough to achieve their goals. In addition, some participants appeared to struggle with the concept of intensity and felt this could have been emphasised more in the programme.

***Acceptability and refinement of the delivery format:*** The group format was preferred by many; helping participants to feel they were “*not alone and there are other people out there ... living full lives [which] was helpful*” (PACT 12 male, aged 40). Participants felt that they grew with confidence as the session went on, which allowed them to open-up more and share their own perspectives and experiences. Whilst group dynamics were important, one participant felt that the group discussion should be more

structured to stay on topic. Overall, the length of the session was acceptable. Some participants felt that the session could be longer if more participants were present, whilst others felt this may lead to the session "*dragging on a little*" (PACT05 male, aged 55). Participants stated that the session would benefit from a few extra participants, although there was an appreciation for the smaller group where "*everybody's experiences were quite different*" (PACT 18 female, aged 31).

***Acceptability and refinement of intervention components:*** Interactive elements were well received by participants: "...*just to visualise it like that [risk demonstration] ... it really did stick in my mind. I just think that every time ..I don't want to go for a run I just think about that tray and that teacup... I don't want diabetes in there... it's just something else to deal with*" (PACT 18 female, aged 31). Telephone calls were described as motivating, appropriate and of a suitable frequency. However, it was suggested that contact frequency should be tailored to suit the needs of the individual. The written materials were said to be "*good resources to refer to*" (PACT 01 male, aged 55), and the pedometer was described as "...*one of the things that really stuck out*" (PACT 13 male, aged 68). Although, a few participants questioned the accuracy of the device, and some felt real-time monitoring via a mobile phone or app would be easier.

**Table 6.10 Participant quotations illustrating extent of refinement to improve acceptability.**

Minor themes	
<i>Acceptability and refinement of content</i>	
Emotional management	<i>“...I would add... the psychological aspect...I was told I couldn’t do certain things in the beginning...and it was in my mind I was telling myself you can’t get up and do that. So I gave up a lot of things...” (PACT 12 male, aged 40).</i>
Diet	<i>“...my main purpose to join ...was to be able to monitor the progress of my kidney function... and what foods to eat and what is good for me....” (PACT 19 male, aged 64).</i>
Additional exercises	<i>“...the walking is not enough. I’ve got to add physical exercises, I’ve got to do a little bit of weight, maybe one kilo or something like that” (PACT 06, male aged 64).</i>
Exercise intensity	<i>“...I frog march, I don’t just doddle, and I think the information we were given could have emphasised that slightly more” (PACT 01 male, aged 55).</i>
<i>Acceptability and refinement of delivery</i>	
Staying on topic	<i>“...some people they were going on and on about some things which were not totally relevant... which [was] a little bit annoying actually because you are using up time which could be more useful focused on the actual study...” (PACT19, male aged 64).</i>
Additional participants	<i>“Yes, it could probably have done with a couple more perhaps but it was quite interesting” (PACT 13 male, aged 68).</i>
<i>Acceptability of intervention components</i>	
Recording intensity	<i>“...putting down the intensity of what you’re doing each day is more difficult because I mean once you’re doing it as a routine then it’s, I don’t know, it doesn’t seem intense” (PACT 05 male, aged 55).</i>
Smart phone app	<i>“...you can tie your apps in together if you have got a smartphone ... It would be like oh actually if I walk for an extra so and so my lung capacity increases by whatever, I know it doesn't but, you know my fitness levels will have increased by so and so percent” (PACT 18 female, aged 31).</i>

#### **6.4.4.2 Mechanisms of action**

Exemplar patient quotations are shown in Table 6.11

Behaviour change is complex and most successfully implemented when underpinned by theory. Theory represents the knowledge derived from the mechanism of action, which provides an understanding of how the factors may influence an individual's behaviour (Davis et al., 2015). Potential mechanisms of action drawn from SCT and the CSM included goal setting, self-efficacy, and changes in negative illness perceptions.

***Goal setting:*** Goal setting was described as important, but strategies differed among participants. A better understanding of intensity reflected more specific goal setting, focused around timed walking. However, all participants found step monitoring useful and motivating even if they did not set specific step based goals. Goal setting was important to initiate behaviour change, however, it seemed that getting into a routine or having a long term personalised goal was most beneficial.

***Self-efficacy:*** Participants described how the programme had helped them to gain confidence in their exercise ability, which was enhanced by taking a graded approach to exercise. In addition, vicarious learning was a potential mechanism informing efficacy beliefs, as participants expressed how seeing others in a similar position, or those who were older/younger helped them feel more confident about their own situation and abilities.

***Illness perceptions:*** Participant verbalisations indicated some changes in negative illness perceptions. The programme helped participants to feel as though they were doing something positive for their own health.

**Table 6.11 Participant quotations illustrating mechanism of action.**

<i>Minor theme</i>	
<b><i>Goal setting</i></b>	
Personalised goal	<i>“I think that was very good, because my goal was getting up that hill in the park and that, the park on the right-hand side is, the hill is very steep and on the left-hand side it’s steep but it’s not as steep” (PACT 16 female, aged 46).</i>
Timed goals	<i>“...timing the steps was important to me. Not being lethargic, not getting the job over, just doing the walking for the sake of walking. I was walking to reach some sort of a benefit” (PACT 06 male, aged 64).</i>
Non-specific goals	<i>“Well no I didn't set a target as such...I just did what I could [and] just monitored the number of steps that I did” (PACT 19 male, aged 64).</i>
<b><i>Self-efficacy</i></b>	
Confidence	<i>“I felt more comfortable, more confident ...when I first found out I’d got the disease I was moping around, I didn’t want to do any exercise. I didn’t want to do anything but then coming on this course it’s just pushed me a bit further...” (PACT 14 male, aged 38).</i>
Vicarious learning	<i>“...there was a couple of older people there and they were still living their lives. So, it’s [CKD] not the be all and end all” (PACT 12 male, aged 40).</i>
Mastery	<i>“...at the programme I realised if you gradually build up to it, you can overcome the problem with your mind, you can build up and get a bit more healthy and a bit fitter” (PACT 12 male, aged 40).</i>
<b><i>Illness perceptions</i></b>	
Influence over illness	<i>“Not necessarily in control of the condition but in control of things that you can do to influence it” (PACT 01male, aged 55).</i>



#### **6.4.4.3 Benefits/ challenges to participating**

Exemplar patient quotations are shown in Table 6.12

All participants felt that the programme had been beneficial. Participants described seeing positive changes in energy levels, as well as functional and psychological improvements. Furthermore, participants fulfilled social aspirations such as getting back to dancing lessons and spending more active time with their family members. No participants described any harmful effects from participating in the physical activity programme. However, several challenges to goal attainment were inferred. These predominately included issues with time management and disruption to walking plans due to symptoms or other co-morbidities such as sleep disturbance and gout.

#### **6.4.4.4 Outcome assessments**

Exemplar patient quotations are shown in Table 6.13.

The majority of outcome assessments were deemed acceptable. Baseline functional assessments were described as interesting, a confidence boost, proof of achievement and suitable for a wide range of participants. Similarly, participants showed interest in their body composition results. However, whilst participants thought baseline physical activity monitoring was interesting, the ActiGraph GTX3 used was not well tolerated. The study protocol included several questionnaires, however, whilst participants commented on the amount and repetitiveness of questions, the general perspective was that they all were important and the burden to complete them was acceptable.

**Table 6.12 Participant quotations illustrating benefits/ challenges to participating.**

<b>Minor Themes</b>	
<b>Benefits</b>	
Energy	<i>“I’m certainly not getting as tired at work..I used to have a system whereas I wanted to be able to do as much work as I could but if I felt myself getting tired I’d sit down for ten minutes. I’m finding I’m not having to do that now” (PACT 12 male, aged 40).</i>
Function	<i>“Before the programme, I wouldn’t have even ventured going far, I would never have walked up here to be honest, they would have had to get me a wheelchair...I was that bad” (PACT 07 male, aged 64).</i>
Strength	<i>“I had lost some muscle which meant I wasn’t confident, I am now much more confident, as to lifting things. Even lifting a chair at the dining table, I never used to do it..Not anymore, I’ve started lifting. They were very, very small things but it’s a normality, things are getting normal...” (PACT 06 male, aged 64).</i>
Mental health	<i>“Yes, I think for me that’s, you know, rather than any sort of feeling fitter, I feel better mentally” (PACT 05 male, aged 55).</i>
Independence	<i>“My wife has been by my side ever since I got ill, this is the first time she’s let me loose in the sense that you can go on your own. She has got confidence that I will be ok to go” (PACT 06 male, aged 64)</i>
Social	<i>“...after that session, I thought I’m feeling a lot better now, we’ll do the dancing once a week and we’ll start walking once a week with the group...” (PACT 13 male aged, 68).</i>
<b>Challenges</b>	
Time management / sleep difficulties	<i>“... I am not working regular hours, sleeping regular hours, ..it’s difficult for me to put a proper timetable, get a routine, go for a walk every evening for an hour” (PACT 19 male, aged 64).</i>
Other co-morbidities	<i>“Towards the end, I was thinking oh yes, this is good and I perhaps ought to be doing more, and then ended up getting a bad knee which then immediately stops you doing things” (PACT 05 male, aged 55).</i>

**Table 6.13 Participant quotations illustrating satisfaction with outcome assessments.**

<b>Minor themes</b>	
	<i><b>Outcomes measures</b></i>
Build confidence	<i>“It [functional assessments] gives you more confidence, it gives you more confidence I think. It gave me confidence anyway” (PACT 06 male, aged 64).</i>
Measure of improvement	<i>“...having done it again [sit to stand 60] ..I did manage to do more I could feel the work, where my thighs had been working... So yes, the tests were actually quite good” (PACT 15 male, aged 60).</i>
Suitable for all	<i>“They definitely tested your fitness and stamina without going too far...” (PACT 01 male, aged 55).</i>
Interesting	<i>“...when we did the first weigh-in we got a detailed report from the set of scales that said your different constituents of your body and of course that’s numbers and figures so that quite fascinated me...” (PACT 01 male, aged 55).</i>
Assessment burden	<i>“...the band thing is a bit annoying, it’s nice when that week is over to get rid of that. That’s probably the only slightly irritating thing I found about the trial” (PACT 15 male, aged 60).</i>
Questionnaires	<i>“There were several questionnaires. Some about your mood and are you depressed and all those things, which I was quite happy to answer, they were easy questions, there were no trick questions or anything like that” (PACT 01 male, aged 55).</i>

#### 6.4.4.5 Satisfaction with trial running procedures

Exemplar patient quotations are shown in Table 6.14

**Recruitment:** Observations indicated that face to face recruitment was the most successful strategy. However, whilst participants were complimentary about recruiter characteristics; more generally the recruitment structure may have had a sense of unexpectedness, with participants describing being “grabbed” to participate or meeting the researchers as a positive “*coincidence*” (PACT 07, PACT 06). In comparison, participants approached by their consultants described a pleasant introduction to the researcher and described how the study had been explained in a helpful manner. Participants were strongly motivated to be part of research if there was the potential that it could help others in the future. However, the perspective of some participants towards research changed, from the researchers getting what they needed for a degree, to an understanding of the rationale for an experimental design and a willingness to participate in further studies.

**Study information:** Participants provided diverse accounts regarding how well informed they felt about the study. Whilst all potential participants were carefully taken through the information sheet and provided with at least 48 hours to process before contact, some participants described some uncertainty regarding the study and the reasons for certain procedural methods.

**Trial management:** Any problems with communication seemed to be resolved during the trial, all participants reported that the trial had been run methodically and they felt fully supported throughout. Participants found it useful to know that they could contact the researcher at any time, that all appointments were confirmed by text message, and that they had received reminders the day before assessments took place. There was a unanimous consensus from all participants that they would recommend the programme to others, and some said they would have happily participated in another 4 weeks of the intervention had it been a 12-week programme.

**Table 6.14 Participant quotations illustrating satisfaction with trial running procedures.**

<b>Minor</b>	
<b><i>Recruitment</i></b>	
Consultant	<i>“It was mentioned to me by my consultant ..and I was quite happy to be involved in that...He introduced me or said to have a chat with Amy, which I did, and she explained broadly what the programme was about and some of the sort of aims and objectives, which was helpful” (PACT 01 male, aged 55).</i>
Coincidence	<i>“I think that was a coincidence that [researcher] happened to be in the hospital at the same time as I was seeing [the doctor] ..I mean I wouldn’t have known about this otherwise” (PACT 06 male, aged 64).</i>
Helping with research	<i>“...it helps to know that there are people like you, your society that are looking in to it to try to help others and that’s the reason I went on the trial if it’s going to help somebody else. I am not saying it will but it might do” (PACT 07 male, aged 77).</i>
<b><i>Study information</i></b>	
Uninformed	<i>“Well when I signed up for it I didn’t really know what I was signing up for, to be honest” (PACT 12 male, aged 40).</i>
More information	<i>“I mean maybe in hindsight it perhaps would have, you know, to have a little bit more information beforehand, but, yes, it was fine and I was able to do everything without any problems” (PACT 05 male, aged 55).</i>
<b><i>Trial management</i></b>	
Supported	<i>“...if I had a question or a query I could just pick the phone up and it wouldn’t be a problem” (PACT 18 female, aged 31).</i>
Motivating	<i>“...[the researcher] has run a brilliant trial very motivating...”(PACT 15 male, aged 60).</i>
Appointment organisation	<i>“Very useful having the texts actually just to remind me of appointment times...”(PACT 15 male, aged 60).</i>

## 6.5 Discussion

The purpose of this feasibility trial was to determine patient acceptability and engagement with the PACT intervention and methods used. Whilst the study showed a reasonable result and could be useful in guiding a future larger trial, it also highlighted some key areas for refinement.

Feasibility was explored by assessing the implementation, acceptability and limited efficacy testing of the PACT intervention. The findings of this trial indicated the intervention feasible to implement and timing allocated to assessments and the group session acceptable. Furthermore, the content of the programme was pitched at the right level and the interactive delivery was well received. However, participants suggested some refinements, these predominantly included the inclusion of a more holistic view of lifestyle including dietary information and emotional management; and more information regarding other types of exercise including home-based resistance training. Further consideration would need to be given to the purpose of the proposed intervention if including a more holistic approach to lifestyle management, as evidence suggests that interventions targeting multiple risk behaviours result in only small changes to diet and physical activity (Meader et al., 2017).

The protocol was acceptable with regards to outcome measures except for the accelerometer, which was described as uncomfortable. As increasing physical activity was the aim of the PACT intervention, dissatisfaction with this outcome could cause problems in a future trial. Wear time analysis showed few concerns with the accelerometer, with only two participants failing to meet the wear time threshold, but overall patients described strong levels of dissatisfaction with this outcome measure. Compliance with accelerometers is an issue often reported among older adults (Murphy, 2009), although in the present study the majority of patients were compliant, it is important to limit the burden on the patient as much as possible. As such if the waist worn accelerometer was not acceptable other avenues for capturing physical activity should be explored. Fortunately, objective physical activity assessment is an area rapidly advancing, as such; wrist-worn accelerometers have now been validated against established methods of energy expenditure. Furthermore, the National Health and Nutrition Examination Survey (NHANES), implemented a protocol change from the

cycle of data collection in 2003-2004 to 2011-2012, which saw the waist worn accelerometer substituted for a wrist-worn device (Troiano et al., 2014). Preliminary data indicated that compliance measured by days of data and wear time improved from 40-70% to 70-80% in the later trial (Troiano et al., 2014). Therefore, wrist-worn accelerometers may offer a suitable surrogate to improve patient acceptability of this outcome measure in future trials.

Group delivery has been shown to be an important intervention component for CKD education (Lopez-Vargas et al., 2016), and was well received by patients of this study. However, most participants felt that more participants in the group session may have improved the quality of discussion. Anecdotally, researchers felt that sessions were more dynamic and enjoyable when more individuals were present be it patients or family members. However, recruitment was an issue. This study had a recruitment rate of 23%, which is in line with recruitment for lifestyle and exercise studies conducted in patients with CKD in this centre, which range from 10-30% (Watson et al., 2015, Byrne et al., 2011). The majority of patients consented to the study were recruited from outpatient clinics, suggesting that this was the most effective recruitment strategy. Whilst, recruitment strategies were perceived as acceptable by the patients, there was a sense of unexpectedness around recruitment that may have put some individuals off. This may be reflected in relatively high interest rates compared to consent. However, this was not the case for participants introduced by their consultant but this approach yielded fewer participants and it was unclear how many patients were invited by the clinical staff and declined participation. Other reasons for low recruitment may have included: high levels of research activity; busy clinics where this study may have been of low priority to clinicians; the fact that this study was a feasibility project which may not have yielded a direct benefit to the patient, and that the trial was being undertaken by a student. Furthermore, the communication of study information to the patients was delivered in a busy clinic waiting room, as side rooms were often unavailable. Therefore, this situation may have had too many distractions for participants to absorb the information provided, and some participants felt that more information would have been beneficial. Further research may be required to determine the best recruitment strategies for lifestyle interventions among patients with CKD.

This trial was not powered to assess efficacy. However, limited efficacy testing was performed and as mentioned above the key aim of the PACT intervention was to increase levels of physical activity with a focus on step counts. A mean change of 2127 (-774, 5029) steps/per day was observed, resulting in an increase of 38% from baseline. This is similar to the steps per/day increases observed in physical activity interventions targeting other chronic disease populations (Tudor-Locke et al., 2011). A review of pedometer based physical activity interventions reported mean weighted step increases of 562, 2840 and 2405 among patients with COPD, coronary heart disease and type 2 diabetes, respectively (Tudor-Locke et al., 2006). Whilst, Chapter 3 showed the benefits of walking and improved outcome in patients with CKD, the clinical implications of increasing steps by ~2000 are unknown in this population. However, the Navigator Trial, a large prospective observational study indicated that an increase of 2,000 steps is associated with an 8% reduction in cardiovascular events among patients with impaired glucose tolerance (Yates et al., 2014). This may be relevant as impaired glucose tolerance can often precede type 2 diabetes, which accounts for 30-35% of all CKD cases (Webster et al., 2017). Furthermore, even an increase of 1,000 steps per day (approximately 10 minutes of walking) may be clinically relevant, having been associated with improvements in disease management, QoL, pain and physical function in patients with fibromyalgia (Fontaine et al., 2010, Kaleth et al., 2014). In the present the mean change was in the direction of improvement with regards to step increases, but the results varied among individuals and improvements were not always coupled with an increase in MVPA. Integrating the qualitative findings of this work is useful in helping to gain a fuller understanding of the accelerometry data. The qualitative work showed a lack of understanding from some participants regarding physical activity intensity, with some participants feeling that the importance of intensity could have been emphasised more within the group education session. If this part of the session failed to resonate it may explain why some patients managed to increase their steps but not their level of MVPA. As such this highlights an area for improvement. Options for improving knowledge or self-efficacy to perform walking at a higher intensity could be delivered in the form of a demonstration or practice session. Alternatively, goal setting practices to include time based step goals may help patients achieve a greater level of walking intensity.



Mean changes denoting improvements of a small–medium effect size were also observed for some of the secondary outcome measures including physical performance, QoL, anxiety, knowledge and patient activation. No effect was shown for depression. However, only two patients were classified as depressed by the HADS at baseline. Of those participants, one maintained a depressive score of 8 at post intervention testing, and the other participant reported an improvement in their depression, scoring 11 at baseline and 5 at post intervention.

The PACT programme was underpinned largely by SCT which describes outcome expectations and self-efficacy as the two primary constructs for influencing behaviour (Bandura, 1977). Walking self-efficacy showed a positive mean change, indicating that patients' efficacy beliefs in their ability to execute walking for longer durations increased over the programme. Self-efficacy as a mechanism of change was supported by the qualitative work conducted within this feasibility study, with participants describing an increased level of confidence to be physically active after the intervention. Outcome expectations were classified into three major classes including physical, social and self-evaluative perspectives (Wójcicki et al., 2009). A positive mean change in self-evaluative outcomes of a small–moderate effect was observed. However, physical outcomes showed no effect; and social outcomes showed a negative mean change of a small-moderate effect. Reasons for this are unclear as participants clearly stated in the qualitative work many physical benefits including increased energy, fitness, and strength; as well as social benefits: such as returning to walking groups and more quality time with the family. However, on reflection, the use of the MOEES questionnaire as an assessment tool post intervention may have been inappropriate as the wording asks about perceptions of exercise as opposed to experienced benefits. Instead, assessment could have been conducted after the education session to determine if the group session had changed outcome expectations and whether this could be used to predict or understand changes in physical activity behaviour.

The findings also showed a positive mean change for illness coherence indicating that participants felt they had a better understanding of their disease. This was supported by the knowledge questionnaire as well as the qualitative work. Knowledge is a pre-determinant to change (Bandura, 2004), and alongside a positive mean change in patient activation (Hibbard et al., 2007), may predict lifestyle behaviour change. All

participants stated that they wanted to continue to increase their level of physical activity post intervention, however, a longer follow-up would be required to determine physical activity maintenance. Furthermore, whilst the personal control construct showed no effect, participants described how the intervention had helped them to feel more in control of aspects of their lifestyle that they could change to influence their condition. Participants felt like this programme was something they could do to benefit themselves over and above their medication.

Goal setting and self-monitoring tools such as the pedometer were particularly well received by participants. However, goal setting was not undertaken by all the participants in the way that was advised within the group session. Some participants decided not to build up daily steps gradually, but instead performed as much walking as they could in week 1 with 3 participants exceeding their final goal in the first week. Others felt goal setting was more useful if they set timed goals around routine walks once they knew how many steps it would be to complete their circuit. As mentioned above, time based step goals may be helpful in encouraging patients to increase their walking intensity. Others described a vague approach to goal setting, stating that they were just trying to do a bit more, and described a difficulty in sticking to the step goals they set in the session because of barriers such as the weather, time and symptoms. Several participants indicated a desire to find out how others had done or suggested the inclusion of friendly competition. The pedometer was well received, but some participants felt that recording the steps could be improved by the inclusion of a smartphone app that combines goals and real-time self-monitoring. A recent review has demonstrated a growing interest within the renal community for wearable sensors, and with advancing technology these devices may be able to help support patients self-regulate lifestyle behaviours and allow for peer interaction and support (Wieringa et al., 2017).

### **6.5.1 Limitations**

This feasibility trial was conducted in only one site and had a very small sample size. Whilst, recruitment is in line with that previously described in CKD patients for lifestyle interventions at this centre, this is not sufficient data to estimate recruitment

rates. Missing data were minimal, and implementation of the protocol was both feasible and acceptable to patients. However, further work is required to determine an acceptable measure of objective physical activity to improve patient satisfaction with the trial. Furthermore, goals were set using baseline physical activity collected from the ActiGraph GTX3 accelerometer, however, participants were provided with a pedometer (Yamax SW200) to self-monitor their walking throughout the intervention, thus creating a problem of inter-instrument comparability. However, the Yamax SW200 has previously been shown to be an accurate measure of steps (Rowlands et al., 2007), and pedometers of the Yamax brand often score within 1% absolute percent error on treadmill tests and as such are recommended as research grade (Tudor-Locke et al., 2006). In addition, pedometers are relatively inexpensive and easy to use, making them suitable for most clinical and health promotion campaigns. Furthermore, the output from the Yamax SW200 has been shown to be highly correlated with the Actigraph GTX3 ( $r=0.83$ ) (Barriera et al., 2013).

## **6.6 Conclusion**

Overall, engagement and acceptability of the PACT intervention and the trial were reasonable with 85% of patients complying with the primary outcome (steps measured using the ActiGraph) and 85% returning physical activity diaries, that were 61-100% complete. However, trial refinements with regards to patient recruitment need to be considered, as do intervention refinements to improve patient satisfaction. These include: ensuring that the activity monitor of choice is comfortable to wear, considering a more holistic approach to lifestyle education, emphasis on physical activity intensity, further exercises and real-time self-monitoring via a smartphone app. Patients described a number of benefits from participating in this programme which for the most part were confirmed via the patient reported outcomes and performance based outcomes undertaken. The trial was not powered or designed to assess efficacy or effectiveness but did demonstrate a potential to increase steps and improve physical performance, domains related to quality of life, knowledge, patient activation, and self-efficacy. All participants stated that they would recommend this trial to others and as such this approach to lifestyle management has great promise in CKD and deserves further attention.

# Chapter 7

## **General Discussion, Thesis Summary and Implications for Research and Practice.**

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The previous chapters 2-6 have detailed the studies undertaken to inform, develop and test the PACT intervention. This final chapter will discuss the main findings of each and highlight implications for further research and practice.

## **7.1 Thesis aims**

NICE guidelines recommend that CKD patients receive an education tailored to the cause and severity of their disease; with one aspect of this education focusing on what the patient can do themselves to help manage and influence their own condition (NICE, 2014). Exercise and regular physical activity have been shown to be important in modulating several factors associated with co-morbidity and disease progression in CKD. However, currently CKD patients receive no structured education or advice regarding their level of physical activity despite the benefits, previous research outside of the UK has indicated that CKD patients lead insufficiently active lifestyles (Beddhu et al., 2009). Until now little was known about physical activity behaviours among CKD patients in the UK. This included a paucity of information regarding the prevalence of inactivity, correlates of physical activity behaviour, and understanding of the patient perspective towards exercise, all of which would be required to inform the development of a physical activity behaviour change intervention. This thesis aimed to outline the development of an evidence based, theory driven and self-directed behaviour change intervention.

### **7.1.1 Thesis Objectives**

Specific objectives included:

1. To identify the prevalence of physical inactivity among non-dialysis patients with CKD in the UK, to provide evidence for the need of a behaviour change intervention to increase levels of physical activity in this patient group.
2. To explore correlates of physical activity, to contribute to the evidence based planning of a physical activity intervention.
3. Investigate the association between walking behaviours and survival, to understand the importance of walking in a UK non-dialysis CKD population.
4. Explore patient's perspectives to exercise, focusing on beliefs, motivations, barriers and future intervention requirements.

5. To develop a structured group based education programme (PACT) to provide encouraging physical activity among non-dialysis CKD patients, and detail the development processes undertaken using evidence, theory and Person-Based Approach.

6. To explore patient acceptability and engagement with the PACT intervention via feasibility testing.

The work presented in this thesis fits broadly into the Behavioural Epidemiology Framework, which proposes a sequence of studies that can lead to the implementation of evidence based health promotion campaigns. Behavioural epidemiology refers to the explicit understanding and influencing of current patterns of behavioural immunogens among the population to improve health and prevent disease. Achieving this goal is complex and requires an array of research including analytic, descriptive and intervention studies. A systematic approach is likely to be of use, and in response to this need, Sallis et al. (2002) presented the Behavioural Epidemiology Framework which consists of five phases which are outlined below:

**Phase 1** Establishing links between behaviours and health

**Phase 2** Developing methods for measuring behaviour,

**Phase 3** Identifying factors that influence the behaviour,

**Phase 4** Evaluating interventions to change behaviour and

**Phase 5** Translating research into practice.

The framework describes an ordered sequence of studies; however, the authors acknowledge a varying degree of interaction between the phases including a degree of feedback and feedforward elements. The work described in this thesis did not set out to follow the linear process described by the Framework of Behaviour Epidemiology, it

provides a useful structure to summarise the findings, strengths, limitations and future areas of research.

However, whilst the Behavioural Epidemiology Framework provides a broad rationale for the implementation of a health promotion campaign, it does not provide specific guidance with regards to intervention development. Therefore, thesis objectives related to intervention development were informed by the MRC Framework for the Development and Evaluation of Complex Interventions (Craig et al., 2013). Which advocates that best practice consists of systematic development utilising both theory and evidence and then a phased approach to testing.

## **7.2 Summary of key findings and contributions to knowledge**

This thesis provides original research that directly relates to Phases 1, 3 and 4 of the Behavioural Epidemiology Framework and makes unique contributions to knowledge in the following ways:

### **Phases 1: Establishing links between behaviours and health**

- Chapter 2 reports previous unknown data on the prevalence of self-reported physical inactivity in a non-dialysis UK CKD population. A cross-sectional survey of 1015 CKD patients indicated a high prevalence of physical activity insufficiency (85.3%).
- Chapter 3 reports an observational study of walking and survival, confirming through Cox proportional hazard modelling that hours of walking and walking pace are independently associated with mortality in a non-dialysis UK CKD patient cohort.

### **Phase 3 Identifying factors that influence the behaviour**

- Chapter 2 identified through regression modelling self-efficacy, physical function, older age and sex to be independent predictors of PA in CKD patients.

However, when considering walking as a primary activity only self-efficacy and physical function were independent predictors.

- Chapter 4 confirmed the usefulness of the social cognitive perspective for framing exercise behaviours, and identified previously unknown influences from personal, behavioural and environmental considerations held by patients with CKD.
- Chapters 4 and 5 detailed previously unknown patient preferences for components of a physical activity intervention including: group based delivery to foster peer support and learning; topics that covered both CKD and physical activity; the opportunity to set goals and self-monitor progress; and to receive follow-up support via telephone counselling.

#### **Phase 4 Evaluating interventions to change behaviour**

- Chapter 5 applied methods from the Person-Based Approach to the planning, design and development of an evidence based and theory driven structured group based education programme in patients with CKD. Demonstrating the usefulness of this systematic and collaborative approach to the development of a physical activity intervention in patients with CKD to ensure user acceptability.
- Chapter 6 demonstrated PACT a structured group based education programme to be both feasible to implement and acceptable to patients.



## **7.3 Chapter Summaries**

Each chapter will now be summarised below in more detail, indicating what phase of the Behavioural Epidemiology Framework it aligns to, alongside the key findings and limitations.

### **7.3.1 Chapter 2: Prevalence and correlates of physical activity in non-dialysis-CKD**

Chapter two is concerned with Phase 3 of the Behavioural Epidemiology Framework: Identifying factors that influence the behaviour. This phase is designed to describe demographic correlates of the behaviour to identify how the behaviour varies by sex, age, ethnic group, socioeconomic status and other variables. In addition, theory derived constructs that may represent modifiable influences on the behaviour can be explored.

This chapter reported the results of the “QCKD” trial a large cross sectional study designed to investigate habitual levels of physical activity and how levels differed across demographics, health status, physical function and psychological determinants of exercise. Furthermore, associations between factors mentioned above and physical activity were explored.

This study provided a novel insight into the prevalence of physical inactivity among CKD patients stages 1-5 not requiring RRT and residing in the UK. In total 1015 participants were available for analysis. This study was carried out to define the problem of physical inactivity in this population, gain an understanding of the behaviour and potentially identify modifiable psychological constructs that could be targeted within an intervention to promote physical activity. As expected this study highlighted widespread physical inactivity among CKD patients, with the GPPAQ classifying 85.5% of patients as not meeting the minimum physical activity guidelines recommendations. Findings were comparable to other CKD cohort studies conducted outside of the UK (Beddhu et al., 2009).

However, whilst physical activity levels were low, most participants were in a receptive stage of change, providing evidence for the need for a physical activity intervention and an indication that overall patients would be receptive to strategies designed to increase

physical activity. Furthermore, findings indicated that walking was the most commonly performed type of physical activity. Moreover, younger age, male sex, better physical function and higher levels of exercise self-efficacy were associated with meeting physical activity guidelines, after adjusting for eGFR, haemoglobin, co-morbidities, and readiness to change. Self-efficacy is a modifiable target for physical activity and this work in line with the SCT highlighted that individuals who felt more confident to self-regulate their exercise behaviour even in the face of barriers were more likely to be meeting minimum physical activity recommendations.

Walking was the most commonly reported physical activity undertaken by patients. Interestingly, meeting physical activity recommendations through walking was not associated with male gender or younger age, as previously indicated from the original scoring of the GPPAQ. However, physical function and self-efficacy remained consistent correlates. As such the findings of this chapter indicated that walking may be an acceptable physical activity for CKD patients to engage in and promotion interventions may not need to be stratified by age, sex, eGFR, co-morbidities, or readiness to change. This finding may be due to the inclusive nature of walking, as it can often be undertaken as part of leisure, work or transport.

However, this work has several limitations. Phase 2 of the Behavioural Epidemiology Framework describes the needs for developing high quality measures and establishing the reliability and validity of such measurement tools. This phase was unfortunately outside the scope of this thesis and as such the results of chapter 2 relied solely on self-reported measures. Furthermore, the cross-sectional design only allowed for associations to be observed between self-efficacy and meeting physical activity recommendations. As such causal inferences cannot be made, and it remains unknown that if targeting self-efficacy can produce changes in physical activity behaviours among patients with CKD. However, this work adds a large cohort to the evidence base regarding physical activity levels in patients with CKD not requiring RRT living in the UK and enhances our understanding of the correlates of physical activity.

**Key findings:**

- The majority of non-dialysis CKD patients are insufficiently active.
- Despite this many patients indicate a readiness to change.
- Walking is the most commonly performed physical activity.
- Physical inactivity is associated with older age, female sex, lower self-reported physical function and weaker exercise efficacy beliefs.

**7.3.2 Chapter 3: Association of self-reported walking behaviours and survival in patients with chronic kidney disease.**

Chapter 3 can be linked to Phase 1 of the Behavioural Epidemiology Framework which describes the importance of studies to document the association between behaviours. This phase is carried out to provide a rationale for proceeding with the subsequent phases of behaviour epidemiology.

Following on directly from the cross-sectional study described in Chapter 2, this study used follow-up data to investigate the association between walking behaviours and survival in patients with CKD not requiring RRT. Walking was previously indicated as the most commonly performed type of physical activity among this patients group, however, no existing studies had previously explored the survival benefits of walking in a UK CKD population. The findings of Chapter 3 corroborated what had previously been shown within a large observation study conducted in Taiwan, where walking was shown to be associated with a reduced risk of all-cause mortality among CKD patients stages 3-5 not requiring RRT (Chen et al., 2014). However, the work presented in this thesis made an original contribution to the literature as this association had not previously been described in CKD patients living in the UK, nor in patients at an earlier stage of disease progression. This work showed no clear indication of dose response between walking and survival. Instead the findings indicated that all walking durations per week ranging from <1 hours of walking to >3hours of walking confer a survival benefit when compared to no walking after adjustment for demographics, clinical parameters and co-morbidity. This finding differs from the study reported by Chen et al.

(2014), which reported a clear dose response between better survival and days of walking per week. However, the present study looked at hours of walking using a different measurement tool, therefore, may not be comparable. Neither study reported intensity, which would be required alongside frequency and duration to fully investigate a dose-response relationship.

Additionally, whilst gait speed measured objectively has been shown to be associated with survival among non-dialysis CKD patients stages 3-4 (Roshanravan et al., 2013), these simple physical performance measures are still not readily available in UK clinical outpatient settings. This work shows that a simple self-reported walking pace questionnaire predicts survival over a median 44 month follow-up. The walking pace questionnaire showed that individuals who reported a usual walking speed of >3mph have a reduced risk of death of 62% when compared to the reference group of a usual walking pace of <3mph.

In addition to the limitations mentioned above regarding a lack of dose-response relationship, this work had a relatively short follow-up duration and the causal relationship between walking behaviours and mortality cannot be determined. Although, findings that indicate that individuals who walk are at a lower risk of mortality when compared to those who are inactive, does corroborate what has previously been shown in patients with CKD and the general population. Furthermore, whilst there are limitations pertaining to chapter 2 with regards to measurement tool used, this work demonstrated the potential of a simple self-reported measure to be used as a potential surrogate in the absence of more objective measures. Self-reported measures in this are relatively inexpensive, require no specific training, space or observer and may act as a clinical conversation opener to discuss levels of physical activity. Therefore, a simple question of self-reported walking pace may help to identify those at risk for poor outcomes.

### **Key findings**

- Any walking per week confers a survival benefits for non-dialysis CKD patients when compared to patients who do no walking, however, the dose response relationship remains unclear.

- Self-reported walking pace of >3mph confers survival benefits for non-dialysis CKD patients when compared to patients who report a walking pace of <3mph.
- In the absence of objective walking and gait speed assessments, self-reported measures may provide a suitable surrogate for use in a clinical setting to predict individuals at risk of poorer outcomes, identifying areas for intervention.

### **7.3.3 Chapters 4, 5 & 6**

Chapter 4, 5 & 6 are aligned with Phase 4 of the Behavioural Epidemiology Framework, to evaluate interventions to change behaviour. This phase draws on the knowledge derived from the work undertaken in the previous phases, prior to conducting an efficacy or effectiveness study. This thesis details a systematic approach to the development of the physical activity intervention, in addition to conducting a feasibility study. Chapters 4 & 5 detail the planning, design, and development of the PACT intervention, a structured group based education programme designed to encourage physical activity in non-dialysis CKD patients. These chapters were informed by the MRC Framework and mapped closely to the stages of modelling and development (Craig et al., 2013); and the complementary Person-Based Approach (Yardley et al., 2015b) for intervention development. Whereas Chapter 6 reports the findings of The PACT feasibility trial, guided by the feasibility and piloting process.

#### **Chapter 4: Motivations and Barriers to Exercise in Chronic Kidney Disease: A Qualitative Study.**

The qualitative study presented in Chapter 4, utilised thematic analysis (Braun and Clarke, 2006) and employed focus groups and semi-structured interviews to explore beliefs, motivations, and barriers held by patients with CKD towards exercise. Themes were organised using a conceptual framework based on SCT reciprocal determinism triad including personal, behavioural and environmental factors, and were presented as both motivators and barriers (Bandura, 2004). The major themes are presented in Table 7.1.

**Table 7.1 Summary of major themes conceptualised via focus groups and semi-structured interviews with CKD patients presented in Chapter 4.**

<b>Personal</b>	<b>Behavioural</b>	<b>Environmental</b>
Poor physical condition and exercise related health concerns	Self-regulation and goal setting	Social interaction and support
Self-incentives for personal change	Benefits of exercise on health and well-being Individual preferences for activities	Informational support Physical environment

Furthermore, themes related to patient desires and requirements for a physical activity intervention were captured. Identified themes included delivery format, time of approach, nature of follow-up support, the tone of education and resources required. Findings supported: group delivery, early intervention after diagnosis, telephone follow-up support, emphasis on the positive benefits of physical activity, and suitable written resources, and a pedometer. However, this study did have some limitations. Due to the self-selecting recruitment strategy, it is likely that patients involved in this qualitative study probably had more interest in physical activity and exercise than that of the general CKD population. Although, despite this limitation, this study provided a unique exploration of patient's beliefs held towards physical activity in patients with non-dialysis CKD and underpinned all the development work described in Chapter 5.

Engagement with physical activity may be particularly difficult for patients with multiple co-morbidities, poor physical function, high symptom burden, previous negative experiences of exercise, low knowledge of physical activity guidelines and benefits, and those with limited social support. Evidence from both Chapters 2 and 4 indicate that patients of an older age who experience one or more of these influences might find physical activity initiation most challenging. However, it was unclear if biological age was perceived as a barrier, or if functional limitations related to high CKD symptom burden, led to feelings of negativity associated with ageing. Therefore, interventions that aim to improve levels of physical activity must first explore patients

emotional and cognitive representations of their illness, as well as their perceptions of possible treatments e.g. physical activity. Leventhal et al. (1992) suggested that perceptions about treatment can impact adherence. Engagement in physical activity therefore, may be best further explained with constructs from SCT including outcome expectations and self-efficacy, which may also influence constructs of the CSM such as controllability. For example, if an individual perceives that physical activity will be beneficial e.g. lead to less pain, perceives fewer negative consequences e.g. taking part in physical activity will not make me more tired (outcome expectations); they may feel like they have more control over their condition (controllability), thus reinforcing positive treatment perceptions. For some this may be enough to try and engage in a little more physical activity; whereby if outcome expectations hold true may increase a person's efficacy beliefs to partake in the activity again (self-efficacy). Of course, other factors such as the encouragement of family members and health care professionals (verbal persuasion); seeing other patients in a group session discuss the benefits of physical activity (vicarious learning); and gaining a better understanding of physical activity guidelines, may help to overcome fear barriers associated with physical activity and aid ability to recognise own performance limits (emotional and physiological response). Furthermore, a graded approach to physical activity should be offered providing participants with opportunities to experience small accomplishments (mastery). This may be most effective if participants are setting themselves goals and monitoring their own physical activity (goal setting). Detailed plans should be created to ensure that patients feel that their physical activity is purposeful (Gollwitzer et al., 1999), especially for persons experiencing life transitions such as retirement. This work demonstrated how multiple theories can be used to enhance our understanding of physical activity in patients with CKD.

### **7.3.3.1 Chapter 5: Rationale and development of a structured group education programme to increase physical activity in CKD: The PACT-Project.**

Chapter five reports how evidence, theory, and the Person-Based Approach were utilised to develop PACT, a structured group based education programme designed to increase levels of physical activity in CKD patients not requiring renal replacement therapy. Previous behaviour change interventions targeting physical activity in this

population have been limited, and either did not report physical activity as a primary outcome measure or provided no systematic approach to development, hindering any attempts at replication. With regards to the work presented in Chapter 5, approaches undertaken were informed by the development process reported for structured group education interventions in other cohorts, however, undertaking this approach was novel within the CKD non-dialysis population. As such the development work undertaken to produce this intervention was substantial and including a literature review, qualitative study, multiple expert panel meetings, programme observations, collaboration with PPI groups, written resources development, and testing, mapping of behaviour change techniques to theory and user testing informed by think aloud techniques and focus group. With each stage of development came refinements. However, the most salient finding was related to risk awareness and communication of risk. Patients involved in the user testing showed limited awareness of co-morbid risks associated with CKD, and open-ended questions originally thought to promote deeper learning and engagement resulted in guessing and caused distress among the group. As such we identified that patients needed more detailed education, and risk information should be introduced at population level prior to relating this information to CKD. Furthermore, risk education should be delivered via a “gain-framed” message approach (Gallagher and Updegraff, 2012) meaning that modifiable factors should be introduced earlier in the session to empower patients and engage them in taking control of aspects of their lifestyle. This approach was deemed more acceptable and patients described feeling appreciative for their new level of awareness. The qualitative work undertaken was essential to the iterative updating of the PACT intervention. However, although there is much guidance on the use of Think-Aloud protocols for the development of digital interventions, there was limited information available to inform the user testing of educational interventions. As such asking participants to perform think aloud whilst under cognitive loading from the intervention may not have been completely suitable. Furthermore, focus group techniques were carried out throughout the intervention delivery, which caused pauses and interruptions deviating from the way in which the intervention was intended to be delivered. However, these methods allowed for rich and informative data to be obtained, and all sessions were audio recorded so that data could be further interrogated.



## **Key findings of Chapter 4&5**

- Patients report several physical, psychological and social barriers to exercise.
- Motivation could be enhanced by learning about the benefits of exercise and safe and practical ways to implement it, as well as a goal setting strategy, autonomy in choosing an activity that is enjoyable e.g. walking and social support.
- A group session may offer individuals the chance to share experiences and facilitate peer learning.
- The Person-Based Approach incorporating evidence and theory proved to be a systematic and feasible method to produce a structured group education programme designed to increase levels of physical activity.
- Qualitative enquiry was essential to understand patient acceptability of intervention delivery and content, allowing for iterative changes to the programme prior to feasibility testing.

### **7.3.4 Chapter 6: “It’s opened up my eyes to how much I can actually do”: A mixed methods study exploring the feasibility of a physical activity education programme in chronic kidney disease.**

The PACT feasibility trial (Chapter 6) proved feasible to implement and acceptable to patients, with the intervention deemed interesting and motivating. Whilst this study was not adequately powered nor designed to test efficacy, under limited efficacy testing the intervention demonstrated a moderate potential to increase steps from baseline (mean change [95% CI] = 2127 (-0.774, 5029)). Similarly, changes in the direction of improvement were also observed for measures of physical performance, quality of life, knowledge, patient activation, self-efficacy, self-evaluation and certain illness perceptions. However, this work also highlighted important areas for trial and intervention refinement. Firstly, the primary outcome measure waist worn Actigraph was not well tolerated and was described as uncomfortable and irritating. Furthermore, this would likely be a limitation if the study protocol was implemented for use in a RCT, as wear time fell short of recommendation for 2 participants. However, a refined

protocol including wrist-worn accelerometers are likely to be better tolerated (Troiano et al., 2014). Furthermore, participants indicated that slightly large group sizes would offer better quality discussion and that the session would benefit from a more holistic approach to lifestyle including advice regarding diet and emotional management in CKD.

This study had a number of limitations, as a small feasibility study this work was underpowered to determine the efficacy or effectiveness of the intervention for changing physical activity behaviour. In addition, whilst Chapter 2 highlighted self-efficacy as a potentially modifiable target to increase levels of physical activity, the study design was unable to determine the elements of the intervention or “active ingredients” that might be mediators of change. However, whilst limited due to the small sample size, the PACT intervention and trial was shown to be feasible with regards to patient acceptability and implementation. The trial showed changes in the direction of improvement for steps and a number of secondary outcomes related to patient quality of life. However, further work is now required to determine if the intervention should be carried forward into more rigorous testing to assess its effectiveness to promote physical activity in patients with CKD, this will be discussed in section 7.3 (further research).

## **Key Findings**

- The PACT intervention and trial procedures were feasible to implement and deemed acceptable to patients, with some suggestions for refinement.
- Limited efficacy testing showed potential for the intervention to increase steps and positively impact physical function, quality of life, knowledge, patient activation, walking self-efficacy and illness perceptions.
- Further research should identify a suitable recruitment strategy and consider other lifestyle advice.

## **7.4 Further research**

### **7.4.1 Feasibility, piloting and decision-making**

This thesis reports the conceptualisation, development and preliminary testing of a structured group based education programme designed to increase levels of physical activity. However, further work is now required before this intervention can be translated into practice, which is the aim of Phase 5 of the Behavioural Epidemiology Framework. Prior to translation, an intervention must first be shown to be effective, meaning that it affects a change in the desired outcome, which in the context of the PACT intervention is an increase in levels of physical activity.

However, prior to this more rigorous form of testing the MRC Framework for the Development and Evaluation of Complex Interventions advocates undertaking feasibility and pilot studies prior to the more definitive RCT trial. This phase is designed to pre-empt problems with the intervention itself and to reduce problems associated with larger trial implementation, evaluation and translation into practice. This is an important stage leading to evidence-based health interventions due to the costs of high quality trials, the number of trials failing to demonstrate effectiveness, and difficulties translating interventions into practice or a real-world setting.

Taking this into consideration the work presented in this thesis has mapped closely to the guidance provided by the MRC focusing on the development and feasibility/piloting phases. However, whilst the MRC Framework for the Development and Evaluation of Complex Interventions recommends feasibility and piloting, it does not appear to differentiate between the two (Craig et al., 2013). Instead, feasibility and pilot studies are both presented under a larger category of “assessing feasibility”, with the role of this phase being to test the acceptability of the intervention/ trial procedures, estimate recruitment/retention rates and determine a sample size required for a larger trial. This leaves the definition of feasibility and/or pilot somewhat ambiguous. Others including Thabane et al. (2010) have agreed that the terms may not be mutually exclusive, stating that the main aim of the pilot study should be to assess the feasibility.

However, the National Institute for Health Research (NIHR) provides exclusive definitions of feasibility and piloting trials, whereby a feasibility study usually precedes intervention piloting (National Institute for Health Research, 2017). The NIHR state that the aim of a feasibility trial is to answer whether a study can be done. A pilot study is described as “a smaller version of the main study used to test whether the components of the main study can all work together”. This lack of agreement has led to problematic reporting of feasibility/piloting studies and a lack of clarity regarding suitable trial aims. However, there appears to be a growing consensus that feasibility should be used as an overarching term for preliminary studies (Whitehead et al., 2014). Eldridge et al. (2016) developed this idea into a conceptual framework simplifying all types of preliminary studies and presenting feasibility as an overarching term for describing three different types of pilot studies including non-randomised pilot study, randomised pilot study, and other feasibility study. Following this new framework, the feasibility study reported in Chapter 6 would be considered as a non-randomised pilot study, described under the larger umbrella term of a feasibility study. A non-randomised pilot study subjects all or part of the intervention to be evaluated and describes other processes to be undertaken in a future trial such as secondary outcomes assessments, which are carried out without randomisation. Having these clear definitions is vital to determine what stage of development has been conducted and indicate future required research.

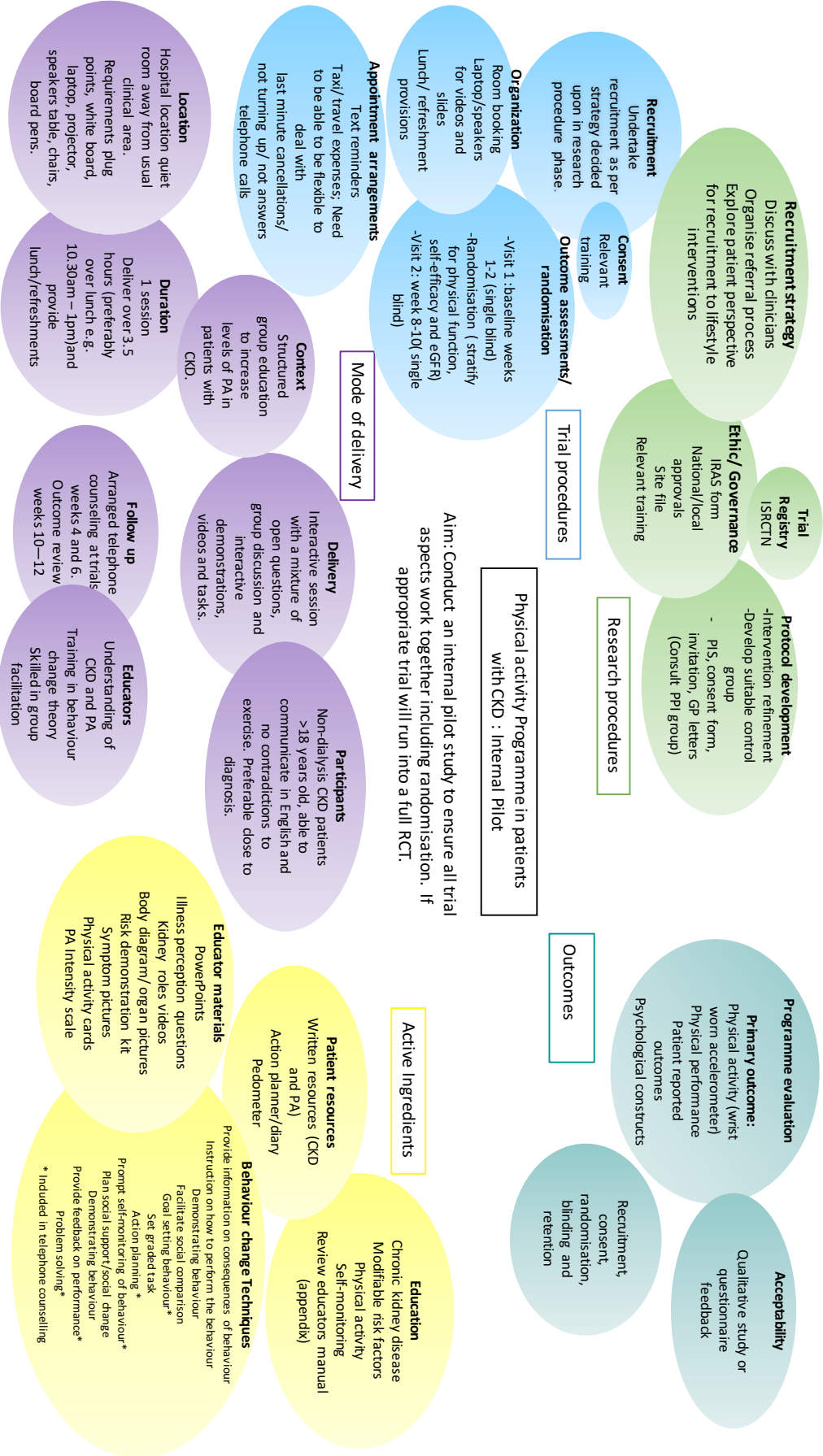
As suggested, not all studies should be progressed to effectiveness testing and as such feasibility studies in the umbrella sense, need to be evaluated against a success criterion. Shanyinde et al. (2011) recommend 14 methodological issues that require evaluation within a RCT, however, 6 can be accessed via feasibility testing and are considered in the context of the PACT intervention in Table 7.2.

**Table 7.2: Methodological issues addressed within the PACT feasibility study presented in Chapter 6.**

<b>Methodological issue</b>	<b>Comments</b>
<b>Sample size</b>	The sample size for a potential future main trial was calculated using an A Priori power analysis and mean difference (one sample) test. Specifically, the mean pre-post scores (5672, 7799) and the SD of the mean difference (4318) score based on the accelerometer primary outcome data. It was estimated that to see the observed difference of approximately 2000 steps that 27 participants per intervention and control group would be required (80 % power, 0.05 significance, two sided). Calculations were performed using the software G* Power (Faul et al., 2007).
<b>Eligibility</b>	The eligibility criteria were described in Chapter 6. However, the inclusion criteria were broad, meaning that eligibility often came down to the consultants' discretion. As such eligibility was not assessed within this trial.
<b>Compliance/adherence</b>	Compliance and adherence were assessed by attendance to the group session, outcome visits and use of pedometer and exercise diary. Overall, this was considered good. Of the 19 participants consented 17 attended a group session, with 13 participants completing the trial. Physical activity diaries were returned by 11 participants and completed at a rate of 61-100%. Similarly, 12 patients self-reported that they had worn the pedometer all the time throughout the trial.
<b>Acceptability of intervention</b>	Patient acceptability of intervention delivery, content, follow-up and resources were high. Some participants did recommend some refinements e.g. inclusion of more holistic lifestyle management, real time step monitoring and further instruction on intensity.
<b>Duration/Cost</b>	Duration of the study ranged between 9-13 weeks and on average was completed within 10.5 weeks. The cost of the trial per participant was not calculated.
<b>Outcome assessments</b>	The primary outcome was accelerometry measured using a waist worn device. The qualitative work indicated that this device was not well tolerated, with participants describing it as uncomfortable. Despite this qualitative report only 2 participants failed to reach the threshold for minimum wear time. Secondary outcome assessments had 100% completion except for some questionnaires. Chapter 6 suggests reasons for poor completion of the IPAQ-SF due to trial design.
<b>Selection of most appropriate outcomes.</b>	Outcome assessments were perceived as relevant to the participant. Based on the literature, wrist worn accelerometers are deemed more acceptable to patients and should be used in future trials. Furthermore, the use of the MOEES questionnaire as an outcome measure may not have been suitable to detect changes in outcome expectations and should have been delivered after the education session as opposed to after the walking period of the intervention, to assess the effect of the group session on exercise expectations.

Overall, the feasibility study presented in Chapter 6 indicated that both the intervention and trial procedures were acceptable to patients and that the study fulfilled much of the success criteria shown in Table 7.2. With some minor intervention refinements, PACT could be progressed to more rigorous testing. The next phase of the MRC framework is Evaluation, which concerns the assessment of effectiveness, understanding of change processes and cost-effectiveness evaluation (Craig et al., 2013). This would require a RCT design with an adequate control group. The feasibility study presented in Chapter 6 did not include a control group, therefore, informed by Figure 7.1 an internal pilot may be a suitable progression. An internal pilot would allow for the testing of a suitable control group, which would likely consist of usual care with the addition of written resources and pedometer. However, this would be discussed with the PPI group to ensure patient acceptability. Ensuring acceptability of the control group is important in health promotion interventions, as most individuals willing to sign up have already considered making a change, and as such may be disappointed because of randomisation. Consideration should also be given to how patients should be stratified for randomisation to ensure a certain degree of balance between the control and intervention group. Chapter 2 indicated that self-efficacy and physical function are important independent correlates of physical activity, and therefore baseline levels may influence performance in the intervention. Internal pilots often run straight into the larger RCT trials if all elements are working well together. The main aim of this future RCT trial would be to assess the effectiveness of the PACT intervention to increase steps, powered to detect a difference of 2,000 steps from baseline. This potential future primary outcome was chosen after seeing an increase of ~2000 steps from the feasibility trial (Chapter 6). Evidence from a large prospective study indicated how an increase of 2,000 steps may have clinical relevance, as this increase was shown to be associated with a reduced risk of cardiovascular events among individuals with impaired glucose tolerance (Yates et al., 2014). Other considerations would include the assessment of secondary outcomes e.g. physical function and quality of life, recruitment to the RCT, randomisation, blinding of the researcher conducting outcome assessments and participant retention in the trial. Figure 7.1 provides a schematic based on the candidate's recommendations for running this future RCT trial.

Figure 7.1 Schematic based on the candidate's recommendation for future research proceedings.



### **7.4.2 Translation**

If shown to be effective at increasing levels of physical activity, the aim will be to translate this intervention into practice in accordance with Phase 5 of the Behavioural Epidemiology Framework.

The translation of an intervention into practice should be informed by a suitable framework such as the Reach Effectiveness - Adoption Implementation Maintenance (RE-AIM) Framework (Glasgow et al, 1999). This provides a standard criterion for the implementation of health initiatives and can be useful at varying stages of implementation including pre-planning, planning, and evaluation.

Adoption refers to the number of settings that would be willing to participate in implementing the intervention and reach refers to the number of people that would be affected by the intervention. Recent advances in the UK have led to the development of The Improving Patient care and Awareness of Kidney Disease Progression Together (IMPAKT) tool, which is a way of utilizing technology to identify patients who have un-diagnosed CKD or uncontrolled hypertension (Xu et al., 2017). During the application of this tool, the prevalence of CKD changed and demonstrated a fall in the number of patients with un-coded CKD. As such more patients are now registered as having CKD in primary care. This suggests that the PACT intervention if adopted into primary care may have the most reach. However, future work would need to identify stakeholder support for the intervention prior to implementation. Qualitative interviews may be useful to identify healthcare professional and patient motivations and barriers to the implementation of the PACT intervention within the primary care context. Other considerations impacting implementation would also include how the intervention would be delivered, and what staff training may be required, and at what cost. Such training could be facilitated by the educator's manual shown in Appendix 1, but staff would also need an understanding of CKD and physical activity, training in behaviour change theory and skills in facilitating groups.



As used in the development phase, pilot tests for initiating and evaluating intervention delivery in the context of primary care may help to facilitate implementation. However, as mentioned above, prior to this, the effectiveness of the intervention needs to be demonstrated. Ideally, the intervention should be tested for effectiveness within the context that it will be delivered. Challenges may present when trying to recruit primary care practices to adopt an intervention that is yet to be shown to be effective. Although, being able to demonstrate the feasibility of the PACT intervention via studies such as that conducted in Chapter 6 in the context of secondary care may be crucial to persuading centres to adopt such an intervention. However, the intervention delivery and trial may have to undergo refinement to be suitable for primary care, a process that should occur with the input of primary care practitioners and patients.

The final consideration of the RE-AIM framework is maintenance, which refers to the effectiveness of the intervention to promote lasting effects. The PACT intervention was designed to initiate a change in behaviour, however, future consideration will need to be given to how the intervention promotes long-term changes in physical activity, and what adaptations and improvements can be done to improve maintenance. One promising option may be the inclusion of e-health or m-health initiatives to provide on-going support past the 8-week initial intervention. Such initiatives have been successfully implemented in patients with impaired glucose tolerance, in the PROPELS intervention (Morton, 2015). This may demonstrate a cost-effective approach and is also in line with patient suggestions for a Smartphone app for self-monitoring and support (Chapter 6).

## **7.5 Clinical Implications and Conclusions**

The body of work presented in this thesis highlights the high prevalence of physical inactivity in non-dialysis CKD patients in the UK. However, the majority of patients are interested in increasing their current levels of physical activity but desire specific education and adequate support to enable this behaviour change. The PACT intervention that was presented in Chapter 5 and 6, may provide a feasible and cost-effective way of addressing

physical inactivity among patients with CKD, with important future clinical implications. However, the intervention requires minor refinements and more rigorous testing within a RCT to understand the effectiveness of the intervention to initiate increases in physical activity, but also over a long-term follow-up to explore issues around maintenance. Similarly, further work is required to develop the evidence base of physical activity in patients with CKD, not only to determine the optimal dose, but also to explore other types of home-based exercises such as modes of strength training which patients described as important in Chapter 6.

In the meantime, healthcare professionals should be regularly consulting their patients with regards to their physical activity habits. Routine assessments of self-reported walking behaviours were shown to be associated with survival in Chapter 3 and may be useful for identifying patients at risk of adverse events. Furthermore, such questionnaires may also act as an opening to improving the communication of lifestyle habits between patients and their healthcare professional. Based on our qualitative findings discussions of this nature would be well received close to the diagnosis.

# **Appendix 1**

Educator manual and written support documents developed for the PACT intervention.

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# Module A: Introductions and housekeeping

## Key Message

- The overall aim of the course is to enable participants to understand more about chronic kidney disease, the associated risks and role that physical activity can play in reducing these risks and improving quality of life.

## Participant Learning Opportunity

Participants will have the opportunity to explore/learn:

- That refreshments will be served
- The atmosphere of the course is relaxed and friendly
- The overall aim of the course and the main topics that will be covered
- That it is designed to run in a group setting so some of the information will be very general but please feel free to ask questions.
- That no one will be singled out to look stupid.
- That it is important to respect others rights in the group.

## Educator activity

- Prepare room and resource for the programme
- Welcome participants and their accompanying person
- Complete a register of attendance
- Introduce themselves and any observers (and their roles)
- Explain the aim and style of the sessions
- Answer questions relevant to the session
- Introduce written support material

**Participant activity**

- Listen to introductions
- Ask questions

**Content covered**

- Introduction to the session and to the educators delivering the programme
- Housekeeping details e.g. fire drill, refreshment breaks, location of toilets
- Background to the course
- Outline of the day and main topics to be covered

**Resources needed**

- Register of attenders
- Flip chart and pens/ interactive white board
- Prepared flip chart
- Blue/ white tac
- List of participants
- Written support documents
- Name badges

### ON ARRIVAL

When participants arrive, welcome them and confirm whether they can stay for the whole session. Ask each person to sign in, participant and accompanying person, so that you have a register of attendees not only for your records but in case of a fire or other emergency.

### INTRODUCTIONS

Start the group promptly on time or if you are waiting for others to attend then explain this to the group. To begin each educator should introduce themselves. If any additional people are present they should be introduced to e.g. name, job title, where they are from and their roles. Ensure that you check these details with them in advance. Inform the group about practical housekeeping information, such as where the toilets are fire escape and assembly point.

Explain the format of the session and when the breaks will occur.

In your own words explain the purpose of the sessions i.e. that participant leaves the course with:

- A better understanding of the kidneys and chronic kidney disease
- Knowing the other health risk associated and what they can do to reduce their risk
- Having answers to most of their questions about chronic kidney disease and physical activity

### CONFIDENTIALITY

Encourage some setting of ground rules to ensure that everyone appreciated the need to respect one another and their confidentiality.

You might want to explain that although some materials have been prepared during the session, you hope that people will be encouraged to ask questions or make observations, as this is the best way for them to learn about the things they really want.

Explain how the resources pack is their personal resource which has been written to summarise the information covered on the course. Participants will be using the materials from the pack in certain sessions to carry out some activities such as making action plans based on their number of steps.

# Module B: Patient story

## Key Message

- Everyone has a different story to tell about their experiencing of living with chronic kidney disease
- People have different beliefs, knowledge and experiences of their condition
- People may have different questions that they would like to be answered

## Participant Learning Opportunity

Participants will have the opportunity to explore/learn:

- The different experiences and perceptions of living with chronic kidney disease as held by the group
- Their own experiences and perceptions of chronic kidney disease

## Educator activity

- Enable participants to talk about their experiences and perceptions of chronic kidney disease, by asking open ended questions
- On prepared flip boards/ interactive white board compile a summary of what each participant says, in order to understand the group's perceptions about the identity, causes, consequences, treatments, control beliefs and timeline
- Ensure that everyone in the group is heard and given the opportunity to share their story
- Demonstrate empathy by using reflections
- Clarify if appropriate what participants say before adding it to the white board

### Participant activity

Describe their personal experience of living with chronic kidney disease  
Discuss their beliefs and perceptions towards chronic kidney disease and its impact on their lives  
Identify questions about living with chronic kidney disease

### Content covered

- Signs and Symptoms
- Causes
- Timeline
- Consequences
- Emotional response
- Treatment
- Understanding

### Key Questions

### Resources needed

- Flip charts
  1. How did you find out that you had a problem with your kidneys?
  2. What sort of symptoms have you experienced?
  3. What impact does your kidney problem have on your life?
  4. How do you feel when you think about your kidney problem?
  5. Do you think there is anything you can do to help manage chronic kidney disease?
  6. How well do you feel you understand your kidney problem?
  7. Do you have any burning questions that you would like to have answered by the end of the session?

### Theory thought

This sessions use the **Common Sense Model** to enable participants to explore their cognitions towards chronic kidney disease. Ensure that you write down participants' own words as at this stage it is important to collect all information even if something is "incorrect or wrong". At this stage we are collecting information about how the participants perceives their own condition, and how this may impact on their willingness to engage in health enhancing behaviours e.g. physical activity. If you do not understand the meaning or the words that the participant uses seek clarification.



## **ILLNESS PERCEPTIONS**

Introduce the session by explaining that you are going to give each individual the opportunity to share their experience of chronic kidney disease. Explain that you will do this by asking a series of questions and capturing what is said on the relevant flip charts.

Use the flip charts to write headings which will act as your guide.

As you note participants' responses on the flip charts ask clarifying questions where appropriate.

Start with an individual on the left or right of the group, or the person who looks most comfortable to begin talking. Having found a person to begin, in your own words ask them their first name or establish what they would like to be called. Write this down in the relevant place on flip chart 1. It may be a good idea to use different coloured pens for each participant.

With each individual continue to use the flip chart heading to guide their telling of their own story.

Once all the questions have been completed for the first individual, move on to the next person in the group and repeat the process. If this is someone's accompanying person, ask his or her name and add their name to the board. Check there is nothing worrying them and in your own words asks if there is any one question that they would like to have an answer to by the end of the course.

### **Flip Chart 1: Name**

What is your name?

*Collect answers on the flip board.*

### **Flip Chart 2: Understanding**

How well do you feel you understand your kidney condition?

*Collect answers under "understanding"*

### **Flip Chart 3: Symptoms**

Have you experienced any symptoms that you feel may be a result of your kidney condition?

*Write answers down under "Signs and symptoms".*

### **Flip Chart 5: Emotional and consequence response**

How does your kidney condition make you feel or impact your life?

*Collect answers under "emotional and consequences"*

**Flip Chart 6: Treatment**

Do you think there is anything you can do to help manage CKD?

*Collect answers under "treatment"*

**Flip Chart 7: Key Questions**

Do you have any burning questions that you would like to have answered by the end of the session?

*Note their answers on the flip chart and explain that during the programme, as a group, we will attempt to answer this question by the end of the course. Everyone needs to be able to identify his or her question at the end of the day. As you repeat this exercise for each member of the group, when a person gives a response that is repeated or agreeing with something that is already on the flip chart, just add a check (tick) mark to the response on the flip chart.*

*Thank everyone for his or her contributions and explain that you will use the information they have generated in the forthcoming sessions.*

# Module C: Professional story about chronic kidney disease

## Key Message

- Explore the role of the kidneys
- Explore what happens in the body when the kidneys are not working sufficiently

## Participant Learning Opportunity

- Participants will have the opportunity to explore/learn:
- How the kidneys normally work in the body
- What happens in the body when the kidneys stop working as well as they should
- What symptoms people can experience when they have chronic kidney disease
- The main causes of chronic kidney disease
- How kidney function is measured
- The consequences of living with chronic kidney disease
- Ways to help manage chronic kidney disease

## Educator activity

- Ensure that all participants feel able to contribute in a way in which they feel comfortable by acknowledging and thanking them for all their contributions
- Use participants words, phrases and analogies when talking through the session content
- Ask open questions to elicit information from participants, so as to develop an understanding of what happens in the body and how it feels to have chronic kidney disease
- Refer participants to comments on the flip board as appropriate.

**Participant activity**

- Explore what the kidneys are and what they do
- Explore what happens in the body when the kidneys are not functioning as well as they should
- Explore the tests that are used to monitor how well the kidneys work
- Explore the symptoms of having chronic kidney disease and the impact on their life.

**Content covered**

- What are the kidneys and what role do they play in keeping us healthy? OR 'What the kidneys do and their role in keeping us healthy'
- What happens in the body when the kidneys do not function as well as they should
- What it means to live with chronic kidney disease and how it can make you feel
- What symptoms you may experience as a result of your chronic kidney condition
- What are the main causes of chronic kidney disease
- How is it tested for and treated
- How long will your chronic kidney disease last and will it change overtime?
- How chronic kidney disease is treated
- What you can do yourself to help manage your condition.

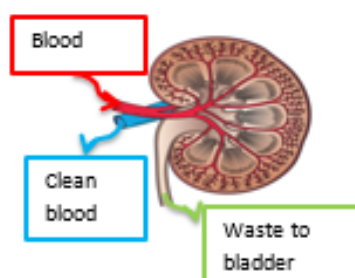
**Theory Thought**

- The process of systematic learning (dual processing) encourages participants to think more deeply about the message. It usually entails asking the participants to scrutinise, ask questions for themselves and work things out for themselves.
- The educator will ask mainly open questions to elicit the information from the group. Eliciting information from participants facilitates them to realise what they already know. Educators can put some support in place to help the group understand the missing elements and put these into place and move forward – for example supplying a piece of information the group cannot work out or do not know.
- If a person comes up with the correct answer straight away avoid taking this and moving on. Check with the group to see if they agree with what has been said.

### INTRODUCING THE KIDNEYS

We are going to try and make sense of some of the information that you have just shared. This session is designed to give you the opportunity to learn a little bit more about chronic kidney disease.

Using this picture/magnetic man  
Let us think about the kidneys for a little while.



**What are the kidneys? (Prompt shape, size, and location)**

*Listen and acknowledge responses.*

The kidneys are (usually) a pair of bean-shaped organs each the size of your fist. They are located in the small of your back on either side of the spine.

*Educator should make two small fists and place them their back and then turn around to show the participants. Add a picture of the kidneys to the magnetic man.*

### EXPLORING THE FUNCTIONS OF THE KIDNEY

The kidneys have a number of jobs and some are better known than others.

*Show short video clip.*

**What do you think the kidneys do?**

*Collect answers and acknowledge responses and try to elicit the following. If no answers are forthcoming move on and give the correct answer.*

1. They clean the blood of toxins and excess fluid and this is expelled from the blood into the urine.
2. They reabsorb things that the body needs including filtered proteins.
3. They monitor and adjust the amount of acids, salts (electrolytes) and fluid in the blood to ensure the body does not become too acidic or too alkaline.
4. They produce a hormone (EPO) that tells bone marrow to make red blood cells (the part of the blood that carries oxygen).
5. They make a hormone (renin) that helps to regulate blood pressure.
6. They activate vitamin D which allows us to absorb calcium & keep our bones healthy and strong.

Now we know what healthy kidneys do, we are going to discuss chronic kidney disease.

### **EXPLORING CHRONIC KIDNEY DISEASE**

**What does chronic mean?**

Collect answers and acknowledge responses, if none are forthcoming move on and give the correct answer.

*Chronic means long lasting and is usually refers to a condition that will need to be managed over your life time.*

**What do we mean by chronic kidney disease?**

Collect answers and acknowledge responses and try to elicit the following. If no answers are forthcoming move on and give the correct answer.

Chronic kidney disease is where the kidneys are less able to perform their usual functions. Chronic means there is no cure so we have to look at ways in which to manage your kidney problem.

### **EXPLORING THE CAUSES OF CHRONIC KIDNEY DISEASE**

**Chronic kidney disease has a number of different causes, but whatever the cause, the kidneys usually respond in the same way and this is a gradual loss of kidney function.**

Refer to flipchart at this point if no answers were given move on to explain the main causes of chronic kidney disease. If no answers are listed move on and give the correct answer.

The main causes of kidney problems are **high blood pressure and diabetes**. It usually takes many years of experiencing these conditions before the kidneys become affected. Other causes include **inflammation (glomerulonephritis)**, **infection of the kidney (pyelonephritis)** and **inherited diseases** for example polycystic kidney disease and sometimes it is not possible to say what has caused the kidney problem.

**How is kidney function measured? (Prompt what tests do you usually have when you go to the doctors?)** Collect answers and acknowledge responses and try to elicit the following. If no answers are forthcoming move on and give the correct answer.

Urine tests measure the amount of protein in the urine. Protein is not usually lost in the urine when the kidneys are healthy but protein in your blood can pass into the urine when kidneys become damaged or scarred.

Blood tests check how well your kidneys work this is shown by your eGFR. In healthy functioning kidneys the eGFR will be approx. 100 so 100% kidney functions. **For example if**

a person has an eGFR of 45 what percentage will their kidneys are working at?

### EXPLORING THE SYMPTOMS RELATED TO CHRONIC KIDNEY DISEASE

Refer to symptom board from module B: Patient story.

In your own words highlight difference and explain how symptoms vary considerably between patients. Some people may experience no symptoms or very few and this is especially true for people in the early stages of kidney disease.

The symptoms of kidney disease are very broad and it is not always obvious that the symptom you might be experiencing is linked to your kidney problem.

This task is designed to raise your awareness to the different types of symptoms that a person with kidney disease could experience.

Knowing what symptoms are linked to kidney disease and being able to communicate these to your doctor is important for your well-being.

How confident do you feel that if you were experiencing these symptoms that you could bring them up at your next doctor's appointment?

*Presenting Detailed Information* relates to pre-visit preparation e.g. symptom diary.

*Asking Questions* pertains to having a preset list of questions.

*Checking Understanding* asking the clinician to repeat or clarify information.

*Expressing Concerns* aims to bring forward any conflicts or concerns (e.g., religious or cultural beliefs) that may hinder treatment or the clinician-patient relationship.

# Module D: Modifying risk factors for health complications

## Key Message

- Is it possible to reduce your health risks?

## Participant Learning Opportunity

- Participants will have the opportunity to explore/learn:
- What factors contribute to causing increased risk of cardiovascular disease
- Understanding chronic kidney disease as a risk factor.
- The different options to reduce their risk of cardiovascular disease.

## Educator activity

- Ask open questions to enable participants to explore what increases the risk of developing cardiovascular disease as a chronic kidney disease patient
- Enable the participant to work out what they can do to manage their risk
- Use open ended questions to check understanding
- Use participants' words and phrases when working through the session
- Refers to participants' comments on the flip chart
- Ensure that all participants are comfortable in contributing in a way in which they feel comfortable, by acknowledging them and thanking them for their contributions.



**Participant activity**

- Work out what causes their increased risk of cardiovascular disease
- Work out what contributing factors are in their control and can be changed.

**Content covered**

- The factors that contribute to other health complications
- How to improve modifiable risk factors associated mainly with cardiovascular disease

**Theory Thought**

The sessions use the Common Sense Model applied to illness risk perceptions to elicit participants beliefs about their risk of developing what are potentially abstract concepts e.g. cardiovascular disease. This session is enhanced by using visual aids as concrete images regarding the participants personal control of modifiable risk factors.

The delivery of this session supports social cognitive theory in action.

This session is designed to explore how risk factors can be changed to reduce the chance of developing health problems. All of the health problems we will speak about are treatable and in many cases preventable. However, many people don't know what puts them at risk, which is why diseases affecting the heart and blood vessels for example heart attacks and strokes are a big problem in the general population.

This type of health information can seem a bit scary but each and every one of us including myself has our own risk factors. Being aware of what the risk factors are is what gives you control to choose to do something about your risk of developing these health problems.

Not all risk factors can be changed. Having chronic kidney disease is unfortunately a risk factor for these health problems that is not in your control. However, there are many things that are in your personal control that can be modified to reduce your risk. This includes how you manage your kidney problem. We are going to discuss all the ways to reduce risk as a group in just a few minutes.

**Firstly, I would just like us to consider the word risk. Can anyone tell me what they think I mean by risk factors?** *Collects answers and try to elicit some of those given below. If no answers are forthcoming move on and give the correct answer.*

Risk factors are conditions or habits that make a person more likely to develop a disease. They can also increase the chances that an existing disease will get worse. An example of a risk factor is not being physically active.

To understand more about risk, let us think about things you do every day that can carry risk.

**Let's consider carrying a tray with a pot of tea from the kitchen. What is the chance you will drop it?**

*Collect answers*

Possibly low

**What about if you add 4 tea cups?**

*Collect answers*

Maybe a bit more of a risk.

**What about if you are talking on the phone whilst holding the tray?**

*Collect answers*

Higher again

Finally, if a cat runs under your feet?

*Collect answers*

Pretend to trip.

**What do you think this story is telling you about risk?**

*Collect answers if none are forthcoming move on and give correct answer*

The more risks you stack up the greater the chance of dropping the tray!

**Let us imagine that chronic kidney disease is the teapot on the tray as we already know it is a risk factor. If you remember the risk of dropping the tray was lowest when we just had the teapot. What risk factors could the phone, tea cups and lion represent? I gave you an example earlier physical inactivity.**

**Therefore, what do you think this demonstration is telling you?**

*Collects answers and try to elicit some of those given below. If no answers are forthcoming move on and give the correct answer.*

You may be able to balance one condition but by adding other risk factors it will increase your chance of experiencing a serious ill health event.

Like everyone patients with chronic kidney disease have their own risk factors for developing these health complications. Some are kidney specific and some are non-kidney specif. Understanding what the risk factors are and how to modify them to reduce risk is important for everyone. However, as your kidneys get worse the teapot gets bigger and it becomes even more important to avoid other risk factors if possible.

**Can anyone name any risk factors (conditions or habits) that they think might increase the risk of developing one of these conditions?**

**Interactive Task**

Some of the risk factors we just mentioned are in our hands to change. However, some are not. I am now going to give each of you a picture and then ask you to come up and place it either on the modifiable board or the non-modifiable board.

#### Not modifiable

Family  
Getting older  
Ethnicity

#### Modifiable

Activity levels  
Depression/ Stress  
High BP  
High cholesterol  
Overweight/Obesity  
Smoking  
Taking medication  
Diet  
Alcohol.

Let us now consider a quick scenario. The person in it could represent any one of us at any time in our lives.

A person is told at their clinic appointment with their doctor that their eGFR (kidney function) is 40. When they attend their appointment 12 months' later time their kidney function has fallen to 32.

**What has happened to their risk for developing other health conditions?**

Collect answers, if none are forthcoming move on and give the correct answer.

It has increased

What types of things could you suggest that might help this person to slow the rate at which their kidney function is getting worse and reduce their risk of developing health complications? Collect answers and acknowledge responses try and refer back to the flipchart tick them off as you go. If no answers are forthcoming move on and give the correct answer.

- Keep your blood pressure, blood glucose and blood cholesterol in your target range.
- Choose foods that are healthy for your heart and cut back on salt.
- **Be more physically active.**
- If you smoke, take steps to quit.
- Take medicines the way your provider tells you to.

The goal of this programme is to focus on the importance of being more physically active. This modifiable risk factor can have an impact on the other factors too e.g. it can reduce cholesterol, help to control blood pressure and obesity. It can also help to improve some of the symptoms that you might experience as a result of your kidney problem or other conditions.

However, all of the risk factors we have spoken about today are very important.

**Challenge the participant to consider ways in which they could gain their desired information.**

**Diet is also very important. If you wanted to know more about specific diets for patients with kidney disease where could you find this information?**

Collect answers, if none are forthcoming move on and give the correct answer.

You can talk to your kidney doctor and ask them about referrals to see the renal dietician.

**If you are having trouble with your medication or wish to know more about it, who could you contact?**

Collect answers, if none are forthcoming move on and give the correct answer.

**If you wanted to know more about managing depression and anxiety what could you do?**

Collect answers, if none are forthcoming move on and give the correct answer.

Discuss with your GP, kidney doctor, renal psychologist, library or local support groups.

# Module E: Physical activity



## Key Message

- Increasing physical activity will have a positive effect on aerobic fitness, cardiovascular health and quality of life.

## Participant Learning Opportunity

- Participants will have the opportunity to explore/learn:
- Benefits of exercise for patients with chronic kidney disease
- The current recommendations for activity and what it means for them

## Participant activity

- Explore their understanding of the potential benefits of being more physically active
- Play the physical activity card game
- Reflect on their personal options to change and explore their own barriers to change
- Play the measuring activity game
- Complete an action plan for physical activity

## Educator activity

- Use open questions to generate a list of the benefits of physical activity, current recommendations and options for increasing physical activity
- Encourages the group to consider strategies for overcoming barriers to physical activity
- Encourages the use of pedometers for self-monitoring of physical activity
- Enables participants to appreciate the benefits of forming action plans and monitoring their progress
- Enables participants to explore personal options for change and barriers to success
- Provides information, where necessary, to address gaps in the participants' knowledge

**Content covered**

- The benefits of physical activity on health and emotional well-being for patients with chronic kidney disease.
- The current national guidelines for activity levels
- Strategies to overcome barriers to exercise and how to become more active
- Ways to become more active in their personal environment
- Barriers to exercise
- Benefits of wearing a pedometer, forming an action plan and keeping a physical activity diary.
- The importance of building up to goals slowly

**Theory Thought**

These are examples of activities within this session that support social cognitive theory in action and are provided to enhance the key construct self-efficacy:

**Mastery experiences**

- Provide new means of delivering key messages
- Provide new time and tools to enable participants to consider how they will increase their activity

**Vicarious learning (role modelling)**

- Facilitate discussions within the group of their experiences of physical activity and prompt discussions of positive and negatives
- Facilitate individuals to share their stories about positive attempts to increase activity
- Facilitate group members to share their barriers to physical activity and then support the group to discuss options for overcoming these barriers
- Facilitate the participants to "group solves" problems.

**Verbal persuasion**

- Provision of up to date information about activity, and encouraging self-talk about how these risks apply to them
- Provide time to reflect on and decide "what am I going to do now as a result of this session"
- Verbally explore barriers to integrating activity into their lives
- Support the personal setting of the action plan

**Physiological or emotional state**

- Support participants to explore their confidence related to activity
- Encourage participants to use imagery of what it might feel like to be taking part in moderate activity

This session is designed to give you the opportunity to learn more about the benefits of physical activity.

### What is physical activity?

*Collect answers, acknowledging responses and try to elicit the following*

Physical activity is activity that requires you to use more energy than when you are resting.

Earlier we discussed how not being physically active is a risk factor for conditions such as heart disease.

### What benefits do you think being active has for your heart and vascular system?

*Collect answers, acknowledging responses and try to elicit the following:*

Regular physical activity can help to **protect the heart** of kidney patients.

The heart is a muscle, like any muscle doing exercise can make it stronger.

Exercise can help to control **blood pressure** and **improve the health of your blood vessels**. With age our arteries can harden and this can happen earlier in people with CKD.

However, physical activity can help to **reverse** this reducing your risk of developing further health complications.

Walking has been shown to **reduce inflammation**, which is a key player in the development of heart disease and loss of muscle size and strength.

### What benefits do you think being active has for your muscles?

*Collect answers, acknowledging responses and try to elicit the following:*

As people age, muscles work on a 'use it or lose it' basis, therefore if you are inactive muscles will weaken with time.

Kidney disease can cause a person to lose muscle more quickly.

When the kidneys are not working as well as they should (acid build up, inflammation and hormone imbalances) it can affect the muscles causing them to break down protein – the building blocks of muscle too quickly.

Exercise is particularly important to help maintain muscle size and strength in chronic kidney disease patients.



**Even by increasing our PA level by a small amount can have numerous benefits. Has anyone heard of any other benefits from being active?**

*Elicit the following answers and place images that represent the health benefits on the magnetic chart labelled "Health benefits":*

- Helps to improve your fitness
- Helps you to feel better
- Helps you to manage stress and deal with emotions
- Helps to maintain strong healthy joints
- Helps to reduce aches and pains
- Helps you to have more energy and feel less tired
- Helps to keep your mind active
- Helps you to sleep better

Being active can help to protect your heart and your muscles, improve some of your symptoms and increase your general well-being.

For example:

**If you suffer with feelings of fatigue, what benefits would you get from being more active?**

*Listen carefully to answers and clarify*

Being more active can improve the ability of the muscles to use oxygen for energy. This can help you feel less tired when you are undertaking daily activities.

### **PHYSICAL ACTIVITY RECOMMENDATION GUIDELINES**

Now we know the benefits of being more physically active.

**What is the current recommendation for physical activity for patients with chronic kidney disease?**

*Listen to responses*

The recommendation is 30 minutes of moderate activity 4-5 times a week (BASES).

**Do you think this recommendation would be suitable for other populations as well e.g. older age, heart disease, diabetes, lung problems, arthritis?**

30 minutes of moderate physical activity on most of the days of the week is recommended for everyone.

**What do you understand by the term “moderate” activity?**

*Collect answers, acknowledge responses. If no answers are forthcoming move on and give the correct answer.*

Moderate activity makes you **breathe harder** and makes you **warm and a little sweaty**.

You should still be able to hold a brief conversation but not be able to sing. (Sing Talk Test)

**How can we measure how hard we are working?**

An easy way to do this is to listen to our minds and our body and then estimate how hard we are working on a scale.

**Give out copies of the RPE scale or turn to page 9 of green booklet.**

The Borg of Perceived Exertion scales measures the amount of strain, effort or discomfort you feel when being active. The scale ranges from 6 – 20. 6 should feel as though you are completely at rest e.g. sitting still. 20 would be the most amounts of discomfort and effort you can imagine.

There is no right or wrong answer. Research has shown that using this scale is linked to your heart rate. Ideally when walking you should be aiming to walk at a moderate intensity which is between 12-14 on the scale.

**What I am going to do now is show you a number of different video clips of a people being active at different intensities and in different ways. Please shout out how hard you think they are working on the scale...**

**Video Clips: Different intensities and different activities.**

**How would we rate this on the scale?**

Although we have had a bit of a guess at the different intensities linked to each activity. It is important to remember that a “one size fits all” does not apply here. In fact what might be moderate for one person may be vigorous for another. That is why it is important to be aware of what moderate feels like for you.

**Why might it be important to understand what intensity of exercise you are working at?**

*Collect answers, acknowledge responses.*

See improvements and identify problems to stay safe when exercising.

#### **EXPLORING HOW TO EXERCISE SAFELY**

**What may be the signs that you are exercising beyond a moderate intensity and might be at risk for overdoing it?** *Collect answers, acknowledge responses.*

Pain that is more severe than usual

Muscle ache (it is normal to feel muscle ache after being active, however if this ache interrupts your next activity session it is too much)

Dizzy or lightheaded

Unable to speak

Chest pain

Feeling nauseous

Very short of breath

Leg cramps

**If you did feel this way, what could you do next time?**

*Collect answers, acknowledge responses. If no answers are forthcoming move on and give the correct answer.*

Slow down and try to aim for a lower intensity on the scale.

**Can you think of any times when you should not exercise?**

*Collect answers, acknowledge responses. If no answers are forthcoming move on and give the correct answer.*

Fever

Change in medication

Change in physical condition

Eaten too much

Weather is very hot and humid

Joint or bone problems that become worse with exercise.

#### **EXPLORING HOW EXERCISE CAN BE BROKEN DOWN INTO SMALLER BOUTS OF TIME**

**Do you think the 30 minutes of exercise has to be done all at once?**

*Collect answers, acknowledge responses. If no answers are forthcoming move on and give the correct answer.*

The 30 minutes can be broken down into smaller chunks and accumulated throughout the day.

**What is the smallest amount of time you need to undertake activity for in order for you to gain the benefits?**

*Listen to and acknowledge responses. If no answers are forthcoming move on and give the correct answer.*

The smallest amount of time is 10 minutes e.g. 3x10 minutes at different times of the day. Remember this is individualised. If you can only do 3 or 4 minutes of moderate physical activity to begin with you will have the most to gain from building up slowly to 10 minutes.

### **EXPLORING DIFFERENT ACTIVITIES ON A CONTINUUM**

#### **Activity Continuum**

This activity is aimed at getting you to work out which physical activities might count towards your goals, and how it might be possible to change some low intensity activities into moderately intensity activities.

**(Educator: place activity cards on a table and invite participants to pick up an activity card and place it on the activity continuum).**

Here are some cards with examples of everyday physical activities and exercises. Take a card and place it in the position on the line that indicates the amount of physical effort required. At one end of the line are activities that require little physical effort (low intensity) and at the other end are activities that require more physical effort (high intensity). Some activities will fall somewhere between those levels of effort.

**(Watching TV, riding a bike, vacuuming, brisk walk, gentle walk, dusting, tennis)**  
This is an example of what the group may suggest.

Facilitate a discussion about cards that are misplaced exploring why the card is placed in the position. For example dusting placed next to tennis. The participant may explain that it is an activity performed as part of their job and performed vigorously for a number of hours. **Ask if there is any activities participants enjoy that are not indicated by the cards and discuss where it would be placed on the continuum.**

As we can see there are a range of activities from those that require little effort to activities that require more physical effort.

**Explore how the activities at the lower end could move up the continuum e.g. how the low intensity activities could be made into moderate intensity activities.**

**How could you try and use these activities to make up 30 minutes of moderate activity a day?**

Demonstrate with the cards how 30 minutes could be made up of small chunks of activity i.e. walking for 10 minutes, vacuuming for 10 minutes and mowing the lawn for 10 minutes = 30 minutes of moderate intensity activity.

# Module F: SELF-REGULATION FOR PHYSICAL ACTIVITY

## Key Message

- Goals and action plans are important in helping us plan our physical activity and track the progress that we make.

## Participant Learning Opportunity

- The benefits of wearing a pedometer, forming an action plan and keeping a physical activity logbook.
- The importance of building up to their goals slowly
- The possible options and barriers for implementing activity within their personal lives
- Useful strategies for becoming more active around the house and local environment
- Potential solutions to their personal exercise barriers

## Participant activity

- Play the measuring activity game
- Complete an action plan for physical activity

## Educator activity

- Encourages the use of pedometers for self-monitoring of physical activity
- Uses open questions to explore the importance of tracking progress
- Enables participants to appreciate the benefits of forming action plans and monitoring their progress
- Enables participants to explore personal options for change and barriers to success
- Provides information, where necessary, to address gaps in the participants' knowledge

**Content covered**

- Benefits of wearing a pedometer, forming an action plan and keeping a physical activity diary.
- The importance of building up to goals slowly

**Theory Thought**

Enabling participants to successfully use their pedometer is key to promoting self-regulation and meaningful long-term changes to physical activity levels. This is because the primary goal of structured education is to help participants actively self-regulate their behaviour in their own environments using self-monitoring and goal setting strategies. Therefore, as pedometers provide objective feedback to the wearer and facilitate clear and simple goal setting, they are ideally suited to this task.

Research has clearly demonstrated that physical activity interventions will be most effective if they encourage individuals to:

- Wear a pedometer on a regular basis
- Keep a daily log of steps
- Form realistic, personalised steps per day goals.

This session is designed to give you the opportunity to think about ways in which you can fit more physical activity into your life. Then you will have some time to set some goals and a plan of action to help you achieve it.

### **EXPLORING WAYS OF MEASURING PHYSICAL ACTIVITY**

Some people find it useful to think about the 30 minutes activity recommendation in terms of the number of steps.

**What have you heard regarding how many steps you need to walk daily?**

*Listen to and acknowledge responses*

10,000 steps

**Hold up the walking activity continuum card.**

**If you think about the 30 minute activity recommendation, take a guess as to how many steps you would walk if you walked for 30 minutes?**

*Listen to and acknowledge responses*

It would be approximately 3,000 steps.

Another way of thinking about the 30 minute activity recommendation is to think of it as aiming to walk 3,000 extra steps a day.

**How could you measure the number of steps you walk?**

*Listen to and acknowledge responses*

You could use a pedometer.

**How can wearing a pedometer help you to be more active?**

A pedometer is a way of measuring how many steps you are doing; it can help you to see what you are doing and help you to decide how much you want to do it. It can also help you to set yourself small targets to get to where you want to be.

**Will everyone in this room have the same long term goal/end point?**

*Listen to and acknowledge responses*

Each person's long term goal will be different depending on your starting point.

### CALCULATING LONG TERM GOALS

#### **How can you work out your long term goal?**

To work out your long term goal you will first need to know how many steps you take now.

Your result is shown in the front of the orange booklet. This has been calculated from the accelerometer (red device) you have been wearing over the last 7 days. You could do this yourself by wearing your pedometer for 7 days and recording your daily steps. With this information it is now possible to work out your average steps per day that you do now.

Educators may wish to have calculators available for the participant to work through the example in small groups.

*Educators to demonstrate on flip board.*

Add up 7 days of steps = 24,000

Divide your total steps by the number of days 7 = 3500

Your average daily steps are 3500 per day.

#### **If your average step count is 3500 steps per day, how many extra steps will you need to walk to add the 30 minute activity recommendation?**

You would need to walk an extra 3000 steps to reach the 30 minute activity recommendation.

#### **If you start off with 3500 steps and you add 3000 to reach the 30 minute activity recommendation how many steps will you walk?**

$3500 + 3000 = 6500$  steps (long term goal)

For those of you who have worn your accelerometer there is now time for you to look at your average daily steps and work out your own long term goal. You can write this in the orange booklet.

#### **If you are not used to being active what would happen if you suddenly started to do an extra 2000 steps?**

It is better to build up to the 30 minutes of extra steps slowly. Big changes straight away are likely to lead to sore muscles or injury. It is then unlikely that the activity will be sustained. Trying to make such a big change in one go is mentally challenging and could lead to de-motivation and not achieving goals.



**What do you think is a realistic amount to increase your daily steps by each week?**

For example increasing activity by 300-500 steps a day may be a more realistic and achievable amount.

You may have a long term goal of walking an extra 3000 steps a day; a realistic short term goal might be 500 steps more a day or for a week depending on what is realistic for you.

**Remember the steps that you are adding on to your usual daily activity need to be performed at a moderate intensity.**

*Allow time for participants who have been wearing the accelerometer to fill in their activity sheet to set a short term goal or review their short term goal to ensure it is realistic for them. If participants have not worn the accelerometer give them the pedometer and explain how they can find the activity sheet in their own diary. Explain how they will be able to record and set their own goals at home.*

**If you were doing an activity where you could not wear the pedometer e.g. swimming, how could you work out the equivalent number of steps? (This is also useful if you forget to put the pedometer on).**

*Listen and acknowledge answers*

We can think of steps as time. 30 minutes of walking would be the equivalent to 3,000 steps. Similarly 15 minutes of walking would be the equivalent to 1500 steps.

**Hand out step count cards and invite participants to match cards with number of steps.**

**What does this tell you about swimming compared to walking?**

**What does that tell you about dusting compared to moving the lawn?**

**Looking back at the types of activities you do, how do you think they would relate to steps?**

*Listen for responses.* Acknowledge that it can be difficult to equate all different activities with steps, but comparing the activity to similar one that we have spoken about to give an estimation.

Now as a group I want us to think about ways in which we can increase the amount of moderate physical activity we do in our different environments. Let's start with our homes.

**Can anyone think of ways to increase our moderate intensity levels of physical activity in your home environment?**

Write participants ideas down on the flip chart. Depending on who you have in the group use open questions to elicit the following ideas:

Encourage your friends to come on walks  
Vacuum the house vigorously  
Walk your dog  
Walk to your neighbours  
Park your car further along the road from your house  
Walk whilst you are on the phone  
Use a watering can instead of the hosepipe  
When watching television stand up during the adverts.

Ok thanks everyone they are some really good ideas.

**Can anyone think of ways to increase their physical activity when we are out and about in town or shopping?**

Avoid lifts and escalators if possible take the stairs.  
walk briskly between shops  
Don't drive for journeys less than 1 mile  
Park your car further away at the supermarket  
Take more trips when unloading the car

**How has this conversation helped you to consider how you might fit 3,000 extra steps into your day.**

Listen and acknowledge answers

It can also be important to consider what might make it difficult for you to stick to your goal.

**Can anyone think what might make it difficult to increase the amount of steps you do?**

Time, weather, pain, fatigue...

|

[Discussion around this point \(collect barriers\)](#)

**Thank you for sharing those barriers with me.**

**Can anyone think of any ways to overcome these barriers?**

[Discussion around this point](#)

When you have been making a lifestyle change for a while what types of thing can happen?

You can relapse for a number of reasons and sometimes it takes a few goes until you can find the right type of activity that you can fit into your life and maintain for the long term?

**Are there any benefits to relapse?**

Collect and acknowledge answers.

Yes, it means that you succeeded once so the next time you try you will feel more confident.

### **ACTION PLAN DEVELOPMENT**

There is now some time for you to set some personal goals and make an action plan.

Now we have explored some ideas about increasing activity in your daily lives the next part of this session will be to focus on how to start to make some of these changes.

**Has anyone ever heard of an action plan?**

Collect and acknowledge answers.

**How might making an action plan help you to be more active?**

Collect and acknowledge answers.

**What do you think are the most important things that need to go into your action plan?**

Collect and acknowledge answers. Provide answers if none are forthcoming.

Elicit: What are you going to do? Is it personal to me? Can I do it? When am I going to start?

How much activity am I going to do? Is it realistic and achievable?

Counting steps is a great way to stay on target and learn how to add activity into your life.

Seeing you walking more steps and feeling fitter can be very motivating. However, it is important to identify something meaningful in your life that you want to achieve.

**MAKING IT COUNT IN A REAL LIFE CONTEXT**

Can you think of an activity you enjoy that requires some sort of physical effort?

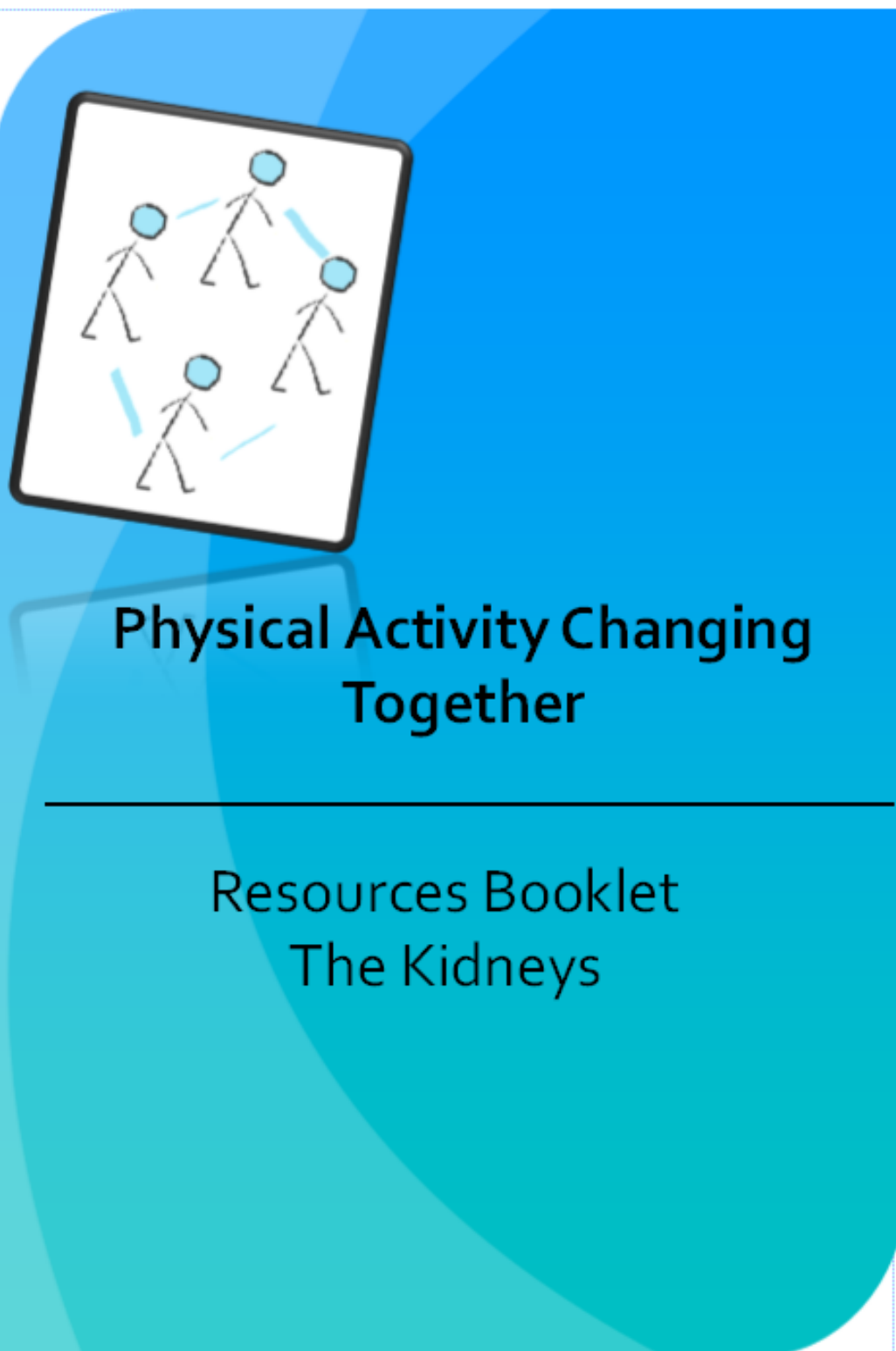
Provide an example e.g. being active on holiday.

How might increase your physical activity benefit and this activity you enjoy?

Collect and share ideas.

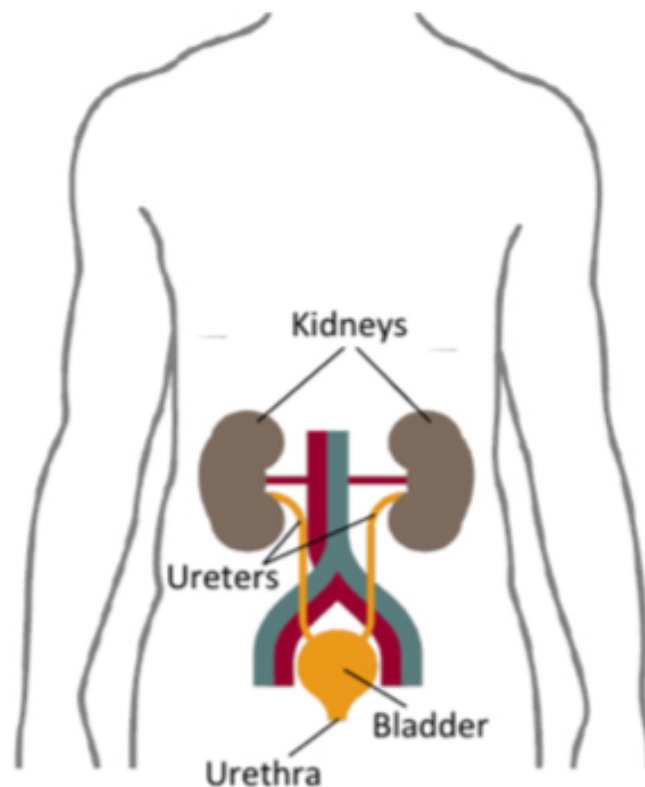
Finally turn to the question board and try and put a tick by each one.

**END OF SESSION**



## What are the kidneys?

- The kidneys are important organs just like your heart, lungs and liver and we need them to keep us alive.
- Most of us have two kidneys usually the size of our fists that sit at the back of the body under the lower ribs.
- Each kidney is around 10-15cm long and 160 grams in weight.
- The kidneys are part of your urinary or renal system, this includes your: kidneys; ureters; bladder and urethra.



## What do the kidneys do?

### Clean the blood:

The kidneys get rid of waste products that occur in the blood after the body has used food for energy and self-repair. They filter the waste and toxins, excreting them as urine. When the kidneys are not filtering well waste products build up and can cause symptoms e.g. itching.

Blood with waste

### Produce a hormone called Erythropoietin (EPO):

EPO tells your bones to produce red blood cells. If the kidneys do not produce enough EPO you may develop **anaemia** (too few red blood cells) this can contribute to feeling tired and short of breath.

Clean blood

### Keep bones strong:

The kidneys help to manage levels of **calcium and phosphate (minerals)** in the body. They also activate **Vitamin D** which helps your body use calcium. Uneven levels of any of these substances can mean that you are at risk for painful bones or fractures if not treated.

### Keep levels of salts and acid in the body stable:

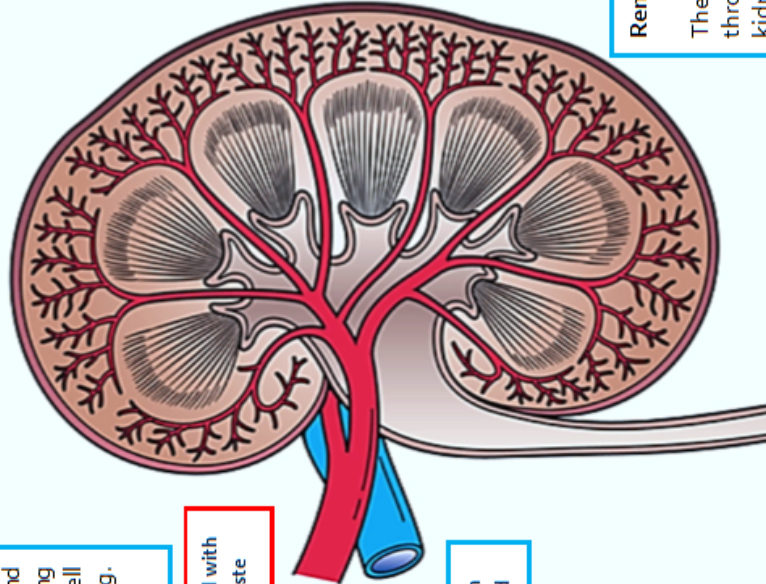
Balance is maintained by a series of hormones that help to manage the level of salt, minerals and acids in the body.

### Look after blood pressure:

**Renin** (a hormone released by the kidneys) helps to control blood pressure by tightening blood vessels. If the kidneys produce too much renin it can cause **high blood pressure (hypertension)**. High blood pressure can cause the kidneys to deteriorate more rapidly.

### Remove fluid from the body:

The body responds to increases in water through a number of messages and the kidneys get rid of the excess fluid in the body via urine. When the kidneys are not working well, fluid can build up in your body. This can cause swelling in your legs making it more difficult to move around.



Waste to bladder

### What is chronic kidney disease?

Chronic kidney disease means that your kidneys are no longer filtering your blood or performing their other roles as well as they should. This means that harmful toxins and fluid can build up in your body.

Damage to the kidneys is usually permanent and can sometimes **(but not always)** slowly get worse over time.

Estimated glomerular function (eGFR) is a measure of how well your kidneys are working. You would not expect this to improve but your doctor will help you to manage your illness through treatment to keep your kidney function stable.

### How common is chronic kidney disease?

Research shows that kidney problems are fairly common and affect around 6-8% of people in the U.K. Unfortunately it is more common if you are from an South Asian or Black background.

### What causes chronic kidney disease?

There are a number of different causes of CKD including:

- High blood pressure
- Diabetes
- Inflammation (glomerulonephritis)
- Infection (pyelonephritis)
- Inherited problems such as polycystic kidney disease.
- Some tablets
- Sometimes it's not possible to know.

### Are there any symptoms associated with chronic kidney disease?

Yes, but some people may have no symptoms. Often people who are in the earlier stages of CKD do not experience any symptoms at all; however, this is different for everyone. Some of the common symptoms described by other kidney patients are listed below. **Not all kidney patients will experience these symptoms or you may only have one or two!**





Is there anything I can do to help look after myself?

Yes! The main advice is to keep as healthy as possible. This means following all of the advice listed on the pages below.

It is also really important to ask your doctor any questions that you might have. When it comes to being a partner in your healthcare there is no such thing as a silly question.

Be more physically active

It is recommended that patients with chronic kidney disease try to be active for 30 minutes on most days of the week. Regular physical activity has been shown to increase fitness levels, improve the function of your heart and blood vessels and also improve quality of life. To find out more about the benefits of being more active have a look at the resources booklet provided: **Becoming More Active**.



10

Take medications as prescribed

If your target blood pressure, cholesterol or blood sugar level (if you are diabetic) is not achieved, the doctors may have to increase your medication. Physical activity can work along side your medication and help you to manage all of the above. This may mean that your medication dose will not need to increase and may even potentially decrease over time with regular physical activity.



Follow any dietary advice

You should follow any dietary advice that you have been given. Not everyone needs to see a renal dietitian. However, if you feel that you would like to know more about how to eat a healthy diet you can speak to your doctor.



11

# Finding more information

Asking questions and getting them answered by a health care professional or someone who you feel is able to help is critical for you to begin a more active lifestyle. Never feel shy about asking anything to do with your physical activity

You can also access information on the internet and below are a few links:

National Health Service

<http://www.nhs.uk/Livewell/fitness/Pages/physical-activity-guidelines-for-adults.aspx>

Patient.co.uk

<http://www.patient.co.uk/health/Physical-Activity-For-Health.htm>

World Health Organization

[http://www.who.int/topics/physical\\_activity/en/](http://www.who.int/topics/physical_activity/en/)

British Renal Society

<http://www.britishrenal.org/Physical-Activity.aspx>

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## Physical Activity Changing Together

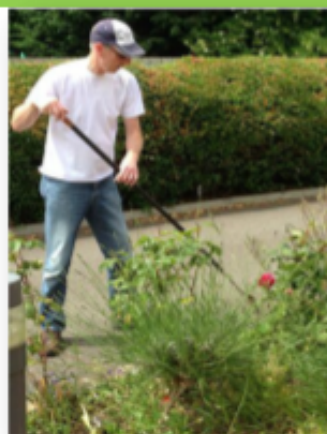
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### Resources Booklet Becoming More Active

*"Well it keeps me able to move about well and the more you do the more you are able to do I think. It keeps you going, do it in small doses to begin with and the more you can do the better. "Female Patient 76 Years Old.*

## What is physical activity?

Physical activity is activity that requires you to use more energy than when you are resting. This includes activities such as brisk walking and gardening. An active lifestyle is important for everyone, but especially important for people with chronic kidney disease. As a kidney patient you are at a higher risk than the general population for developing heart and blood vessel diseases including heart attacks and strokes. **This risk is reduced by being more physically active.**



## There are 4 main activity types:

**Aerobic:** Activities that get your heart rate and breathing up and increase your overall fitness e.g. brisk walking, swimming, cycling and dancing.

**Strength:** Activities that can help you to maintain and build muscle e.g. using weights at home or in the gym, carrying bags of shopping or using resistance bands at home.

**Flexibility:** Activities that stretch your muscles to help you stay limber e.g. yoga, calf stretch, upper body stretches.

**Balance:** Activities that help your balance and prevent falls as we get older e.g. standing on one foot and tai-chi.

## What are the benefits of being more active?

### Keeps your mind active

Do you ever find it difficult to concentrate or remember where you left the car keys? **Exercise is a great way to keep your mind sharp.** Kidney patients have reported that taking regular exercise has helped them to keep their mind active.



*Dr Chapman showed that walking can improve brain health and mental processes after as little as 3 months.*

### Protects your heart

Regular physical activity e.g. brisk walking can help to **manage your weight, control levels of cholesterol in your body and reduce your blood pressure.** Keeping all of these factors within your normal ranges can help to reduce your risk of heart attacks and strokes.



*After reviewing 45 exercise studies, Drs Hewie and Jacob found that aerobic exercise improves cardiovascular health, fitness and quality of life in kidney patients.*

### More energy

Kidney patients who take part in regular exercise reported **feeling less tired in general and felt they recovered quicker** from physical activity.



*The Leicester Kidney Exercise Team showed that walking 5 times a week for 30 minutes significantly improves general-well-being this started to happen within 4 weeks.*

### Improves mood

Feeling stressed, angry, worried or upset about your illness is normal. Having a chronic illness can be a frightening experience for you and those close to you. Normal stresses can sometimes seem more difficult to deal with. **Physical activity is a great way to distract yourself from these feelings and it will lift your mood.** Plus "feel good" substances are released in the brain when we are active.

### Improves strength and fitness

Even in the earlier stages of the disease, kidney patients can lose up to 20-25% of their skeletal muscle (the muscle you can see and feel). This can make activities feel harder. **The right type of exercise can make your muscles stronger and improve your fitness.**

### Reduce aches and pains

Physical activity can help to **warm up the muscles, loosen stiff joints by increasing range of movement and make you feel better.** Getting up and doing something can be a distraction from pain and improve your confidence in managing it.



**It is normal to have some concerns about getting more active!**

**Is physical activity safe?**

Moderate physical activity is safe for kidney patients. Physical activity is recommended as a treatment for a number of conditions including: chronic kidney disease; diabetes; heart disease; arthritis; cancer and lung disease.

However consult with your doctor first if you:

- Have a history of heart problems or other existing medical issues
- Get chest pain or feel dizzy when exercising
- If you have diabetes
- Are considering more vigorous exercise e.g. heavy weight lifting and running

**Will I have to join the gym?**

No you do not need to join a gym to get fit! Choose an exercise you enjoy. A walk outside might feel more refreshing than a walk on a treadmill. Places to walk include parks and shopping centers. If you are interested in the gym, check it out as lots of things happen in the day that are very different to the evening classes.

**"We are all in our 60's, 70's and 80's but we love a walk or Pilates or Yoga..." Female Patient aged 65 years old.**



**Are there times when I should not exercise?**

Yes, you should avoid exercise or consult your doctor first if any of the statements below apply to you:



- You have a fever.
- Your medication has been changed.
- Your physical condition has changed.
- You have joint or bone problems that become worse with exercise.

**Will it be hard and make me tired?**

Chronic kidney disease can make you feel: tired, in pain and short of breath. This can make moving around more difficult. If we don't move our muscles get smaller and weaker (this includes the heart as it is also a muscle). This can make activities such as climbing the stairs feel harder. Finding the level of activity that you can manage that makes you feel warm, your heart beat a bit faster and makes you a little out of breath is important. These are signs of **moderate physical activity** and mean you are working at the right intensity.

You do not need to push yourself to exhaustion to see benefits. However, the more you do the easier it gets and by adding small amounts of physical activity into your life you will see the benefits.



**No matter where your starting point is everyone can get fitter!**

### What you need to know about physical activity to get started...

#### What do I need to do?

Guidelines recommend that a person with chronic kidney disease does some form of aerobic activity e.g. walking, cycling, jogging or swimming on most days of the week. This can also include everyday activities such as: digging in the garden, vacuuming the house and washing the floor as long as these activities are performed at a vigorous level (quicker than usual) for at least 10 minutes at a time. Lifting weights is also important and has been shown to improve muscle strength and walking in patients with CKD.

To begin with this can just be lifting shopping bags or standing up from a chair 5 times in a row trying not to use your hands. Have a rest and then repeat.

### How hard do I need to work?

You should aim to perform exercise at a moderate intensity. Moderate means that your heart will be beating a bit faster than normal, you may feel a little bit hot and sweaty and a little bit out of breath. You should be able to talk but not be able to burst into song.

**This is between 12-14 on the scale.**

RPE Scale	
6	Very, Very Light
7	
8	Very Light
9	
10	Fairly Light
11	
12	Somewhat Hard
13	
14	Hard
15	
16	Very Hard
17	
18	Very, Very Hard
19	
20	

### How often and for how long do I need to be active for?

A good target to build up to is 30 minutes of aerobic activity a day. However, to begin with just try your best to get up and get out, even if you start with just 5 minutes of walking a day.

**Tip!** Energy levels can differ during the day. Try and perform your activities when you have most energy.

### **How long until I see the benefits of being active?**

Just doing it once is not going to do the trick. Physical activity is something you need to keep doing to see the benefits and the longer you keep it up the more benefits you will see.

**You should start to see benefits such as recovering quicker after your walk, having more energy and feeling pleased at achieving your goals after a few weeks.**

If for any reason you take time off exercise e.g. due to illness or a holiday, you will need to start off slowly again and build up. Changing your level of physical activity takes time, a good plan and a lot of will power. However, by just making small changes you will see big benefits.

### **Physical activity is safe for kidney patients.**



However, there are things that we all need to do to ensure that we keep ourselves safe when being physically active.

- To avoid injury make sure you warm up e.g. a slow walk to begin.
- Stay hydrated.
- Keep an eye on your blood sugar levels if you are diabetic.
- Let someone know where you are going or take a mobile phone.
- Wear comfy shoes with a good grip.



# Finding more information

Asking questions and getting them answered by a health care professional or someone who you feel is able to help is critical for you to begin a more active lifestyle. Never feel shy about asking anything to do with your physical activity

You can also access information on the internet and below are a few links:

National Health Service

<http://www.nhs.uk/Livewell/fitness/Pages/physical-activity-guidelines-for-adults.aspx>

Patient.co.uk

<http://www.patient.co.uk/health/Physical-Activity-For-Health.htm>

World Health Organization

[http://www.who.int/topics/physical\\_activity/en/](http://www.who.int/topics/physical_activity/en/)

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## Physical Activity Changing Together

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Action Plan &  
Physical Activity Diary

## My Goals

- A goal represents a target that is achieved through doing a specific task.
- Targets must be something we can measure e.g. how many times, how many minutes, how far.
- During the session you have learnt how to set long term and short term goals using step counts.
- **Long term goals** are something you want to achieve in the future that need time and planning.
- **Short term goals** are realistic and manageable that can help you to reach your long term goal over time.

My **long term goal** is to walk .....steps per day.

My **short term goal** is to add .....steps per day,  
every.....weeks.

### Step goal example :

- 1) Add up 7 days of steps: 24,500 total steps
- 2) Divide your total step counts by 7 days = 3500
- 3) Your average step count is 3500 steps per day.
- 4)  $24,500 \div 7 = 3,500$  average daily steps.
- 5) Add 3,00 to current average daily steps for long term goal.  
 $3,500 + 3,000 = 6500$

***My long term goal is to do 6,500 steps a day.***

**Action Plan**

What activities could I do?

What activity am I most likely to do?

How exactly am I going to do this?

What is going to stop me?

What will I do to overcome the barriers? (Think about and include the support you may need).

How confident am I that I can do this?

Choose a number between 1 and 10 (1 is not confident 10 is very confident).

12345678910

The number I choose is

What can I do to increase my confidence (If my confidence is less than 7)

When will I start my plan?

Date :

When will I review my plan?

Date :

## Week 1 My goal for this week is:

S	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
u				
n				
M	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
o				
n				
T	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
u				
e				
s				
W	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
e				
d				
T	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
h				
u				
r				
F	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
r				
i				
S	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
a				
t				

How did I do? .....

What might I change this week? .....

## Week 2 My goal for this week is:

S	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
u				
n				
M	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
o				
n				
T	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
u				
e				
s				
W	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
e				
d				
T	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
h				
u				
r				
F	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
r				
i				
S	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
a				
t				

How did I do? .....

What might I change this week? .....

### Week 3 My goal for this week is:

S	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
u				
n				
M	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
o				
n				
T	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
u				
e				
s				
W	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
e				
d				
T	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
h				
u				
r				
F	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
r				
i				
S	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
a				
t				

How did I do? .....

What might I change this week? .....

### Week 4 My goal for this week is:

S	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
u				
n				
M	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
o				
n				
T	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
u				
e				
s				
W	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
e				
d				
T	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
h				
u				
r				
F	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
r				
i				
S	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
a				
t				

How did I do? .....

What might I change this week? .....

## Week 5 My goal for this week is:.....

S	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
u				
n				
M	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
o				
n				
T	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
u				
e				
s				
W	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
e				
d				
T	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
h				
u				
r				
F	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
r				
i				
S	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
a				
t				

How did I do? .....

What might I change this week?.....

## Week 6 My goal for this week is:.....

S	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
u				
n				
M	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
o				
n				
T	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
u				
e				
s				
W	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
e				
d				
T	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
h				
u				
r				
F	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
r				
i				
S	What did I do today?	For how long?	Total steps?	How hard did it feel? RPE 6-20
a				
t				

How did I do? .....

What might I change this week?.....

.....

How did I do? .....

12

.....

How did I do? .....

13



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Extra Comments

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Extra Comments

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# Finding more information

Asking questions and getting them answered by a health care professional or someone who you feel is able to help is critical for you to begin a more active lifestyle. Never feel shy about asking anything to do with your physical activity

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Date of phone-call:  
Time Point: 1

Time of phone-call:

Duration:

Topic discussed	Comments
<b>When you left the group were you clear with what you needed to do?</b>	
<b>Did the programme help you to understand the importance of physical activity?</b>	
<b>Have you been able to start walking more?</b>	
<b>Have you been able to count and record steps?</b>	
<b>Have you achieved your goal set in the group session?</b>	
<b>Further comments</b>	
<b>How easy or difficult have you found this?</b>	
<b>Positive reflections</b>	

<b>Negative reflections</b>	
<b>How have you coped with any challenges?</b>	
<b>New action plans formed</b>	
<b>How confident are you on a scale of 1-10 that you can do this?</b>	
<b>Next phone-call time agreed</b>	
<b>Agree to send summary of phone-call out in post.</b>	
<b>Other comments</b>	

## **Appendix 2**

Questionnaires used within this thesis.

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## Leicester Kidney Patient Physical Activity Questionnaire

(LKP-PAQ) (version 4, 17<sup>th</sup> March 2015)

Participant Code

PEARL .....

### **Section 1: About You**

Date questionnaire filled in : .....

*These questions ask a few details about you which will help us make sense of the research findings.  
Please tick the boxes to indicate your answers or write the information where indicated.*

1. Are you    Male            ☐                      Female            ☐
2. What was your age in years at your last birthday? \_\_\_\_\_ Years
3. Do you smoke?                      Yes, I am a current smoker ☐                      No, I have never smoked ☐  
I used to smoke but I gave up \_\_\_\_\_ years ago ☐
4. Do you live alone? Yes ☐                      No ☐  
a. If no, who do you live with? \_\_\_\_\_
5. How old were you when you left school/education? \_\_\_\_\_ Years
6. Are you diabetic? Yes ☐                      No ☐
7. Have you ever had a heart problem or a stroke?                      Yes ☐                      No ☐
8. Do you have any other medical conditions as well as your kidney disease?  
Yes ☐                      No ☐  
If yes, please write here what other conditions you have :
9. Is there anything else which makes physical activity difficult for you?  
Yes ☐                      No ☐  
If yes, please briefly explain :

Continued overleaf ....

## Leicester Kidney Patient Physical Activity Questionnaire

(LKP-PAQ) (version 4, 17<sup>th</sup> March 2015)

Participant Code

PEARL .....

### 10. What is your ethnic group?

*Choose ONE section from A to E, then tick the appropriate box to indicate your ethnic group :*

#### **A: White**

☐ British

☐ Irish

☐ Any other White background  
(please write in) .....

#### **B: Mixed**

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

☐ Any other mixed background  
(please write in).....

#### **C: Asian or Asian British**

☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Any other Asian background  
(please write in) .....

#### **D: Black or Black British**

☐ Caribbean

☐ African

☐ Any other Black background  
(please write in) .....

#### **E : Chinese or other ethnic group**

☐ Chinese

☐ Any other

(please write in).....

#### **Not stated**

☐ I prefer not to say

**Section Two : About your physical activity and exercise habits**

**2A : DUKE ACTIVITY STATUS INDEX**

Can you: (please circle yes or no)

1	Take care of yourself, that is, eat, dress, bathe or use the toilet?	Yes	No
2	Walk indoors, such as around your house?	Yes	No
3	Walk a block or two on level ground?	Yes	No
4	Climb a flight of stairs or walk up a hill?	Yes	No
5	Run a short distance?	Yes	No
6	Do light work around the house like dusting or washing dishes	Yes	No
7	Do moderate work around the house like vacuuming, sweeping floors or carrying groceries?	Yes	No
8	Do heavy work around the house like scrubbing floors or lifting or moving heavy furniture?	Yes	No
9	Do garden work like raking leaves, weeding or pushing a lawn mower?	Yes	No
10	Have sexual relations?	Yes	No
11	Participate in moderate recreational activities like golf, bowling, dancing, doubles tennis or throwing a ball?	Yes	No
12	Participate in strenuous sports like swimming, singles tennis, football, basketball or skiing?	Yes	No



**2B : GP PHYSICAL ACTIVITY QUESTIONNAIRE**

1. Please tell us the type and amount of physical activity involved in your work :

(if you do not work, please tick box a)

		Please tick one box only
a	I am not in employment (e.g. retired, retired for health reasons, unemployed, fulltime carer etc)	
b	I spend most of my time at work sitting (such as in an office)	
c	I spend most of my time at work standing or walking. However, my work does not require much intense physical effort (e.g. shop assistant, hairdresser, security guard, childminder, etc.)	
d	My work involves definite physical effort including handling of heavy objects and use of tools (e.g. plumber, electrician, carpenter, cleaner, hospital nurse, gardener, postal delivery worker etc)	
e	My work involves vigorous physical activity including handling of very heavy objects (e.g. scaffolder, construction worker, refuse collector, etc.)	

Continued overleaf ....

**2B : GP PHYSICAL ACTIVITY QUESTIONNAIRE** *continued*

2. During the **last week** how many hours did you spend on each of the following activities?

*Please answer whether you are in employment or not*

		Please tick one box only on each row			
		None	Some but less than 1 hour	1 hour but less than 3 hours	3 hours or more
a	Physical exercise such as swimming, jogging, aerobics, football, tennis, gym workout etc				
b	Cycling, including cycling to work and during leisure time				
c	Walking, including walking to work, shopping, for pleasure etc				
d	Housework or Childcare				
e	Gardening or DIY				

3. How would you describe your usual walking pace? Please tick one box only.

Slow pace  
(i.e. less than 3 mph)

Brisk pace


Steady average pace

Fast pace  
(i.e. over 4mph)


## 2D : STAGE OF CHANGE QUESTIONNAIRE

Please tick ONE statement that best describes your current exercise levels

Regular exercise = 3 times or more leisure time exercise sessions per week for 25 minutes or longer, during which you get sweaty

	Tick one only
1 I currently do not exercise regularly and I do not intend to start exercising regularly in the next 6 months	<input type="checkbox"/>
2 I currently do not exercise regularly, but I am thinking about starting to exercise regularly in the next 6 months	<input type="checkbox"/>
3 I currently exercise sometimes, but not regularly	<input type="checkbox"/>
4 I currently exercise regularly but I have only begun doing so within the last 6 months	<input type="checkbox"/>
5 I currently exercise regularly and have done so for longer than 6 months	<input type="checkbox"/>

## 2E : SELF EFFICACY QUESTIONNAIRE

Please circle the number that best represents your response to each statement.

I am confident that I can participate in regular exercise when :

		Not at all confident		Moderately confident		Extremely confident
1	I am tired	1	2	3	4	5
2	I am in a bad mood.	1	2	3	4	5
3	I feel I don't have time	1	2	3	4	5
4	I am on vacation/holiday	1	2	3	4	5
5	The weather is bad	1	2	3	4	5

## Leicester Kidney Patient Physical Activity Questionnaire

(LKP-PAQ) (version 4, 17<sup>th</sup> March 2015)

Participant Code

PEArL .....

### **Section 3 : Your comments and further information**

This section is for you to tell us more about exercise or physical activity for kidney patients, if you would like to do so. If you need more space, you can write on the back of this page.

1. What do you think are the benefits of being more active?  
*(please list the benefits here)*
  
2. What do you think are the drawbacks or negative effects of being more active?  
*(please list the drawbacks here)*
  
3. What might help people with a kidney disease to become more active?
  
4. What can make it difficult for people with a kidney disease to be more active?
  
5. Is there anything else you would like to add?

### **Thank you for completing our survey**

If you need to return this form to us at a later date, or you would like to contact us for any reason, please use the following address: Dr Alice Smith, Leicester Kidney Exercise Team, Academic Unit, Leicester General Hospital, LE5 4PW.

Tel 0116 258 4346, email : [kidney.exercise@uhl-tr.nhs.uk](mailto:kidney.exercise@uhl-tr.nhs.uk)

## Leicester Kidney Patient Physical Activity Questionnaire

(LKP-PAQ) (version 4, 17<sup>th</sup> March 2015)

Participant Code

PEArL .....

### 2E WALKING SELF-EFFICACY QUESTIONNAIRE

Please indicate how confident you are that you can successfully walk at a moderately fast pace without stopping. A moderately fast pace is sufficient to increase your heart rate and to work up a sweat.

Remember to answer honestly and accurately. There is no right or wrong answer.

FOR EXAMPLE:

If you have complete confidence that you could walk for 5 minutes at a moderately fast pace without stopping, you would circle 100%. However, if you had no confidence at all that you could walk for 5 minutes at a moderately fast pace without stopping, you would circle 0%.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Not at all confident					Moderately Confident					Highly Confident

I BELIEVE THAT I CAN WALK:

1. For 5 minutes at a moderately fast pace without stopping

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Not at all confident					Moderately Confident					Highly Confident

2. For 10 minutes at a moderately fast pace without stopping

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Not at all confident					Moderately Confident					Highly Confident

## Leicester Kidney Patient Physical Activity Questionnaire

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Participant Code

PEARL .....

### I BELIEVE THAT I CAN WALK:

#### 3. For 15 minutes at a moderately fast pace without stopping

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%	
Not at all						Moderately					Highly
confident						Confident					Confident

#### 4. For 20 minutes at a moderately fast pace without stopping

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%	
Not at all					Moderately					Highly confident	
Confident					Confident						

#### 5. For 25 minutes at a moderately fast pace without stopping

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%	
Not at all						Moderately					Highly
confident						Confident					Confident

#### 6. For 30 minutes at a moderately fast pace without stopping

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%	
Not at all					Moderately					Highly	
confident					Confident					Confident	

#### 7. For 35 minutes at a moderately fast pace without stopping

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%	
Not at all											ModeratelyCon
confident											fident

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PEARL .....

Highly

Confident

### 8. For 40 minutes at a moderately fast pace without stopping

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Not at all					Moderately					Highly
confident					Confident					Confident

## I BELIEVE THAT I CAN WALK:

### 9. For 45 minutes at a moderately fast pace without stopping

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Not at all					Moderately					Highly
confident					Confident					Confident

### 10. For 50 minutes at a moderately fast pace without stopping

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Not at all					Moderately					Highly
confident					Confident					Confident

**INSTRUCTIONS:** The following items reflect your beliefs or expectations about the benefits of regular exercise or physical activity. Please respond to the following statements marking your answer honestly and by circling the appropriate number/statement. Remember to read each question carefully.

**EXAMPLE:**

Q) Exercise will....:

1 STRONGLY DISAGREE	2 DISAGREE	3 NEUTRAL	4 AGREE	5 STRONGLY AGREE
---------------------------	---------------	--------------	------------	------------------------

1) Exercise will improve my ability to perform daily activities:

1 STRONGLY DISAGREE	2 DISAGREE	3 NEUTRAL	4 AGREE	5 STRONGLY AGREE
---------------------------	---------------	--------------	------------	------------------------

2) Exercise will improve my social standing:

1 STRONGLY DISAGREE	2 DISAGREE	3 NEUTRAL	4 AGREE	5 STRONGLY AGREE
---------------------------	---------------	--------------	------------	------------------------

3) Exercise will improve my overall body functioning:

1 STRONGLY DISAGREE	2 DISAGREE	3 NEUTRAL	4 AGREE	5 STRONGLY AGREE
---------------------------	---------------	--------------	------------	------------------------

4) Exercise will help manage stress:

1 STRONGLY DISAGREE	2 DISAGREE	3 NEUTRAL	4 AGREE	5 STRONGLY AGREE
---------------------------	---------------	--------------	------------	------------------------



5) Exercise will strengthen my bones:

1 STRONGLY DISAGREE	2 DISAGREE	3 NEUTRAL	4 AGREE	5 STRONGLY AGREE
---------------------------	---------------	--------------	------------	------------------------

6) Exercise will improve my mood:

1 STRONGLY DISAGREE	2 DISAGREE	3 NEUTRAL	4 AGREE	5 STRONGLY AGREE
---------------------------	---------------	--------------	------------	------------------------

7) Exercise will increase my muscle strength:

1 STRONGLY DISAGREE	2 DISAGREE	3 NEUTRAL	4 AGREE	5 STRONGLY AGREE
---------------------------	---------------	--------------	------------	------------------------

8) Exercise will make me more at ease with people:

1 STRONGLY DISAGREE	2 DISAGREE	3 NEUTRAL	4 AGREE	5 STRONGLY AGREE
---------------------------	---------------	--------------	------------	------------------------

9) Exercise will aid in weight control:

1 STRONGLY DISAGREE	2 DISAGREE	3 NEUTRAL	4 AGREE	5 STRONGLY AGREE
---------------------------	---------------	--------------	------------	------------------------

10) Exercise will improve my psychological state:

1 STRONGLY DISAGREE	2 DISAGREE	3 NEUTRAL	4 AGREE	5 STRONGLY AGREE
---------------------------	---------------	--------------	------------	------------------------



Name	
ID	
Date	

Below are statements people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally.

Circle the answer that is most true for you today. If the statement does not apply, select N/A.

1.	When all is said and done, I am the person who is responsible for taking care of my health.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
2.	Taking an active role in my own health care is the most important thing that affects my health.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
3.	I am confident I can help prevent or reduce problems associated with my health.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
4.	I know what each of my prescribed medications do.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
5.	I am confident that I can tell whether I need to go to the doctor or nurse specialist, or whether I can take care of a health problem myself.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
6.	I am confident that I can tell a doctor or nurse specialist concerns I have even when he or she does not ask.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
7.	I am confident that I can follow through on medical treatments I may need to do at home.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
8.	I understand my health problems and what causes them.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
9.	I know what treatments are available for my health problems.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
10.	I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
11.	I know how to prevent problems with my health.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
12.	I am confident I can figure out solutions when new problems arise with my health.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
13.	I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A

---

## Your Health and Well-Being

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This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. *Thank you for completing this survey!*

For each of the following questions, please tick the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf .....	 <input type="checkbox"/>	 <input type="checkbox"/>	 <input type="checkbox"/>
b. Climbing <u>several</u> flights of stairs.....	 <input type="checkbox"/>	 <input type="checkbox"/>	 <input type="checkbox"/>

3. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. <u>Accomplished less</u> than you would like .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Were limited in the <u>kind</u> of work or other activities .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. <u>Accomplished less</u> than you would like .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Did work or other activities <u>less carefully than usual</u> .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
1. Have you felt calm and peaceful? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. Did you have a lot of energy? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. Have you felt downhearted and low? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

*Thank you for completing these questions!*

## Leicester Kidney Patient Physical Activity Questionnaire

(LKP-PAQ) (version 4, 17<sup>th</sup> March 2015)

Participant Code

PEARL .....

### 2C: INTERNATIONAL PHYSICAL ACTIVITY QUESTIONNAIRE (IPAQ)

We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the **last 7 days**. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Think about all the **vigorous** activities that you did in the **last 7 days**. **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.

1. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling?

\_\_\_\_\_ **days per week**

☐

No vigorous physical activities



**Skip to question 3**

2. How much time did you usually spend doing **vigorous** physical activities on one of those days?

\_\_\_\_\_ **hours per day**

\_\_\_\_\_ **minutes per day**

☐

Don't know/Not sure

Think about all the **moderate** activities that you did in the **last 7 days**. **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.

3. During the **last 7 days**, on how many days did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

\_\_\_\_\_ **days per week**

☐

No moderate physical activities



**Skip to question 5**

## Leicester Kidney Patient Physical Activity Questionnaire

(LKP-PAQ) (version 4, 17<sup>th</sup> March 2015)

Participant Code

PEArL .....

4. How much time did you usually spend doing **moderate** physical activities on one of those days?

\_\_\_\_\_ **hours per day**

\_\_\_\_\_ **minutes per day**

☐ Don't know/Not sure

Think about the time you spent **walking** in the **last 7 days**. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.

5. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?

\_\_\_\_\_ **days per week**

☐ No walking → **Skip to question 7**

6. How much time did you usually spend **walking** on one of those days?

\_\_\_\_\_ **hours per day**

\_\_\_\_\_ **minutes per day**

☐ Don't know/Not sure

The last question is about the time you spent **sitting** on weekdays during the **last 7 days**. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

7. During the **last 7 days**, how much time did you spend **sitting** on a **week day**?

\_\_\_\_\_ **hours per day**

\_\_\_\_\_ **minutes per day**

☐ Don't know/Not sure

Participant Code

.....

**Kidney Knowledge Survey (KiKS)**  
**Explanatory Notes for patients**

We would like you to fill in the Kidney Knowledge Survey because we are interested to find out how much you know about kidney disease. This questionnaire has been developed and validated in the USA and so a couple of the terms are not easily understandable in the UK. This sheet aims to provide explanation of what these terms mean:

In the fourth question:

“Select the ONE MEDICATION from the list below that a person with CHRONIC kidney disease should AVOID:”

The question asks about “Tylenol” – this is another name for Paracetamol  
The question also asks about “Motrin” – this is another name for Ibuprofen

**Thank you for filling in the questionnaire. If you have any questions or need help, please ask a member of the research team.**



### Kidney Knowledge Survey (KIKS)

1. On average, your blood pressure should be:
  - ☐ 160/90
  - ☐ 150/100
  - ☐ 170/80
  - ☐ Lower than 130/80
2. Are there certain medications your doctor can prescribe to help keep your kidney(s) as healthy as possible?
  - ☐ Yes   ☐ No
3. Why is too much protein in the urine not good for the kidney?
  - ☐ It can scar the kidney
  - ☐ It is a sign of kidney damage
  - ☐ It is a sign of kidney damage AND can scar the kidney
  - ☐ It can cause an infection in the urine
  - ☐ All of the above
4. Select the ONE MEDICATION from the list below that a person with CHRONIC kidney disease should AVOID:
  - ☐ Lisinopril
  - ☐ Tylenol
  - ☐ Motrin / Ibuprofen
  - ☐ Vitamin E
  - ☐ Iron Pills
5. If the kidney(s) fail, treatment might include (FOR THIS QUESTION you can PICK up to TWO ANSWERS):
  - ☐ Lung biopsy
  - ☐ Hemodialysis
  - ☐ Bronchoscopy
  - ☐ Colonoscopy
  - ☐ Kidney transplant
6. What does "GFR" stand for?
  - ☐ Glomerular Filtration Rate - tells us level of kidney function
  - ☐ Good Flow Renal - tells us about flow of urine from kidney
  - ☐ Gain For Real - tells us if your kidney function is improving
  - ☐ Glucose Function Rate - tells us about your blood sugar level
7. Are there stages of CHRONIC kidney disease?
  - ☐ Yes   ☐ No
8. Does CHRONIC kidney disease increase a person's chances for a heart attack?
  - ☐ Yes   ☐ No
9. Does CHRONIC kidney disease increase a person's chance for death from any cause?
  - ☐ Yes   ☐ No

10. This section is about WHAT THE KIDNEY DOES. Please select one answer to each question below.

	Yes	No
Does the kidney make urine?	<input type="checkbox"/>	<input type="checkbox"/>
Does the kidney clean blood?	<input type="checkbox"/>	<input type="checkbox"/>
Does the kidney help keep bones healthy?	<input type="checkbox"/>	<input type="checkbox"/>
Does the kidney keep a person from losing hair?	<input type="checkbox"/>	<input type="checkbox"/>
Does the kidney help keep red blood cell counts normal?	<input type="checkbox"/>	<input type="checkbox"/>
Does the kidney help keep blood pressure normal?	<input type="checkbox"/>	<input type="checkbox"/>
Does the kidney help keep blood sugar normal?	<input type="checkbox"/>	<input type="checkbox"/>
Does the kidney help keep potassium levels in the blood normal?	<input type="checkbox"/>	<input type="checkbox"/>
Does the kidney help keep phosphorus levels in the blood normal?	<input type="checkbox"/>	<input type="checkbox"/>

11. This section is about SYMPTOMS. Please select from the list, all of the symptoms a person might have if they have chronic kidney disease or kidney failure.

	Yes	No
Increased fatigue?	<input type="checkbox"/>	<input type="checkbox"/>
Shortness of breath?	<input type="checkbox"/>	<input type="checkbox"/>
Metal taste / bad taste in the mouth?	<input type="checkbox"/>	<input type="checkbox"/>
Unusual itching?	<input type="checkbox"/>	<input type="checkbox"/>
Nausea and / or vomiting?	<input type="checkbox"/>	<input type="checkbox"/>
Hair loss?	<input type="checkbox"/>	<input type="checkbox"/>
Increased trouble sleeping?	<input type="checkbox"/>	<input type="checkbox"/>
Weight loss?	<input type="checkbox"/>	<input type="checkbox"/>
Confusion?	<input type="checkbox"/>	<input type="checkbox"/>
No symptoms at all?	<input type="checkbox"/>	<input type="checkbox"/>

## ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

Name.....

Date.....

### YOUR VIEWS ABOUT YOUR KIDNEY PROBLEM

Listed below are a number of symptoms that you may or may not have experienced since your kidney problem. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your kidney problem, and whether you believe that these symptoms are related to your kidney problem.

	I have experienced this symptom since my kidney problem			This symptom is related to my kidney problem	
	Yes	No		Yes	No
Pain					
Sore Throat					
Nausea					
Breathlessness					
Weight Loss					
Fatigue					
Stiff Joints					
Sore Eyes					
Wheeziness					
Headaches					
Upset Stomach					
Sleep Difficulties					
Dizziness					
Loss of Strength					

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your kidney problem by ticking the appropriate box.

	VIEWES ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	My kidney problem will last a short time					
IP2	My kidney problem is likely to be permanent rather than temporary					
IP3	My kidney problem will last for a long time					
IP4	This kidney problem will pass quickly					
IP5	I expect to have this kidney problem for the rest of my life					
IP6	My kidney problem is a serious condition					

	<b>VIEWS ABOUT YOUR ILLNESS</b>	<b>STRONGLY DISAGREE</b>	<b>DISAGREE</b>	<b>NEITHER AGREE NOR DISAGREE</b>	<b>AGREE</b>	<b>STRONGLY AGREE</b>
IP7	My kidney problem has major consequences on my life					
IP8	My kidney problem does not have much effect on my life					
IP9	My kidney problem strongly affects the way others see me					
IP10	My kidney problem has serious financial consequences					
IP11	My kidney problem causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my kidney problem gets better or worse					
IP14	The course of my kidney problem depends on me					
IP15	Nothing I do will affect my kidney problem					
IP16	I have the power to influence my kidney problem					
IP17	My actions will have no affect on the outcome of my kidney problem					
IP18	My kidney problem will improve in time					
IP19	There is very little that can be done to improve my kidney problem					
IP20	Physical activity will be effective in curing my kidney problem					
IP21	The negative effects of my kidney problem can be prevented (avoided) by physical activity					
IP22	Physical activity can control my illness					
IP23	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My kidney problem is a mystery to me					
IP26	I don't understand my kidney problem					
IP27	My kidney problem doesn't make any sense to me					
IP28	I have a clear picture or understanding of my kidney problem					
IP29	The symptoms of my kidney problem change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My kidney problem is very unpredictable					
IP32	I go through cycles in which my kidney problem gets better and worse.					
IP33	I get depressed when I think about my kidney problem					
IP34	When I think about my kidney problem I get upset					
IP35	My kidney problem makes me feel angry					
IP36	My kidney problem does not worry me					
IP37	Having this kidney problem makes me feel anxious					
IP38	My kidney problem makes me feel afraid					

## CAUSES OF MY ILLNESS

We are interested in what **you** consider may have been the cause of your kidney problem. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your kidney problem rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your kidney problem. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
<input type="checkbox"/>	Stress or worry					
<input type="checkbox"/>	Hereditary - it runs in my family					
<input type="checkbox"/>	A Germ or virus					
<input type="checkbox"/>	Diet or eating habits					
<input type="checkbox"/>	Chance or bad luck					
<input type="checkbox"/>	Poor medical care in my past					
<input type="checkbox"/>	Pollution in the environment					
<input type="checkbox"/>	My own behaviour					
<input type="checkbox"/>	My mental attitude e.g. thinking about life negatively					
<input type="checkbox"/>	Family problems or worries caused my illness					
<input type="checkbox"/>	Overwork					
<input type="checkbox"/>	My emotional state e.g. feeling down, lonely, anxious, empty					
<input type="checkbox"/>	Ageing					
<input type="checkbox"/>	Alcohol					
<input type="checkbox"/>	Smoking					
<input type="checkbox"/>	Accident or injury					
<input type="checkbox"/>	My personality					
<input type="checkbox"/>	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused **YOUR kidney problem**. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

### Hospital Anxiety and Depression Scale (HADS)

**Instructions:** Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he or she will be able to help you more. This questionnaire is designed to help your doctor know how you feel. Read each item and circle the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

<b>I feel tense or 'wound up':</b>	<b>A</b>	<b>I feel as if I am slowed down:</b>	<b>D</b>
Most of the time	3	Nearly all of the time	3
A lot of the time	2	Very often	2
Time to time, occasionally	1	Sometimes	1
Not at all	0	Not at all	0
<b>I still enjoy the things I used to enjoy:</b>	<b>D</b>	<b>I get a sort of frightened feeling like 'butterflies in the stomach':</b>	<b>A</b>
Definitely as much	0	Not at all	0
Not quite so much	1	Occasionally	1
Only a little	2	Quite often	2
Not at all	3	Very often	3
<b>I get a sort of frightened feeling like something awful is about to happen:</b>	<b>A</b>	<b>I have lost interest in my appearance:</b>	<b>D</b>
Very definitely and quite badly	3	Definitely	3
Yes, but not too badly	2	I don't take as much care as I should	2
A little, but it doesn't worry me	1	I may not take quite as much care	1
Not at all	0	I take just as much care as ever	0
<b>I can laugh and see the funny side of things:</b>	<b>D</b>	<b>I feel restless as if I have to be on the move:</b>	<b>A</b>
As much as I always could	0	Very much indeed	3
Not quite so much now	1	Quite a lot	2
Definitely not so much now	2	Not very much	1
Not at all	3	Not at all	0
<b>Worrying thoughts go through my mind:</b>	<b>A</b>	<b>I look forward with enjoyment to things:</b>	<b>D</b>
A great deal of the time	3	As much as I ever did	0
A lot of the time	2	Rather less than I used to	1
From time to time but not too often	1	Definitely less than I used to	3
Only occasionally	0	Hardly at all	2
<b>I feel cheerful:</b>	<b>D</b>	<b>I get sudden feelings of panic:</b>	<b>A</b>
Not at all	3	Very often indeed	3
Not often	2	Quite often	2
Sometimes	1	Not very often	1
Most of the time	0	Not at all	0
<b>I can sit at ease and feel relaxed:</b>	<b>A</b>	<b>I can enjoy a good book or radio or TV programme:</b>	<b>D</b>
Definitely	0	Often	0
Usually	1	Sometimes	1
Not often	2	Not often	2
Not at all	3	Very seldom	3

Questions relating to anxiety are indicated by an 'A' while those relating to depression are shown by a 'D'. Scores of 0-7 in respective subscales are considered normal, with 8-10 borderline and 11 or over indicating clinical 'caseness'.

Participant Code:

### The Physical Activity Self-Regulation Questionnaire

These questions are about any walking plans and goals you may have made during the last 8 weeks. Please **circle** the answer that best corresponds to you.

During the last **8 weeks** have you:

1. Have you set yourself regular goals detailing how many steps you would do a day?

Most of the time	Some of the time	Rarely	Never
------------------	------------------	--------	-------

2. Regularly set yourself a plan detailing where and when you would do your walking?

Most of the time	Some of the time	Rarely	Never
------------------	------------------	--------	-------

3. Worn the pedometer device (step counter)?

Most of the time	Some of the time	Rarely	Never
------------------	------------------	--------	-------

4. Kept a log of how many steps you have done a day?

Most of the time	Some of the time	Rarely	Never
------------------	------------------	--------	-------

5. Been aware of your physical activity level?

Most of the time	Some of the time	Rarely	Never
------------------	------------------	--------	-------

6. Tried to be physically active regularly?

Most of the time	Some of the time	Rarely	Never
------------------	------------------	--------	-------

PEARL : The Physical Activity Self-Regulation Questionnaire version 1 20<sup>th</sup> January 2016

# **Appendix 3**

## Study documentation

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**Physical Activity for Kidney Patients: Your Opinions**  
**Part 1**

**QCKD Part 1 Participant Information Sheet**  
Version 2 dated 31st May 2012

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and ask us if there is anything that is not clear or if you would like more information.

**What is the purpose of the study?**

Leading an active lifestyle is beneficial for health, and research shows that this is true for people with kidney problems as well as for everyone else. We want to develop ways to help kidney patients increase their activity levels. First of all, it is important for us to understand more about the current activity levels of kidney patients, and how kidney patients feel about exercise. The purpose of this research is to collect this information.

This research study has two separate parts. Part 1 is a survey of kidney patients' exercise habits. Part 2 involves small group and one-to-one discussions about exercise. At the moment, we would just like to ask you to participate in Part 1.

**Why have I been chosen?**

You have been chosen because you are a patient attending a Nephrology Outpatient Clinic. We will ask up to 600 patients to do the survey.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will be free to withdraw at any time and without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of care you receive in any way.

### **What will happen to me if I take part?**

If you agree to participate, you will be asked to fill in a questionnaire about exercise. This should take no more than 10 minutes to complete. You can fill it in while you are in the clinic waiting area, and the researcher will collect it from you when you have finished, or else you can leave it with the clinic reception staff.

The questionnaire will be marked with a code: it will not have your name or any other identifiable information on it. We can analyse the information you provide on the form without knowing who you are.

However, the information will be even more valuable to us if we can add to it some of your clinical information obtained from your medical records. Therefore, the researcher will ask for your permission to access your records and extract the required information: your blood and urine results, blood pressure, weight, ethnicity, any other medical conditions, and the drugs you are taking.

If you agree, this information will be extracted from your records and will be added to the study database in an anonymous form, separately to any information from which you could be identified. If you agree to this, you will be asked to sign a consent form.

Finally, the researcher will ask you if you are interested in possibly participating in Part 2, when we will talk to patients in more detail about physical activity and exercise. If you may be interested in Part 2, we will ask you to fill in a Contact Form so we can give you more information at a later date. This does not mean you have to take part: the study will be explained to you nearer the time, and you will be free to decide whether or not you wish to participate. We will only be able to talk to a limited number of volunteers in Part 2, so even if you do agree to take part, we may not invite you to participate if too many patients volunteer for it.

On the Contact Form, you can also choose to be informed about other research projects in the future. If you fill in the Contact Form, we will store it securely, separately from your survey form and clinical information, and we will only use it to contact you for the purposes you have chosen.

### *Confidentiality*

Questionnaires and clinical information will be labelled with a code instead of your name, and all your responses and data will be stored securely and separately from your personal details.

**What do I have to do?**

You just need to fill in the survey form and give it back to us. Other than that, we ask you to continue your life in the usual way. You should follow your usual recommended diet, and take your other medicines as prescribed.

**What are the possible disadvantages and risks of taking part?**

The only disadvantage of taking part is that you will need to spend a few minutes filling in the survey form while you are in the clinic waiting room.

**What are the possible benefits of taking part?**

There are no direct benefits to you of taking part in this research.

**What happens when the research study stops?**

Your usual clinical care will continue unchanged.

**What if something goes wrong?**

In the very unlikely event of you being harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms would be available to you.

If you wish to make a complaint about the study you can contact the UHL Patient Information and Liaison Service by writing to PILS, Gwendolen House, Gwendolen Road, Leicester LE5 4QF, or telephoning 08081 788337 (free phone number)

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be labelled with a code instead of your personal details. We will keep a separate list of the codes and patient identities. If you prefer to remain completely anonymous, you can return your questionnaire without your name or personal details.

**What will happen to the results of the research study?**

We expect the results of the research to become available in 2014. We will publicise the results with posters and leaflets in clinical areas so you can read about them while you are there, and we will write a report about them in our Exercise Newsletter. If you would like us to send you a written report of the results, or if you would like to receive our Exercise Newsletter, please ask the researcher or contact the Chief Investigator, Dr Alice Smith (contact details at the end of this document). The results will also be published in a medical journal. All information will be anonymised so you will not be identified in any report or publication.

**Who is organising and funding the research?**

The research is being organised by Senior Research Scientist Dr Alice Smith and staff at the John Walls Renal Unit, and funded by a research grant from the British Renal Society.

**Who has reviewed the study?**

All research that involves NHS patients or staff, information from NHS medical records or uses NHS premises or facilities must be approved by an NHS Research Ethics Committee before it goes ahead. This study has been reviewed by the NHS Research Ethics Committee East Midlands - Northampton. Approval means that the committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits and that you have been given sufficient information on which to make an informed decision.

**Contact for Further Information**

If you would like any further information about this study please contact the Chief Investigator Dr Alice Smith, or Dr James Burton on 0116 252 3061.

**Dr Alice Smith,**  
Leicester Kidney Exercise Team,  
C/O Dr Barratt's secretary,  
John Walls Renal Unit,  
Leicester General Hospital, LE5 4PW.  
Tel 0116 252 5033  
Email [kidney.exercise@uhl-tr.nhs.uk](mailto:kidney.exercise@uhl-tr.nhs.uk)

**Thank you for reading this, and for considering taking part in this study.**

**You will be given a copy of this information sheet and if applicable, your signed consent form to keep**

**Physical Activity for Kidney Patients: Your Opinions  
Part 2**

**QCKD Part 2 Participant Information Sheet**  
Version 2 dated 31st May 2012

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and ask us if there is anything that is not clear or if you would like more information.

**What is the purpose of the study?**

Leading an active lifestyle is beneficial for health, and research shows that this is true for people with kidney problems as well as for everyone else. We want to develop ways to help kidney patients increase their activity levels. First of all, it is important for us to understand more about the current activity levels of kidney patients, and how kidney patients feel about exercise. The purpose of this research is to collect this information.

This research study has two separate parts. Part 1 is a survey of kidney patients' exercise habits. Part 2 involves small group and one-to-one discussions with both kidney patients and clinic staff to find out much more detail about issues around exercise for kidney patients. We would like to ask you to participate in Part 2.

**Why have I been chosen?**

You have been chosen because you are a patient attending a Nephrology Outpatient Clinic. We will ask up to 80 patients to take part in Part 2 of this research study. We will also be carrying out separate focus groups and interviews with kidney clinic staff.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will be free to withdraw at any time and without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of care you receive in any way.



### **What will happen to me if I take part?**

If you agree to participate in Part 2, we may invite you to take part in a focus group with other kidney patients, or a one-to-one interview.

We will only be able to include a limited number of patients in the focus groups and interviews, so even if you agree, we may not invite you to take part if we have a large number of volunteers.

If you take part in a focus group, we may also invite you to come back another time for a one-to-one interview as well, but you can choose whether or not you wish to do this.

More details about the focus groups and interviews are provided below.

#### *Focus Groups*

If you take part in a focus group, you will be asked to attend at a mutually agreed time to discuss your opinions, feelings and ideas about physical activity and exercise as a kidney patient. The focus group will include about 4-8 kidney patients.

As part of this research project, we will also be running similar focus groups with members of kidney clinic staff, but you will only be asked to participate in a focus group with other patients. We will not hold focus groups with mixed patients and staff.

The focus group will be held in a comfortable, private room and will take about 60 to 90 minutes. The discussion will be led by two researchers who have no involvement with the clinical care team, and the discussions will only be heard by the research team. You will only be asked to talk about exercise and related issues.

We intend to hold some focus groups in languages other than English so that we can include the opinions of people from different ethnic populations who do not speak English as a first language. These groups will be led by a trained interpreter. However, if there are small numbers of volunteers who speak languages other than English, these individuals will instead be invited to take part in a one-to-one interview with a trained interpreter (see below for details of the interviews). If this is relevant to you, we will discuss these options with you before focus groups and interviews take place.

#### *Interviews*

Some patients will be invited to take part in a one-to-one interview about their individual experiences of physical activity and exercise. If you agree, you will be asked to attend at a mutually agreed time to discuss your opinions, feelings and

ideas with a researcher who has no involvement with the clinical care team. The interviews will be held in a comfortable, private room and will take about 60 minutes. You will only be asked to talk about exercise, not any other subject. You do not need to have been involved in a focus group earlier in the study to take part in an interview.

Some interviews will be conducted in languages other than English in order to include the opinions of people from different ethnic populations. Non-English interviews will be lead by a trained bilingual researcher from the relevant ethnic group.

#### *Confidentiality*

We will use a digital recorder to record what people say in the focus groups and interviews so that we can analyse them later, and we will also take written notes. You will not be identified by name, and no personal information will be recorded in the notes. The recordings will be transcribed and all the comments analysed together to give us a full picture of peoples' experiences. The recordings and notes will be stored safely and treated in the strictest confidence.

Nothing you say in the focus groups or interviews will be reported back to those involved in your care or anyone who was not present at the time, except anonymously in the form of a report or publication about the study. We may use direct quotations of what you said in the focus group or interview, but this will always be anonymous and no one will be able to tell that it was you who said it.

We want to take into account the views of a wide range of kidney patients in this study. In order to find out about the diversity of the patients involved, a researcher will need to look at your medical records. We will extract information such as your age, gender, ethnicity and the severity of your kidney problems. However, none of this information will be stored with any personal details that you could be identified from, and we will only use this information to report on the diversity of the patients in the study.

While you are taking part in the study, your contact details will be made available to the researchers so that they can contact you to arrange the details of the focus group or interview. These details will be stored securely and separately from the research information above.

#### **What are the possible disadvantages and risks of taking part?**

The only disadvantage of taking part is that you will need to attend for the focus group and/or interview(s). This will take up a few hours of your own time. We will reimburse any travel expenses you incur in taking part in this research study.

**What are the possible benefits of taking part?**

There are no direct benefits to you of taking part in this research.

**What happens when the research study stops?**

Your usual clinical care will continue unchanged.

**What if something goes wrong?**

In the very unlikely event of you being harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms would be available to you.

If you wish to make a complaint about the study you can contact the UHL Patient Information and Liaison Service by writing to PILS, Gwendolen House, Gwendolen Road, Leicester LE5 4QF, or telephoning 08081 788337 (free phone number).

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be anonymous. Any information about you will have your name, address and personal details removed so that you cannot be recognised from it. Your identity will not be associated with the clinical information we store or the recordings we make, and everything you say will be entirely anonymous, including any direct quotations we may use in publications.

**What will happen to the results of the research study?**

We expect the results of the research to become available in 2014. We will publicise the results in posters and leaflets in clinical areas so you can read them while you are there, and we will write a report about them in our Exercise Newsletter. If you would like us to send you a written report of the results, or if you would like to receive our Exercise Newsletter, please ask the researcher or contact the Chief Investigator, Dr Alice Smith (contact details at the end of this document).

The results will also be published in a medical journal. All information will be anonymised so you will not be identified in any report or publication.



**Who is organising and funding the research?**

The research is being organised by Senior Research Scientist Dr Alice Smith and staff at the John Walls Renal Unit, and funded by a research grant from the British Renal Society.

**Who has reviewed the study?**

All research that involves NHS patients or staff, information from NHS medical records or uses NHS premises or facilities must be approved by an NHS Research Ethics Committee before it goes ahead.

This study has been reviewed by the NHS Research Ethics Committee East Midlands - Northampton. Approval means that the committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits and that you have been given sufficient information on which to make an informed decision.

**Contact for Further Information**

If you would like any further information about this study please contact the Chief Investigator Dr Alice Smith, or Dr James Burton on 0116 252 3061.

**Dr Alice Smith,**  
Leicester Kidney Exercise Team,  
Ward 12,  
Leicester General Hospital, LE5 4PW.  
Tel 0116 258 4346  
Email [kidney.exercise@uhl-tr.nhs.uk](mailto:kidney.exercise@uhl-tr.nhs.uk)

**Thank you for reading this, and for considering taking part in this study.**

**You will be given a copy of this information sheet and signed consent form to keep**

SPARK 1:  
Self-Management Program for Improving Health through  
Physical Activity in Chronic Kidney Disease Part 1

Patient Information Sheet

Version 4 dated 5<sup>th</sup> January 2016

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

**What is the purpose of the study?**

People with kidney problems often suffer from poor quality of life and many health problems. Research has shown that taking part in regular exercise can be very beneficial for their health and well-being, however we also know that few people with chronic kidney disease are being active enough. The purpose of this project is to explore ways to encourage patients to start being active at home or in their community. Other projects where researchers have worked with people with different diseases, have shown that using a self-management manual, which includes education, goal setting and problem solving, and a motivational counselling session has helped people start exercising regularly. This approach

helped people to gain the necessary knowledge and confidence to take up exercise and overcome their fears or problems in order for them to keep exercising. This project aims to develop a similar self-management intervention for kidney patients. We have already designed a first draft version of a manual for kidney patients, but we want to know what kidney patients think about it and hear their suggestions for improvements. In this project we will hold focus groups to discuss the manual and the way we propose to use it. We will then make any changes and hold a further focus group to discuss the updated version.

**Why have I been chosen?**

You have been chosen because you have kidney disease (CKD). We are doing this research so we can understand more about your perspectives on exercise, and find ways to help people like you become more active at home or in the community. Altogether we will ask up to 25 patients to take part in the study.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of care you receive.

**What will happen to me if I take part?**

During the study, we will ask you to continue your life in the usual way. You should follow your usual recommended diet, and take your usual medicines as prescribed.

You will be asked to attend a focus group with other kidney patients, at a mutually agreed date and time. The focus group will include about 4-8 kidney patients. However, if you would prefer, you can also meet a researcher on a one-to-one basis to tell us your opinions.

#### **What will happen in the focus group?**

In the focus group, we will discuss the manual and how we intend to use it to help kidney patients become more active. We will send you the manual to look at in advance of the meeting, with some information about how we think we might use it. We would like to hear your views on :

- the content and layout of the manual;
- whether you think it would help you or other people;
- any ways you think we could improve it;
- how we might present it to patients;
- how they might use it;
- what other support might be helpful as well;
- what progress tests or assessments we might do to monitor the effectiveness of the intervention

The focus group will be held in a comfortable, private room and will take about 1 to 3 hours depending on how much everyone wants to say. We will have regular refreshment and comfort breaks when required. The discussion will be led by two researchers who have no involvement with the clinical care team, and the discussions will only be heard by the research team. You will only be asked to talk about the manual and its use, exercise in general, and related issues.

If you prefer to have a one-to-one meeting with a researcher, we will send you the manual in advance and discuss the same things as outlined above for the focus groups.

#### **What will be done with the information from the focus group?**

We will use a digital recorder to record what people say in the focus group or interview so that we can analyse it later, and we will also take written notes. You will not be identified by name, and no personal information will be recorded in the notes. The recordings will be transcribed and all the comments analysed together to give us a full picture of peoples' opinions. The recordings and notes will be stored safely and treated in the strictest confidence. We may use direct quotations of what you said in the focus group or interview, but this will always be anonymous and no one will be able to tell that it was you who said it.

**Will the data be stored securely?**

All of the information we collect will be stored anonymously using a study participant code and will not be identifiable as belonging to you. Nothing you say in the focus groups or interviews will be reported back to those involved in your care or anyone who was not present at the time, except anonymously in the form of a report or publication about the study. While you are taking part in the study, your contact details will be made available to the researchers so that they can contact you to arrange the details of the focus group or interview. These details will be stored securely and separately from the research information above.

**What about access to medical records?**

We want to take into account the views of a wide range of kidney patients in this study. In order to find out about the diversity of the patients involved, a researcher will need to look at your medical records. We will extract information such as your age, gender, ethnicity and the severity of your kidney problems. However, none of this information will be stored with any personal details that you could be identified from, and we will only use this information to report on the diversity of the patients in the study.

**What are the possible disadvantages and risks of taking part?**

The only disadvantage of taking part is that you will need to attend for the focus group or interview. This will take up a few hours of your own time. We will reimburse any travel expenses you incur in taking part in this research study.

**What are the possible benefits of taking part?**

There are no direct benefits to you of taking part in this research. We hope that the results of the study will help us develop a self-management intervention that in the future will help kidney patients become more active and hence increase their chances of having a better quality of life.

**What happens when the research study stops?**

Your usual clinical care will continue unchanged.

**What if something goes wrong?**

In the very unlikely event of you being harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms would be available to you.

If you wish to make a complaint about the study you can contact the UHL Patient Information and Liaison Service by post to PILS, The Firs, Glenfield Hospital, Leicester LE39QP, telephone 08081 788337 (free phone number), or email [pils@uhl-tr.nhs.uk](mailto:pils@uhl-tr.nhs.uk)

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be anonymous. Any information about you will have your name, address and personal details removed so that you cannot be recognised from it. Your identity will not be associated with the clinical information we store or the recordings we make, and everything you say will be entirely anonymous, including any direct quotations we may use in publications.

**What will happen to the results of the research study?**

We expect the results of the research to become available from 2015. We will publicise the results in posters and leaflets in clinical areas so you can read them while you are there, and we will write a report about them in our Kidney Research Newsletter. If you would like us to send you a written report of the results, or if you would like to receive our Kidney Research Newsletter, please ask the researcher or contact the Chief Investigator, Dr Alice Smith (contact details at the end of this document).

The results may also be published in a medical journal. All information will be anonymised so you will not be identified in any report or publication.

**Who is organising and funding the research?**

The research is being organised by Senior Research Scientist Dr Alice Smith and staff at the Leicester Kidney Exercise Team and the John Walls Renal Unit, and funded by a research grant from Kidney Research UK.

**Who has reviewed the study?**

All research that involves NHS patients or staff, information from NHS medical records or uses NHS premises or facilities must be reviewed by an NHS Research Ethics Committee before it goes ahead.

This study has been reviewed by the NHS Research Ethics Committee West Midlands - Solihull. A favourable opinion means that the committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits and that you have been given sufficient information on which to make an informed decision.

**Contact for Further Information**

If you would like any further information about this study please contact the Chief Investigator Dr Alice Smith, or Dr James Burton on 0116 258 4346.

Alternatively, if you have questions about the study and you would prefer to ask someone not directly involved with the research team, you can contact the University Hospitals of Leicester Research and Development Office, Leicester General Hospital, LE5 4PW, by phone on 0116 258 8351, or email [RDAdmin@uhl-tr.nhs.uk](mailto:RDAdmin@uhl-tr.nhs.uk)

**Thank you for reading this Information Sheet, and for considering taking part in this study.**

**Dr Alice Smith**

Leicester Kidney Exercise Team,  
Academic Unit,  
Leicester General Hospital, LE5 4PW.  
Tel 0116 258 4346  
Email [kidney.exercise@uhl-tr.nhs.uk](mailto:kidney.exercise@uhl-tr.nhs.uk)

**You will be given a copy of this information sheet and signed consent form to keep**

**PEARL: Programmes to encourage Exercise and  
Active Lifestyle in Kidney Disease**

**Patient Information Sheet**

**Version 4 dated 13<sup>th</sup> July 2016**

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

**What is the purpose of the study?**

People with kidney problems often suffer from poor quality of life and many health problems. Research has shown that taking part in regular exercise can be very beneficial for their health and well-being, however we also know that few people with chronic kidney disease are being active enough. The purpose of this project is to explore ways to encourage patients to start being active at home or in their community. Other projects where researchers have worked with people with different diseases, have shown that using a self-directed approach, which includes education, goal setting and problem solving, with the support of a health-care professional has helped people start exercising regularly. This approach helped people to gain the necessary knowledge and confidence to become more



active and overcome their fears or problems in order for them to keep active. This project aims to develop similar self-directed interventions for kidney patients. We have already designed a first draft version of a programme and now we want to ask patients to try it and tell us what they think. We aim to update the design of the intervention after each round of testing, based on what people tell us does or doesn't work about the design. As a result of this, the intervention might vary for each round of testing which is why this Information Sheet has a range of tick-boxes, rather than just being a simple list.

In this study we will invite kidney patients to take part in a self-directed physical activity programme, where we are aiming for people to increase their daily activity to a level which is suitable for them e.g. 30mins up to 5 days per week, although we will not ask anyone to attempt exercise levels that are too much for them. At the beginning and the end of the research study we will ask the participant to complete some fitness tests and some questionnaires.

#### **Why have I been chosen?**

You have been chosen because you have chronic kidney disease or a kidney transplant and attend Nephrology or Transplant Outpatient Clinics. We are doing this research so we can find ways to help people like you become more active at home or in the community. Altogether we will ask up to 24 patients to take part in the study.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of care you receive.

#### **What will happen to me if I take part?**

During the study, we will ask you to continue your life in the usual way. You should follow your usual recommended diet, and take your usual medicines as prescribed.

If you decide to take part you will be asked to come to the research centre for five visits which will be flexible and scheduled at your convenience.

At **Visit 1**, you will be asked to complete some simple fitness tests and fill in some questionnaires. Visit 1 will take between 1 and 3 hours. More details of the tests are given below and in Appendix 2 at the end of this Information Sheet.

**Visit 2** will be the motivational counselling and education session, which will take about 1 to 3 hours. This will either be delivered as a group or as an individual depending on the design of the project for testing at that point. Which type of session we would invite you to is shown in Appendix 1 at the end of this Information Sheet. More details of the session are given below. After visit 2 you will be asked to gradually increase how much physical activity or exercise you do, for the next 6-12 weeks. The exact duration of the study period for you is shown in Appendix 1 at the end of this Information Sheet.

**Visit 3** will take place at the end of the study period above (6-12 weeks after the counselling session). You will be asked to repeat the same fitness tests and questionnaires that you did in Visit 1;

**Visit 4** will be either a focus group or an individual interview, as one of the aims of the project is to hear how you got on throughout the study period and how we could improve it. You will be asked to attend either a focus group, with other kidney patients, or an individual interview, at a mutually agreed date and time. The focus group will include about 4-8 kidney patients. However, if you would prefer, you can also meet a researcher on a one-to-one basis to tell us your opinions.

**Visit 5** will include some of, or all of the assessments that you performed in visits 1 and 3. This visit will take place up to 12 months after visit 3 and is a follow up to see how you have kept up your fitness and used the programme. We may also ask you to attend an interview/ focus group to hear more about your experiences of using the programme and any motivations or barriers you have experienced with regards to maintaining regular physical activity.

If you decide to stop the study before visit 5, you are free to do so and you do not have to tell us the reason. However, we will send you a brief questionnaire in the post (with a pre-paid return addressed envelope) and we will also include an invitation to come for a short interview, as we would be really interested to hear why you decided not to complete the study. This would be completely voluntary, but would just help us understand how we could improve the study so that it suited people better. If you prefer, you can ignore this questionnaire and invitation, and we will not ask you anything else.

#### **Motivational counselling & education session (Visit 2)**

The motivational counselling & education session will take place once at visit 2 and will last between 1 to 3 hours depending on whether it is a group or an individual session. We will arrange the session at a time to suit you, and with your permission, the session may be recorded; this will help us to check that we are offering similar sessions to everyone taking part.

At the session you will be given some written and illustrated material, which we will go through during the session, and which will be yours to keep and take home afterwards. The session will be conducted by a trained member of the research team. In the session, we will talk about :

- Kidney disease and your health
- Exercise and physical activity and the reasons they can help to improve your health and wellbeing
- How you might use exercise and physical activity in your own lifestyle

During the individual session you may have the opportunity to take part in a supervised walk to learn more about walking at a moderate intensity. We hope this will help you to feel more confident in your walking ability. This walk will take place on the hospital site. You may also be offered the opportunity to learn and practice the strength training exercises to check that you know how to do them properly.

The written material that accompanies the session includes information about all these things, which you can keep to look at again in your own time. We will discuss your experiences and what might help you to start being more active and together you will have

the opportunity to make an exercise plan. The discussion will also include setting some realistic and personal goals about Physical Activity based on what you would like to achieve. After the session, we hope you will use the plan to try to increase your exercise levels over the next few weeks. As an example, you may aim to gradually increase your activity up to a target of 30 minutes per day, 5 days a week. However, the target will be chosen to suit you, and you will never be expected to do more than you are willing and able. We will supply you with a pedometer that we will ask you to wear on the waistband of your clothing whilst you are awake. During the study, you will be asked to record how much physical activity and how many steps you do each day, and how hard it was. Recording this information in the Physical Activity diary should only take 5 minutes each day that you exercise. We will contact you via telephone regularly throughout the intervention period to see how you are getting on.

#### **Fitness Assessments and Questionnaires (Visits 1, 3 and 5)**

During the assessment visits, which will be at visit 1, 3 and 5 we will ask you to complete some of the tests listed below. More detailed information about all these tests can be found in **Appendix 2** at the end of this Information Sheet. We will arrange the dates and times of the assessment visits to suit you. We will be trying out these assessments and questionnaires on different people to see how useful each one is and how easy they are to do and to use. You will not be asked to do all these tests – we will just select some of them for each person! The list of tests we will ask you to do is shown in Appendix 1.

1. **Height, weight and waist circumference**
2. **Measure of fat to muscle bulk (body composition)**
3. **Physical performance tests:** Your physical performance will be tested using some walking tests, strength, sit to stand tests (rising from chair) and some balance tests.
4. **Heart function:** We will use a very easy and non-invasive test to measure your heart function.
5. **Physical activity level:** We will ask you to wear a device similar to a wrist watch continuously for 7 days to measure how much physical activity you do. The watches can be sent in the post to you.

6. **Questionnaires:** to assess your quality of life, the impact of symptoms associated with your kidney problem, your level of fatigue and your physical activity habits and opinions. We will explain the questionnaires to you and allow you to fill them in during the quiet time while you are resting between your walking tests. If you prefer, you can take some, or all, of the questionnaires home with you to complete in your own time. (We will supply a postage-paid envelope for you to post them back).

#### **Focus group/Interview (Visit 4)**

We will ask you to come to either a focus group or an individual interview as we want to hear how you got on during the study and what things could be improved. This session will be held in a comfortable, private room and will take about 60 to 90 minutes. The discussion will be led by two researchers who have no involvement with the clinical care team, and the discussions will only be heard by the research team. You will only be asked to talk about the study and what you thought about it, exercise in general, and related issues.

#### **Follow up (Visit 5)**

We may invite you to attend a follow up visit with one of the researchers up to 12 months after visit 3. This visit would include a repeat of all of the outcomes assessments or only some of the outcome assessments conducted at visits 1 and 3. The exact details of this visit will be decided on after a discussion between yourself and the researcher. We may also invite you to take part in an optional semi-structured interview or focus group to discuss how you have used the programme and your experience of physical activity since visit 3.

#### **What about access to medical records?**

We want to take into account the views of a wide range of kidney patients in this study. In order to find out about the diversity of the patients involved, a researcher will need to look at your medical records. We will extract information such as your age, gender, ethnicity and the severity of your kidney problems. However, none of this information will be stored with any personal details that you could be identified from, and we will only use this information to report on the diversity of the patients in the study.

**What are the possible disadvantages and risks of taking part?**

The main disadvantage of taking part is the time commitment involved in the research visits for assessments and the motivational session (5 visits, each between 1-3 hours). We will reimburse your travel expenses and car parking for these visits.

As with all physical activity, there is a very small risk of accident or injury during the assessment visits or whilst being physically active. All the tests will be supervised by trained research staff and will take place at a specialist research centre.

You will need to fill in a series of questionnaires, which takes about an hour. You will be given quiet time during a rest period to do this, or you can take them home to complete if you prefer.

We will fit you with an accelerometer, which is a lightweight waterproof device worn on the wrist like a watch. We will ask you to wear it continuously for 7 days on two occasions. The device is not uncomfortable and should not cause you any problems.

We will also ask you to wear a pedometer during the study period on the waistband of your clothing during the study period, during waking hours. Although this is inconvenient, it is not uncomfortable and should not cause you any problems.

**What are the possible benefits of taking part?**

There are no direct benefits to you of taking part in this research, although we anticipate being more physically active might help you to improve your fitness levels. We hope that the results of the study will help us design improved treatments for other kidney patients in the future.

**What happens when the research study stops?**

Your usual clinical care will continue unchanged.

**What if something goes wrong?**

In the very unlikely event of you being harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action but you may have to pay for it. Regardless of

this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms would be available to you.

If you wish to make a complaint about the study you can contact the UHL Patient Information and Liaison Service by post to PILS, The Firs, Glenfield Hospital, Leicester LE39QP, telephone 08081 788337 (free phone number), or email [pils@uhl-tr.nhs.uk](mailto:pils@uhl-tr.nhs.uk)

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be anonymous. All of the information we collect will be stored anonymously using a study participant code and will not be identifiable as belonging to you. Nothing you say in the focus group or interview will be reported back to those involved in your care or anyone who was not present at the time, except anonymously in the form of a report or publication about the study. While you are taking part in the study, your contact details will be made available to the researchers so that they can contact you to arrange the details of the visits. These details will be stored securely and separately from the research information above.

We will send your GP a letter, if you decide to take part in the study, just so that are fully informed about what is happening.

**What will happen to the results of the research study?**

We expect the results of the research to become available from 2017. We will publicise the results in posters and leaflets in clinical areas so you can read them while you are there, and we will write a report about them in our Kidney Research Newsletter. If you would like us to send you a written report of the results, or if you would like to receive our Kidney Research Newsletter, please ask the researcher or contact the Chief Investigator, Dr Alice Smith (contact details at the end of this document). The results will also be published in a medical journal. All information will be anonymised so you will not be identified in any report or publication.



**Who is organising and funding the research?**

The research is being organised by Senior Lecturer Dr Alice Smith and staff at the Leicester Kidney Exercise Team and the John Walls Renal Unit, and funded by a research grant from Kidney Research UK.

**Who has reviewed the study?**

All research that involves NHS patients or staff, information from NHS medical records or uses NHS premises or facilities must be reviewed by an NHS Research Ethics Committee before it goes ahead.

This study has been reviewed by the NHS Research Ethics Committee East Midlands - Nottingham 2. A favourable opinion means that the committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits and that you have been given sufficient information on which to make an informed decision.

**Contact for Further Information**

If you would like any further information about this study please contact the Chief Investigator Dr Alice Smith on 0116 258 4346.

Alternatively, if you have questions about the study and you would prefer to ask someone not directly involved with the research team, you can contact the University Hospitals of Leicester Research and Development Office, Leicester General Hospital, LE5 4PW, by phone on 0116 258 8351, or email [RDAdmin@uhl-tr.nhs.uk](mailto:RDAdmin@uhl-tr.nhs.uk)

**Thank you for reading this Information Sheet,  
and for considering taking part in this study.**

**Dr Alice Smith**  
Leicester Kidney Exercise Team,  
Academic Unit,  
Leicester General Hospital, LE5 4PW.  
Tel 0116 258 4346



Email [kidney.exercise@uhl-tr.nhs.uk](mailto:kidney.exercise@uhl-tr.nhs.uk)

**Appendix 1A: Details of the counselling session you will be personally asked to do for this study**

Session Type (Visit 2)	
	Group session
	Individual session
	Number of weeks of the study

**Appendix 1B: List of the physical function and clinical tests that you will be personally asked to do for this study**

	<p align="center"><b>Assessment Tests (Visits 1 and 3)</b></p> <p align="center">You will only be asked to do the tests that are ticked below. More details of each of these tests are given in Appendix 2</p>
	<b>Physical Function and Clinical Tests</b>
	Height, weight and waist/ <u>hip</u> measurements
	Measurement of blood pressure (BP)
	Measurement of body fat and muscle (Bioelectric Impedance Analysis (BIA))
	The 6 minute walking test (6MW)
	Incremental Shuttle Walk Test (ISWT)
	Endurance Shuttle Walk Test (ESWT)
	<u>Strength testing</u>
	Short Physical Performance Battery (SPPB)
	Sit-to-stand 60 Test (STS60)
	Timed up and go (TUAG)
	Cardiac Bio-reactance (NICOM)
	Physical Activity Level (Accelerometry)

**Appendix 1C: List of the questionnaires you will be personally asked to do  
for this study**

	<b>Assessment Tests (Visits 1 and 3)</b> You will only be asked to do the tests that are ticked below. More details of each of these tests are given in Appendix 2
	<b>Questionnaires</b>
	Illness perceptions questionnaire (IPQ-R)
	The Medical Outcomes Survey Short Form-12 version 2 (SF-12-v2)
	The Physical Activity Self-Regulation Questionnaire
	Leicester Kidney Patient Physical Activity Questionnaire (LKP-PAQ)
	Kidney Knowledge Survey (KiKS)
	Self-regulation Questionnaire
	CKD-TPB
	Brief Illness Perception Questionnaire (Brief IPQ)
	Behaviour Regulation Exercise Questionnaire (BREX-2)
	Multi-dimension outcome expectancies for exercise scale (MOEES)
	Patient Activation Measure (PAM-13)
	EQ5D5L
	Hospital Anxiety and Depression Scale (HADS)
	Kidney Symptom Questionnaire (KSQ)
	Vitality and Functional Assessment of Chronic Illness Therapy Fatigue (FACIT-fatigue)
	CKD Fatigue Scale
	Montreal Cognitive Assessment (MOCA)

## Appendix 2: Details of the Assessment Tests

This section of the information sheet describes the assessment tests in more detail. You will not be asked to do all these tests – please see Appendix 1B to see which tests we would like you to do.

1. **Height, weight and waist/hip circumference:** These will be measured by members of the research team on 2 occasions. Height and weight will be measured in the same way as your doctor uses during clinic visits. We will also measure waist and hip circumference using a tape measure. This will also provide us with another measure of how the exercise is affecting your body size.
2. **Measurement of blood pressure (BP):** This will be measured using a blood pressure cuff which is wrapped around the top of the arm. The cuff inflates around the arm to give a reading of blood pressure. Some minor discomfort may be felt when the cuff tightens but it is usually very mild and the procedure is quick and safe.
3. **Measurement of body fat and muscle (BIA):** BIA is a simple, safe and quick procedure and we hope to compare two different approaches. The first involves lying flat on a couch for around 2 minutes and having two sticky electrodes (similar to those used for ECG which you may have experienced) placed on one hand and foot. A small electric current which causes no pain is then passed down one side of your body. The second approach involves standing barefoot on the plate of a machine similar to a normal weighing scale and holding the two handgrips while the reading is taken. Both procedures take around two minutes and involve no discomfort.
4. **The 6 minute walking test (6MW):** During this walking test you will be asked to walk around a 60 metre circuit as quickly as you can for 6 minutes. You will be in control of how fast you walk and you will be allowed to stop and rest when you need to. This test is designed to measure your submaximal exercise capacity and is a measure of exercise endurance.
5. **Incremental and Endurance Shuttle walk tests (ISWT & ESWT):** For the first shuttle walk test (Incremental Shuttle Walk Test (ISWT)) you will be asked to walk around two cones placed on the floor 9 metres apart, at a speed timed by a recorded bleep sound. For the first part, the bleep signal gets a little faster every minute so that you have to increase your walking speed to keep up. The test is stopped when you can no longer walk fast enough to keep up with the bleep. This test measures your maximum physical capacity. After this you will have a rest and the researcher will calculate a walking speed that equates to 85% of your maximum capacity. For the second test (the Endurance Shuttle

Walk Test (ESWT)), you will walk at this 85% speed (in time with a steady bleep) for as long as you can. The test is stopped when you can no longer keep walking at that speed. This test measures your stamina. Before doing these tests, you will be taught how to do it and allowed to practice.

6. **Strength testing using the Fysiometer.** You will be asked to sit on a hard, upright chair (like a dining chair) and a harness will be firmly but comfortably put around your hips. The harness clips onto a Nintendo Wii Balance Board which is held at an angle in a specially designed support on the floor. You will be asked to take your shoes off and put your feet on the Board. You will then be asked to push as hard and as long as you can through your feet onto the Board three times. Before doing the test, you will be taught how to do it and given 3-5 practices before we record your results.
7. **Short Physical Performance Battery (SPPB)** The SPPB measures balance, how fast you walk and your ability to stand from a chair. The SPPB has 3 parts
  - a. Chair stands - you start from a seated position on a hard, upright chair (such as a dining chair), with the feet flat on the floor and the knees bent at 90°. For the test, the time taken for you to stand up fully and then returning to sitting 5 times, without using the hands, is measured.
  - b. Standing balance tests in three progressive positions. If you are able to complete 10 seconds in the first position then you progress to the next stage as described below:
    - Feet together
    - Semi-tandem (one foot in front of the other but slightly out to the side, as if taking a step forward)
    - Tandem (one foot in front of the other, like walking a tightrope)
  - c. Gait speed – the time you take to walk 4m on a level course. It is measured a second time after a short break.
8. **Sit to Stand 60.** This test is very similar to the chair stands test described above, but this time we measure how many times you can do this in 1 minute. You will be given time to recover between each test.
9. **Timed Up and Go (TUAG)** This test involves timing you whilst you stand from a seated chair position, walk 3 metres, turn around, walk back to the chair and sit down again.
10. **Heart Function (Cardiac Bio-reactance):** This is a safe, simple, non-invasive test which measures several aspects of heart function. The test involves lying on a couch and having four sticky electrodes (like those used for ECG which you may have had before) placed on your chest. A small, painless electric current is then passed through your body. The test is quick and will take around five minutes.

11. **Physical activity level (Accelerometry):** We will ask you to wear a device like a wrist watch continuously for 7 days that will measure how much physical activity you do. We will ask you to wear it for a week before and after the study period, i.e. between visit 1 and visit 2 and then again between visit 3 and visit 4, we may also ask you to wear it for a week prior to visit 5.
12. **Questionnaires:** The names of the questionnaires we will ask you to fill in are shown in the table in Appendix 1C. They are all quite short and simple to complete. Some, or all, of these can be filled out during assessment visits 1, 3, or 5 or you may take them home to complete them there if you prefer, in which case we will give you a postage-paid return envelope. These are assessing your quality of life, the impact of symptoms associated with your kidney problem, your level of fatigue and your physical activity habits and opinions.

#### **Focus group/interview details (Visit 4)**

We are really keen to hear your perspective of how you got on during the study period and so we will invite you to either a focus group or an individual interview (visit 4). The focus groups/interviews will be led and facilitated by a trained researcher and a second researcher will also be present to operate the audio-recording equipment and to take written notes for back-up and support if required. To allow you to be completely honest, sessions will take place in a comfortable, quiet room away from clinical areas, and the researchers will be uninvolved in the usual clinical care of the participants or in the intervention session. On arrival at the focus group/interview location, you will be welcomed and allowed to settle comfortably. The facilitator will introduce the session, explaining the background and reasons for the study, how the focus group/interview will proceed, and details of audio-recording and note-taking. Ground rules for the discussion will be set (e.g. preservation of anonymity and confidentiality) and you will be given the opportunity to ask questions.

Once everyone is ready, the discussion will begin. At this point, the audio-recording will start and the second person will start to take written back-up notes. The discussion will last for 60-90 minutes and we want to hear your views about your

- o experience of trying to be more physically active
- o what you thought about the written material you were given
- o whether the level of support given by the telephone calls was helpful
- o what you think about the design of the study
- o what you thought about the outcome measures used
- o what made it harder or easier for you to be more active.

At the end of the discussion, you will be given another opportunity to ask questions and we will make sure you have our contact details in case you have any further questions. Your travel expenses will be reimbursed, and light refreshments will be provided during the focus group/interview meeting.

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