Technical Report for the

Kidney Patient Reported Experience Measure (Kidney PREM)

and

Pilot Paediatric Patient Reported Experience Measure (Paediatric PREM)

2023

Contents

Kidney PREM/Paediatric PREM facilitators

The UK Kidney Association (UKKA) and Kidney Care UK jointly commission the Kidney Patient Reported Experience Measure (Kidney PREM) each year. The UKKA are predominantly responsible for delivering resources to centres, and hosting the data (via the data portal) and results on their website, including the annual report. Kidney Care UK provide resources aimed at patients to explain results. The University of Hertfordshire (UH) hosts the online survey and analyses the data, producing the national report and additional centre-level results. A Paediatric Patient Reported Experience Measure (PPREM) has been piloted in 2023 following success of the initial pilot in 2022, held in parallel to the Kidney PREM. The British Association of Paediatric Nephrologists (BAPN) supports the Paediatric PREM.

Kidney PREM and pilot Paediatric PREM 2023 data

Questions about participants and their kidney treatment
Information about participant characteristics and kidney treatment was collected, Table 1.

Table 1: Information collected about participants and their treatment

Section		Abridged question	Responses
Help to complete	D01	Completing with help	With help/alone
	D02	Who is helping	Friend, relative or carer/volunteer/other (please state)
	D03	Why they are helping	Language/health/disability/technology/connection to HD/ eyesight/other (please state)
Treatment	D04	Current treatment	Peritoneal dialysis/haemodialysis/transplant/attending clinic but not receiving KRT
	D05	Haemodialysis location	At home/in hospital/in satellite
	D06	Shared care for HD	Participating/invited & declined/not invited/don't know
	D07	Current care if not KRT	Monitoring/transplant, HD or PD chosen/Conservative/ Undecided treatment/Don't know
Characteristics	D08	Age (years)	0, 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16$^\$$ 17-21 / 22-30 / 31-40 / 41-55 / 56-64 / 65-74 / 75-84 / 85+
	D09	Gender	Male/Female/Rather not say
	D10	Ethnicity	Asian: Indian, Pakistani, Bangladeshi, Chinese, any other Asian background Black: Caribbean, African, any other Black background Mixed/multiple: White/Black Caribbean, White/Black African, White/Asian, any other Mixed/multiple background White: British, Irish, Gypsy/Irish Traveller, Roma, any other white background Other ethnic groups: Arab, any other ethnic group
Additional	D11	English first language	Yes/no
	D12	Other first language	[free text]
	D13	Use of Patients Know Best	Yes/no (unavailable)/no (Don't know what this is)/ no (another reason)/don't know
	P01	Medication*	Hospital pharmacy/community pharmacy/delivered/other/ mixture/don't know/not applicable
	D14	Postcode	[free text]/no thank you

*KRT: kidney replacement therapy, HD: haemodialysis, PD: peritoneal dialysis. *Paediatrics only*

The Kidney PREM/pilot Paediatric PREM

The Kidney PREM consisted of 39 questions covering 13 themes plus an overall experience question, using the validated measure, used annually since 2018. Patients responded to each question on a scale from 1 to 7. All questions had the option of 'don't know' and 'not applicable', with the exception of question 39 'Your Overall Experience'. The themes, corresponding questions and relevant response scales of the measure are shown in Table 2.

Table 2: Themes and response scales of the 2023 Kidney PREM and pilot Paediatric PREM

Section	Theme	Questions	Response scale
1	Access to the Kidney Team	Q1-Q3	1 (Never) – 7 (Always)
2	Support	Q4-Q6	
3	Communication	Q7-Q11, P02[$]	
4	Patient Information	Q12-Q13	
5	Fluid Intake and Diet	Q14-Q15	
P1[$]	Medication	P03-P04	
6[¥]	Needling	Q16[#]	
7	Tests	Q17-Q19	
8	Sharing Decisions	Q20-Q22	
9	Privacy and Dignity	Q23-Q24	
10	Scheduling and Planning	Q25-Q26, Q27[#]	
11	How the Kidney Team Treats You	Q28-Q30	
12	Transport	Q31-Q33[#]	
13	The Environment	Q34-Q38, P05[$]	1 (Poor) – 7 (Excellent)
14	Your Overall Experience	Q39*	1 (Worst it can be) – 7 (Best it can be)

[#]*Filtered questions (depending on treatment modality), *Overall experience – not included in scale score, [$]Paediatrics only, [¥]Adults only*

Change in experience of care

A question relating to change in experience of care was added in 2020, focussing on perceived differences in care during the pandemic. It has subsequently been expanded to include any changes in experience, regardless of cause:

> *'Overall, how much better or worse was your kidney care experience during the last year?'*

This was scored on a range of -3 (much worse) to +3 (much better), to correspond to the standard 7-point scale used in the main survey.

Additional questions

Three additional questions were developed by the Kidney PREM working group in collaboration with service users and added to the end of the survey, Table 3. These were intended to obtain a snapshot of services across centres, and there are no plans to repeat these in future Kidney PREM collections.

Table 3: Additional questions asked at the end of Kidney PREM

Section		Abridged question	Responses
Additional questions	A1	Discussed wellbeing	Yes/no
	A2	Where kidney letters are sent	Me only/me & copied to GP/GP only/GP & copied to me/ depends/don't know
	A3	Discussed last year's Kidney PREM report	Yes/no

Comments about experience of care

At the end of the survey, Kidney PREM participants were asked the following question, for which a free-text box was provided to capture responses:

'If there is any other aspect of your experience of kidney care that you would like to comment on that has not already been covered, during COVID-19 or another time, please tell us below'

The methodology of the analysis of this question is reported separately, available here on the UKKA website.

Data collection process

Individuals receiving treatment at each adult kidney centre across England, Wales, Scotland and Northern Ireland were invited to take part in the Kidney PREM survey. Those aged 12-16 attending paediatric centres across the UK and parents/carers of children and young people (CYP) of any age attending centres were invited to participate in the pilot Paediatric PREM. The surveys were available for completion over a period of eight weeks from 11th September to 6th November 2023. With the exception of 2020 during the pandemic, Kidney PREM has previously been available for completion both online and using paper surveys. However, in 2023, both the Kidney/Paediatric PREM surveys were available online only. Centres were sent promotional material in August which provided the website address and encouraged participation.

Online completion

The Kidney/Paediatric PREM surveys were available online via the Kidney Care UK website hosted on the Qualtrics platform. Kidney centres were encouraged to promote the Kidney/Paediatric PREM as much as possible using their existing communication tools, such as email, text messaging or by post. Business cards and posters were also provided, highlighting the website address. In addition, some patients may have accessed the survey directly without being informed by their treating centres. As well as English, the questionnaire was available in Welsh, Gujarati and Urdu.

Paper completion

During the data collection window, one site (Newcastle) approached the Kidney PREM operations group to request paper surveys for patients for whom online completion was challenging. Volunteers at the centre facilitated survey completion, then input results to Qualtrics using a link generated specifically for that purpose. Before the next data collection, the centre and the Kidney PREM working group will reflect on this process to determine whether to continue in the future.
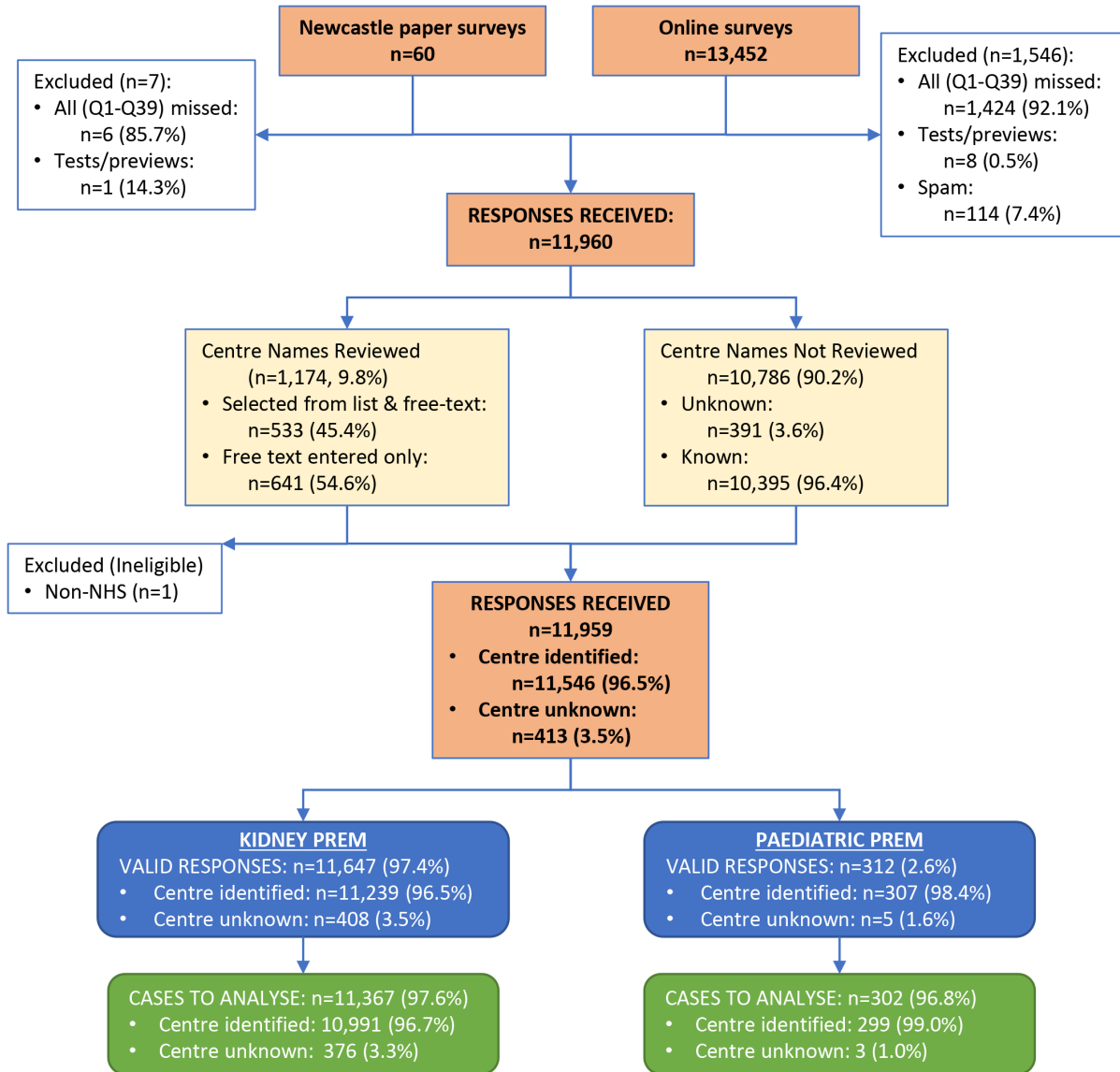
Data cleaning

All data analysis was performed using Excel and Stata/MP version 18.0. Figure 1 illustrates the responses received from each collection method and the initial data cleaning process followed to define the number of 'valid responses'. The criteria used to define these were:

- Completed between 11/09/2023 and 06/11/2023,
- At least one survey question (Q1-Q39) answered,
- From an eligible kidney service.

Participants selected the relevant PREM they wished to complete (adult Kidney PREM or paediatric PREM), then selected their centre from a drop-down list or entered text into the 'Unit Free Text' box, either in addition to or instead of selecting a unit. Out of 1,174 with free text entries, 731 changes were made to centre names. Correct centres had already been selected for 420 responses with entered text and a further 22 could not be identified. One response was excluded since the participant was reporting about a private healthcare setting. All survey responses with free text entered were independently reviewed by staff at both UKKA and UH. Once the review process was complete, UK Renal Registry codes were added to the data.

After merging the datasets and completing the data cleaning process, 11,647 valid responses were identified for Kidney PREM, of which 11,239 (96.5%) centres were known and 408 (3.5%) could not be determined, Figure 1. For the pilot Paediatric PREM, 312 valid responses were identified, of which centre names were determined for 307 (98.4%) and not identified for 5 (1.6%) responses.

Figure 1: Flowchart detailing the Kidney PREM 2023 data cleaning and analysis process

Newcastle paper surveys
n=60

Online surveys
n=13,452

Excluded (n=7):
• All (Q1-Q39) missed:
    n=6 (85.7%)
• Tests/previews:
    n=1 (14.3%)

Excluded (n=1,546):
• All (Q1-Q39) missed:
    n=1,424 (92.1%)
• Tests/previews:
    n=8 (0.5%)
• Spam:
    n=114 (7.4%)

RESPONSES RECEIVED:
n=11,960

Centre Names Reviewed
    (n=1,174, 9.8%)
• Selected from list & free-text:
    n=533 (45.4%)
• Free text entered only:
    n=641 (54.6%)

Centre Names Not Reviewed
    n=10,786 (90.2%)
• Unknown:
    n=391 (3.6%)
• Known:
    n=10,395 (96.4%)

Excluded (Ineligible)
• Non-NHS (n=1)

RESPONSES RECEIVED
n=11,959
• **Centre identified:**
    n=11,546 (96.5%)
• **Centre unknown:**
    n=413 (3.5%)

KIDNEY PREM
VALID RESPONSES: n=11,647 (97.4%)
• Centre identified: n=11,239 (96.5%)
• Centre unknown: n=408 (3.5%)

PAEDIATRIC PREM
VALID RESPONSES: n=312 (2.6%)
• Centre identified: n=307 (98.4%)
• Centre unknown: n=5 (1.6%)

CASES TO ANALYSE: n=11,367 (97.6%)
• Centre identified: 10,991 (96.7%)
• Centre unknown: 376 (3.3%)

CASES TO ANALYSE: n=302 (96.8%)
• Centre identified: 299 (99.0%)
• Centre unknown: 3 (1.0%)

Data analysis

Analysis of demographic, treatment, help to complete and additional questions

Patient characteristics and treatment variables (Table 1) and additional questions (Table 3) were encoded to allow for analysis. Summary characteristics tables were produced based on all patients who provided valid responses and percentages were calculated across each characteristic.

Responses to the question regarding the change in experience of care over the previous year were reported for each treatment group and overall, both as frequencies and proportions. Results were compared to those from 2020, 2021 and 2022 using a stacked bar chart, again with separate columns for each treatment group.

Analysis of postcode data (Measuring participant deprivation using partial postcodes)

Kidney PREM participants provided the first part of their home postcode, used to identify which local authority (LA) each participant resides in. However, sometimes a postcode could map to more than one LA, the maximum being seven. Therefore, the most likely LA was selected for each participant (described below). The relative level of deprivation for each LA was then determined using indices of multiple deprivation (IMD) for each nation within the UK. Each nation publishes slightly different data, so an approach was taken to align nations as much as possible.

England

The IMD decile of each local super output area (LSOA) was obtained, mapped to the LA they belong to. The proportion of LSOAs in deciles 1-3 (i.e., the most deprived 30%) within each of the 317 English LAs was calculated to give a measure of deprivation within each LA.

Scotland

Local councils (equivalent to LAs in England) were ranked according to the highest proportion in deciles 1-3 (i.e., the most deprived 30%). The percentage distribution of deprivation across Scotland's 32 local councils based on the numbers of its zones (equivalent to LSOAs) was obtained.

Wales

Data provided was the percentage of LSOAs in each of Wales's 22 LAs relating to various deprivation deciles. Deciles 1-3 were combined to obtain the proportion of the most deprived 30% LSOAs within each LA, in line with the other nations.

Northern Ireland

Local authority data deprivation data could not be found. Super output area (SOA) data was published and used with the mapping from SOA to each of the 11 local government districts (LGD, equivalent to LAs) to create the same summary data as other nations (i.e., ranked by most deprived 30%)

The local authority deprivation data was combined into a dataset containing LA codes (starting with E for England, W for Wales, S for Scotland, N for Northern Ireland) and the proportion of smaller 'zones' within the most deprived 30%.

The file mapping all (full) [UK postcodes to LA](#), updated in November 2019 (to align most closely with IMD publication dates) was obtained. Given that only the start of the postcode was provided by Kidney PREM participants, there were some instances where more than one LA was possible. To calculate the most likely LA, the following process was followed:

1. The number of possible LAs for each start of postcode was calculated. These ranged from 1 (54.2% of cases) to 7.
2. The number of times each LA was selected for each start of full postcode was counted.
3. The LA with the highest frequency for each postcode was selected.
4. The total frequency of all LAs within a given postcode was calculated.
5. The probability that the select LA with the highest frequency was the correct LA for each postcode was calculated. These probabilities ranged from 50.6% to 100% (Median 99.8%, IQR 93.8% to 100%), Figure 2. 1,408 postcodes have 100% certainty of the correct postcode. A total of 16 postcodes could not be mapped, all of which were within two local authorities.

Figure 2: Probability of selecting correct local authority (LA) for a given postcode)
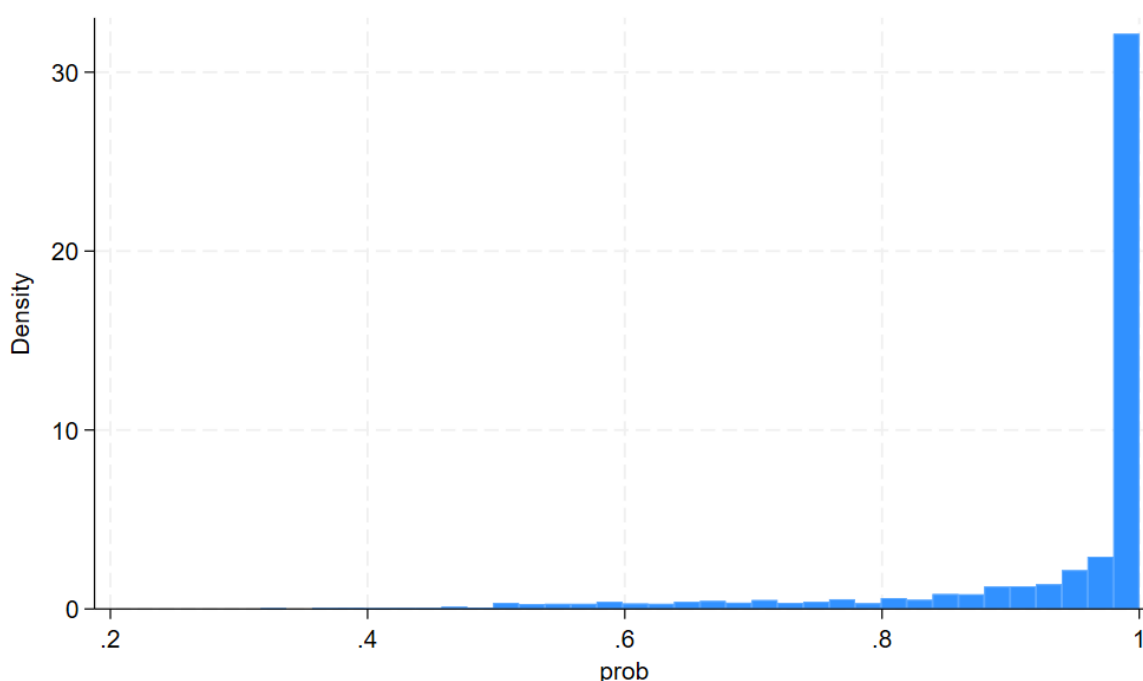
Linear regression models were then used to assess the association between proportion of the most deprived 30% zones and Kidney PREM theme scores.

Estimation of Kidney PREM scale/sub-scale scores

Sub-scale scores were estimated for each theme, for each patient. This produced a score for each theme, with equal weight given to each question. If questions were not answered, theme sub-scale scores could still be estimated so long as there was no more than 1 question missed per theme. For themes containing just one question (Needling and Overall) a score could not be estimated if missed. Questions for themes 6 (Needling) and 12 (Transport) were only asked of in-centre and in-satellite haemodialysis patients. Conversely, question 27 (theme 10) related to outpatient clinic/GP-arranged blood tests and so did not apply to in-centre and in-satellite haemodialysis patients. Theme 10 (Scheduling and Planning) contained only one filtered question out of three, so scores were estimated using the unfiltered questions if applicable.

The total scale score was estimated excluding question 39 (Your Overall Experience). In the adult Kidney PREM, this left 38 questions, of which five were filtered, leaving 33 which were applicable to all patients. Excluding the Overall Experience question, the pilot paediatric PREM contained 41 questions, of which four were filtered, leaving 37 applicable to all paediatric participants.

Scale scores were estimated if there were fewer than four questions missing. If 'Don't Know' or 'N/A' were selected (approx. 9%), the response was not considered missing but could not be used to calculate scale scores. Eight participants (seven completing Kidney PREM and one the pilot paediatric PREM) entered 'not applicable' or 'don't know' for all questions with the exception of question 39, Overall Experience. Scores were calculated even if centre names were missing.

Responses were deemed 'cases to analyse' if the number of missed questions was ≤1 for each theme or ≤4 for the total scale score. Amongst the adult Kidney PREM, 11,367 (97.6% of the 11,647 valid responses,) qualified as cases to analyse. For the pilot paediatric PREM, 302 (96.8% of the 312 valid responses were deemed cases to analyse.

Theme sub-scale and total scale scores were each calculated using the following algorithm:

1. 'Don't Know' and 'N/A' responses were recoded as blank,
2. The number of missed responses from each theme and the overall score were calculated from unfiltered questions (M),
3. The total score for each theme and the overall scale was calculated (R),
4. Each scale or subscale score was calculated: $= \frac{R}{Q-M}$ where Q is the number of questions being evaluated.

Estimation of Mean Scores by Centre

Mean sub-scale and scale scores across each centre were calculated using patient scores. Scores were only reported in the national report/appendices if there were at least seven responses per centre. Just one adult and one paediatric centre had too few participants to be reported, although several centres had insufficient in-centre and in-satellite haemodialysis responses for the Needling and Transport theme scores to be estimated.

The caterpillar plots in both PREM reports (under the heading *'Chapter 6: Patient experience of kidney care across the service'*) provide a visual guide to variation between centres across the 13 themes and the overall question. Each plot (one per theme) shows the median, lower quartile and upper quartile for all centres as a vertical line. For each theme, the data was sorted in descending order by centre, and the mean value for each centre and 95% confidence intervals are shown. Centres with fewer than seven responses for any theme were excluded from the graphs.

For the adult Kidney PREM waterfall plots (2022/23 theme comparisons), mean scores across centres were calculated for each theme. Mean scores for 2022 were previously calculated (excluding centres with fewer than 7 responses). Results were sorted in descending order of the 2023 means and by centre. Plots show 2023 and 2022 means for each centre and theme, with the overall mean of centre scores for 2023 and 2022 as vertical lines.

Estimation of Scores by Treatment Type/Region

To explore differences in scores by treatment modality, medians and interquartile ranges were calculated for each theme. Unlike with centre scores, patient scores were left-skewed, so the small number of treatment types compared to the number of centres (6 v 67 amongst adults) meant that medians were additionally a useful way to measure changes in scores across most patients within each group. Means and confidence intervals were calculated and compared to those from 2022, presented in the main reports, *'Chapter 5 Kidney PREM/Paediatric PREM theme results by treatment'*. Medians and interquartile ranges were also calculated, presented in each report's appendices. Scores for Needling and Transport could only be estimated for in-centre and in-satellite haemodialysis patients.

Mean scores by treatment were also used to produce plots for each theme (under the heading '*Chapter 5: Kidney PREM theme results by treatment and by question'*) in the main Kidney PREM report. In addition, these charts were produced by geographical region and can be seen alongside the centre graphs in the national report.

Question Response Data

Aggregated Question Data

Stacked bar charts were produced for each question in the Kidney PREM, across all patients providing a 'Valid Response'. As a result, the total number of responses may be higher than for the sub-scale and scale scores. 'Don't know' and 'not applicable' entries were not displayed, allowing the easier interpretation of responses using the 1 to 7 Likert scale. The number of values is displayed alongside each question so that the reader can easily identify those questions with fewer responses. These graphs can be viewed in the *'Chapter 5: Kidney PREM theme results by treatment and by question'* section of the Kidney PREM report and *'Chapter 6: Patient experience of kidney care across the service'* in the pilot Paediatric PREM report.

Centre/Unit Level Data (Kidney PREM data portal)

In addition to the main Kidney PREM report, question-level response data was made available via the online portal. The data was relabelled and/or recoded to improve the readability of the dataset. Patient answers of any unit or centre with fewer than 10 responses were removed to preserve the anonymity of individual patients (note the report plots exclude centres with 7 or fewer responses).

Questions answered by any patients included as 'Valid Responses' were included in this presentation. Data for previous years' Kidney PREMs remain online and can be compared to current results for each centre.

Data in the portal is grouped by geographical location (Country, region, main unit and site). Numbers presented in the bar-chart and the table can be separately expanded or contracted to amalgamate sites, centres, regions or countries by using the small (+) and (-) symbols which appear when a user hovers over the geography title in the chart or table. In addition, it is possible to restrict the data to regions, centres or satellites using the filters to the right of the table/chart. Individual questions are selected using the panel under the table. It is not possible to select multiple questions simply because of the volume of data which would potentially being displayed within the panels.

Data in the portal is presented as either numbers of people who gave each response (one to seven, not applicable, don't know or missing), or as a proportion of total group who gave a numerical response (i.e., excluding the NA, don't know and missing responses). In both cases, hovering over the column or the cell displays both the value and proportion in a tooltip. It is crucial to consider the number of people making a response before making a judgement on whether the proportion who responded in that way is large enough to allow firm conclusions to be drawn.

Centre-level patient demographic data are also available on the portal, displaying aggregated treatment, ethnicity, sex and age, alongside question 39 results. Data for previous years are also available to allow for comparison across years.

Limitations and caveats for interpreting plots and data tables

Presenting data to allow for meaningful interpretation is always challenging. In line with previous years, additional tables provide means and confidence intervals for each of the 13 Kidney PREM themes by centre and satellite, by participant demographics at each centre and by treatment modality for each centre, which enhances the information obtained from the caterpillar and waterfall plots. Any summary of data (means, intervals) leads to loss of information but increases the ability to make sense of trends across different groups.

The distribution of responses across the response options (1-7) in the Kidney PREM 2023 data does not follow a 'normal' distribution. Patients tended to score their experience using high (5/6/7) responses rather than 4 or less, referred to as a left-skewed distribution. A common way to deal with a skewed distribution is to use a median with quartiles to display the distribution of the data, as used to demonstrate variation across treatment types in the report appendices. However, most questions and themes have a median of 6 or 7 so considering the median as the central tendency is not as sensitive to variation. In addition, a very large number of responses from the Kidney PREM means that statistical reasons for reporting the median and quartiles are less important, so centre means and 95% confidence intervals provide a robust picture of the responses for most patients, making it straightforward to compare different groups. If a centre's mean and 95% confidence interval centre falls outside of the interquartile range (above the 25th or below the 75th percentile), then the centre can be considered to fall below or above the relevant percentile.

Interpreting the number of responses

Widths of confidence intervals are sensitive to sample size since they are inversely proportional to the square root of the sample size (the confidence interval is produced by dividing by the square root of the sample size). Therefore, as the sample size increases the confidence interval generally gets smaller. If everything else remains the same, the confidence interval for a sample size of 15 will be twice as big as a sample size of 60 (e.g., interval/$\sqrt{4}$). This is critical for small sample sizes of less than 30 where the confidence interval is likely be very large. A large confidence interval indicates uncertainty, reflecting the idea that a small sample size might not be representative of the population. On the other hand, a very small confidence interval may simply reflect a very large sample size.

It is particularly important that where there are a small number of responses that caution is taken in interpreting what this may mean. It is common for numbers to be translated into percentages, but this may be misleading. Testing a new drug can be considered as an example. If 3 out of 5 patients respond well to the drug, does the drug work for 60% of patients? In these circumstances there is an element of chance. If a different group of 5 patients is considered where only 2 or perhaps 4 patients respond to the drug, does the drug work for 20% or 80% of patients? The problem is the uncertainty related to small numbers. Where 100 patients are tested, there will be more confidence in the observed numbers of responses, say 56/100. But even then, the chance of another sample of patients differing by as many as ±10 is considerable. Just looking at the percentage of responses in a particular group, without considering the number of responses may be misleading.

Overview of Kidney PREM/pilot Paediatric PREM outputs

<u>National report:</u>

- **Table 1.1: Kidney PREM 2023 responses by region** (frequencies and proportions, comparison to 2022 responses and comparison to KRT population)
- **Table 1.2: Respondent characteristics for Kidney PREM in 2023, 2022 and 2021** (frequencies and proportions, comparison to previous years and comparison to KRT population)
- **Table 1.3: Treatment modality for Kidney PREM participants in 2023, 2022 and 2021** (frequencies and proportions, comparison to previous years and comparison to KRT population)
- **Figure 1.2: Haemodialysis location of Kidney PREM participants in 2023, 2022 and 2021** (grouped bar chart)
- **Table 1.4: Participation in shared care by those receiving haemodialysis** (frequencies and proportions by patient characteristic)
- **Table 1.5: Reason for attending clinic for participants not receiving kidney replacement therapy** (frequencies and proportions, comparison to previous years)
- **Figure 1.3: Treatment option for individuals approaching end stage kidney disease** (grouped bar chart)
- **Table 1.6: Helpers for Kidney PREM completion in 2023 and 2022** (frequencies and proportions)
- **Figure 1.4: Reason for receiving help to participate in Kidney PREM** (grouped bar chart)
- **Table 1.7: English as first language for Kidney PREM participants by region** (frequencies and proportions)
- **Table 1.8: Primary languages spoken by those for whom English is not their first language** (frequencies)
- **Table 1.9: Partial postcodes provided by region** (frequencies and proportions)
- **Table 1.10: Mean theme scores by deprivation** (mean scores and 95% confidence intervals by deprivation quartile)
- **Figure 1.5: Overall Experience scores by area-level deprivation quartile** (stacked bar chart)
- **Table 1.11: Kidney PREM participant use of Patients Know Best, by treatment** (frequencies and proportions)
- **Figure 2.1: Results for 'Who are your clinic letters sent to?'** (bar chart)
- **Table 2.1: Kidney PREM participants who have been spoken to about their wellbeing or previous year's Kidney PREM report** (frequencies and proportions)
- **Figure 3.1: Changes in patient experience over past year for 2023, 2022, 2021 and 2020, by treatment** (stacked bar chart, grouped by treatment modality)
- **Figure 4.1: Mean centre scores for Kidney PREM themes in 2023, 2022 and 2021** (bar chart grouped by year)
- **Table 4.1: A summary of mean scores by centre, to nearest decimal point, sorted from highest to lowest theme** (range of centre scores, mean of scores)

- **Figure 4.2: Centre scores for Overall Experience of the service provided by kidney centres (Q39 in Kidney PREM)** (stacked bar chart, overlaid with mean scores and 95% confidence intervals for each centre)
- **Table 5.1: Comparison of mean Kidney PREM scores by treatment group for 2023 and 2022** (means and 95% confidence intervals for each theme by treatment type)
- **Theme breakdown by question graphs**:
  - Mean scores and 95% confidence intervals for each theme by treatment type
  - Stacked bar charts for each question across all Kidney PREM participants
- **Patient experience of kidney care across the service graphs (chapter 6):**
  - Mean scores and 95% confidence intervals for each theme by centre
  - Mean scores and 95% confidence intervals for each theme by region

The Kidney PREM Comments report
- **Table 1: Total and number of comments by sentiment, for Kidney PREM themes** (frequencies)
- **Table 2: Characteristics of individuals leaving a comment in Kidney PREM** (frequencies, proportions and comparison to total Kidney PREM)
- **Table 2: Response profile by region** (frequencies, proportions, comparison to total Kidney PREM and comparison to 2022)
- **Chapters 2-17 (by theme, including Emerging Themes):**
  - **Tables: Breakdown of subthemes for each theme by sentiment** (frequencies)
  - **Figures: Scores for Kidney PREM themes in 2021, 2022 and 2023** (grouped bar charts)
  - **Where numbers allow:**
    - **Tables: Breakdown of codes for subthemes by sentiment** (frequencies)
    - **Figures: Characteristics of respondents commenting on themes** (stacked bar charts by age, gender, treatment and ethnicity)
    - **Figures: Theme sentiments by region** (stacked bar charts)

2023 Additional results and information:

- **Kidney PREM report highlights 2023**
- **Summary report of patient comments 2023**
- **Appendices:**
  - **Appendix A: Responses by centre compared to 2022**
    - Figure A1: Kidney PREM responses by treating centre in 2023 and 2022
  - **Appendix B: Age ranges across modalities**
  - **Appendix C: Proportion of Kidney PREM responses for each ethnicity group by centre**
  - **Appendix D: Proportion of Kidney PREM responses for each treatment group by centre**
  - **Appendix E: Characteristics of participants receiving help**
  - **Appendix F: First languages spoken by Kidney PREM participants**
  - **Appendix G: Participant partial postcodes**
  - **Appendix H: Centre results of additional questions**
    - Table H1: Centre results for 'Who are your kidney clinic letters sent to?'
    - Table H2: Centre results for 'Have your kidney team talked to you about your wellbeing in the last year? For example: benefits/housing/mental health.'
    - Table H3: Centre results for 'Has anyone from your unit talked to you about last year's Kidney PREM report?'
  - **Appendix I: Kidney PREM 2022 treatment-level theme scores**
  - **Appendix J: Unit abbreviations, satellites and response numbers**
- **Kidney PREM 2023 Waterfall plots**
- **Online Spreadsheets:**
  - **Centre and Satellite Means:**
    - **By centre** (theme means and response numbers for each centre, sorted by region)
    - **By satellite** (theme means, 95% confidence intervals and response numbers for each satellite, sorted by region)
  - **Centre means by demographics:**
    - **By age** (theme means, 95% confidence intervals and response numbers for each age group within centres, sorted by region)
    - **By ethnicity** (theme means, 95% confidence intervals and response numbers for each ethnicity group within centres, sorted by region)
  - **Centre means by treatment:**
    - **By treatment** (theme means, 95% confidence intervals and response numbers for each treatment group within centres, sorted by region)
    - **By HD location** (theme means, 95% confidence intervals and response numbers for each haemodialysis group [in-centre, in-satellite, at home] within centres, sorted by region)
    - **By year** (theme means and response numbers for each treatment group within centres, sorted by region, for 2021, 2022 and 2023)

- **Table 1.1: Pilot Paediatric PREM 2023 Responses by Treating Centre** (frequencies, proportions, comparison to 2022, comparison to proportion of KRT patients)
- **Table 1.2: Pilot Paediatric PREM age of patient receiving care** (frequencies and proportions, 2022 and 2023)
- **Table 1.3: Pilot Paediatric PREM gender of patient receiving care** (frequencies and proportions, 2022 and 2023)
- **Table 1.4: Pilot Paediatric PREM ethnicity of patient receiving care** (frequencies and proportions, 2022 and 2023)
- **Table 1.5: Treatment modality of patient receiving care** (frequencies and proportions, 2022 and 2023)
- **Table 1.6: Participation in shared care by those receiving haemodialysis in centres** (frequencies and proportions, by respondent group [parent/carer <12 years, parent/carer 12+ years, child/young person])
- **Table 1.7: Reason for attending clinic for patients not receiving kidney replacement therapy** (frequencies and proportions, by respondent group [parent/carer <12 years, parent/carer 12+ years, child/young person], 2022 and 2023)
- **Table 1.8: Pilot Paediatric PREM participant use of Patients Know Best** (frequencies and proportions, by respondent group [parent/carer <12 years, parent/carer 12+ years, child/young person])
- **Table 1.9: Medication provider** (frequencies and proportions, by respondent group [parent/carer <12 years, parent/carer 12+ years, child/young person])
- **Figure 2.1: Results for 'Who are your clinic letters sent to?'** (bar chart)
- **Table 2.1: Pilot Paediatric PREM participants who have been spoken to about their wellbeing or previous year's report** (frequencies and proportions)
- **Figure 3.1: Changes in patient experience over past year for 2022 and 2023, by treatment** (stacked bar chart, grouped by treatment modality)
- **Figure 4.1: Mean scores for pilot Paediatric PREM themes in 2023 and 2022, sorted by CYP score** (bar chart grouped by respondent group [parent/carer <12 years, parent/carer 12+ years, child/young person])
- **Table 4.1 Means for each pPPREM theme, by response group, sorted from highest to lowest** (mean scores for 2023, 2022 and difference, by respondent group [parent/carer <12 years, parent/carer 12+ years, child/young person])
- **Table 4.2: Summary of centre scores across all participant types, sorted from highest to lowest** (range of centre scores, mean of scores, 2023 and 2022)
- **Figure 4.2: Centre scores for Overall Experience of the service provided by kidney centres (Q39 in pPPREM)** (stacked bar chart for each centre)
- **Table 5.1: Comparison of mean pPPREM scores by treatment group for 2023 and 2022** (means and 95% confidence intervals for each theme by treatment type, 2023 and 2022)
- **Patient experience of kidney care across the service graphs (chapter 6):**
  - Mean scores and 95% confidence intervals for each theme by centre

- o Stacked bar charts for each question across all pPPREM participants by respondent group [parent/carer <12 years, parent/carer 12+ years, child/young person])
- **Appendix:**
  - o **Table A1: Mean theme scores and 95% confidence intervals, by response group** (theme means, 95% confidence intervals and response numbers by respondent group [parent/carer <12 years, parent/carer 12+ years, child/young person])
  - o **Table A2: Mean theme scores and 95% confidence intervals, by centre** (theme means, 95% confidence intervals and response numbers by centre
  - o **Table A3: Median theme scores and interquartile ranges, by treatment group** (theme medians, interquartile ranges and responses numbers by patient treatment group)