

Kidney PREM Data Portal – Notes for Interpretation

This Kidney Patient Reported Experience Measure (PREM) Data portal has been developed by UK Renal Registry and Kidney Care UK to give renal centres and units across the UK sight of patient responses to the latest Kidney PREM. This report is intended to allow centres and units the time to engage with their data and begin to plan local quality improvement initiatives. A written report will also be published annually, including national averages, key findings from the Kidney PREM, recommendations and further information on acting on your Kidney PREM results.

How are the Kidney PREM results presented?

There are 13 sections to the Kidney PREM, covering a number of aspects of renal services which patients have said are important, including access to the renal team, patient information, support, transport and an overall experience question.

As shown on the Kidney PREM, the responses for questions 1- 33 ranged from 1 [never] to 7 [always], questions 34-38 (section 13: the environment) ranged from 1 [poor] to 7 [excellent] and question 39 (overall experience) ranged from 1 [worst it can be] to 7 [best it can be]. In addition, “Don’t Know” and “Not applicable” could be selected for all but question 39. Alternatively, the answer could be missing. Some sections (e.g. hospital transport, needling) had filters as the questions only applied to some patients.

The responses to each section are shown in two tables. One table shows the number of responses (including “Don’t Know”, “Not Applicable”, and Missing) to each response option, the second table show the same data as a percentage of the responses. The stacked bar charts show each question separately, with each column showing the proportions of responses to the question.

Please refer to the UKRR website for a full list of units included and the number of responses by unit.

Notes for interpretation

Any comparison between the responses within the questionnaire and between centres is limited by the error of measurement, and the number of patients responding. Small differences may not be particularly helpful at identifying real differences between centres. The values used have been rounded to the nearest whole number.

Units with less than 7 responses are not reported in order to preserve anonymity of responders. These responses will appear as ‘missing’ in the PREM portal, however have been included when working out the centre level mean for each theme which is reported in the national Kidney PREM report.

Changes to the Kidney PREM from 2017

The changes in the Kidney PREM from 2017 to 2018 were limited, building on considerable changes from 2016 to 2017, when the measure was validated.

The Kidney PREM was modified for 2018 to reduce its length (from 50 to 39 questions), with the aim of maintaining the overall mean scores, while increasing the overall response variation between people responding. The intention was to try to maximise any apparent differences within the 13

themes so that the questionnaire would become more sensitive to those differences. There is a remarkable consistency in the overall mean scores from 2017 to 2018 that is not affected by an increase in the score ranges for all but three questions. The data reported in 2017 can therefore be compared to future years (the survey had no changes from 2018 to 2019), but with caution where there is a change in the number and pattern of patients responding.

The question numbering used in the visualisation are taken from the 2018 and 2019 survey - which means that some questions from the 2017 PREM are not included. The full text of the question is presented in the selection pane and we suggest that it is the question text and not the question number which you use to find the correct question. Two questions relating to diet and fluid changed between the surveys, and the responses to these questions are presented separately (as 'a' and 'b') to prevent direct comparison.

In 2016 the scale had 42 questions in 12 themes, and several questions were changed, along with the response scale (expanded from 4 to 7), and the addition of a new theme (Needling). Caution is therefore needed in interpreting the data reported in 2016 in comparison to future years which is why the 2016 data is not included in the on-line portal.

Some differences were made in the way that mean scores for Needling and Scheduling & Planning themes were estimated in 2019 to improve the interpretability of the results. Previously, all patients who had answered those questions were included in the analysis. For this years' results, answers were cross-referenced with each patient's treatment type so that scores for Needling were only estimated for in-hospital and in-satellite haemodialysis patients. Questions about blood tests (in the Scheduling & Planning theme) were analysed for all other patients. The comparison between 2019 and previous years' results may be influenced by this change for these areas.