

## THE EXPERIENCE OF CHRONIC KIDNEY DISEASE PATIENTS: THE RESULTS OF THE 2017 UK RENAL REGISTRY / KIDNEY CARE UK *CHRONIC KIDNEY DISEASE PATIENT REPORTED EXPERIENCE MEASURE*

### PURPOSE

The UK Renal Registry (UKRR) and Kidney Care UK's (KCUK) Chronic Kidney Disease Patient Reported Experience Measure (CKDPREM) was developed by patients, academics and clinicians in 2016. The CKDPREM was designed to provide clinical directors with information about their services from the user perspective, inform quality improvement initiatives and contribute to research. Following a pilot of over 8,000 patients in 2016, and subsequent validation, the UKRR surveyed renal units in 2017 using the revised CKDPREM; this abstract reports the results.

### METHODS

CKDPREM consists of 50 items across 13 domains covering patient experience of their renal unit, kidney disease and treatment. There are six demographic questions including age, sex, ethnicity and modality. The CKDPREM was distributed to all renal units in England and Wales in July 2017, with accompanying survey guidance and support provided to invite outpatient, pre-dialysis, dialysis and transplant renal patients to complete the CKDPREM online or in hard copy format. The survey was provided online in Welsh, Gujarati and Urdu as well as in English. Patients participated anonymously, returning hard copy CKDPREMs to their unit in return boxes or directly to the UKRR by post. Experience was scored on a scale of 1 (negative) to 7 (positive), and the mean score for all questions was estimated for each respondent. Analysis was conducted at individual unit and aggregate centre level (aggregate being the main hospital and all of its satellite units). Unit and centre means were estimated across respondents for that unit or centre. Patient characteristics were evaluated by comparing mean scores, and via regression models.

### RESULTS

11,027 analysable responses to the CKDPREM were received from 56 centres incorporating 231 units in total. Demographically, respondents represented the patient population as a whole, although there were relatively low numbers of respondents in the pre-dialysis (15%) and transplant (14%) groups. Patient experience was high (6.3 out of 7) but with significant variation between centres. The largest variation was seen in Fluid and Diet (20%), Sharing Decisions (21%), Needling (29%, a new domain) and Transport (52%). More consistent experience was reported by patients for Access to the Team (11%), Privacy and Dignity (13%), and Scheduling and Planning (10%), however the mean difference between the best and worst centre remains greater than 10%. Patient characteristics contributed little to variation; only differences smaller than 10% (.7) of the scale range were seen (men and women, age, type or location of treatment, and ethnicity). Variation was instead explained by differences between centres, with ranges of mean scores from .73 (Scheduling and Planning) to 3.7 (Transport).

### CONCLUSIONS

Participation in the CKDPREM increased in 2017 compared to 2016, suggesting that post-validation changes made to the 2016 version of the CKDPREM have worked well. The outcome of the 2017 CKDPREM offers significant insight into renal patient experience. Importantly, the biggest factor driving variation in patient experience is the treating centre, and not patient characteristics. Sharing Decisions and Transport are consistently identified as areas with large variation (in both 2016 and 2017) and Scheduling and Planning with the lowest variation. UKRR and KCUK will continue to run the CKDPREM on an annual basis from late spring 2018 and also be making a short form version available.

Control/Tracking Number: 18-A-873-ERA-EDTA  
Activity: Abstract  
Current Date/Time: 1/12/2018 8:18:04 AM

**THE EXPERIENCE OF CHRONIC KIDNEY DISEASE PATIENTS: THE RESULTS OF THE 2017 UK RENAL REGISTRY / KIDNEY CARE UK CHRONIC KIDNEY DISEASE PATIENT REPORTED EXPERIENCE MEASURE**

**Author Block:** Janine Hawkins<sup>1</sup>, David M. Wellsted<sup>1</sup>, Catherine Stannard<sup>2</sup>, Amanda D. Busby<sup>1</sup>, Rachel Gair<sup>2</sup>, Sabine N. van der Veer<sup>3</sup>, <sup>1</sup>University of Hertfordshire, Centre for Health Services and Clinical Research, Hatfield, UNITED KINGDOM, <sup>2</sup>UK Renal Registry, Bristol, UNITED KINGDOM, <sup>3</sup>University of Manchester, Centre for Health Informatics, Manchester, UNITED KINGDOM.

**Abstract:**

**INTRODUCTION AND AIMS:** The UK Renal Registry (UKRR) and Kidney Care UK's (KCUK) Chronic Kidney Disease Patient Reported Experience Measure (CKDPREM) was developed by patients, academics and clinicians in 2016. The CKDPREM was designed to provide clinical directors with information about their services from the user perspective, inform quality improvement initiatives and contribute to research. Following a pilot of over 8,000 patients in 2016, and subsequent validation, the UKRR surveyed renal units in 2017 using the revised CKDPREM; this abstract reports the results.

**METHODS:** CKDPREM consists of 50 items across 13 domains covering patient experience of their renal unit, kidney disease and treatment. The CKDPREM was distributed to all renal units in England and Wales in July 2017, with accompanying survey guidance and support provided to invite outpatient, pre-dialysis, dialysis and transplant renal patients to complete the CKDPREM online or in hard copy format. The survey was provided online in Welsh, Gujarati and Urdu as well as in English. Patients participated anonymously, returning hard copy CKDPREMs to their unit in return boxes or directly to the UKRR by post. Experience was scored on a scale of 1 (negative) to 7 (positive), and the mean score for all questions was estimated for each respondent. Analysis was conducted at individual unit and aggregate centre level (aggregate being the main hospital and all of its satellite units). Unit and centre means were estimated across respondents for that unit or centre. Patient characteristics were evaluated by comparing mean scores, and via regression models.

**RESULTS:** 11,027 analysable responses to the CKDPREM were received from 56 centres incorporating 231 units in total. Demographically, respondents represented the patient population as a whole, although there were relatively low numbers of respondents in the pre-dialysis (15%) and transplant (14%) groups. Patient experience was high (6.3 out of 7) but with significant variation between centres. The largest variation was seen in Fluid and Diet (20%), Sharing Decisions (21%), Needling (29%, a new domain) and Transport (52%). More consistent experience was reported by patients for Access to the Team (11%), Privacy and Dignity (13%), and Scheduling and Planning (10%), however the mean difference between the best and worst centre remains greater than 10%. Patient characteristics contributed little to variation; only differences smaller than 10% (.7) of the scale range were seen (men and women, age, type or location of treatment, and ethnicity). Variation was instead explained by differences between centres, with ranges of mean scores from .73 (Scheduling and Planning) to 3.7 (Transport).

**CONCLUSIONS:** Participation in the CKDPREM increased in 2017 compared to 2016, suggesting that post-validation changes made to the 2016 version of the CKDPREM have worked well. The outcome of the 2017 CKDPREM offers significant insight into renal patient experience. Importantly, the biggest factor driving variation in patient experience is the treating centre, and not patient characteristics. Sharing Decisions and Transport are consistently identified as areas with large variation (in both 2016 and 2017) and Scheduling and Planning with the lowest variation. UKRR and KCUK will continue to run the CKDPREM on an annual basis from late spring 2018 and also be making a short form version available.

**Content of Work Agreement (Complete):**

: Agree

**Category (Complete):** K3 - CKD. Clinical epidemiology

**Presentation Type (Complete):** Either Poster or Oral

**Questionnaire (Complete):**

\* **Accept/Reject:** Agree

**ERA-EDTA Fellowship winner (past or present)?:** No

\* **Accept/Reject:** Agree

\* **Area of Interest 1:** Chronic Kidney Diseases (CKD)

**Area of Interest 2:** Epidemiology

**Transparency:** No

\* **Are you a member of the Young Nephrologists' Platform?:** No

**ERA-EDTA Travel Grants (Complete):**

\* **Select below if you are applying for the ERA-EDTA 2018 Travel Grant:** No, I am not applying for the ERA-EDTA 2018 Travel Grants

**Keyword (Complete):** 065) chronic kidney disease ; 245) patient self-assessment ; 275) registries ; 312) treatment

**Payment (Complete):** Your credit card order has been processed on Friday 12 January 2018 at 7:23 AM.

**Attached Files:** No Files Attached