

CareKnowDo: A pilot Randomized Controlled Trial of multichannel support for people with Chronic Kidney Disease

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Background

Chronic Kidney Disease (CKD) is a common, progressive condition. Lifestyle changes and antihypertensive medication can delay progression to Stage 5 (end stage). End Stage Kidney Disease (ESKD) requires transplant or ongoing renal replacement therapy, and is fatal if untreated. However, adherence to these recommendations is often low. Atlantis Healthcare, in collaboration with the UK's National Health Service (NHS), developed CareKnowDo, an online support tool that provides educational guidance for people with CKD. CareKnowDo integrates with a pre-existing Electronic Health Record, Patient View (PV). CareKnowDo aims to slow decline in kidney function, by helping patients reduce their blood pressure through adherence to medication and lifestyle recommendations.

The aim of study was to assess the feasibility of rolling out this support programme in two NHS sites in the UK. It also aimed to collect preliminary measures for key outcomes for a full trial and gathering of qualitative feedback to inform improvements to the programme's design and applicability.

Take home messages:

- CareKnowDo is an online support tool to help people with CKD manage their lifestyle and blood pressure to delay CKD progression
- Patients found it feasible and acceptable to receive this support
- People who have lived with CKD for a long time feel like self-management support is more relevant to people diagnosed more recently
 - However, people more recently diagnosed are less likely to sign up to the programme
 - Addressing this paradox is key to delivering effective support early and delay disease progression

Figure 1: The CareKnowDo website homepage

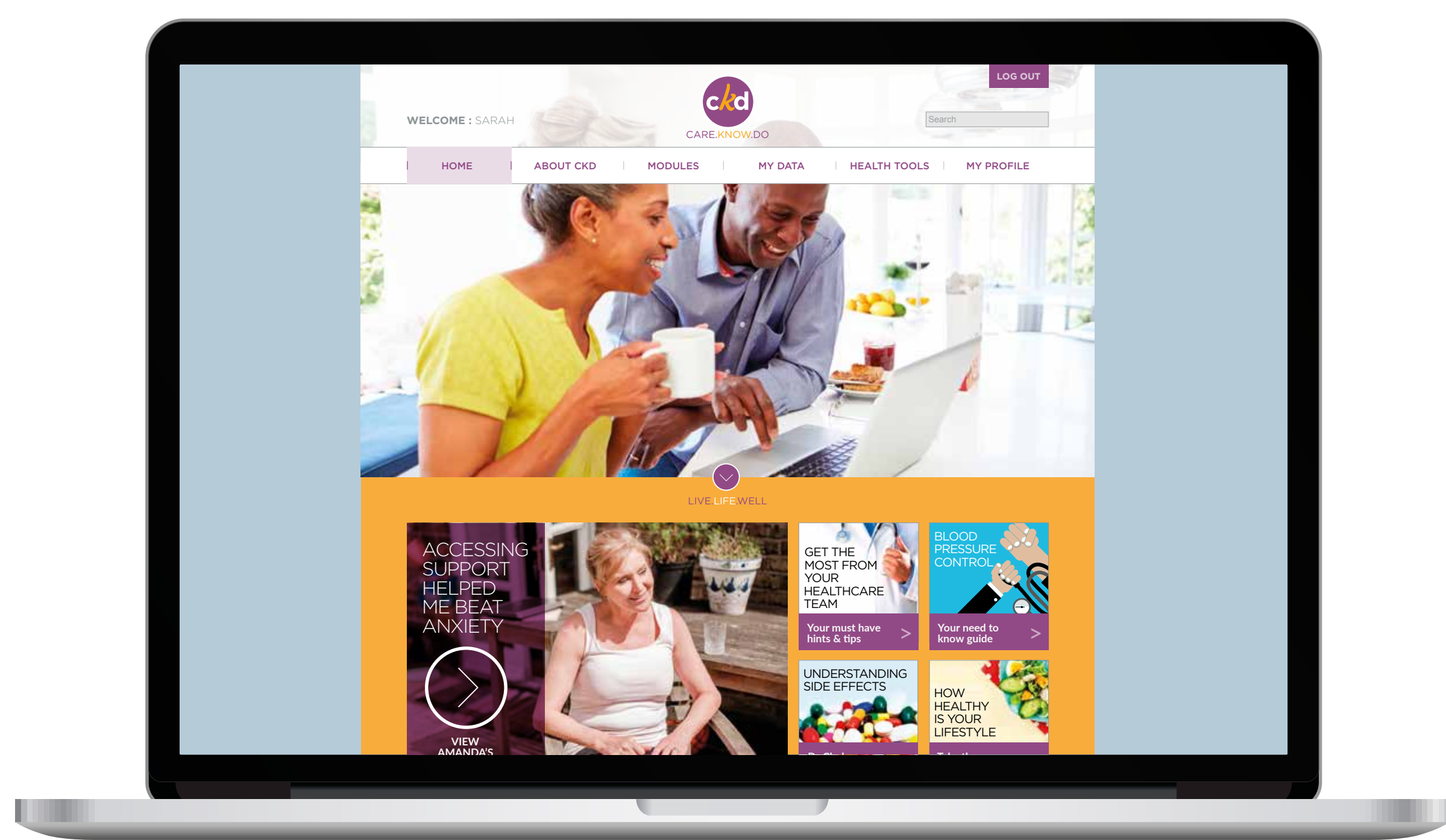


Figure 2: The CareKnowDo programme journey

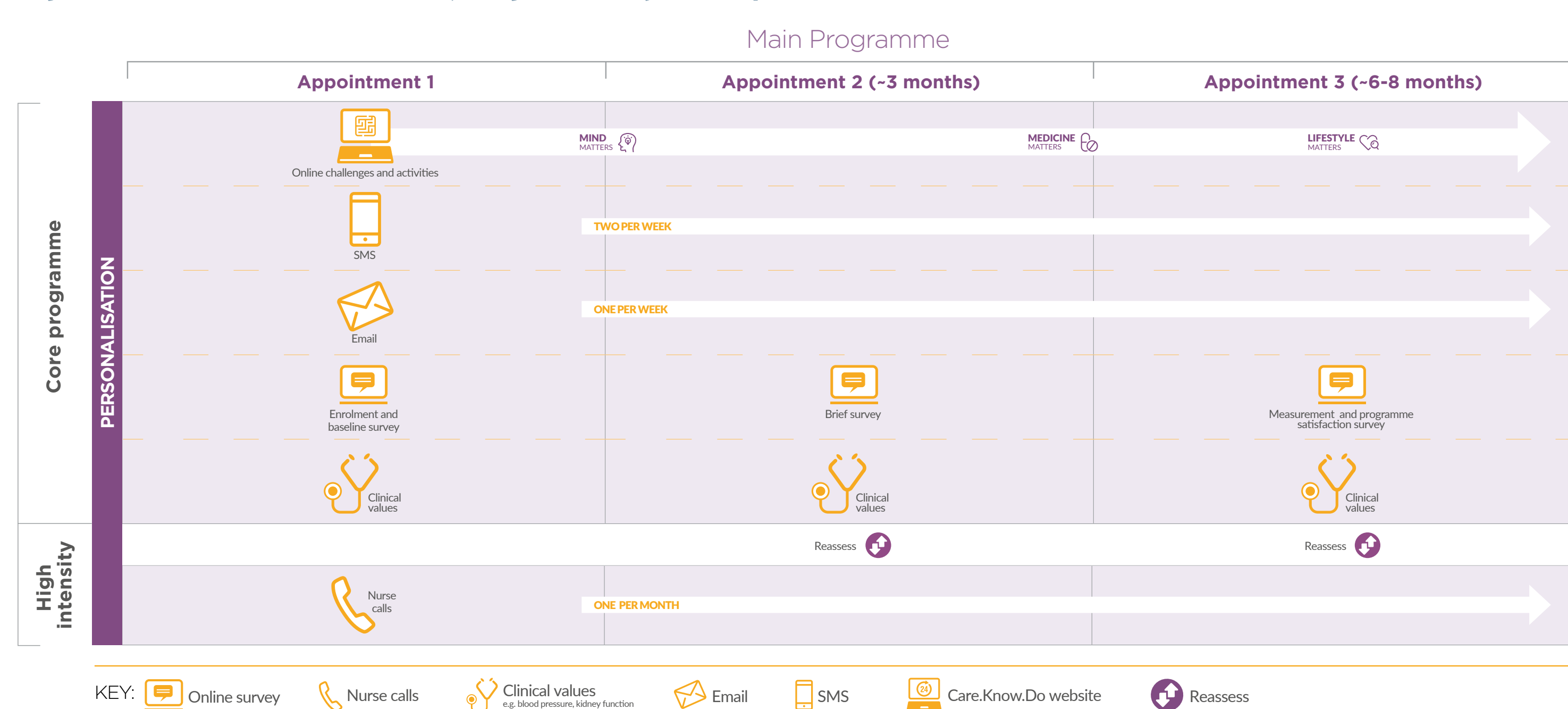


Figure 3: The CareKnowDo educational modules



The UK's National Institute for Health and Clinical Excellence (NICE) recommends the following self-management education is provided to all CKD patients:

- "1.4.10 Ensure that systems are in place to:
- Inform people with CKD of their diagnosis
 - Enable people with CKD to share in decision-making about their care
 - Support self-management (this includes providing information about blood pressure, smoking cessation, exercise, diet and medicines) and enable people to make informed choices. [new 2014]"

Methods

A two arm, parallel, blinded, individual-level pragmatic feasibility pilot RCT, running in two NHS sites in the UK. Sixty-one patients with CKD were randomized 1:1 into two groups and provided with either a new tailored, digital support programme (CareKnowDo, n = 31) integrated with PV, or standard care (PV alone, n = 30). Quantitative measures included clinical and psychosocial measures. Qualitative methods included five in-depth interviews, and online feedback forms. The primary outcomes were feasibility based; recruitment rate, drop-out, and exploration of associations.

Results

Quantitative results

Out of 1,392 patients screened in local kidney clinics, 269 met the basic inclusion criteria, the first eligible 61 of whom were recruited to participate in the study. Twenty-three patients (37.7%) completed the final 6-month follow-up survey. Reasons for attrition were explored. Higher belief in the ability of treatment to control CKD was associated with lower blood pressure at baseline ($r = 0.52, p < 0.01$), and higher perceived understanding of CKD at baseline was associated with lower blood pressure at follow-up ($r = 0.66, p < 0.01$).

Table 1: Clinical and psychological variables by group at baseline and follow-up

	Baseline Mean(SD)		Follow-up Mean(SD)	
	CKD	PV	CKD	PV
BPSys (mmHg)	139.6 (19.0)	133.5 (11.0)	137.2 (14.9)	135.7 (18.9)
eGFR (ml/min/1.73m ²)	34.0 (14.7)	33.0 (12.6)	34.4 (17.1)	31.8 (13.8)
HbA1c (mmol/mol)	47.3 (16.9)	56.9 (24.5)	46.2 (15.9)	58.3 (26.0)
Psychosocial				
Illness perceptions	5.3 (2.1)	5.3 (1.6)	5.0 (1.6)	5.5 (1.9)
Beliefs about medicines (concerns)	2.8 (0.8)	2.4 (1.1)	2.8 (0.8)	2.7 (0.8)
Beliefs about medicines (necessity)	3.5 (0.8)	3.8 (0.9)	3.6 (0.6)	3.7 (1.1)
Self-efficacy	7.4 (2.2)	7.1 (2.2)	6.7 (2.2)	5.8 (2.5)
Depressive symptoms	2.5 (0.6)	2.6 (0.5)	3.0 (0.5)	2.9 (0.5)
Adherence	6.3 (1.7)	5.9 (1.7)	3.7 (2.0)	2.9 (1.7)

Quantitative results

In-depth interviews and online feedback forms allowed patients to share their experiences of CareKnowDo. It emerged that patients who had been diagnosed a long time ago felt they already knew a lot of what the programme had to offer, but that it would be very useful for newly diagnosed patients. However, newly diagnosed patients were difficult to recruit, as many were either not on anti-hypertensive medication, or were unsure about their diagnosis and therefore not interested in the programme.

Table 2: Excerpts from qualitative feedback on CareKnowDo

Theme	Example comment
Finding the service helpful	
Integration with PV	"Very useful to have blood test results instantly" "Helps you see your results quickly"
Additional information, education, and lifestyle tips provided by CareKnowDo	"We're living in an information age now. It's about giving information back to the patients relatively easily, to help them understand exactly what's going on with their condition" "It told me a bit more information that the doctor hadn't mentioned about what I've got. It was fairly clear, and clear cut. All the information was pretty clearly displayed on there. And it was relatively easy to get to everything"
Providing a feeling of being supported	"[The programme] enables you to monitor your condition via showing blood test result and providing information. This programme provides reassurance that interest in you and your condition is ongoing and gives hope that your welfare is being considered."
Suggestions for improvement	
Readability and clarity of information	"The nursing personnel that I have met are excellent. I find the website as scary as reading the information sheets that come with the medication. The website information seems to be written by medical experts and can only be understood by medical experts. Have you considered a review of the presentation by a panel of sufferers to see if they can understand the content?"
Perceived usefulness for asymptomatic condition	"I do not see the programme being of great benefit to transplant patients." "Other people may find it more useful than I personally do."
Mode of delivery	"Better to speak to a person" "I haven't felt well enough to stare a computer screen as it brings on the fatigue"

Conclusion

A digital support programme to enhance support for patients with CKD was piloted in two NHS sites in the UK, and found to be both feasible and acceptable.

There is a tension between who the programme is likely to be a greatest use to, and who is likely to actually use it (as the intervention is currently designed). It is of great importance to ensure that the program is launched with the appropriate messaging to encourage newly diagnosed CKD patients to use the support tool.