National Kidney Patient Survey

Improving patient experience · Case study

Working with patients to improve kidney care

Newcastle

Acting on the Kidney PREM results

UKKA UK Kidney Association

Kidney Care UK

Background and outcomes

Background

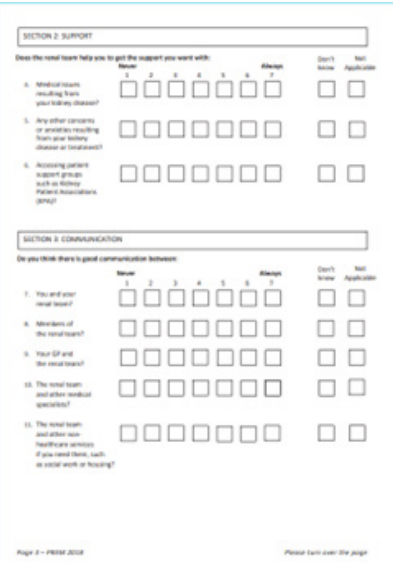
Patient Reported Experience Measures (PREMs) are measures of patient experience in health care settings. The results of PREMs can be used to improve services in areas identified as important by patients; and tailor care by identifying the impact it has on patients (Aiyegbusi et al., 2017) The Kidney PREM is a questionnaire measuring kidney patients' experiences whilst receiving renal care. Results marked out of maximum score of 7.

History

- Attended national development meetings in 2016 with TKPA.
- Piloted in 2016.
- Early adopter and always co-working with TKPA.
- TKPA funding where needed.

Original survey questionnaire


The Annual Survey of Patient Reported Experience Measures (PREM)



Outcomes

- Always returned high numbers of surveys compared to the size of the unit
- Achieved comparatively high numbers of non-dialysis patient surveys
- Less good at responding to feedback
- Specific responses later facilitated by addition of free-text comments; numbers are a less informative tool
- Built strong team to tackle this challenge and others

Methodology from 2019 to 2021

2019 (prior to COVID)

- Tyneside KPA led interaction with our fellow patients.
- Covered all Renal Clinics for 2-3 weeks resulting in high number of returns.
- Stressing the importance for future treatment development.
- Assisted with mailing out surveys from the Department (envelope stuffing).
- Assisted patients to complete survey i.e. poor eyesight, English not first language, etc.
- Volunteers on both Ward 31, 32 and 38 where needed ie evenings.
- Mailed out to our members twice (1100+) to encourage completion.
- Volunteers are themselves renal patients, common issues.
- Feeding back non-Survey comments ie travel expenses.
- In addition, encouraged patients to sign up to Renal Patient View by circulating information.

2020

- PREM did run in 2020.
- Switch to a digital format (estimates of paper surveys required low).
- Locally intense workload pressures; visiting policies did not allow for Tyneside Kidney Patient Association in-person support.

2021

- Digital format.
- Free-text box allowed for written comments* (digital only).
- Planning meetings held with TKPA.
  - Petitioned National PREM Team for higher than planned number of paper copies.
  - TKPA purchased tablets for use on ward 31 (satellite units already had).
- Intense workload pressures; visiting policies did not allow for Tyneside Kidney Patient Association in-person support.
- Newcastle survey numbers improved compared to 2020.
- Nationally some units did vastly increase numbers of surveys returned.

** "If there is any other aspect of your experience of kidney care that you would like to comment on, please tell us below."*

2022 methodology and 2019 returns

2022 methodology

- Approached NENC Renal Network about patient voice; interested to hear about and support PREM 2022.
- Co-produced Volunteer Guidelines with NENC Renal Network and National PREM Team.
- Co-production between patients, staff, Tyneside KPA leadership; tried to replicate model across NE.
- Publicity using posters, KPA newsletters, direct emails from Clinical Teams to some patient groups (in Newcastle).
- PREM driven by volunteers (peers) and staff champions in HD and Renal OPD and on wards.
  - TKPA and Trust volunteers.
  - Colleagues including nursing students.
  - NB need to be independent if helping patient to complete.
- Sensitivity to barriers to completion (poor eyesight, language, literacy).
- Surveys posted to patients who are not attending during survey.
- IT barriers significant (tablets purchased previously and in 2022; governance).

2019 success

- 870 surveys in total.
- 66% of our HD patients (n=235).
- 65% of PD patients (n=39).
- 33% transplant patients (n=240).
- Surveys were returned by:
  - Alnwick (19)
  - Newcastle (800)
  - North Tyneside (38)
  - Team Valley (13)

2019 scores and 2020 returns

Survey theme	National average (2019)	Newcastle average (2019)
Overall	6.30	6.40
Privacy and dignity	6.40	6.60
Access to team	6.30	6.40
Patient information	6.30	6.40
Scheduling	6.20	6.30
Tests	6.20	6.20
How the team treats you	6.10	6.20
Environment	6.10	6.20
Diet and fluid	6.10	5.70
Communication	6.00	6.10
Support	5.80	5.80
Needling	5.80	5.80
Sharing decision	5.50	5.80
Transport	5.50	5.80

2020 returns

- 86 surveys were returned
- Numbers of surveys submitted small in comparison to our previous levels; our experience mirrored across the Northeast
- Results reviewed with colleagues and TKPA and feedback provided to National PREM Team - concerns about digital exclusion and embedding of inequalities highlighted

2021 scores and patient information

Survey theme	National average (2021)	Newcastle average (2021)
Overall	6.24	6.36
Privacy and dignity	6.42	6.41
Access to team	6.31	6.40
Patient information	6.33	6.40
Scheduling	6.19	6.14
Tests	6.15	6.10
How the team treats you	6.09	6.31
Environment	6.05	6.31
Diet and fluid	5.93	5.82
Communication	5.83	5.87
Support	5.70	5.94
Needling	5.77	5.66
Sharing decision	5.52	5.46
Transport	5.60	5.57

Patient information in 2021

Year	National mean score	Newcastle mean score	Local respondents
2019	6.30	6.40	870
2021	6.33	6.40	271

Survey questions

- Explain things to you in a way that is easy to understand?
- Give you as much information about your kidney disease or treatment as you want?

Patient information by modality

Patient information results, 2019 to 2021

Modality	Year	Score	Number
Transplant	2019	6.70	227
Transplant	2020	6.67	23
Transplant	2021	6.62	50
PD	2019	6.25	35
PD	2020	6.74	18
PD	2021	6.68	11
HD	2019	6.30	214
HD	2020	6.32	22
HD	2021	6.26	154
CKD	2019	6.52	279
CKD	2020	6.63	19
CKD	2021	6.88	16

Sharing decisions about your care

Sharing decisions in 2021

Year	National mean score	Newcastle mean score	Local respondents
2019	5.50	5.80	870
2021	5.52	5.46	241

Survey questions

- Does the renal team talk to you about your treatment ad life goals?
- Does the renal team enable you to participate in decisions about your kidney care as as you want?
- Does the renal team talk to you about taking a more active role in managing your own kidney care?

Scores by modality

Modality	Year	Score	Number
Transplant	2019	6.15	229
Transplant	2020	6.05	23
Transplant	2021	5.77	50
PD	2019	5.72	35
PD	2020	6.26	18
PD	2021	5.45	11
HD	2019	5.39	214
HD	2020	5.64	22
HD	2021	5.36	154
CKD	2019	5.90	279
CKD	2020	6.37	19
CKD	2021	6.25	16

2022 scores compared with 2021

Survey theme	National average (2021)	Newcastle average (2021)	National average (2022)	Newcastle average (2022)
Overall	6.24	6.36	6.25	6.36
Privacy and dignity	6.42	6.41	6.41	6.70
Access to team	6.31	6.40	6.33	6.48
Patient information	6.33	6.40	6.24	6.58
Scheduling	6.19	6.14	6.20	6.41
Tests	6.15	6.10	6.13	6.29
How the team treats you	6.09	6.31	6.08	6.38
Environment	6.05	6.31	6.08	6.38
Diet and fluid	5.93	5.82	5.93	5.69
Communication	5.83	5.87	5.85	6.06
Support	5.70	5.94	5.77	6.06
Needling	5.77	5.66	5.81	6.02
Sharing decision	5.52	5.46	5.54	5.93
Transport	5.60	5.57	5.46	5.90
Scale score			6.02	6.26

Survey returns and comments

Newcastle survey total returns: 292

Newcastle 223; Alnwick 16; N Tyneside 39; Team Valley 14

Patient type

HD 76; Transplant 87; CKD 108; PD 9

Impact of digital

Centre or region	Online returns	Paper returns	Total returns	% of responses online
Newcastle	170	214	384	44.3
Sunderland	121	89	210	57.6
Carlisle	21	4	25	84.0
Middlesbrough	64	11	75	85.3
North East and North Cumbria	376	318	694	54.2

Free-text comments

"If there is any other aspect of your experience of kidney care that you would like to comment on, please tell us below"

- 46 free text comments; 1 uninterpretable
- No info about patient type on spreadsheet
- 16 positive (home HD team; co-working with other departments)

Remaining comments are categorised into themes:

Theme	Access	Patient information	Caring	Bloods	Staffing	Pharmacy	Dietetic support	TV	Point of contact
Comments	9	2	12	3	3	3	2	3	2

Next steps

All free-text comments reviewed with TKPA colleagues (specialists involved where appropriate)

Pharmacy

- Repeat prescriptions plan
- Communication of waiting times in pharmacy - Lloyds
- Medication delivery for phone appointments - clarify availability
- Review agreement for repatriation (clarify KPIs in Lloyds Pharmacy)

Patient information

Posters, leaflets and letter footer

- doing prescription at start of consultation - so that there is a head-start in Pharmacy
- please know what you need
  - Advise patients that prescription is kept for 2 weeks, so you/someone can come back to collect it
  - consider longer prescriptions for patients who are stable
  - Highlights need to rotate stock at home