Clinical Directors’ Forum 2019

Renal Association
Kidney Patient Reported Experience Measure (PREM)

#KidneyPREM
Who are we?

• We are the RA Quality Improvement programme managers

What do we do?

• Every day we work with renal teams around the country to support them with Quality Improvement through the Kidney Quality Improvement Partnership

How?

• Build QI capability
• Develop leadership – MDT
• Develop and establish collaboration through regional networks

Why are we here?

• We believe in improving care through quality improvement
• To do that we need to make sure we are measuring the right thing (what’s the point of measuring for an increase HHD rates if pt experience or QOL is poor)
Why is it so important?

What drives all of us?

The financial model is based on making us happy to ensure we come back – credibility – longevity

If they tap into us as humans, and respond, they will use the knowledge to transform their business
What can we learn?

What can we learn from a business model?

IT’S THE HUMAN FACTOR

d‘customer experience includes the feelings, emotions, and perceptions of those interactions along the way. .. how we are left to feel after an interaction certainly dictates if we will do business with the brand again.”

g‘great customer experience is personalised, timely, relevant, effortless/simple, seamless, remarkable, memorable, and consistent. Consistency is an important “umbrella quality” in that all the other qualities need to describe your every experience with a brand. Always. Every time. Consistency sets expectations and creates predictability. And that leads to trust. When a brand earns a customer’s trust, the relationship is solid.’
What have WE got?

- A fantastic resource – no other community has something like this
- Co-produced by patients, statisticians, researchers and clinicians
- Three years worth of data saying the same thing – centre level – SDM, Transport and needling
- Validation in 2016-17 - ensuring fit for purpose

https://www.renalreg.org/projects/prem

#KidneyPREM
Kidney PREM

- Annual (June – SOON!)
- Hard copy and online in:
  - English
  - Welsh
  - Urdu
  - Gujarati
- 2018 – online comments

The patient’s “whisper” can also be hidden in written feedback:

“A significant percentage of patients provide perfect domain scores only to follow up with negative comments”

https://www.renalreg.org/projects/prem/ #KidneyPREM
What did it show?

71 UK adult renal centres / 13,770 responses

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>PREM 2018</th>
<th>PREM 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>13,770</td>
<td>11,027</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤30</td>
<td>391 (2.8%)</td>
<td>353 (3.2%)</td>
</tr>
<tr>
<td>31-55</td>
<td>3,095 (22.5%)</td>
<td>2,797 (25.4%)</td>
</tr>
<tr>
<td>56-74</td>
<td>6,042 (43.9%)</td>
<td>4,731 (42.9%)</td>
</tr>
<tr>
<td>≥75</td>
<td>3,970 (28.8%)</td>
<td>2,902 (26.3%)</td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td>272 (2.0%)</td>
<td>244 (2.2%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>4,891 (35.5%)</td>
<td>4,031 (36.6%)</td>
</tr>
<tr>
<td>Male</td>
<td>7,295 (53.0%)</td>
<td>5,907 (53.6%)</td>
</tr>
<tr>
<td>Rather not say</td>
<td>57 (0.4%)</td>
<td>39 (0.4%)</td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td>1,527 (11.1%)</td>
<td>1,050 (9.5%)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>1,275 (9.3%)</td>
<td>1,049 (9.5%)</td>
</tr>
<tr>
<td>Black</td>
<td>829 (6.0%)</td>
<td>774 (7.0%)</td>
</tr>
<tr>
<td>White</td>
<td>1,0267 (74.6%)</td>
<td>8,184 (74.2%)</td>
</tr>
<tr>
<td>Rather Not Say</td>
<td>202 (1.5%)</td>
<td>155 (1.4%)</td>
</tr>
<tr>
<td>Other</td>
<td>355 (2.6%)</td>
<td>265 (2.4%)</td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td>842 (6.1%)</td>
<td>601 (5.5%)</td>
</tr>
</tbody>
</table>

Current Treatment
- Transplant: 1384 (10.2%)
- Haemodialysis: 8698 (64.1%)
- Peritoneal: 973 (7.2%)
- Pre-dialysis: 1632 (12%)
- Missing: 885 (6.5%)

Do you use PatientView?
- Yes: 2881 (21.3%)
- No: 5493 (40.5%)
- Don't know: 2339 (17.2%)
- Missing: 2859 (21.0%)

https://www.renalreg.org/projects/prem/  

#KidneyPREM
How patients experience renal services

https://www.renalreg.org/projects/prem/

#KidneyPREM
Key themes

The aspects of patient experience that came out as needing most improvement in both 2017 and 2018 were:

- **Shared decision making**: 5.4 (range 3.1)
- **Needling**: 5.6 (range 2.6)
- **Transport**: 5.7 (range 1.9)

https://www.renalreg.org/projects/prem/  #KidneyPREM
“Satisfying experiences lead to happier, more engaged patients. Engaged patients will ask questions, follow advice, show up for appointments and take their medication as recommended. This all leads to better outcomes. Better engagement also means patients will become more educated about their health, which benefits them and the healthcare system by empowering patients to keep a closer eye on their well-being.”

We need your help to know how we can use this data as a kidney community to improve patient experience
What would help support participation? You said...

“Target patient numbers”

“Timely feedback and results”

“The full engagement of the entire consultant body”

“A designated Nurse Lead for PREM driving PREM in each unit”

“Support worker/relative and friends to help patient”

“More volunteers to assist patients”

“Reminding the staff that finding out what keeps patients happy has a knock on effect for all”

https://www.renalreg.org/projects/prem/

#KidneyPREM
What would help units to use the data? You said…

“RR to request unit’s response to the report in writing”

“Results shared in App form”

“Skills and knowledge in Quality Improvement”

“Individual unit brochure-style PDFs with pie charts, tables and commentary”

“A designated Nurse Lead for PREM driving PREM in each unit”

“Patient and staff together attending PREM event”

“Examples of how PREMs have changed practice, examples of positive patient feedback from PREM”

https://www.renalreg.org/projects/prem/ #KidneyPREM
**What we are doing: Improving the process**

- Encouraging wider use of the online Kidney PREM (which includes opportunity for patients to comment)
- **Pre-populating some paper surveys** with UKRR codes (main centres only) to reduce workload for staff
- Shortening the time lag between collection and results through the of **UKRR online data portal** for releasing the data
- Offering **resources for PREM champions** to engage their teams (e.g. 5 slides on what, why, how)
- Developing sub-PREMs and SF PREM for more regular ‘measurement for improvement’
- Collaborating with KCUK – advocacy officers, patient awareness, KPAs

[https://www.renalreg.org/projects/prem](https://www.renalreg.org/projects/prem)  #KidneyPREM
What we can offer

• We have a measurement tool
• We have the QI framework and methodology
• Let’s join the dots…

https://www.renalreg.org/projects/prem
#KidneyPREM
• Aligning and embedding the Kidney PREM in national kidney quality improvement work (KQuIP) and drivers

• NHS England – Personalised care plan with a focus on SDM and tools to support it

https://www.renalreg.org/projects/prem #KidneyPREM
Imperial:
Head Nurse Clinics, held at all our Satellite Dialysis Centres to allow unhurried, long term and short term care planning and discussion about treatment goals.

“...it was not always easy to allocate sufficient time for thoughtful, unhurried discussions with Consultants about issues such as increasing frailty, or bespoke identification of goals of care. Our Head Nurses work in close partnership with a dedicated Consultant Nephrologist and are ideally placed and experienced, able to offer longer appointments, with patients and their families, at times that suit all concerned. Most of our Dialysis Head Nurses are non-medical prescribers, and can offer thorough medication reviews too”
In an effort to improve communication and shared decision making we have instituted a new QA outcome form, so that we are documenting that we have discussed any potential changes to dialysis prescriptions and meds with the patients.

We are rolling out our Shared Care pilot from one unit to all the satellites.

Although the SW KQUIP group have taken on Transplant First, we are looking at using the MAGIC data to improve our needling; this is only at a very early stage.
Key things to remember…

• Don’t think of it as a separate project – use PREM as a measure in all projects
• Involve patients and clinicians in design and development to address the priority areas of your unit
• Having a PREM champion at unit level – staff and patient
• Data sharing – important to share beyond the Clinical Directors – MDT and patients
• Who has the influence to make changes?
• Share your results and response – with trust QI leads / UKRR / local press
• Use notice-boards (you said we did)

The national Kidney PREM results are a signal – not the full story

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#KidneyPREM
RD&E:

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Thank you

Questions?

Add in other comments
Executive summary at front of survey – sheet of A4 – don’t do leaflets
Will need paper and online
Need a champion to drive it
Increase online – need an IPAD within units and a facilitator to help with it
Put it in service specs
Use KPA’s through Trust volunteer model
Link PREM to complaints
Add in a picture of data portal

Acknowledgements:
All units and patients taking part
Kidney Care UK
The University of Hertfordshire
TP-CKD measurement work-stream
Kidney PREM steering group members