



HOME DIALYSIS: WHY AND WHY NOT. A PATIENT'S PERSPECTIVE

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DISCLOSURES

- No COIs

OVERVIEW

- How does kidney care and modality education feel to the service user?
- What matters to the individual – what are the priorities and trade-offs?
- How should services respond better to those priorities?
- What barriers, incentives, resources from a patient perspective that would help in home dialysis selection?

HOW DOES KIDNEY CARE AND MODALITY EDUCATION FEEL TO THE SERVICE USER?

- Variable
- Currently, remote
- Some love fewer checkups
- Personal touch greatly valued

February 2020 just before I started PD. Now I have a video call every three months. I really like this as it means I don't have a three hour round trip from my home in Epping to the Lister Hospital in Stevenage.

Autumn 2019. I had 2 phone consultations last year. Next is due in April, Really hoping it will be face to face

4 months ago for me, then a phone appointment this week. I have seen the PD nurses a couple of times in between.

REDUCED ACCESS TO SURGERY

- Dialysis access seen as ‘elective’
- Built up throughout 2020
- Some areas did not catch up
- Variable access

A dad-of-two says he fears he could die after a life saving operation was cancelled at the last minute due to coronavirus.

Darren Walsh was “about to put the gown on” ahead of a procedure to have a catheter fitted so he can receive dialysis when doctors told him they had to call off the operation.

The 42-year-old, from **South Belfast**, told Belfast Live his kidney function fallen from 16% to 11% in the last three months and believes he is “going to die” if he cannot get started on dialysis as soon as possible.

Oct 2020

I went on home PD while waiting for testing to be completed on my husband as he volunteered to be my donor. I stayed on it for 4 months before we went ahead with the transplant. Going on PD really helped me get through it all until I had the op.

Dec 2020

My consultant encouraged me to get the PD catheter fitted in the summer when things were quiet (and hopefully safer) in the hospital even though my EGFR was 9. At least part of the benefit was to avoid having to fit a neck line for hemo if hospital admissions were problematic; but also I could better undertake the PD training without brain fog affecting my concentration levels. As a result I had roughly two months with the catheter fitted before I started dialysis. The home dialysis team up here in Edinburgh have been wonderful and, while it hasn't always been easy my overall fitness and health has improved since starting dialysis.

WHAT MATTERS TO THE INDIVIDUAL – WHAT ARE THE PRIORITIES AND TRADE-OFFS?

- Protection from Covid
- Independence
- Ability to work
- Chance of a transplant
- Easier to shield
- Easier to travel (in a non-Covid time)

- Space
- Loneliness
- Lack of confidence in technique
- Burden on family
- Deliveries – drivers not bringing supplies in
- Lack of peer support in a dialysis unit

'WORRIED SICK' KIDNEY CARE UK PATIENT EXPERIENCE SURVEY

- **May/June 2020 - 1211 participants, published July 2020**
- 4/10 people reported a mental health impact
- Nearly 7/10 reported disruption to care
 - e.g. 35% had surgery/appointments cancelled & 26% had not had their checkups
- 25% reported worries about getting food
- Some family members chose to co-shield
- Confusion over government advice
 - 13% didn't know they were advised to shield
 - 18% had verbal confirmation but received nothing in writing & weren't able to access government support such as food boxes, employment support
- www.kidneycareuk.org/coronavirus created in March 2020

STEVE AND DONNA'S STORY

- Isolated since March 2020
- Supportive employers
- Home visits for PD training
- Very anxious but managed it
- Shared their story
- Walked 150 mountains since diagnosis in 2010
- Transplanted Dec 2020! ❤️



HOW SHOULD SERVICES RESPOND BETTER TO THOSE PRIORITIES?

- Ask, don't wait to be told how someone is doing
- Use every interaction to understand physical or mental difficulties
- 'Meet the patient' half way to understand what's going on with their life
- Involve family members
- Listen, learn and then commission accordingly
- Collaborate to improve
- Quality improvement, partnership approach
 - KQUIP - Kidney Quality Improvement Partnership DAYLife
<https://renal.org/kquip/projects/day-life>

KIDNEY CARE UK COVID-19 SURVEY 2 – OUT OF SIGHT, OUT OF MIND

September 2020, published October 2020 with 860 participants

Mental health



29%

respondents reported feeling **anxious, lonely or isolated**



36%

said they were concerned about their **emotional wellbeing**

Disruption to health services



47%

reported **disruption to the care** they received



1 in 5

had surgery or appointments **cancelled**



20%

are **struggling to get advice** on their health concerns and worries

Employment



62%

were expected to **go back to work** as normal



63%

were **concerned about safety** but had to return to work regardless



19%

said their employer has been **'very unhelpful'** or **'unhelpful'** in their return

<https://www.kidneycareuk.org/news-and-campaigns/news/thousands-kidney-patients-need-more-support/>

WHAT BARRIERS, INCENTIVES, RESOURCES FROM A PATIENT PERSPECTIVE THAT WOULD HELP IN HOME DIALYSIS SELECTION

- Education
- Peer support
- Practical help e.g. home insurance, storage space, utility bills
- Great technical support
- Check-in a lot in the early days – use the phone!
- Signpost to local support services e.g. from councils, grants etc

EDUCATION

- Peer support – show and tell
- Roadshows – untapped appetite for home dialysis but now this is online
- Webinars
- Remote consultations
- Built around system convenience and need
- Advocacy officers



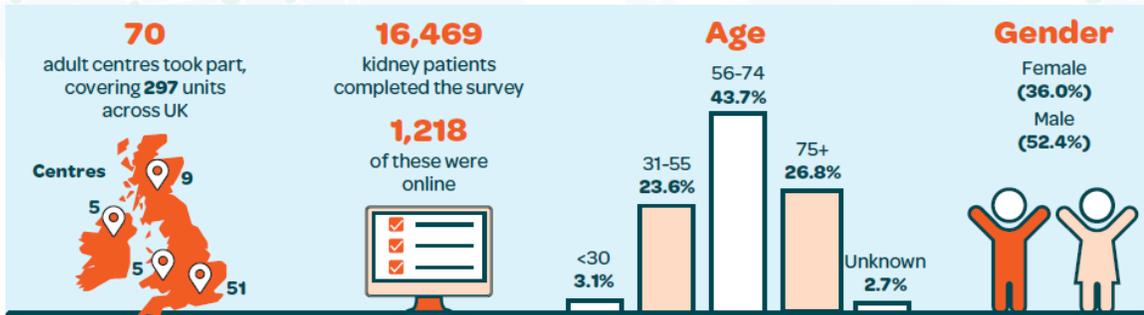
WHAT IS THE KIDNEY PREM?

- Patient Reported Experience Measures - PREMs - are measures which gather data on the experience of patients in health care settings
- The results of PREMs 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 renal care.

“The Renal 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.**”

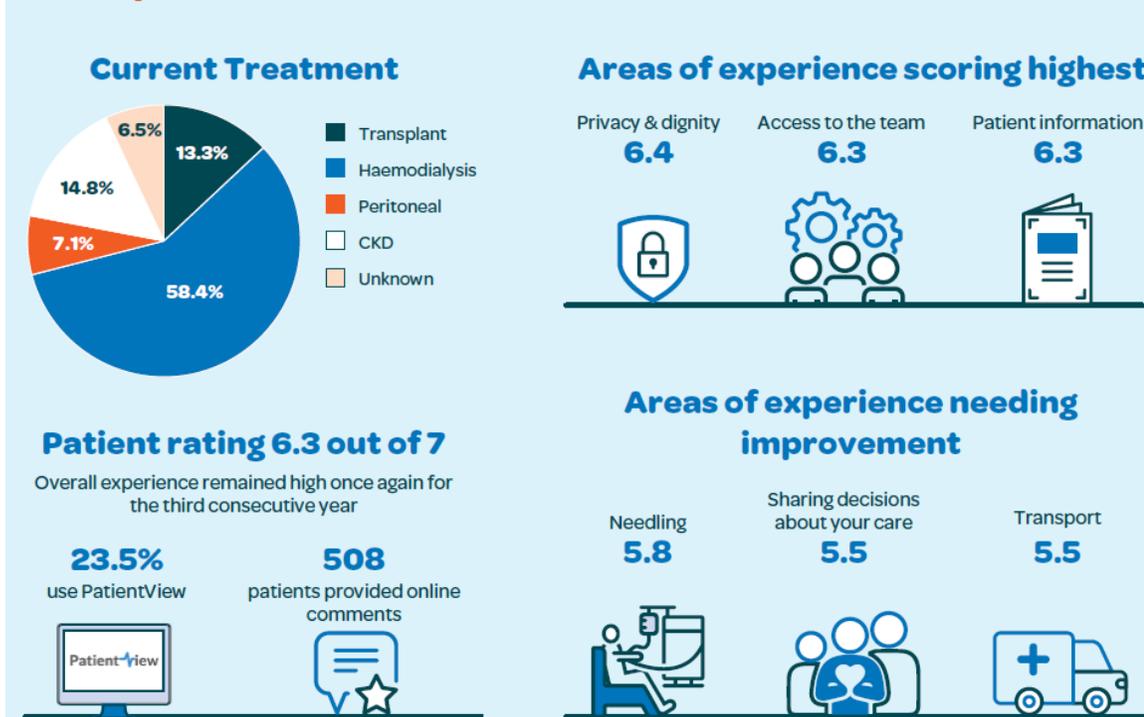
The image shows a screenshot of the 'Annual Survey of Patient Reported Experience Measures (PREM)' form. At the top, it features logos for the Renal Association (RA), Kidney Care UK, and NHS. The title is 'The Annual Survey of Patient Reported Experience Measures (PREM)'. Below the title, there is a paragraph explaining the purpose of the survey: 'The annual PREM survey has been designed by patients and professionals working together to find out how you feel about the services your kidney unit provides. The survey gives us feedback on renal services both locally for your unit, and nationally, and ensures that the views of kidney patients are heard. From this information, we can see what we are doing well and where we can do better. Your views matter and we act on them to help us improve services. We will provide you with feedback on the results, information on the national results can be obtained from the UK Renal Registry or Kidney Care UK websites, along with the previous year's results.' It also states 'The survey is completely anonymous, your name will not appear anywhere on the survey.' and 'Completing the survey' instructions: 'The survey should take about 15 minutes to complete. Please only tick one box for each question or statement, otherwise your answer will not count.' It provides options for online completion at www.renal.org/yourprems or a paper form. There are instructions on how to complete the survey, including asking for help from family or friends. A section for 'On completion' asks to place the questionnaire in an envelope, seal it, and post it in a post box or hand it to a staff member. It also provides contact information for the UK Renal Registry: CustomerServices@renal.org.uk or 0127 414 8151. There are fields for 'Renal Unit' and 'Current treatment' (peritoneal dialysis, haemodialysis, transplant, attending kidney clinic but not on dialysis or transplantation). A section asks 'If you currently receive Haemodialysis, do you receive this...' with options 'At Home', 'In Hospital', and 'In-Satellite'. The form includes a 5-point Likert scale (4, 5, 6, 7) with 'Always' and 'Don't know' labels. At the bottom, there is a photo of a patient receiving dialysis from a healthcare worker. Below the photo is a red banner with the text 'Patient Reported Experience of Kidney Care in the UK 2018'. The page number 'Page 2 - PREM 2018' and 'Please turn over the page' are also visible.

KIDNEY PREM 2019 – THE NATIONAL RESULTS



Analysis by age, sex, ethnicity, stage of disease showed no significant difference in experience based on those characteristics

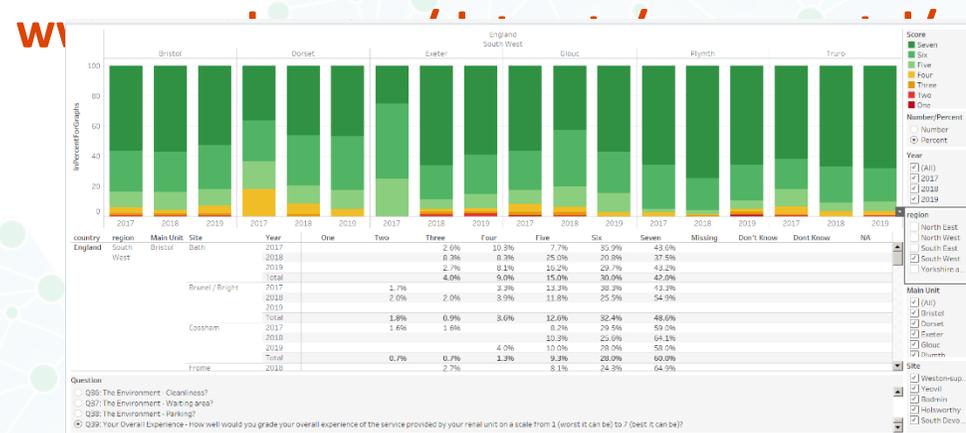
- The main factor affecting overall patient experience of kidney services is the renal unit where they are treated
- Privacy and dignity and Access to the renal team are the areas which patients rate most highly, with limited variation in experience across centres
- Sharing decisions about your care, transport, and needling are the 3 areas which patients score lowest, with the most variation between centres



REVIEW AND SHARE YOUR LOCAL RESULTS

The Kidney PREM will have the greatest impact when renal centres review, share and act on their local findings in partnership with patients and make improvements to care identified as necessary by their own patients

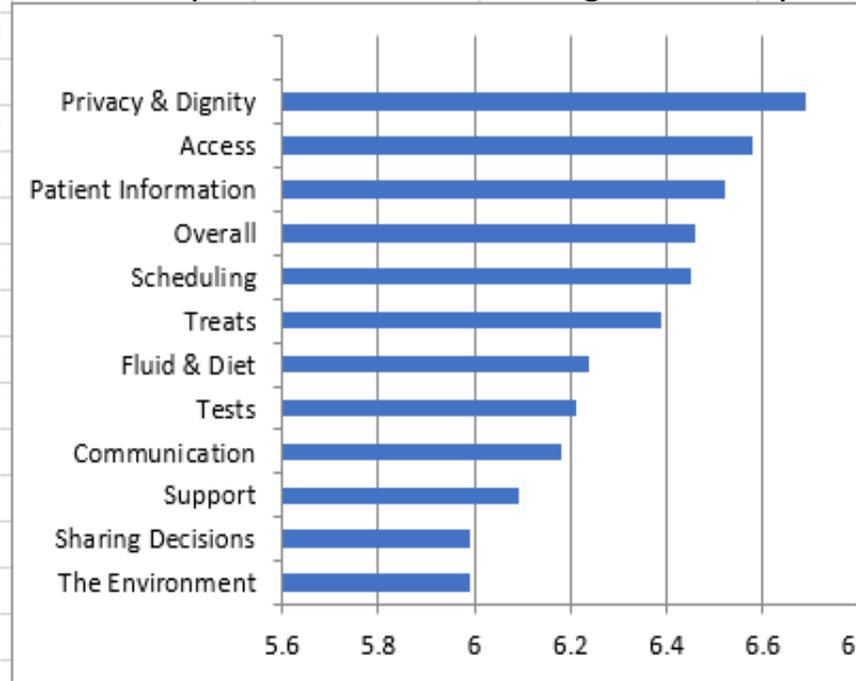
Access the portal at



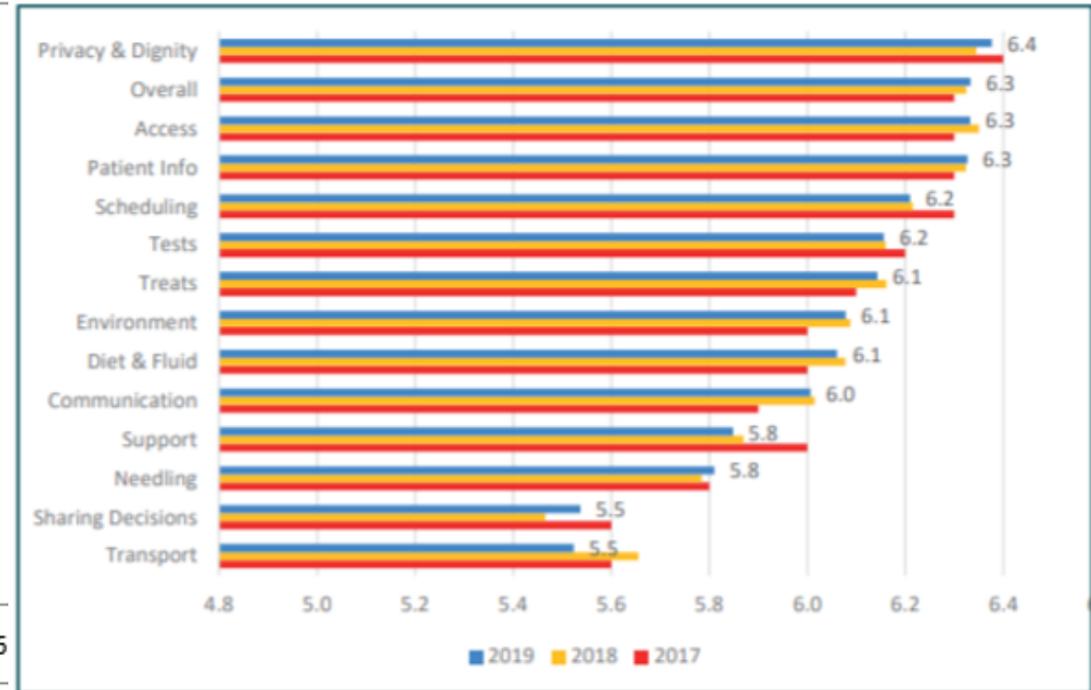
You can select the relevant year, centre, renal unit and question to review how patients at your unit responded to each of the Kidney PREM questions

PD PATIENT REPORTED EXPERIENCE - 2019

Patient experience – mean average – PD only



Patient experience - national mean average by theme - all modalities



Shared treatment decisions
Environment

ANNUAL PATIENT REPORTED EXPERIENCE (PREM) 2020

	PREM 2020	PREM 2019	PREM 2018	UK RRT Patients as of end of 2018*
Total	9645	16469	13770	65112
Age				
≤30	400 (4.1%)	514 (3.2%)	391 (2.9%)	4.8%
31-55	2929 (30.4%)	3892 (24.3%)	3095 (22.9%)	36.1%
56-74	4537 (47%)	7198 (44.9%)	6042 (44.8%)	43.4%
≥75	1779 (18.4%)	4416 (27.6%)	3970 (29.4%)	15.7%
Treatment				
Transplant	2172 (22.5%)	2183 (14.2%)	1399 (10.9%)	55.7%
Haemodialysis	4959 (51.4%)	9618 (62.4%)	8834 (68.6%)	38.8%
Peritoneal	632 (6.6%)	1166 (7.6%)	982 (7.6%)	5.5%
CKD	1882 (19.5%)	2437 (15.8%)	1659 (12.9%)	Unknown
Missing	-	1065	896	-

KEY MESSAGES

- 100% of patients want timely, clear advice on Covid-19 and need support and protection
- Don't make the health service feel like a Covid-only service
- Bring modality choices to people where they are
- Fear and anxiety continues to be very high – don't ignore it
- Use every interaction
- Sort out practical issues so they don't become unnecessary barriers
- Inequalities highlighted – engage with those affected
- Work with patient representatives and their charities e.g. advocacy officers, counsellors, information, campaigns
- www.kidneycareuk.org/coronavirus



15 February **MONDAY**

MONDAY



DIY SOS: The Big Build

**PICK
OF THE
DAY**

A big team for a big project

The team give a desperate family their life back

● REAL LIFE / 9pm / BBC1

NEW Better put tissues on your next online shopping list, it's another emotional one, as Nick Knowles, Lawrence Llewelyn-Bowen and an army of volunteers help another deserving family get the home they desperately need. They are in Devon with Jan and Lucy, who have five young children, including six-year-old triplets Lola, Amber and Daisy. Amber and Daisy have a kidney disease that requires 70 hours of dialysis a week. Frequent trips to hospital are tearing the family apart, so having room to house the equipment at home would change *all* their lives. Cue the team...
★★★★ LP

