

Kidney Patient Reported Experience Measure



RaDaR Meeting
12th July 2024

The Rationale

- Kidney community good at measuring biochemical outputs, safety and effectiveness...BUT
- The way people experience health services important component of quality of care
 - important to inform service improvement
 - Linked to clinical outcomes and costs
- NHS England emphasises crucial role of patient experience
- Measures of patient experience can reveal important system problems, such as delays in returning test results and gaps in communication that may have broad implications for clinical quality, safety, and efficiency.



The Rationale

A person with kidney disease who has a **positive experience** will feel more **settled**, more **comfortable**, and less **anxious**, and be more ready and able to **engage** with their health and care, **leading to better outcomes**.



Our aims

To establish an **annual, national survey** of patient experience

AND

Embed a **strong patient voice** to inform and guide quality improvement in kidney care.



What is a PREM?

- Patient Reported Experience Measures - PREMs - are measures which gather data on the experience of patients in health care settings
- The results of PREM's can be used to improve services in areas identified as important by patients; and tailor care by identifying the impact it has on patients (Aiyegbusi et al., 2017)
- **The Kidney PREM** is a questionnaire measuring kidney patients' perceptions of their experience whilst receiving kidney care.

“The UK Kidney Association and Kidney Care UK are committed to improving the patient experience of kidney care, to have a positive impact on patient quality of life. Kidney PREM is available annually.... to give patients the opportunity to feed into service improvement by sharing what matters most to them.”

A screenshot of the Kidney PREM questionnaire. The form is titled 'The UK Kidney Association of Patient Reported Experience Measures (PREM)' and includes sections for 'Patient Information', 'Patient Consent', and 'Patient Experience'. It contains various Likert scales and checkboxes for patients to rate their experience with different aspects of kidney care.

What does the Kidney PREM cover?

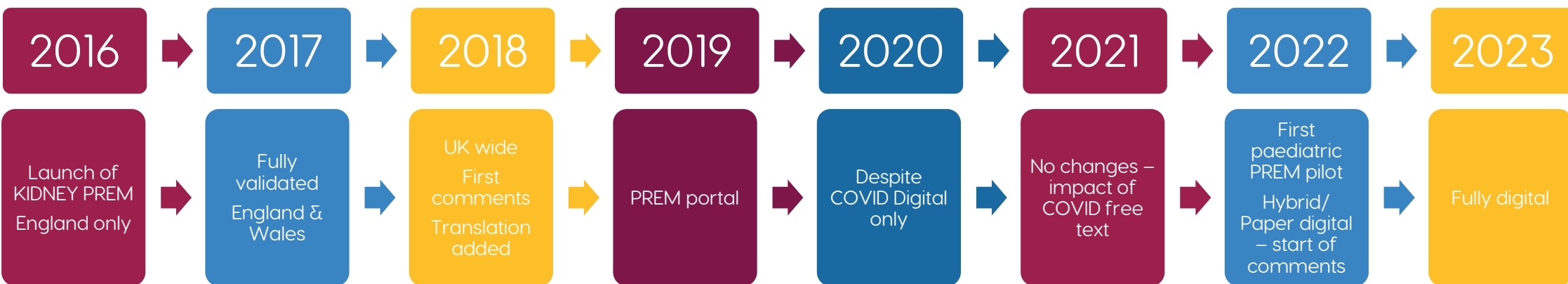


- **39 questions** under **13 themes** of care agreed as important by people with kidney disease, health professionals and researchers.
- A rating of **overall experience** of care – from worst to best it can be
- Free text comments on ‘**anything else** about your kidney care’
- Participation in **Shared Care** by people on haemodialysis
- Use of **Patient Knows Best**

1. **Access to the renal team**
2. **Support**
3. **Communication**
4. **Patient information**
5. **Fluid intake and diet**
6. **Needling**
7. **Tests**
8. **Sharing decisions about your care**
9. **Privacy and dignity**
10. **Scheduling and planning**
11. **How the renal team treats you**
12. **Transport**
13. **Environment**



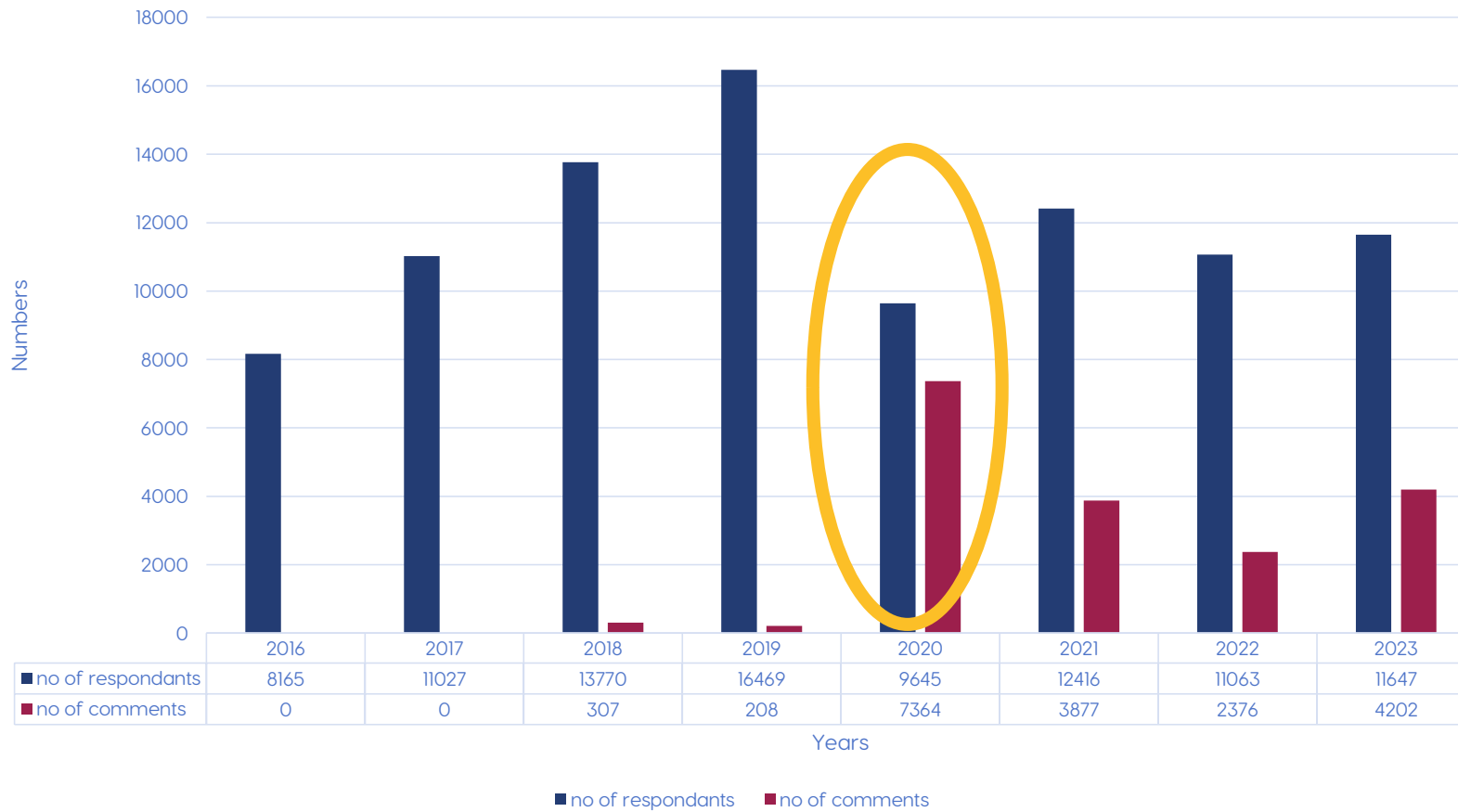
PREM – The Story so Far



PREM – The Story so Far



PREM stats



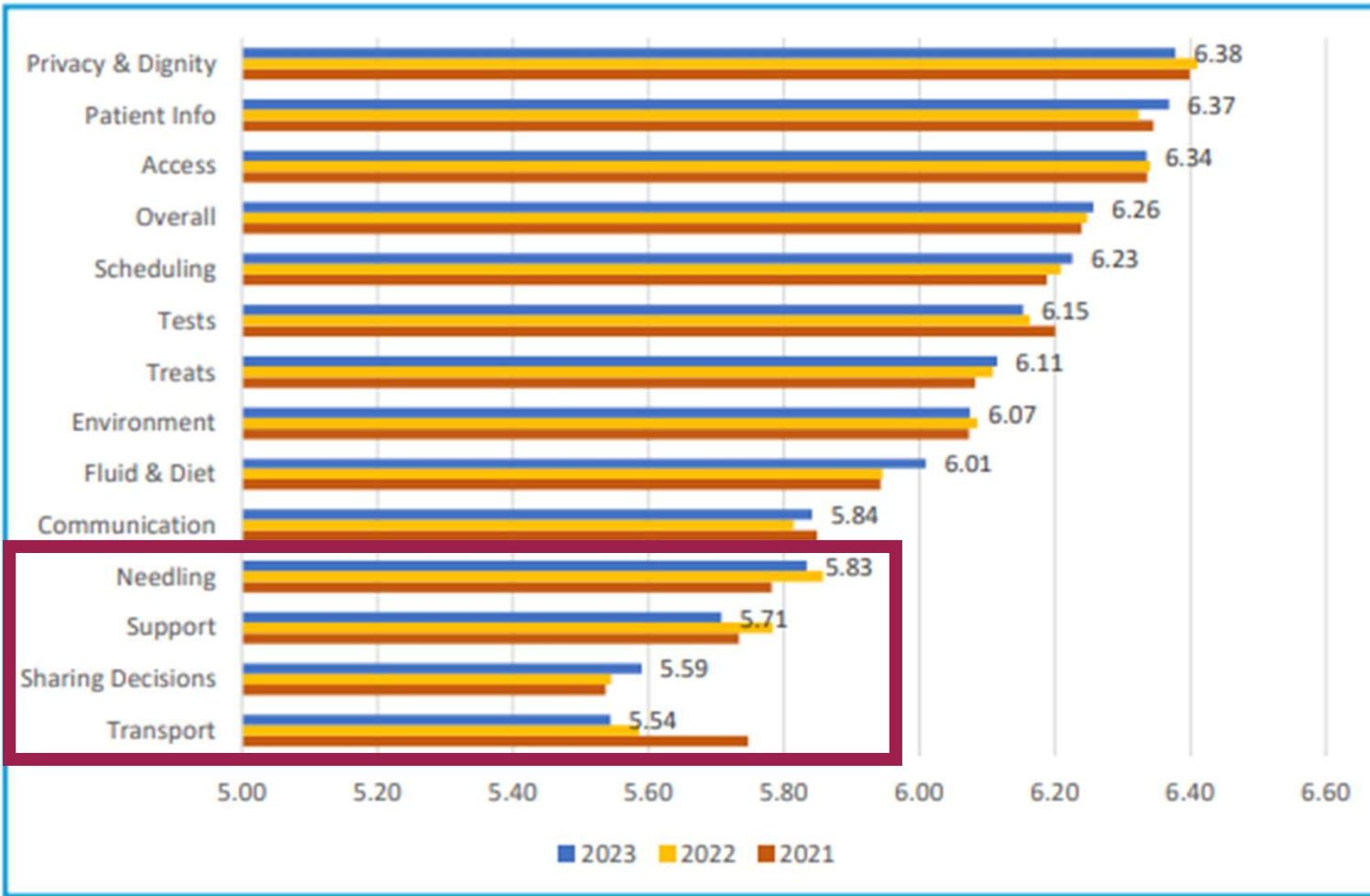
2023 – fully digital

Key Messages/learnings

- Patient rating of their Overall Experience remains high
- Centre differences are more closely related to patient experience than any other characteristic.
- A fantastic resource
- An opportunity to use the PREM to engage with the patient community to drive improvement



Key Messages/learnings



Areas of experience scoring highest

Score out of 7

Privacy & Dignity

6.4



Patient Information

6.4



Access to the Team

6.3



Areas of experience scoring lowest

Score out of 7

Support

5.7



Sharing Decisions

5.6

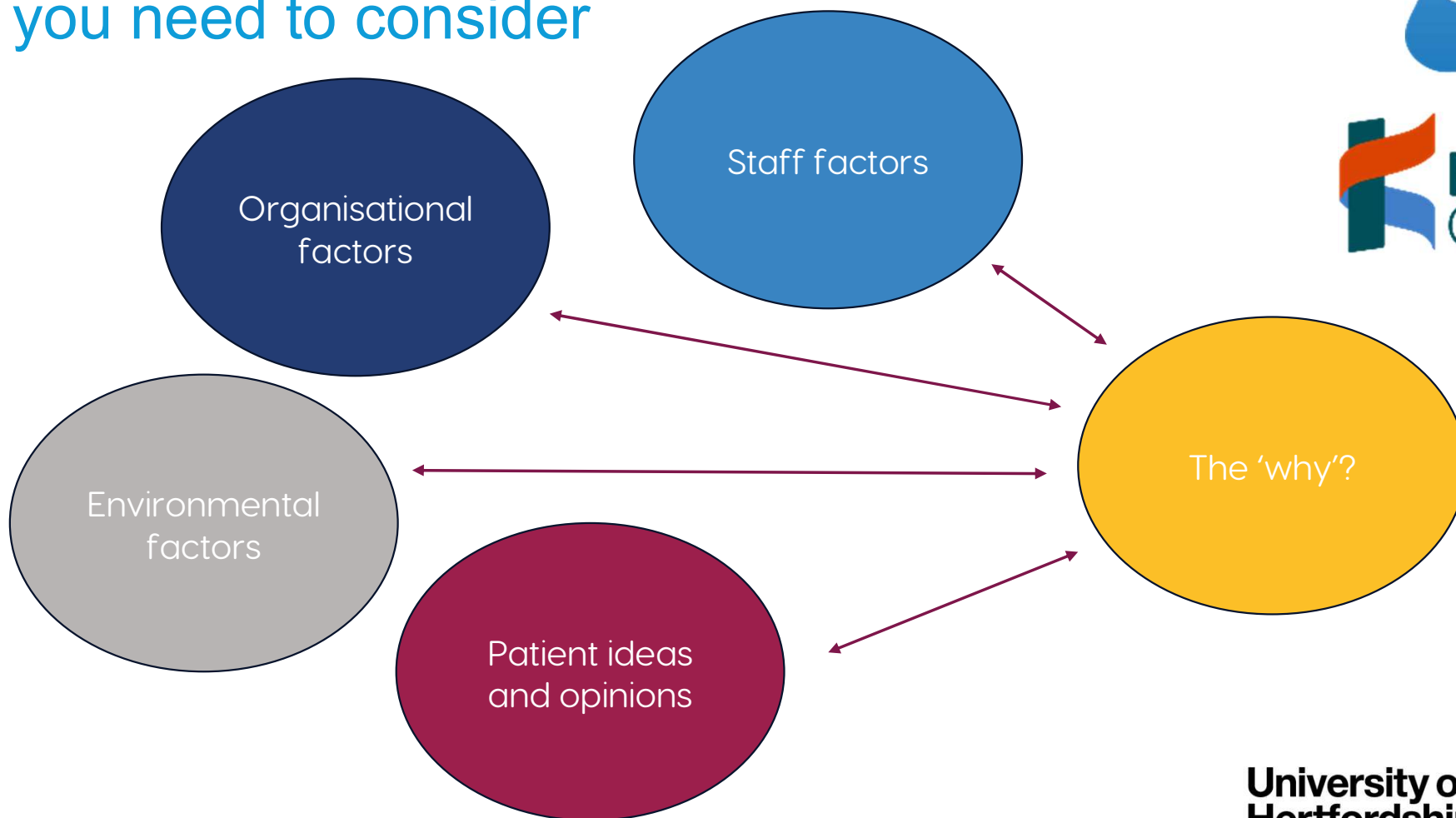


Transport

5.5



What is not available from national PREM team but that you need to consider



Kidney PREM results

1. **National** Kidney PREM report

- **National data** on each **theme** of experience, by treatment type
- National data on themes broken down **by question**

2. **Regional** information in national report

- Patient experience of kidney care across **centres** by theme
- Patient experience of kidney care across **regions** by theme

3. **Centre** and question level information on PREM portal

- Filters by year, region, **centre, satellite**, by question
- Also demographics and comments overview

4. PREM **comments**

- **National** PREM comments report
- **Centre** level comments – returned directly to centres

5. Additional data available for **deep dives**

- Centre and satellite data by **theme** and **modality, age, satellite units**
- **Responses by centre**



How do you find all this information?



The screenshot shows the UK Kidney Association website. At the top, there is a dark blue navigation bar with social media icons (LinkedIn, Twitter, Instagram, YouTube) on the left and 'Login', 'Join UKKA', 'Donate', and a search icon on the right. Below this is the UKKA logo and the text 'UK Kidney Association'. A horizontal menu contains 'UKKA', 'About us', 'Audit & research', 'Quality Improvement', 'Health professionals', and 'Patients'. A breadcrumb trail reads 'Home / Kidney Patient Reported Experience Measure'. The main heading is 'Kidney Patient Reported Experience Measure'. Below this is a photograph of a young girl smiling between a man and a woman. Under the photo, the text reads: 'The Kidney PREM is a national annual survey of kidney patients'. It then lists three aims: 'Help teams understand how patients feel about their experience of care', 'Show where improvement can be made', and 'Give the UKRR a national picture of people's experience of care.' At the bottom of the section, it says 'Kidney PREM 2023'.



www.ukkidney.org/kidney-patient-reported-experience-measure

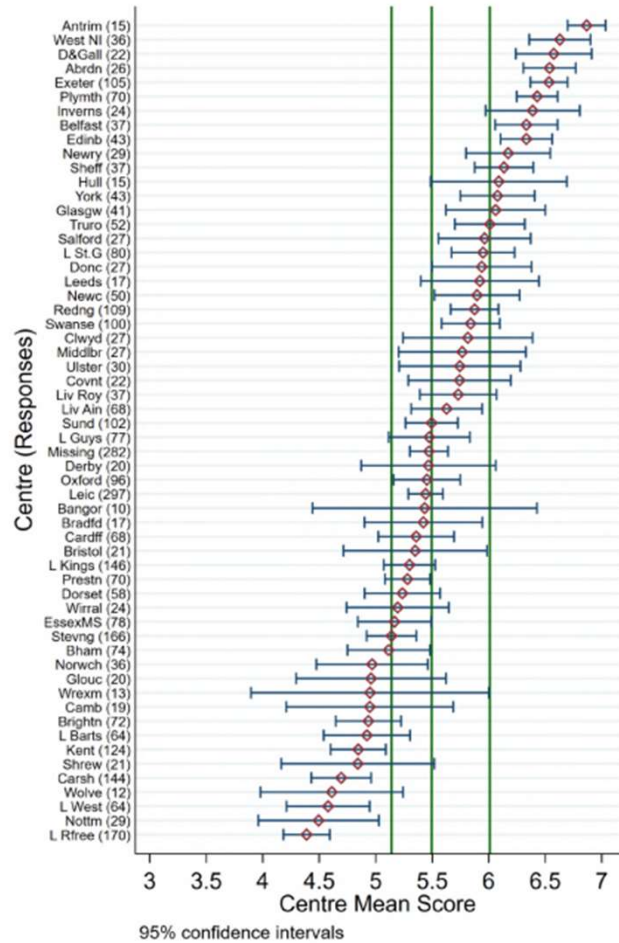
1. National Kidney PREM report



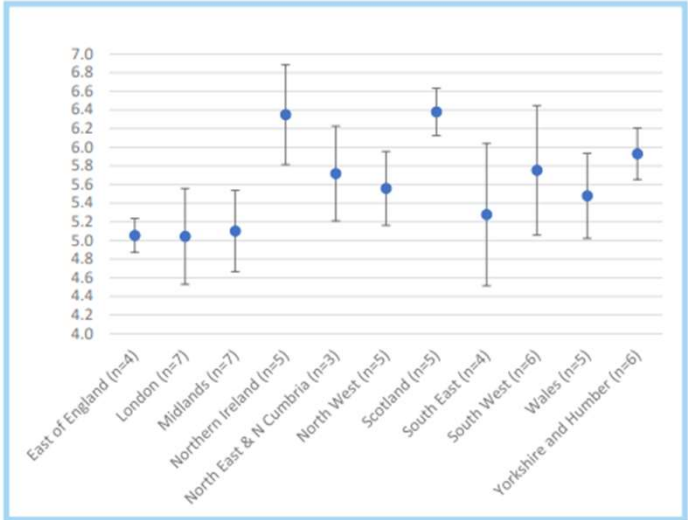
[REPORT LINK](#)

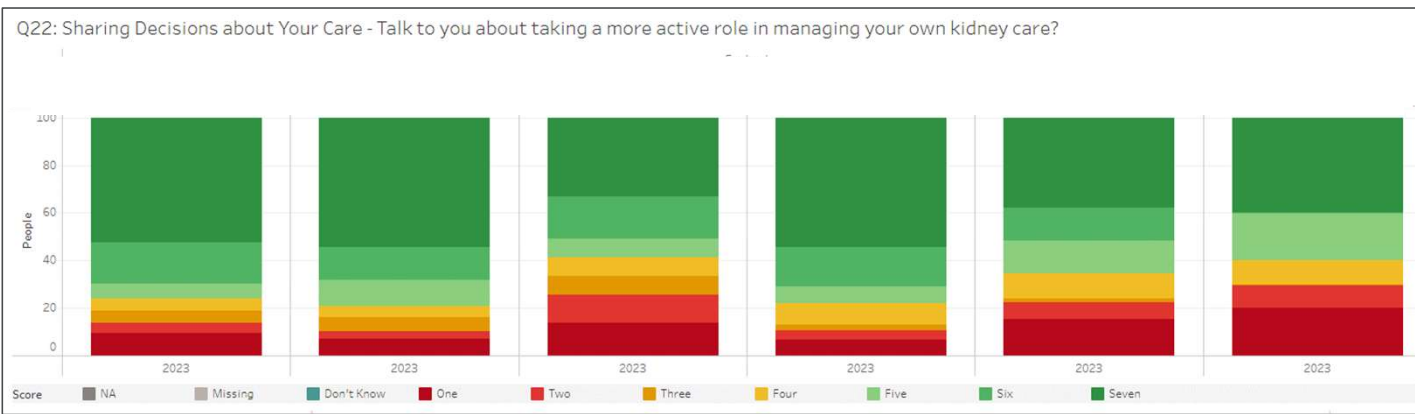
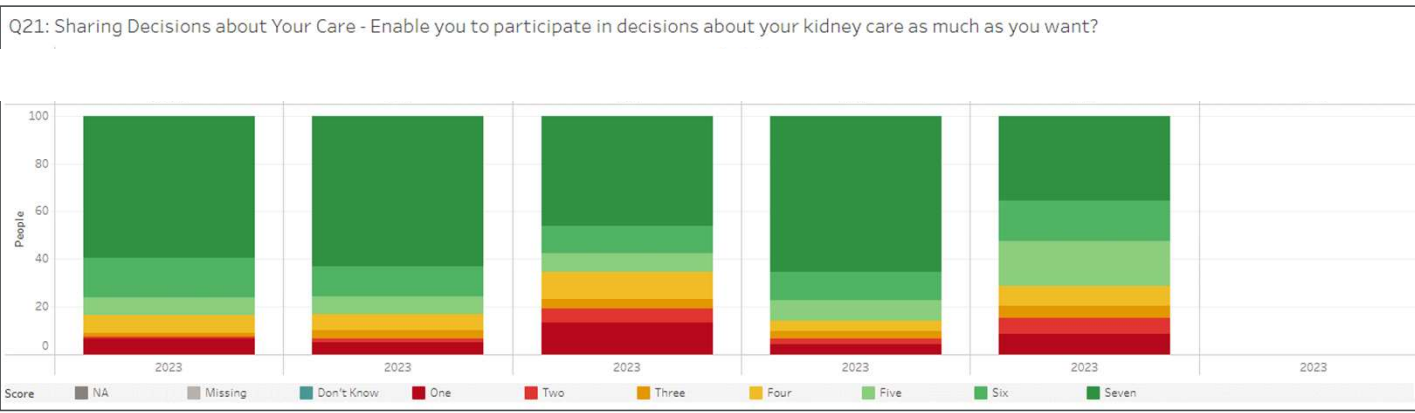
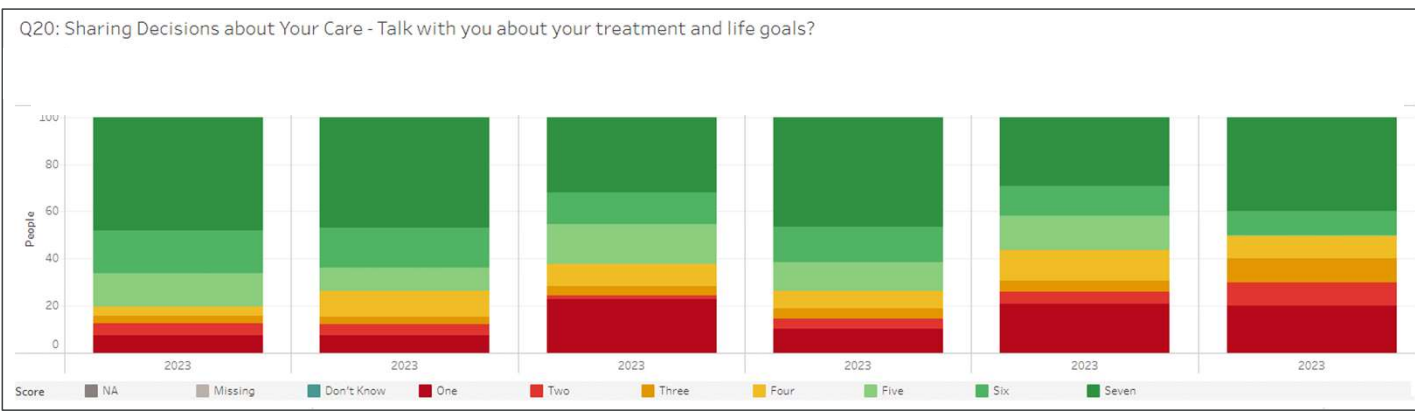
2. Regional information in national report

Theme 12: Transport



Q31. Is the vehicle provided suitable for you?
 Q32. Is the time it takes to travel between your home and the Kidney unit acceptable to you?
 Q33. Once your visit to the Kidney unit is finished and you are ready to leave, are you able to leave within less than 30 minutes?



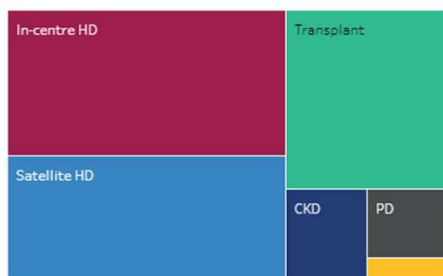


3. Centre and question level information on PREM portal

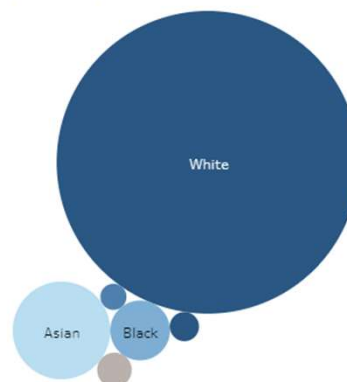
3. PREM portal - demographics



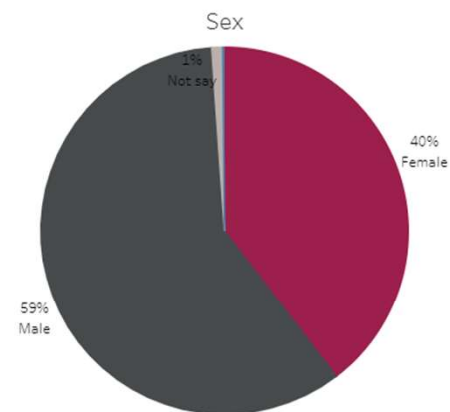
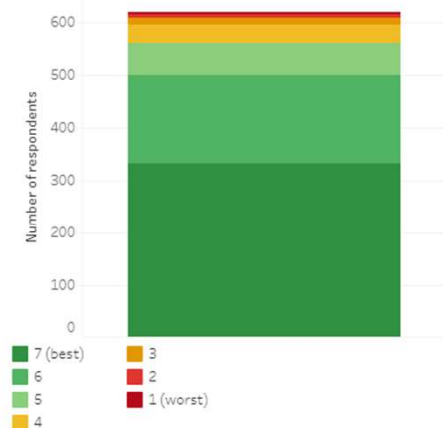
Treatment



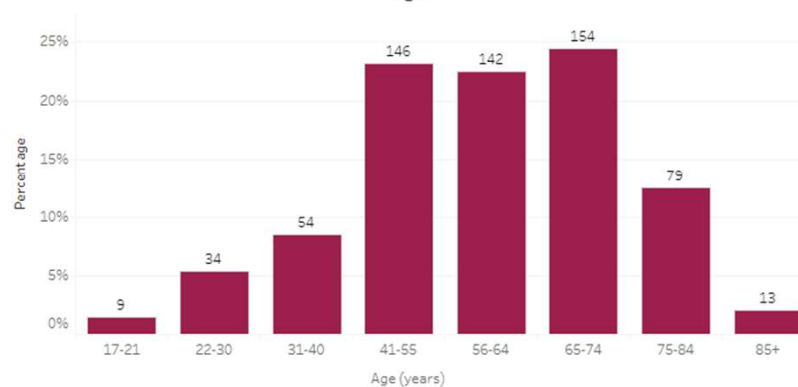
Ethnicity



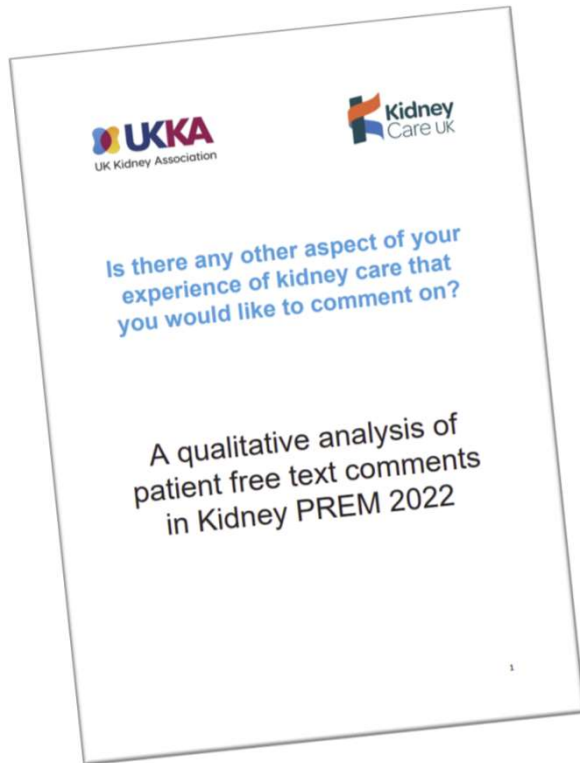
Overall Experience
PREM only



Age



4. PREM comments

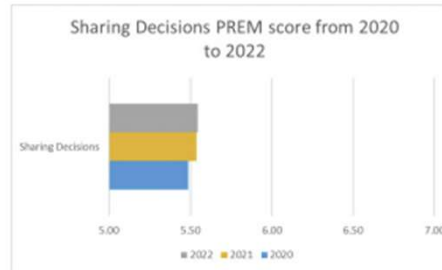


CHAPTER 9: SHARING DECISIONS

Sharing Decisions received 44 comments and includes comments on respondents' experiences of being involved with decisions within their care. Though overall Kidney PREM scores were low, there has been a slight improvement since 2020, perhaps reflecting some resolution of COVID-19 related issues.

Table 10: Breakdown of Sharing Decisions codes by sentiment

	Total (n)	Negative	Neutral	Positive
Shared Decisions Comments	14	9	1	4



Those who have had a positive experience of **Sharing Decisions** gave examples of how consultants and other members of the MDT had involved them in discussions about their care, clearly explaining each process so that they could help to manage the future of their care.

Some individuals, whose responses were negative, stated a need for more control within their care and for consultants to listen to them more to allow them to contribute.

Responses to this theme were most likely to come from individuals aged 41-64 years old, of White ethnic heritage, and those with functioning transplants or not yet receiving KRT.

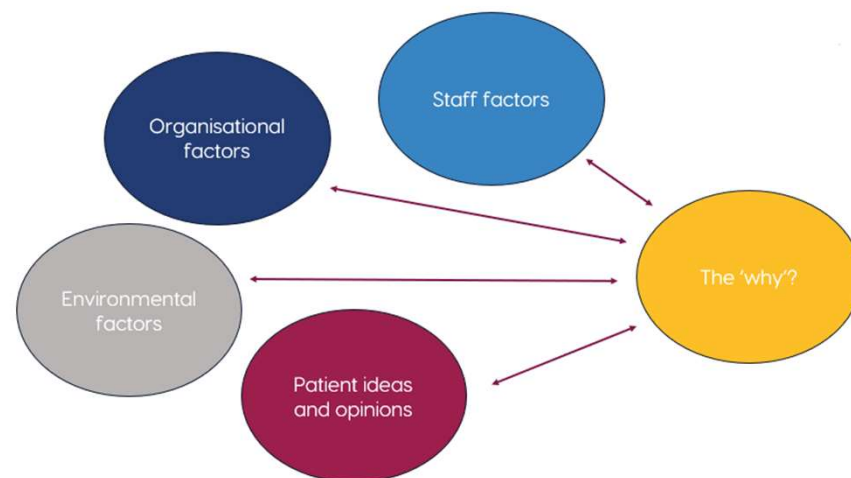
	<p>Sharing Decisions</p>	<p>"Would love to know my personal plan but nobody around to discuss." (ICHD, White, Female, 31-40)</p>
		<p>"My plans for the future are ignored even though they are time sensitive." (CKD, Mixed, Female, 41-55)</p>



Looking at results

The Kidney PREM will have the greatest impact when kidney centres:

- **Review** the data from people being treated at their centre
- **Share** these local findings with staff and patients
- Think about the **local context** – why have people given these scores?
- **What's going well** and where is there room for improvement?
- Agree areas for action – some **simple and immediate** as well as longer term
- **Communicate** and **encourage involvement**



Has anyone from your unit talked to you about last year's kidney PREM report?

Centre	Total yes	% Yes
East of England	96	13.2
London	258	10.5%
Midlands	340	19.4
North East and North Cumbria	77	10.5
North West	66	8.4
South East	115	8.3
South West	113	9.5
Yorkshire and Humber	79	12.8
Northern Ireland	33	14.6
Scotland	27	7.5
Wales	88	12.5
Total	1,349	11.9%



Next Steps

Digital

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Kidney PREM survey 2023
How your feedback made a difference

You said...	We did

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The Annual
PREM is run by



University of
Hertfordshire **UH**



University of Hertfordshire **UH**

The logo for the University of Hertfordshire (UH) features the text 'University of Hertfordshire' in a black, sans-serif font, followed by the letters 'UH' in a large, bold, black, sans-serif font. The logo is positioned on the right side of the slide, overlaid on a large, abstract graphic consisting of three overlapping, rounded shapes in light blue, light orange, and light purple.

Thank you for listening!

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