Digital physical activity intervention via the Kidney BEAM platform in patients with polycystic kidney disease: a randomised controlled trial

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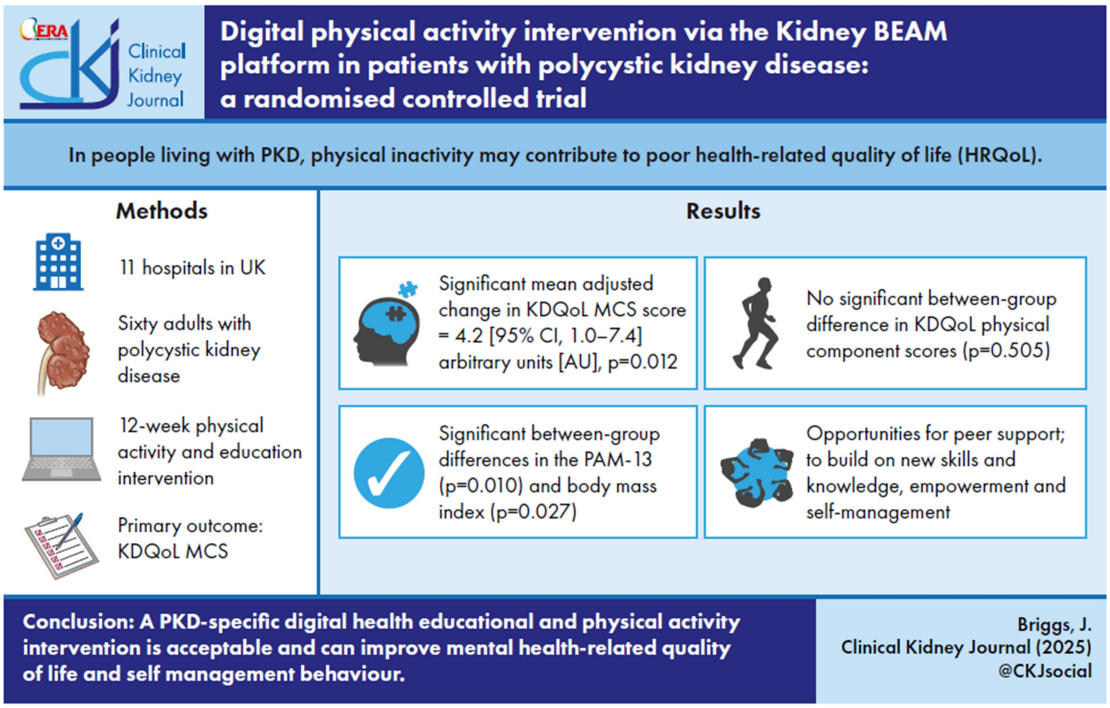
GRAPHICAL ABSTRACT



ABSTRACT

Background.

In people living with polycystic kidney disease (PKD), physical inactivity may contribute to poor health-related quality of life (HRQoL). To date, no research has elucidated the impact of a PKD-specific physical activity programme on HRQoL and physical health. This sub-study of the Kidney BEAM Trial evaluated the impact of a PKD-specific 12-week educational and physical activity digital health intervention for people living with PKD.

Methods.

This study was a mixed-methods, single-blind, randomised waitlist-controlled trial. Sixty adults with a diagnosis of PKD, were randomised 1:1 to the intervention or a wait-list control group. Primary outcome was difference in the Kidney Disease QoL Short Form 1.3 Mental Component Summary

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(KDQoL MCS) between baseline and 12 weeks. Six participants completed individualised semi-structured interviews.

Results.

All 60 individuals (mean 53 years, 37% male) were included in the intention-to-treat analysis. At 12 weeks, there was a significant difference in mean adjusted change in KDQoL MCS score between the intervention group and waitlist control (4.2 [95% confidence interval, CI: 1.0–7.4] arbitrary units [AU], p=0.012). Significant between-group differences in KDQoL sub-scales; burden of kidney disease (p=0.034), emotional wellbeing (p=0.001), and energy/fatigue (p=0.001) were also achieved. There was no significant between-group difference in KDQoL PCS scores (p=0.505). Per protocol analyses revealed significant between group differences in the PAM-13 patient activation score (p=0.010) and body mass (p=0.027). Mixed-methods analyses revealed key influences of the programme, including opportunities for peer support and to build on new skills and knowledge, as well as the empowerment and self-management.

Conclusion.

A PKD-specific digital health educational and physical activity intervention is acceptable and has the potential to improve HRQoL. Further research is needed to better understand how specific education and lifestyle management may help to support self-management behaviour.

KEY LEARNING POINTS

What was known:

- Mental health is detrimentally impacted for people with late stage ADPKD.
- Sedentary behaviour is high within the chronic kidney disease population.

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- Despite recommendations for individuals living with PKD to engage in physical activity interventions, limited research has been undertaken.

This study adds:

- A kidney-specific digital health physical activity platform, with specific PKD education, may improve an individual's HRQoL.
- Individuals valued a focus on health and well-being, particularly the opportunity for education, peer support, and self-management.

Potential impact:

- The use of a PKD-specific education and physical activity digital health intervention may have the potential to support individuals living with the condition to improve their HRQoL and self-manage aspects of their condition.
- This specific digital health intervention may be of benefit as an adjunct to standard clinical management of people living with PKD.
- Further research is needed to focus on when this intervention could be offered to individuals living with PKD as part of their kidney care journey.

Keywords:

- digital health intervention
- exercise
- physical activity
- polycystic kidney disease
- quality of life

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Introduction

Autosomal dominant polycystic kidney disease (ADPKD) is the most commonly inherited type of kidney disease, affecting approximately 12.5 million people worldwide (1), and is responsible for up to 10% of end-stage kidney disease (ESKD) (2, 3). PKD significantly affects psychological health and health-related quality of life (HRQoL), by causing pain, discomfort, fatigue, emotional distress, and impaired mobility (4-6).

In recent years there have been advances in treatment approaches, which have improved the HRQoL, as well as the lifespan, of these individuals. These approaches include early detection, lifestyle and weight management, hypertension optimisation, and review of kidney and extra-kidney complications (2, 7). Although no specific studies have investigated physical activity behaviours in people living with PKD, high levels of sedentariness are likely common, given similar patterns in individuals with chronic kidney disease (CKD) (8, 9). As such, support to facilitate a physically active lifestyle could be beneficial for this population.

Despite the recommendations for people with PKD to take part in exercise-based rehabilitation, albeit with specific precautions to avoid high-impact sports due to the risks of cyst rupture (10), very little research has investigated the impact of physical activity and exercise interventions in people living with PKD (2). Physical activity is likely to confer many physiological benefits, given that individuals with PKD have lower cardio-respiratory fitness compared to healthy controls (11, 12), along with a dysregulated cardiovascular response (10, 13) to exercise, reduced submaximal anaerobic threshold (11), diastolic dysfunction, raised sympathetic autonomous system response, and early signs of arterial stiffness (10). Early positive evidence in murine models with PKD has demonstrated that long-term exercise slows the progression of markers of PKD (14), but further research is needed to see if these observations translate to humans.

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The use of digital health interventions (DHIs), as a vehicle to deliver lifestyle interventions for individuals with a range of health conditions, are gaining global popularity. In the United Kingdom (UK), they are central to the National Health Service (NHS) Long Term Plan, which highlights the importance of DHIs to facilitate self-management of health and wellbeing needs in people living with long-term conditions, such as CKD (15). A multi-centre randomised controlled trial (RCT) recently showed that Kidney BEAM (www.kidneybeam.com), a kidney-specific DHI that delivers online lifestyle support interventions for individuals living with CKD, is an efficacious and cost-effective solution to improve mental HRQoL (16, 17). This type of intervention is particularly important as, unlike other long-term conditions, currently there are very limited services that provide specific rehabilitation interventions for PKD (18) as part of routine clinical practice. This is despite best practice recommendations being in place (19). The Kidney BEAM platform, which is now widely available for people living with CKD in the UK, is therefore an ideal place to create a bespoke education and physical activity training module to specifically support people living with PKD to engage in physical activity.

This study therefore aimed to understand whether a 12-week PKD-specific physical activity and educational DHI could effectively to improve HRQoL for people with PKD, and whether this would be an acceptable approach.

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Materials and Methods

The main Kidney BEAM trial was a multi-centre, single-blind, wait-list controlled trial designed to assess the effectiveness of a specific physical activity DHI on HRQoL in people living with CKD in the UK. Full trial design and protocol have been previously published (20). The PKD Kidney Beam sub-study was an exploratory pilot RCT that included 60 adults living with PKD, recruited in addition to participants within the main trial. The PKD sub-study was approved by the Bromley NHS Research Ethics Committee, (Ref: 21/LO/0243) and Health Research Authority, and was pre-registered on ClinicalTrials.gov (NCT04872933).

Participants

Adults ≥18 years of age with a diagnosis of PKD were considered eligible. Individuals needed to be able to access a DHI, using a digital device and WiFi connectivity, to be considered for the trial. Participants were recruited from 11 UK kidney centres. Potential participants were screened by their clinical team, and recent clinical records were reviewed to confirm eligibility at the time of enrolment. Suitable adults were approached in person during routine clinic visits, or via telephone, by trained research staff. A complete list of the inclusion and exclusion criteria has been published previously (20). All participants provided fully informed written consent. Eight individuals in the intervention group were later purposively sampled and invited to participate in a semi-structured telephone interview, to explore their experiences and views around the acceptability of the PKD-specific content on the Kidney BEAM platform.

Randomisation

Participants were randomly assigned 1:1 to the Kidney BEAM intervention group or the waiting list control group (usual care). Randomisation was performed by an independent member of the research team using the Sealed Envelope web-based system. Due to the nature of the intervention, it was not possible to blind either the healthcare professionals delivering the physical activity intervention, or participants.

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Procedures

The Kidney Beam trial intervention has been described in detail previously (20). The PKD-Kidney Beam sub-study participants who were randomised to the intervention group were directed to complete a PKD-specific education module, before starting the 12-week physical activity training programme, as per protocol (20). The education module provided participants with tailored information around the importance of keeping active whilst living with PKD, as well as specific physical activity guidance and advice around how to keep active, and what physical activity is beneficial for this population. This was delivered by a specialist kidney exercise physiologist. The physical activity training has been described elsewhere (20). Briefly, it consisted of two physical activity sessions per week, including a graded warm-up and cool-down. Structured aerobic and strength training exercises were led by specialist kidney physiotherapists, and involved two practitioners, one demonstrating the movements in standing and one demonstrating the movements seated in a chair. Participants completed baseline and 12-week assessments, as per protocol, and were invited to feedback on the acceptability of the module via one-to-one semi-structured telephone interviews. Interviews were conducted between September and October 2023 by one of the research team independent from the quantitative data collection

Outcomes

The primary outcome for this exploratory sub-study was the between-group difference in KDQoL-SF1.3 MCS at 12-weeks.

Secondary outcomes included the between-group difference in the Kidney Disease QoL Short Form version 1.3 Physical Component Score (KDQoL-SF1.3 PCS) and other subscales, patient activation (Patient Activation Measure-13, PAM-13), the EQ-5D-3L utility score, physical function via the 60-s sit-to-stand test (STS-60), body mass index (BMI), haemoglobin (Hb), and estimated glomerular filtration rate (eGFR), at 12-weeks, and a qualitative exploration of participant experiences of the intervention and trial procedures. Participants for the qualitative

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study were purposively sampled to ensure there was good representation in terms of age, sex, gender, and ethnicity. All outcome measures chosen are known valid and reliable tools to measure the primary and secondary outcomes in CKD (21, 22), and all questionnaires were completed online. The STS-60 test was completed at home and observed via video conference by a research assistant.

Statistical Analysis

Quantitative Analysis

In this *a priori* planned sub-study, by design the study was not powered to detect statistical differences between intervention and control groups. Statistical analysis followed the same as the main Kidney BEAM Trial intervention (16). Exploratory analyses, with the presentation of confidence intervals, were used to explore differences between groups and answer the primary question: whether people living with PKD respond positively to the Kidney BEAM intervention, as was shown previously in the main study/complete sample. Primary and secondary outcomes were analysed with an analysis of covariance model, with baseline data and age as covariates. Independence of covariates, and approximated normality of residuals, were confirmed for all analyses. Quantitative analyses were performed in the intention-to-treat population, using a last observation carried forward (LOCF) approach to missing data, which gives the most conservative result. Per-protocol analyses were also completed, in which only cases with observations at both baseline and week 12 were included. Two-sided p-values of $< 0{\cdot}05$ were considered to indicate statistical significance. Analyses were performed using IBM SPSS (version 28).

Qualitative Analysis

Interviews were audio recorded, manually transcribed verbatim (ER), and subsequently analysed using an inductive thematic analysis approach (ER) (23). Qualitative data were managed using Nvivo V14 (version 14.23), The coding and themes were reviewed independently by an author not involved in the coding process (JB), to check for suitability on two randomly selected

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transcripts. Reporting of qualitative data is informed by the qualitative research reporting guidelines (COREQ) (24). Please see supplementary material 5.0.

Mixed Methods Analyses

Quantitative and qualitative data collection and analyses occurred concurrently, and independently before being analysed and combined. Results are discussed together in a 'joint display' to facilitate an overall assessment of acceptability (Supplementary Material 3.0).

Results

Participant characteristics

Sixty individuals participated, 31 in the intervention group and 29 in the waitlist control group (see Figure 1). Six out of eight individuals approached via telephone for an interview participated. Baseline characteristics of the total cohort are presented in Table 1.

Overall, the groups were well-balanced at baseline (see Table 1), with a higher proportion of females in both (63%). A higher proportion of individuals had non-dialysis dependent PKD (65%), in comparison to kidney transplant (27%), and dialysis therapy (8%). Baseline creatinine and C-reactive protein (CRP) were higher in the intervention group (Creatinine: 152 micromole/L; CRP: 9.0mg/L), compared to the usual care group (Creatinine 100 micromole/L, CRP 2.7 mg/L). There were no significant differences in characteristics for those participants who completed, or did not complete, the intervention. A median of 14 (IQR 6-20) of the recommended 24 sessions of structured physical activity were completed by participants in the Kidney BEAM intervention group, representing a median adherence rate of 67% (IQR 46-117). Participants completed a median of 481 min (IQR 156–945) of structured physical activity (on-platform and off-platform), which is the equivalent of 40 min per week. A median of 7 (IQR 2-11) of the

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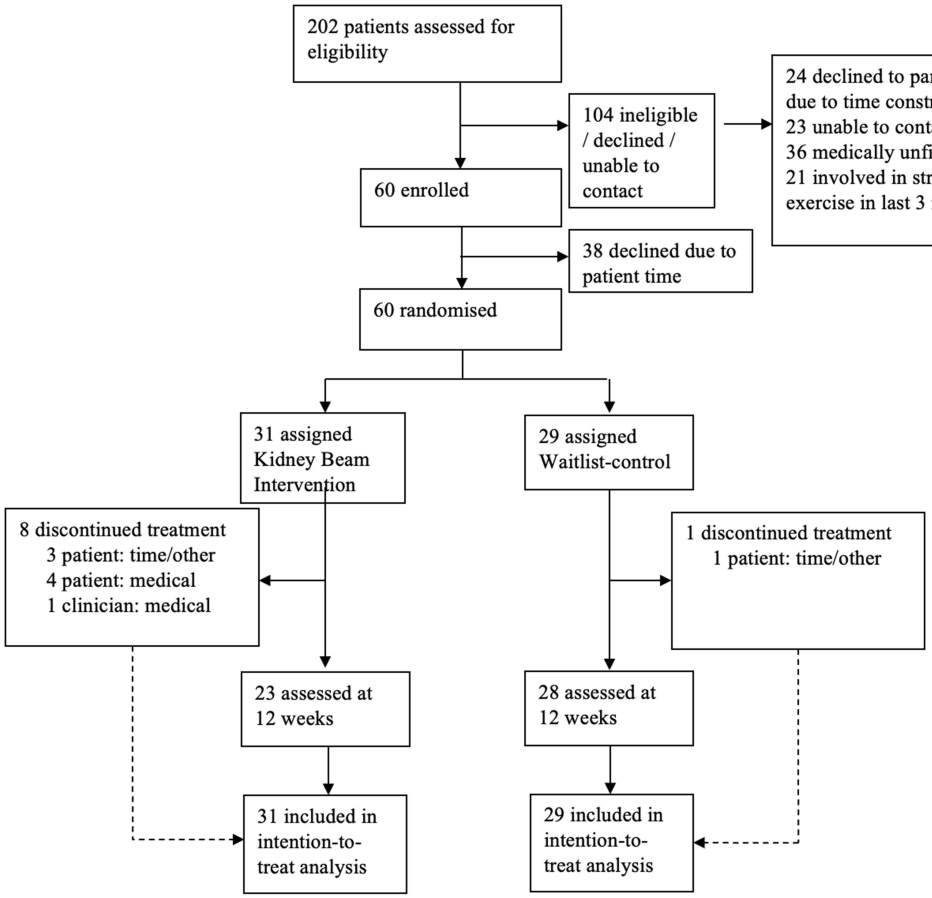
recommended 12 sessions of education were completed, representing a median adherence rate of 58% (IQR 13-92).

Figure 1. Trial Profile



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267 **Table 1**. Baseline Characteristics

		Total (n=60)	**Intervention Group (*n*=31)**	**Waitlist Control Group (*n*=29)**
Age (years, standard deviation)		53.2 (11.8)	53.2 (11.8)	50.3 (11.2)
Sex (*n*, %)				
	Female		19 (61%)	19 (65%)
	Male		12 (39%)	10 (35%)
Ethnicity (*n*, %)				
	Black	2 (3%)	0 (0%)	2 (7%)
	White	50 (83%)	27 (87%)	23 (79%)
	Asian	7 (12%)	4 (13%)	3 (10%)
	Biracial	1 (2%)	0 (0%)	1 (3%)
BMI (Kg/m2)				
	Median		26.3	29.2
	IQR		23.9-31.0	24.0-32.7
Smoking (*n*, %)				
	Current	1 (2%)	1 (3%)	0 (0%)
	Former	19 (32%)	12 (39%)	7 (24%)
	Never	40 (67%)	18 (58%)	22 (76%)
Alcohol (*n*, %)				
	More than recommended	3 (5%)	3 (10%)	0 (0%)

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	Less than recommended	31 (52%)	24 (77%)	7 (24%)
	Non-Drinker	26 (43%)	4 (13%)	22 (76%)
Blood Pressure (mm Hg)				
	Systolic Blood Pressure		135.4 (17.0)	133.9 (16.5)
	Diastolic Blood Pressure		81.8 (10.1)	82.8 (7.2)
Resting Heart Rate Beats Per Minute				
	Mean		75.5	72.9
	SD		16.7	13.3
Co-morbidities (*n*, %)				
	Cerebrovascular Accident	2 (3%)	2 (7%)	0 (0%)
	Myocardial Infarction	0 (0%)	0 (0%)	0 (0%)
	Diabetes Mellitus	6 (10%)	3 (10%)	3 (10%)
	Hypertension	45 (75%)	25 (81%)	20 (69%)
Chronic Kidney Disease Stage (*n*, %)				
	n			
	2	14 (23%)	6 (19%)	8 (28%)
	3a	13 (22%)	4 (13%)	9 (31%)
	3b	15 (25%)	8 (26%)	7 (24%)
	4	9 (15%)	7 (23%)	2 (7%)

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	5	9 (15%)	6 (19%)	3 (10%)
Treatment Modality (*n*, %)				
	Non-Dialysis Dependent Kidney Disease	39 (65%)	19 (61%)	20 (69%)
	Kidney Transplant Recipient	16 (27%)	8 (26%)	8 (26%)
	Dialysis Therapy	5 (8%)	4 (13%)	1 (3%)
HbA1c (mmol/mol)				
	Median		33.5	36
	IQR		33-39	35-43
Hb (g/L)				
	Mean		130.7	129.3
	SD		15.3	20.2
eGFR (mL/min)				
	Median		33.5	50.0
	IQR		19.2-52.2	30.0-60.0
C-reactive Protein (mg/L)				
	Median		9.0	2.7
	IQR		1.1-16.3	1.1-6.5
Sit to Stand 60 (reps)				
	Median		25	25
	IQR		20-32	19-31

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PKD, polycystic kidney disease; eGFR, estimated glomerular filtration rate; Hb, haemoglobin; IQR, inter-quartile range; SD, standard deviation.

Participants invited to qualitative interviews were purposively sampled. Baseline characteristics are presented in Table 2.

Table 2. Baseline characteristics of qualitative interview participants

Sex	Age	Ethnicity	eGFR (ml/min/1.73 m^2) [1]	CKD stage	Unit	No. of Physical activity sessions completed	No. of PKD education sessions completed
Male	63	White	24	4	Tx	11	3
Female	63	White	10	5	CKD	1	2
Male	45	White	59	3	CKD	9	3
Female	67	Other	34	3	CKD	10	3
Female	43	Other	>90	1	CKD	3	3
Male	42	White	45	3	CKD	6	3

Note. [1] Calculated using Chronic Kidney Disease Epidemiology Collaboration 2009 equation without ethnicity adjustment

Tx, Transplant; CKD, chronic kidney disease

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278 **Primary outcome – KDQoL-SF 1.3 MCS**

279 Table 3 and the Supplementary Material 1.0 present changes in HRQoL, as measured by the
280 KDQoL-SF 1.3 MCS. ITT analyses (Table 3) revealed statistically significant between-group
281 differences in mental HRQoL at 12-weeks (+4.2 (95%CI 1.0 to 7.4), p=0.012). This was also
282 reflected in the per protocol (PP) analysis (Supplementary Material 1.0), which demonstrated a
283 statistically significant difference in the KDQoL-SF 1.3 MCS score (+4.2 (95%CI 1.0 to 7.4), p=
284 0.001).

285

286 **Secondary outcomes**

287 Secondary outcomes, as measured through the KDQoL PCS, did not show significant
288 significance in ITT (p=0.505) or PP analysis (p=0.621). However, several of the sub-scale
289 components were significantly improved in the ITT results, including the burden of kidney
290 disease (p=0.034), emotional wellbeing (p=0.001), and energy/fatigue (p=0.001). These results
291 were also demonstrated in the PP analyses, where the burden of kidney disease (p=0.019),
292 emotional wellbeing (p=0.001), energy/fatigue (p=0.004), and cognitive function (p=0.022) were
293 significantly improved at 12 weeks.

294 The EQ-5D-3L utility score was not significantly different between groups at 12 weeks (p=0.428)
295 in either the ITT or PP analyses. PP analyses demonstrated a statistically significant improvement
296 in the PAM-13 patient activation score (p=0.010), eGFR (p=0.043), and body mass (p=0.027).
297 The Work and Social Adjustment Scale (WSAS) (p=0.691) and the anxiety and depression
298 questionnaire, as measured by the PHQ-4 (p=0.622), were not significantly changed by the
299 intervention. For full results please see Table 3 and Supplementary material 1.0.

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302 **Table 3.** Intention to Treat Analysis Results (LOCF)

Outcome measure	**n**	**Baseline**	**12 weeks**	**Mean difference in change between groups (Kidney BEAM – waitlist control)**	**p value**
		mean (SD)	mean (SD)	mean 95% CI	
Primary outcome					
KDQoL MCS (AU)					
Kidney BEAM	31	45.4 (10.2)	49.1 (10.7)	4.2 (1.0-7.4)	0.012
Waitlist control	29	47.9 (10.0)	46.4 (9.3)		
Secondary outcomes					
KDQoL PCS (AU)					
Kidney BEAM	31	44.6 (10.9)	44.1 (11.0)	-1.2 (-4.8-2.4)	0.505
Waitlist control	29	43.7 (11.9)	44.7 (13.1)		
Symptom problem list					
Kidney BEAM	26	83.2 (12.3)	83.7 (12.1)	-0.8 (-4.5-2.9)	0.676

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Waitlist control	28	81.6 (17.2)	82.9 (16.7)		
Effects of Kidney Disease					
Kidney BEAM	31	77.8 (20.6)	74.7 (22.5)	-2.1 (-12.1-7.9)	0.673
Waitlist control	29	83.9 (15.5)	81.9 (22.7)		
Burden of Kidney Disease					
Kidney BEAM	31	62.5 (30.3)	68.7 (26.7)	8.0 (0.6-15.3)	0.034
Waitlist control	29	73.7 (23.4)	70.3 (26.2)		
Work status					
Kidney BEAM	31	75.0 (38.1)	75.0 (35.9)	4.3 (-15.3-6.6)	0.43
Waitlist control	29	81.0 (33.8)	84.5 (33.0)		
Cognitive function					
Kidney BEAM	31	78.1 (16.1)	84.4 (12.4)	5.4 (-0.6-11.4)	0.078
Waitlist control	29	78.6 (17.6)	79.8 (21.4)		
Quality of social interaction					

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Kidney BEAM	31	75.2 (17.4)	77.1 (14.8)	-1.3 (-8.2-5.6)	0.701
Waitlist control	29	73.8 (15.9)	77.7 (19.5)		
Sexual function					
Kidney BEAM	15	28.3 (41.0)	30.6 (42.5)	-15.3 (-48.2-17.6)	0.348
Waitlist control	14	48.2 (46.5)	57.1 (46.7)		
Sleep					
Kidney BEAM	31	55.7 (17.2)	58.2 (19.0)	0.3 (-6.9-7.5)	0.934
Waitlist control	29	64.2 (17.1)	65.4 (20.8)		
Social support					
Kidney BEAM	30	77.4 (30.9)	83.8 (22.6)	9.5 (-2.9-22.0)	0.129
Waitlist control	25	79.3 (24.2)	79.5 (30.6)		
Dialysis staff encouragement					
Kidney BEAM	9	86.1 (22.0)	86.1 (22.0)	-2.3 (-9.7-5.0)	0.506
Waitlist control	7	75.0 (23.9)	72.2 (22.3)		
Overall health					
Kidney BEAM	31	61.2	62.8 (18.5)	-4.3 (-11.1-2.4)	0.201

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		(19.1)			
Waitlist control	29	61.7 (20.0)	67.6 (21.5)		
Patient satisfaction					
Kidney BEAM	12	80.5 (12.0)	76.7 (25.0)	1.5 (-9.0-12.1)	0.766
Waitlist control	11	78.8 (21.2)	76.2 (21.4)		
Physical functioning					
Kidney BEAM	31	74.1 (21.7)	73.6 (22.4)	-0.6 (-10.2-9.0)	0.904
Waitlist control	29	76.5 (28.8)	75.7 (28.2)		
Role physical					
Kidney BEAM	31	67.2 (35.6)	68.7 (35.9)	2.5 (-14.8-19.7)	0.776
Waitlist control	29	63.8 (43.6)	65.5 (45.0)		
Pain					
Kidney BEAM	31	67.3 (26.4)	66.2 (23.7)	-3.6 (-13.4-6.1)	0.458
Waitlist control	29	63.7 (29.1)	67.2 (33.2)		
General health					
Kidney BEAM	31	43.9	43.1 (22.3)	-4.1 (-10.5-2.3)	0.208

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		(21.7)			
Waitlist control	29	42.6 (21.2)	45.7 (23.4)		
Emotional wellbeing					
Kidney BEAM	31	70.1 (17.2)	76.2 (15.8)	9.5 (3.9-15.1)	0.001
Waitlist control	29	73.0 (17.5)	69.1 (18.2)		
Role emotional					
Kidney BEAM	31	71.9 (40.7)	71.9 (41.6)	-8.9 (-24.1-6.3)	0.245
Waitlist control	29	75.9 (38.7)	81.6 (32.8)		
Social function					
Kidney BEAM	31	69.1 (23.5)	75.4 (24.1)	2.8 (-6.5-12.0)	0.552
Waitlist control	29	64.6 (34.9)	69.0 (32.0)		
Energy/fatigue					
Kidney BEAM	31	43.3 (22.9)	52.5 (23.2)	8.9 (2.1-15.7)	0.011
Waitlist control	29	44.0 (24.4)	44.1 (24.7)		
EQ-5D-3L utility score					
Kidney BEAM	31	0.75	0.74 (0.21)	-0.03 (-0.09-0.04)	0.428

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		(0.18)				
Waitlist control	29	0.76 (0.26)	0.77 (0.20)			
CFS						
Kidney BEAM	31	2.32 (0.83)	2.13 (0.76)	0.14 (-0.15-0.44)	0.337	
Waitlist control	29	2.38 (0.82)	2.03 (0.78)			
STS-60						
Kidney BEAM	31	25.45 (8.21)	26.61 (9.47)	-1.37 (-3.60-0.86)	0.223	
Waitlist Control	29	25.69 (8.61)	28.17 (10.62)			
PAM-13						
Kidney BEAM	31	62.36 (17.28)	68.43 (17.09)	7.4 (1.3-13.5)		0.018
Waitlist control	29	68.90 (16.97)	66.06 (17.63)			
PHQ-4						
Kidney BEAM	31	2.78 (3.65)	2.56 (3.45)	-0.03 (-1.2-1.1)		0.951
Waitlist control	29	2.14 (2.95)	2.24 (3.15)			
WSAS						
Kidney BEAM	30	9.10 (8.77)	8.87 (8.92)	-0.03 (-2.9-2.8)		0.982
Waitlist control	29	9.55 (10.74)	9.28 (10.60)			
eGFR						

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Kidney BEAM	30	37.50 (25.10)	37.33 (25.27)	2.1 (0.3-4.0)	0.026
Waitlist control	23	46.74 (24.07)	44.17 (22.75)		
Hb					
Kidney BEAM	27	130.70 (15.26)	126.70 (20.61)	-3.2 (-11.1-4.6)	0.410
Waitlist control	29	129.34 (20.19)	129.17 (18.74)		
Body mass index					
Kidney BEAM	31	82.87 (17.94)	83.75 (18.24)	1.0 (-0.01-1.9)	.052
Waitlist control	28	82.10 (16.30)	82.02 (16.54)		

LOCF: last observation carried forward approach; KDQoL MCS: Kidney Disease Quality of Life Mental Component Score; KDQoL PCS: Kidney Disease Quality of Life Physical Component Score; AU: arbitrary units; EQ-5D-3L: European Quality of Life 5 dimension 3 level questionnaire; CFS: Chalder Fatigue Score; STS60: sit to stand 60; PAM-13: Patient Activation Measure 13; PHQ9: Physical Health Questionnaire 9; WSAS: Work and Social Adjustment scale; eGFR: estimated glomerular filtration rate; Hb: Haemoglobin.

Two serious adverse events were recorded during the trial, both of which were unrelated to the study treatment. No expected related or unrelated serious adverse events were recorded in either group during the trial period (See Table 4).

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Table 4. Number of patients with at least one serious adverse event during the Kidney BEAM trial by MedDRA system organ class

	Total (*n*=60)	Kidney BEAM group (*n*=31)	Waitlist control group (*n*=29)
Number of patients with any event	2 (3%)	1 (2%)	1 (2%)
Surgical and medical procedures	1 (2%)	0	1 (2%)
Infections and infestations	1 (2%)	1 (2%)	0

Data are *n* (%). MedDRA, Medical Dictionary for Regulatory Activities.

Qualitative Results

The analyses identified three key themes, with two associated sub-themes; 1) Individualised Acceptance; 2) Influences of Engagement; and 3) Complementary Empowerment.

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Theme 1. Individualised acceptance

Individual differences appeared to influence individuals' acceptance and experience of interacting with PKD-Kidney Beam. This includes the attitudes and emotions they have associated with having PKD, as well as their experience of PKD.

1.1 Individual attitudes

Individuals with PKD demonstrated a range of complex emotions, including guilt, a sense of being fortunate in comparison to other people living with PKD, and feelings of unfairness. These emotions were often present in the context of comparing their experiences with others, especially those of family members with PKD. Negative emotions occasionally fostered the desire to avoid the reality of PKD and thus regarded Kidney BEAM as an unwelcome reminder. Whereas others reported positive attitudes towards Kidney BEAM, believing it has the potential to enhance their QoL and improve their PKD experience. For these participants, Kidney BEAM represents a source of hope amidst their struggles with PKD.

> (In a discussion about the participant's brother) "Sadly, he's further down the line in terms of his kidney function, his has taken a rather, you know, serious nosedive and he's heading for dialysis now – even though he's 6 years younger than me, so you can't imagine how I feel about that"
>
> (KB387)

1.2 Identity and symptom experience

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Individuals' personal experience of their PKD, and how they identify their kidney disease, influenced how accepting they were of PKD-Kidney Beam. Those who identified themselves as having PKD, as opposed to CKD generally, were typically? more accepting. Conversely, one individual, who had undergone a kidney? transplant, found PKD-Kidney Beam less appropriate, as they no longer identified as having PKD; rather considering themselves a transplant patient.

"I might not be the ideal subject really for this, cause I never thought of it as polycystic kidney disease, I just thought, the kidney was failing you know."

(KB356)

Theme 2. Influences of engagement

This theme incorporates how factors, such as the sense of community, the timing of when PKD-Kidney Beam is offered, and an individual's PKD severity, can shape people's experiences and acceptance of PKD Kidney Beam.

2.1 PKD Community

Individuals conveyed a desire for a PKD community, and PKD-Kidney Beam contributed towards this need, by offering live sessions which fostered a sense of belonging and personal connection, increased engagement, and increased accountability. The educational sessions were regarded as informative and beneficial, but individuals indicated they may not re-engage with them due to the content not changing. Participants valued a sense of community; to share advice, normalise medication side effects, and exchange lifestyle tips.

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"It's that connection with people in the same position and that there's something you can join that sort of thing."

(KB378)

2.2 Severity and timing

Individuals reported PKD-Kidney Beam to be both an informative and reassuring platform. Although several individuals wished they could have had access to PKD-Kidney Beam at the time of their initial diagnosis, to help them better understand PKD and anticipate their journey, some of those in earlier stages found PKD-Kidney Beam to be less relevant to them and perceived it to be more suitable for those with severe cases.

"I was surprised there was all that information out there actually. I wish I had that from day 1 when I was diagnosed, it would have been so helpful."

(KB387)

Theme 3. Complementary empowerment

It is apparent that PKD Kidney Beam complements individuals' clinical care they receive, through having a resource that enhances knowledge and enables people to have more reassurance and confidence with their PKD.

3.1 Filling in the gaps

Participants described being under a kidney clinical care team, which they occasionally have brief face-to-face contact with. PKD-Kidney Beam helped to maintain their care during the gap between consultations, complementing their medical care. This was most notably through addressing knowledge gaps, which was often attributed to the limited contact time between

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individuals and their healthcare professionals. The educational diagrams and videos within PKD-Kidney Beam were reported to significantly improve understanding and were positively embraced. Individual's clinical care team endorsed and provided PKD-Kidney Beam which enhanced initial engagement and fostered trust.

"Yeah there was one in particular that explained the disease quite well. It explained a bit about the… I think it was explained better to me in the video than it was by my consultant if I'm honest" (KB381)

3.2 Empowerment

Most participants reported that PKD-Kidney Beam offers an accessible and adaptable platform, which helps to empower them within their own PKD journey. Individuals found that easy access to the platform enabled them to engage flexibly, adapting to busy periods while maintaining continuous availability. The PKD specificity of the content encouraged individuals' motivation and provided reassurance. Enabling and embracing individuals to have a proactive role in their PKD journey was regarded as a positive transformation.

"Yeah, I felt good. I felt like I had some exercise which is great. I felt motivated" (KB388)

The themes generated from this analysis suggest that PKD-Kidney Beam is a platform accepted and valued by PKD individuals.

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"…So presumably, you find you've got polycystic kidneys are they now going to introduce you to kidney beam as a matter of course? Cause I think they should."

(KB387)

Mixed Methods Analysis:

The integrated qualitative and quantitative findings allowed for further exploration of the results described from the quantitative analysis regarding; KDQOL-MCS, KDQOL-PCS and relevant sub-scales, PHQ-4 and PAM-13 outcome measures. These results suggest positive agreement regarding HRQoL, and patient activation, in response to 12-weeks of access to PKD-Kidney BEAM. There was partial discord in anxiety and depression scores between quantitative and qualitative results, with interviewees reporting improvement in anxiety and depression despite this not being reflected in the quantitative results. Table 5 combines the qualitative and quantitative results in a joint display table.

Table 5. Joint Display depicting mixed methods results

Concept being assessed	Quantitative Results	Qualitative Theme	Qualitative Results and Meaning	Mixed Methods Inferences
Health Related Quality of Life and sub scales	KDQOL MCS (ITT analysis) (p= 0.012)	Theme 1: Individual Attitudes Theme 2: Influences to engagement	Some individuals expressed a feeling of guilt and unfairness with being diagnosed with PKD however, the specific PKD content on Kidney	Complimentary

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			Beam offered a sense of hope and community engagement.	
	KDQOL PCS (PP analysis) (p= 0.621)	Not discussed as main objective of qualitative interviews however, discussed in main Kidney BEAM trial.		Silence
	Burden of Kidney Disease (p=0.019)	Theme 1.0- individualised acceptance Sub-Theme 1.2 Identity and Experience Theme 2.0- influences to engagement Sub-theme 2.1 PKD community	Individuals reported a range of emotions and feelings around their PKD diagnosis. This largely was influenced by their stage of disease. They felt that utilising a specific platform enabled them to gain peer support which was valued in helping to live with their	Partially complimentary

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		Sub-theme 2.3 severity and timing	condition and links to improvement in perceived burden reflected in quantitative results. Individuals reported the importance of the timing of offering of this resource dependent on the stage of their disease and therefore identity with PKD.	
	Cognitive Function (p=0.022)	N/A	No discussion	Silence
	Emotional Wellbeing (p=0.001)	Theme 2.0- Influences to engagement Theme 3.0- Complimentary empowerment	PKD-Kidney BEAM provided individuals with a sense of community, motivation and engagement which was deemed to be valuable in managing their own condition.	Complimentary

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			This links well to the positive outcome seen with emotional wellbeing in the quantitative data	
Anxiety and Depression	PHQ-4 (p=0.622)	Theme 1.0- Individual Attitudes Sub-theme 2.1- Identity and symptom experience	Individuals discussed their identity and experience of being diagnosed with PKD, alongside potential for guilt with this being an inherited disease. Identity and experience varied amongst interviewees dependent on their stage of disease. This linked to their sense of wellbeing and in some instances feelings of 'being a fraud' in their perceived health in comparison to others.	Partial Discord

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Patient Activation (knowledge skills and confidence)	PAM-13 (PP analysis) p= 0.010	Theme 2.0- Influences to engagement Sub-theme 2.1 PKD community Theme 3.0 Complementary Empowerment	Individuals expressed the positive impact of being able to engage and connect with other individuals in the same position as them, and this influenced motivation to engage with the platform. The educational content provided further insight, and positive re-enforcement in self-management of PKD.	Complimentary

438

439

440 **Discussion**

441 This study aimed to evaluate whether a 12-week PKD-specific educational and physical activity
442 DHI programme (PKD Kidney Beam) could improve mental HRQoL for people living with
443 PKD. The results revealed a significant improvement in the KDQoL MCS, suggesting that this
444 PKD-specific DHI has the potential to improve mental HRQOL for people with this inherited
445 condition. Mixed methods analyses of the data revealed several key influences of the PKD

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Kidney BEAM programme, that contributed to improvements in mental and physical wellbeing. These included the opportunity for peer support and a sense of community, particularly for individuals who struggled with a sense of identity and guilt about their PKD diagnosis, the opportunity to build on new skills and knowledge, as well as the empowerment and self-management of their condition. To our knowledge, this is the first study to investigate the use of a DHI to deliver a PKD-specific physical activity and education programme. These results echo those of the larger Kidney BEAM trial (16) in a broad population of people living with CKD.

PKD often poses a significant symptom burden for individuals living with the condition (25, 26), significantly impacting upon their QoL (25, 27). This has an impact with regards to pain management, fatigue and ability to carry out daily activities (25, 28, 29). Impairments in work productivity and daily activities have shown to be impacted both in early and later stages of disease (29). Promisingly, secondary outcomes including the burden of kidney disease, emotional wellbeing, and energy/fatigue, were improved by the PKD Kidney Beam DHI in this study. This demonstrates the benefit of this type of intervention and the potential to enable individuals to self-manage some of the symptoms experienced.

The psychological impact of PKD has been investigated in recent research (4). This includes the burden of knowledge of the disease process, as well as the psychological impact of PKD being an inherited disease, and often individuals having witnessed other relatives going through treatment for PKD, which may result in significant psychological impact (30). ADPKD presents with a number of physical symptoms, which may also influence an individual's overall QoL. These may include chronic pain, hypertension, the development of cysts in other organs, and gastrointestinal complications (30). The observed significant improvement in HRQOL in this sub-study therefore indicates a clinically meaningful benefit for people living with PKD. Qualitative analysis revealed the mental health impact of living with PKD, and the potential of this intervention to

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support a sense of community, as well as to empower individuals, and facilitate self-management of their condition. Although the PHQ-4 was not shown to be significant, qualitative analysis revealed the impact of living with PKD on mental health, including influencing their sense of identity. However, importantly the use of PKD Kidney BEAM appeared to build a sense of community, and facilitate peer support, which positively influenced emotional wellbeing and provided the opportunity to engage with others living with the same condition.

Self-management is gaining increasing importance in healthcare settings, particularly in relation to managing long-term health conditions, such as CKD (31). Self-management refers to an individual taking an active role in their health and management of their condition (32). To achieve this, individuals are required to achieve a term labelled 'patient activation'. This involves an individual having the knowledge, skills and confidence needed to perform the desired behaviours to manage their own health (32). It is therefore promising that the results from this PKD sub-study revealed significant improvements in patient activation, highlighting its potential in individual lifestyle self-management for people with PKD.

Whilst there were significant improvements in primary and secondary outcomes achieved in this current PKD sub-study, that are comparable with the main Kidney Beam trial (16), a notable contrast in the qualitative results from this PKD sub-study were revealed to be around individual attitudes. Qualitative analyses revealed that those individuals with PKD reported complex emotions, including guilt, particularly if other family members were also diagnosed with this inherited disease, a feeling of in some instances of unfairness or of feeling fortunate in comparison to others. This is echoed in other literature, where counselling to reduce the burden of 'genetic guilt' was seen as an important aspect of care (25). Additionally, whilst the PKD-specific DHI was welcomed by some people with PKD as an opportunity to understand their disease and

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have a focus on lifestyle management of the condition, some found this an unwelcome reminder. Individuals with more advanced PKD, particularly those who had received a kidney transplant, reported feeling that they identified less as someone with PKD, and felt that the programme may be more appropriate for those at earlier stages of diagnosis, and could therefore be utilised as an introduction to disease management. A large qualitative study has demonstrated both clinicians and people living with ADPKD felt that early support is required, to manage psychological distress and address the level of uncertainty that people face, as well as provide education and tailored information (4). It may therefore be important to consider at what stage this PKD-specific DHI is offered within the care pathway.

To date, limited research has been undertaken evaluating the role of physical activity interventions for people with PKD. It is understood from the literature that individuals with ADPKD have impaired physical capacity, as measured by maximal (peak oxygen uptake; VO_2 peak) and submaximal indices of aerobic fitness in comparison to the general population (11). Whilst results from the PKD-specific sub-study did not reveal statistically significant improvements in physical function, as measured by the STS-60, there was a significant reduction in body mass index (BMI), suggesting a potential weight management benefit. Qualitative analyses did not focus on the physical activity content of the platform, as this has been explored through previous research in the main Kidney Beam Trial, which had already demonstrated the ability of the Kidney BEAM platform to support individuals to engage with physical activity interventions (16). Future studies might consider adapting kidney beam to provide bespoke training in other individual kidney diseases where need exists e.g. diabetics with peripheral sensory loss or amputations.

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Strengths and limitations

This work aimed to understand the role of a PKD-specific education and physical activity DHI on the mental HRQoL in adults living with PKD. To date, limited research in this field has focussed specifically on individuals with PKD, and so it is a strength of this sub-study that a 12-week physical activity and educational programme has been able to demonstrate improvements in HRQOL and other important health outcome measures. Due to limited exclusion criteria, a wide range of individuals were included in the trial, making this research widely applicable to the overall PKD population. There was however a larger proportion of females than male participants, and also a lack of black participants recruited to the trial. We further acknowledge that there were few participants with comorbid diabetic and ischaemic heart disease, which limits generalisation of the results for participants with comorbid conditions. Future studies should ensure that there is good representation of all ethnicities, to ensure that the results are applicable to the whole PKD population. The use of a mixed-methods approach provided a rich dataset that allowed for exploration of the use of the PKD Kidney Beam programme as an acceptable solution for people living with PKD. Quantitative and qualitative data sets were collected and analysed separately and concurrently, before being integrated within a comprehensive mixed methods analysis. This ensured equal importance of both datasets. Qualitative reflexivity and rigor were achieved through reflexive diaries as well as collaborative working within both the qualitative team and the wider trial team. Due to the nature of the intervention, individuals in the intervention group of the study were not able to be blinded the intervention. Primary and some secondary outcome measures were self-reported which may have introduced bias. As a sub-study of the Kidney BEAM Trial (16), this sub-study was not designed to have sufficient participants for specified power to detect given effect sizes and thus changes in outcomes must be interpreted with care.

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Conclusion

A PKD-specific DHI has the potential to improve mental HRQoL, self-management behaviour, and the ability to foster a sense of community and peer support for people with PKD. The results may support further implementation of physical activity interventions for individuals living with PKD, and further research should focus on when in the care pathway this type of intervention would be best delivered to support self-management behaviour for people with PKD.

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Data availability statement

The data underlying this article will be shared on reasonable request to the corresponding author.

Conflict of interest statement

None declared.

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