



ORIGINAL ARTICLE

Can we routinely measure patient involvement in treatment decision-making in chronic kidney care?

A service evaluation in 27 renal units in the UK

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Abstract

Background: Shared decision making is considered an important aspect of chronic disease management. We explored the feasibility of routinely measuring kidney patients' involvement in making decisions about renal replacement therapy (RRT) in National Health Service settings.

Methods: We disseminated a 17-item paper questionnaire on involvement in decision-making among adult patients with established kidney failure who made a decision about RRT in the previous 90 days (Phase 1) and patients who had been receiving RRT for 90–180 days (Phase 2). Recruitment rates were calculated as the ratio between the number of included and expected eligible patients (I : E ratio). We assessed our sample's representativeness by comparing demographics between participants and incident patients in the UK Renal Registry.

Results: Three hundred and five (Phase 1) and 187 (Phase 2) patients were included. For Phase 1, the I : E ratio was 0.44 (range, 0.08–2.80) compared with 0.27 (range, 0.04–1.05) in Phase 2. Study participants were more likely to be white compared with incident RRT patients (88 versus 77%; $P < 0.0001$). We found no difference in age, gender or social deprivation. In Phases 1 and 2, the majority reported a collaborative decision-making style (73 and 69%), and had no decisional conflict (85 and 76%); the median score for shared decision-making experience was 12.5 (Phase 1) and 10 (Phase 2) out of 20.

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Conclusion: Our study shows the importance of assessing the feasibility of data collection in a chronic disease context prior to implementation in routine practice. Routine measurement of patient involvement in established kidney disease treatment decisions is feasible, but there are challenges in selecting the measure needed to capture experience of involvement, reducing variation in response rate by service and identifying when to capture experience in a service managing people's chronic disease over time.

Key words: chronic kidney disease, doctor–patient communication, implementation, routine measure, shared decision-making

Introduction

The National Service Framework for Renal Services (2004) in the UK advocates a patient-centred service for all people with chronic kidney disease (CKD), and promotes partnership in decision-making [1]. According to the National Institute for Health and Care Excellence, patients with CKD should be actively engaged in discussions with the kidney team about available treatment options, using evidence-based information tailored to their needs [2–4]. Shared decision-making (SDM) is the process by which patients and their healthcare professionals deliberate about available options to choose a course of care that is aligned with the patient's preferences. It is dependent on the dialogue and partnership between patients and health professionals, and on knowing and understanding the risks and benefits of available options, while ensuring that the patient's values are taken into account [5–7].

Renal services in the UK vary in the format, quality and accessibility of information resources they provide to patients, with few being able to adequately promote and support SDM [8, 9]. Recent initiatives from the National Health Service (NHS) kidney and other services to develop patient decision aids (The Dialysis Decision Aid Booklet; NHS Right Care decision aids) [10], SDM prompts (The Health Foundation's MAGIC project: Making Good decision In Collaboration) [11–14], SDM training for health professionals (Advancing Quality Alliance, MAGIC) [11–13] and to monitor patient involvement in treatment decision-making (Advancing Quality Alliance, MAGIC, Renal Registries) indicate that services are progressively evolving towards a more patient-centred delivery of healthcare. SDM implementation programmes (Advancing Quality Alliance and MAGIC) suggest that services are willing to capture patient experiences of treatment decision-making through the use of questionnaires [14–16]. Furthermore, NHS England has recently funded an improvement programme to promote patient-centred coordinated care in the NHS and measure CKD patients' activation levels using the Patient Activation Measure [17, 18].

The feasibility and utility of capturing patients' experience of SDM practices in usual care is still unknown. Most measures of SDM have been designed for discrete decisions in acute illness contexts (e.g. breast cancer surgery treatments) [7]. It is unclear if and how such measures can be used in chronic illness contexts such as CKD [9]. Treatment decisions are often made over multiple consultations, sometimes spread over months or years, and the implementation of the decision can be delayed (e.g. due to a change in disease state) [9]. It is, thus, difficult to identify the moment at which a definitive treatment decision has been made and when to survey patients about their involvement in treatment decision-making.

Therefore, our aims were to assess the feasibility of recruiting CKD patients to measure their involvement in decisions about renal replacement therapy (RRT) in routine NHS settings, as well as their ability to access and understand information.

Materials and methods

In 2013, the NHS Institute for Innovation and Improvement commissioned the UK Renal Registry to undertake a service evaluation assessing patient involvement in treatment decision-making in CKD. The service evaluation consisted of two 3-month data collection periods. Phase 1 (February–April 2013) included CKD patients who had made a treatment decision about RRT or conservative management within the last 90 days. Phase 2 (June–August 2013) focussed on patients who had been receiving any of these treatments for 90–180 days at the time of recruitment, and had thus recently implemented their treatment decision (see Box 1). A group of 11 clinical and methodological experts in the area of medical decision-making, SDM implementation and/or CKD were selected to inform the planning and development of the service evaluation. They reviewed study materials as well as iterative drafts of the questionnaire and provided advice and governance.

Developing the questionnaire

The expert group considered existing instruments measuring patient involvement in treatment decision-making [19, 20] and used the following criteria to select relevant measures; whether the instrument: (i) had undergone prior validation, (ii) was fit for use in routine care (i.e. quick and simple to administer), (iii) was freely available and (v) had been developed for the clinical context of CKD. The expert group reviewed two iterations of the provisional questionnaire. It was subsequently piloted with 15 CKD patients recruited at two dialysis centres. They provided feedback on the wording, clarity, number and order of the items. Three renal nurses from two centres also reviewed the questionnaire. We analysed all comments thematically and made revisions accordingly. The questionnaire was then converted into a format that allowed machine reading of the completed forms.

The final questionnaire consisted of 4 sections, 17 questions and included 3 existing scales (see Supplementary data A). Section 1 explored patients' awareness of available treatment options and information resources. Section 2 focussed on treatment decision making using the following measures:

- The single-item Control Preference Scale assessing patients' perceived role in the treatment decision [21].
- The 10-item SHARED measure of patients' experience of SDM during a consultation.
- The four-item SURE scale to screen for decisional conflict in clinical settings [22, 23].

Section 3 included demographic items, while Section 4 was to be completed by the renal nurse only [renal centre name, date of patient's first referral to renal centre, patient's selected treatment and time of treatment start (only for Phase 2)].

Box 1. Inclusion criteria for patients in Phase 1 and Phase 2**Phase 1**

CKD patients were eligible if they were 18 years or older, and if they fulfilled at least one of the following criteria:

Listed for chronic haemodialysis

- Listed for arteriovenous fistula and not yet on dialysis.
- Started dialysing on a venous catheter within the last 90 days and listed for arteriovenous fistula construction.
- Started dialysing on a venous catheter within the last 90 days and is thought by their medical team to need to continue dialysis long term (i.e. has definite established renal failure, not acute kidney injury).

Listed for peritoneal dialysis

- Listed for Tenckhoff catheter insertion and not yet on dialysis.
- Started dialysing on a venous catheter within the last 90 days and listed for Tenckhoff catheter insertion.

Listed for kidney transplantation

- Activated on the transplant waiting list within the last 90 days and not yet on dialysis.
- Been given a date for living kidney donor transplantation.

Conservative management

- Opted for conservative management and with an eGFR <10 mL/min/1.73 m².

Phase 2

CKD patients were eligible if they were 18 years or older and fulfilled at least one of the following criteria:

- Receiving chronic haemodialysis and on RRT for between 90 and 180 days.
- Receiving peritoneal dialysis and on RRT for between 90 and 180 days.
- Received a pre-emptive kidney transplant (i.e. before starting any form of dialysis) between 90 and 180 days ago.
- Opted for conservative management with an eGFR < 10 mL/min/1.73 m².

CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate; RRT, renal replacement therapy

Eligible renal centres and CKD patients

For Phase 1, we invited 31 renal centres in England who were receiving funding from NHS Kidney Care to support secondment of nurses working on care planning or SDM projects. For Phase 2, we invited all centres that showed interest in participating in Phase 1 ($n = 22$), as well as all renal centres in Scotland ($n = 9$). In contrast to Phase 1, funding from NHS Kidney Care was no longer available, meaning that participating centres in Phase 2 had to allocate resources for study-related activities within their regular services.

CKD patients were eligible to take part in the service evaluation if they were 18 years or older. The other inclusion criteria differed between Phase 1 and Phase 2 (Box 1). Patients who were not sufficiently proficient in English or lacked the mental and sensory capacity to read, understand and complete the questionnaire were excluded. We also checked with renal nurses whether all criteria were clear and easy to apply in clinical settings.

Data collection

All eligible renal centres received a PDF version of the questionnaire along with an information pack, a weekly recruitment sheet and a cover letter for the postal questionnaires. Each centre was asked to assign a renal nurse in order to identify eligible patients, as well as to distribute, collect and return the questionnaires to the UK Renal Registry for analysis. These local study nurses invited eligible patients to complete the questionnaire in the kidney unit, or sent them a postal version with a cover letter and prepaid envelope.

Data analysis

Recruitment of eligible patients. We assessed the feasibility of routinely measuring CKD patients' involvement in selecting a treatment for their kidney failure. To evaluate whether renal centres had been successful in recruiting eligible patients, we calculated the ratio between the number of included patients and the expected number of eligible patients (I : E ratio). We determined the latter based on the quarterly number of incident patients on RRT, using annual incidence figures derived from the most recent UK Renal Registry report [24]. To assess the degree to which nurses had recruited a representative sample of kidney patients, we compared characteristics of study participants with those of all adult patients starting RRT in participating centres in 2012, using data from the UK Renal Registry database. For both groups, we calculated adjusted Indices of Multiple Deprivation (IMD) as a measure of social deprivation using publicly available IMD data. We adjusted national values following the method of Payne and Abel [25] to allow comparison between countries. We performed χ^2 tests to assess differences in gender and ethnicity, and Kruskal–Wallis tests for age and IMD.

Aspects of treatment decision making. We undertook descriptive analyses to summarize all survey responses. To determine a patient's decision-making style, we categorized respondents who reported to have made the decision alone as 'active', and those scoring the health professional having made the decision as 'passive'. Making the decision together with the health professional or after considering the health professional's opinion was seen as a 'collaborative' style. For each of the 10 SHARED items, we assigned 2 points for 'strongly agree', 1 point for 'agree' and no

points for 'strongly) disagree'; the total SHARED score could, thus, range from 0 to 20 points. Lastly, we categorized respondents reporting 'no' to at least one of four SURE items as experiencing decisional conflict [22].

Results

Participants

Table 1 shows the characteristics of all participating centres and patients for both phases. Nineteen and 18 of the 31 invited renal centres agreed to participate in Phase 1 and Phase 2, respectively. Ten centres participated in both phases. Of the non-participating centres, one was already collecting data on patient involvement in treatment decision making; the remaining centres had competing commitments.

For Phase 1, a total of 385 patients completed the questionnaire, of which 305 fulfilled the inclusion criteria. They were mostly male (67%), white (92%), with educational attainment at GCSE or A levels (52%) or no formal qualification (32%), and either listed for some form of dialysis access procedure (see Box 1) or had been receiving it for <90 days (77%). The median age was 66 years. For Phase 2, we included 187 of 262 patients who completed the questionnaire. They were mostly male (62%), white (83%), with educational attainment at GCSE or A levels (51%) or no formal qualification (32%), and had a median age of 60 years. The majority had been receiving haemodialysis for >90 days (67%). Approximately 5% of questionnaires completed in Phase 1 and 2.5% of questionnaires completed in Phase 2 contained incomplete information. Incomplete questionnaires were included in the analysis by using responses to the items that had been completed.

Recruitment of eligible patients

Table 2 presents the ratio between included and expected eligible patients (I : E ratio) per centre for both phases. For Phase 1, the overall I : E ratio was 0.44 (range, 0.08–2.80), indicating that most centres recruited fewer patients than expected. Almost all centres returned questionnaires of patients who indeed met the inclusion criteria. In Phase 1, one centre (renal centre 4 in Table 2) had to withdraw 80 responses by patients attending pre-dialysis education clinics. They may have reached a decision on intended modality, but had not yet come close to implementing it, and therefore did not meet the inclusion criteria. For Phase 2, the overall I : E ratio decreased to 0.27 (range, 0.04–1.05). Among the 10 centres contributing to both phases, I : E ratios were significantly lower in Phase 2 ($P = 0.01$). Of the 75 excluded questionnaires received from 15 centres, the majority were removed from the analysis because patients had been receiving treatment for <90 or >180 days at the time of recruitment ($n = 51$).

None of the renal centres systematically returned the weekly recruitment sheet, thus making it impossible to estimate the number of invited patients against the number who completed the questionnaire. Nurses involved in the administration and collection of questionnaires provided qualitative information on the ease of data collection. Many reported difficulty in selecting appropriate patients in Phase 1. The inclusion criteria were, thus, simplified in Phase 2.

When comparing characteristics of the complete study sample ($n = 469$; excluding duplicates) with those of all adult patients starting RRT in participating centres in 2012 ($n = 2762$), we found no difference in median age in years [64.5 (interquartile range, IQR, 52.5–75.0) versus 64.4 (IQR, 51.5–74.4); $P = 0.5$], gender

Table 1. Characteristics of participating renal centres and kidney patients [values are numbers (valid percentages)^a unless indicated otherwise]

Characteristics	Phase 1	Phase 2
Centres		
Total number	19	18
Transplant centres	9	8
Median (IQR) number of incident RRT patients in 2012	104 (71–148)	94 (50–139)
Median (IQR) number of patients participating in service evaluation	14 (7–25)	10 (3–16)
Patients		
Number participating	385	262
Number included in the analysis	305	187
Age, years (median, IQR)	66 (54–77)	60 (48–71)
Gender		
Male	204 (67)	116 (62)
Female	99 (33)	71 (38)
Ethnicity		
Asian	12 (4)	12 (6)
Black	11 (4)	15 (8)
White	273 (92)	156 (83)
Other	2 (1)	4 (2)
Educational level		
No formal qualification	94 (32)	59 (32)
O-level to A-level	154 (52)	94 (51)
Degree or higher	47 (16)	31 (17)
Median (IQR) adjusted IMD	12.8 (7.8–22.8)	18.5 (9.9–38.4)
Time between first referral to dialysis centre and completion of questionnaire		
<90 days	57 (19)	n.a. ^b
90–365 days	63 (21)	58 (31)
>365 days	178 (60)	127 (69)
Selected treatment^c		
Listed for chronic haemodialysis ^d	144 (47)	n.a. ^b
Listed for peritoneal dialysis	91 (30)	n.a. ^b
Listed for kidney transplantation	43 (14)	n.a. ^b
Receiving haemodialysis for >90 days	n.a. ^b	126 (67)
Receiving peritoneal dialysis for >90 days	n.a. ^b	31 (17)
Received kidney transplant	n.a. ^b	18 (10)
Conservative management ^e	15 (5)	12 (6)
Missing ^f	37 (12)	0 (0)

IQR, interquartile range; IMD, index of multiple deprivation; n.a., not applicable; RRT, renal replacement therapy.

^aPercentages may not add up to 100% due to rounding, or because patients were counted twice (see footnote e).

^bDid not apply for this phase.

^cFor Phase 1, patients listed for both kidney transplantation and some form of dialysis ($n = 13$) were counted twice.

^dIncluding patients who started on haemodialysis <90 days previously.

^ePatients not receiving dialysis or a kidney transplant while having an estimated glomerular filtration rate <10 mL/min/1.73 m².

^fNo ($n = 37$) or conflicting ($n = 1$) information on treatment provided; we considered being listed for dialysis and having opted for conservative care as conflicting.

distribution (65 versus 62% males; $P = 0.2$) and median-adjusted IMD [15.2 (IQR, 8.3–29) versus 17.4 (IQR, 9.3–31.5); P -value, 0.06]. However, patients in our study sample were more likely to be white compared with the incident RRT population (88 versus 79% whites; $P < 0.0001$).

Options known and discussed with the clinical team

Table 3 reports the results for Phases 1 and 2 (see Box 1 for inclusion and exclusion criteria). In Phase 1, almost all patients (97%)

Table 2. Number of completed questionnaires, and the ratio between the included and expected number of included patients per centre

Renal centre	Eligible patients expected (E) ^a	Phase 1			Phase 2		
		Completed questionnaires	Eligible patients included (I)	I : E ratio	Completed questionnaires	Eligible patients included (I)	I : E ratio
1	34	18	18	0.53	30	17	0.50
2	37	16	16	0.43	16	12	0.32
3	7	9	9	1.24	6	5	0.69
4	19	105	25	1.35	17	14	0.76
5	66	14	14	0.21	23	18	0.27
6	31	6	6	0.19	8	3	0.10
7	23	8	8	0.35	1	1	0.04
8	19	10	10	0.54	7	6	0.32
9	43	18	18	0.42	22	15	0.35
10	13	7	7	0.53	9	5	0.38
11	18	10	10	0.56			
12	31	25	25	0.81			
13	28	5	5	0.18			
14	26	39	39	1.50			
15	19	16	16	0.85			
16	40	3	3	0.08			
17	61	35	35	0.58			
18	13	35	35	2.80			
19	13	6	6	0.48			
20	5				3	2	0.42
21	19				25	20	1.05
24	3				2	2	0.62
25	10				13	8	0.80
26	28				14	14	0.51
27	25				15	13	0.53
Overall	698	385	305	0.44	262	187	0.27

^aBased on the quarterly number of incident patients on RRT in 2012.

reported being aware of unit-based haemodialysis as a treatment option; the majority were also aware of peritoneal dialysis (85%), kidney transplantation (74%) and home-based haemodialysis (74%) (see Table 3). Fewer than half (46%) knew that conservative management was a possible treatment option. In Phase 2, most patients (94%) reported being aware of unit-based haemodialysis, peritoneal dialysis (73%), kidney transplantation (70%) and home-based haemodialysis. Only 35% knew that conservative management was a possible treatment option. For both phases, Kruskal–Wallis tests revealed that patients who were aware of conservative management were significantly older than those who were not ($P = 0.005$ in Phase 1 and $P = 0.002$ in Phase 2). In Phase 1, patients who reported knowing about peritoneal dialysis ($P = 0.04$), home haemodialysis ($P = 0.03$) and transplantation ($P < 0.0001$) were significantly younger than patients who were not aware that those options existed.

After talking to their health professional, the majority of Phase 1 patients perceived unit-based haemodialysis (83%) and peritoneal dialysis (71%) to be options specifically available to them. This was less likely for kidney transplantation (49%), home-based haemodialysis (52%) and conservative management (31%). After talking to their health professional, most Phase 2 patients perceived unit-based haemodialysis (86%) and peritoneal dialysis (59%) to be available to them. Fewer than half felt that kidney transplantation (47%), home-based haemodialysis (35%) and conservative management (18%) were options available to them. In Phase 1, Kruskal–Wallis tests revealed that patients who had been offered peritoneal dialysis ($P = 0.04$), home haemodialysis ($P = 0.0002$) and transplantation ($P < 0.0001$) tended to be younger. Conversely, patients who had discussed conservative management with the

clinical team tended to be older ($P = 0.0003$). In Phase 2, age differences were only significant for transplantation ($P < 0.001$) and conservative management ($P < 0.002$).

In Phase 1, patients most frequently reported health professionals (96%), and leaflets, booklets or DVDs (83%) as sources of information used before making a treatment decision. Group sessions (36%), websites (28%) and patient decision aids (24%) were less commonly reported. In Phase 2, patients most frequently reported talking to health professionals (97%), using leaflets, booklets or DVDs (80%), and attending group sessions with other patients (32%). A minority of patients reported using patient decision aids or websites.

Aspects of treatment decision making

The majority of Phase 1 patients perceived their decision making style as active (18%) or collaborative (73%), while 6% perceived it to be passive (see Table 3). In Phase 2, 14% of patients reported a passive decision making style (i.e. health professionals decided on their behalf), with fewer patients reporting an active (16%) or collaborative style (69%).

With regard to patients' experience of care consultations, the median total SHARED score for Phase 1 was 12.5 (IQR, 10–17) out of 20. The median total SHARED score in Phase 2 was 10 (IQR, 8–14) out of 20. Furthermore, Kruskal–Wallis test revealed that in Phase 1, patients who had used a decision aid (24.2%) tended to score higher on SHARED than patients who had used other sources of information and support ($P = 0.025$). There were no statistically significant differences in SHARED total scores according to gender, age, ethnicity, education or treatment modality.

Table 3. Survey responses regarding treatment awareness and decision making for Phases 1 and 2 [values are numbers (percentages)^a unless indicated otherwise]

Questionnaire item	Phase 1 (N = 305)	Phase 2 (N = 187)
Patients' awareness of treatment options		
Available in general		
Unit-based haemodialysis	293 (97)	176 (94)
Home-based haemodialysis	223 (74)	114 (61)
Peritoneal dialysis	257 (85)	136 (73)
Conservative management	138 (46)	66 (35)
Kidney transplantation	224 (74)	130 (70)
Missing	2 (1)	None
Perceived availability after talking to caregiver		
Unit-based haemodialysis	251 (83)	161 (86)
Home-based haemodialysis	158 (52)	66 (35)
Peritoneal dialysis	215 (71)	111 (59)
Conservative management	95 (31)	33 (18)
Kidney transplantation	148 (49)	88 (47)
Missing	2 (1)	1 (1)
Information sources provided by the centre		
Health professionals	289 (96)	180 (97)
Group sessions with other patients	108 (36)	60 (32)
Leaflet, booklet or DVD	251 (83)	149 (80)
Website with general information	84 (28)	35 (19)
Patient decision aid	73 (24)	26 (14)
Missing	3 (1)	1 (1)
Aspects of the treatment decision making		
Patients' perceived decision-making style (CPS)		
Active	54 (18)	29 (16)
Collaborative	222 (73)	129 (69)
Passive	18 (6)	27 (14)
Missing	11 (4)	2 (1)
Decision-making process (SHARED)		
Total score (median, IQR)	12.5 (10–17)	10 (8–14)
Staff input (median, IQR) ^b	4 (4–7)	4 (3–5)
Patient input (median, IQR) ^c	3.5 (3–6)	3 (2–5)
Shared decision (median, IQR) ^d	4 (3–6)	3 (2–4)
Missing ≥ 1 SHARED item	51 (17)	19 (10)
Answering 'not sure' to ≥ 1	n.a. ^e	91 (49)
SHARED item		
SURE score		
Yes	242 (85)	139 (76)
No	43 (15)	44 (24)
Missing ≥ 1 SURE item	20 (7)	4 (2)
Currently on treatment initially chosen	n.a.	160 (87)

CPS, Control Preference Scale; IQR, interquartile range; n.a., not applicable.

^aPercentages may not add up to 100% due to rounding.

^bItems 1–4 of the SHARED scale with maximum score of 8.

^cItems 5–7 of the SHARED scale with maximum score of 6.

^dItems 8–10 of the SHARED scale with maximum score of 6.

^e'Not sure' was only available as an answering option in Phase 2.

Scores on the SURE test revealed that the majority of patients (85%) in Phase 1 answered yes to all SURE items, thus indicating the absence of decisional conflict. In Phase 2, 76% of patients were devoid of decisional conflict, while 24% indicated some level of decisional conflict. Kruskal–Wallis test revealed that Phase 1 patients who had used a decision aid (24.2%) tended to score higher on SURE, showing less decisional conflict than those who had been provided with alternative sources of

information ($P = 0.003$). There were no statistically significant differences in SURE scores according to gender, age, ethnicity, education or treatment modality.

Discussion

This service evaluation assessed the feasibility of routine measurement of patient involvement in treatment decision making within the complex clinical context of CKD. When compared with annual incidence figures, the recruitment rates (as shown by the I:E ratios) were lower than expected. Despite simplifying Phase 2 inclusion criteria, recruitment rates remained lower than expected. A sizeable proportion of completed questionnaires did not meet the inclusion criteria and were thus excluded from the analysis. Study participants were more likely to be white compared with incident RRT patients. Most participants generally knew and discussed four treatment options with their healthcare professionals: unit-based haemodialysis, peritoneal dialysis, transplantation and home-based haemodialysis. A minority of participants knew of, and were offered, conservative management. Age was a significant predictor of the options known and discussed. About 70% of patients across both phases reported a collaborative role in decision making (Control Preference Scale). The median SHARED score was 12.5 (Phase 1) and 10 (Phase 2) out of 20. The majority of participants were devoid of decisional conflict (SURE score).

The strengths of this service evaluation were the pragmatic recruitment of patients across 27 renal units in NHS routine settings, and the involvement of a dedicated multidisciplinary expert group. However, several limitations need to be considered. First, this work was funded as part of a time-limited 'Call to Action' sponsored by the NHS Institute for Innovation and Improvement, in which the measurement of patient experience of treatment decision making was intended to serve both as a disruptive innovation and provide a tension for change. These time constraints have affected the design of this evaluation and our ability to thoroughly set up the service evaluation, and hindered the optimal recruitment of renal centres and nurses. Second, contextual factors may have influenced patient responses. In Phase 1, NHS Kidney Care funding and SDM programmes conducted in parallel to this service evaluation may have affected data collection. In Phase 2, Scottish centres who had not been involved in Phase 1 took part in the service evaluation. Third, our decision to recruit new patients in Phase 2, as opposed to collecting data at two different time points in the same patient cohort, may be considered a weakness of this project. Using the same cohort would have eliminated any potential influence of case-mix or unit-level factors on the survey responses, and would have enabled us to confidently assign the differences in responses to the timing of the questionnaire. However, this was rendered impossible by the timescales of the service evaluation. In addition, most questionnaires were handed out by the renal nurses and completed at the time of (or close to) the consultation. It is possible that the data being captured by the same professionals as those providing care may have led to response biases (e.g. social acceptability) and ceiling effects, commonly seen in SDM questionnaires used in similar contexts [26]. Finally, given that none of the renal centres systematically returned the weekly recruitment sheet, we are unable to estimate the number of invited patients against those who completed the questionnaire.

Measuring patient involvement in the context of chronic illnesses, and specifically CKD, is possible in routine NHS settings but presents challenges. Establishing routine data collection appeared more complex and time-consuming than expected, and

required significant resources and commitment from the entire renal team at each site. Questionnaire timing was also a significant challenge of this project. Iterative adjustments were required to both the content of the questionnaire, processes of data collection and supporting documents for nurses and other members of the renal team involved in recruitment. In the future, routine data collection of patient involvement in CKD treatment could be facilitated by integrating selected SDM items in patient-reported outcome measures (PROMs) and experience measures (PREMs) routinely collected in renal registries in Europe [16]. Some of the challenges associated with the routine data collection of PROMs and PREMs data are comparable to those we encountered in this service evaluation [16].

While evidence shows that conservative management is accepted across UK renal units [27], our findings suggest that over half of patients facing RRT treatment decisions are not aware of conservative management as a possible treatment option, and do not tend to discuss this treatment with their health professionals. Given the limitations associated with the completion of questionnaires in renal units, with renal nurses, it is difficult to draw firm conclusions about the aspects of treatment decision making in our sample. Further investigation is required.

This service evaluation confirms the importance of assessing the feasibility of routine data collection in complex clinical and decision-making contexts, allowing sufficient set-up time and dedicated resources, before attempting to implement systematic data collection procedures. The study findings are relevant in the context of a National UK programme, recently funded by NHS England, which seeks to improve health-related patient activation in the context of CKD [17, 18]. The present study may, thus, inform some of the data collection procedures (e.g. timing and deployment of the patient activation measure questionnaire), systems and resources required to reliably and sustainably collect information about patient activation across the NHS and promote patient-centred coordinated care.

Supplementary data

Supplementary data are available online at <http://ckj.oxfordjournals.org>.

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Authors' contributions

C.R.V.T., M.-A.D., R.E., H.L.B., A.F., A.L., W.M., R.G.T. and A.M. planned and designed the service evaluation. M.-A.D., C.R.V.T., R.E. and H.L.B. designed the questionnaire. M.-A.D., C.R.V.T., R.E., H.L.B., A.F., A.L., W.M., R.G.T. and A.M. commented on and finalized the questionnaire. H.L.B., R.E., A.F., A.L., W.M., A.M., C.R.V.T., R.G.T. and M.-A.D. were part of the expert group. M.-A.D.

and C.R.V.T. managed the data collection. A.C., C.R.V.T., S.N.v.d.V. and M.-A.D. analysed the data. M.-A.D. and S.N.v.d.V. drafted the manuscript. All authors contributed to all major revisions and final draft of the manuscript. They have all approved the final manuscript.

Conflict of interest statement

None declared.

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