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A Patient-centred approach to measuring quality in kidney care:

PROMS and PREMS

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Purpose of review

Chronic kidney disease (CKD) is associated with symptoms that can significantly reduce the health-related quality of life (HRQOL) of patients. Patient-reported outcome and experience measures (PROMs and PREMs) may assist with the evaluation of HRQOL and quality of care from the patient perspective. This review focuses on evidence from recent studies exploring the role of PROMs and PREMs in the measurement of quality in CKD care.

Recent findings

PROMs are increasingly used in CKD research as measures of clinical effectiveness, whilst the current use of PROMs in routine clinical settings and PREMs in all settings is more limited. Electronic PROMs may be sensitive enough to detect clinically relevant PRO changes. Patients on frequent shorter-hours daily haemodialysis may experience better HRQOL compared to those on conventional haemodialysis. PROM data may correlate significantly with clinical parameters. PREMs are being utilised by healthcare professionals to inform service improvements.

Summary

PROMs and PREMs may facilitate the measurement of quality in renal care and aid the tailoring of care to individual patients. PROMs may have a potential role as prognostic markers.

Keywords

patient-reported outcome measures, PROMs, patient-reported experience measures, PREMs, chronic kidney disease, quality of life, quality of care

Introduction

Chronic kidney disease (CKD) affects up to 14% of the global population [1*, 2]. In many regions of the world, governments and individuals struggle to meet the costs of treating CKD and its complications [3*]. Although recent reviews reported a plateauing of the prevalence of CKD since 2000's [4*, 5], CKD is and will remain a major global public health problem and the focus of detailed attention by healthcare professionals and policy makers [3*].

Patients with CKD often experience a high symptom burden which negatively impacts on their health-related quality of life (HRQOL) [6, 7]. Clinician-reported outcomes such as mortality rates, stage of kidney disease and survival rates are established indicators of health [8]. However, it is increasingly acknowledged that clinician-reported outcomes do not adequately capture patients' HRQOL and underestimate their symptom burden [8, 9]. This may lead to a conflict of priorities between patients and clinicians, as aspects of HRQOL and symptoms that matter to patients may not be prioritised by the clinical team. HRQOL and/or symptoms can be measured from a patient perspective, without interpretation by anyone else, using self-administered, validated questionnaires also known as patient-reported outcome measures (PROMs) [10]. Therefore, the use of PROMs may complement clinician-reported outcomes by eliciting actionable information about patient HRQOL and/or symptoms and possibly assisting with the alignment of patient and clinician care priorities [11**].

Patient experience of care is now formally recognised as a crucial element of healthcare quality alongside patient safety and clinical effectiveness [12, 13] and its measurement can facilitate a patient-centred approach to evaluating healthcare

quality [14*]. Patient experience of care may be objectively measured using patient-reported experience measures (PREMs). Figure 1 shows the inter-relationships between elements of healthcare quality and measures of patient-reported outcomes and experience.

In this review, we present an overview of the use of PROMs/PREMs, and examine evidence from recent studies exploring the role of PROMs/PREMs in the measurement of quality of care specifically in CKD. We also summarize recent evidence of the use of PROMs/PREMs in other health conditions. Finally, we highlight key challenges and technological developments that may influence the use of PROMs and PREMs in future.

Overview of PROMs and PREMs

PROMs are increasingly used in research settings such as clinical trials, cohort studies and prognostic modelling, to appraise the effectiveness and long-term safety of treatments from patients' perspective [10, 15*]. A quick search of 'patient-reported outcome measures' on PubMed for the last 10 years, using the 'clinical trials' filter, yielded 1,878 entries – almost twice the number obtained for the previous decade; demonstrating the increasing use of these measures in clinical trials. On the other hand, the use of PROMs in routine clinical practice, and PREMs in all settings, is limited.

In clinical practice, aggregated PROM data is commonly used to audit and benchmark the performance of hospitals [16]. Since 2009, NHS England has used PROMs to assess the quality of care delivered by NHS providers and quantify post-operative health gains from the patient perspective for surgical procedures comprising: total hip replacement, total knee replacement, varicose vein procedures, and groin hernia repairs [16].

PROMs can also be used at an individual patient level in clinical practice to help to ensure that important aspects of health, that matter to patients, are brought to the attention of clinicians [14*]. Evidence suggests that this contemporary application of PROMs may improve patient-clinician communication [17], and inform and promote shared decision making [17-19].

PREMs are designed to inquire about specific details of care and the actual occurrence of specific processes and/or events [20] rather than satisfaction with care. By adopting this approach, bias and subjectivity that arise from patients' expectations may be minimised [21, 22].

PREMs assess a variety of domains including co-ordination of care, respect for patient preferences, and provision of medical information. Hospitals rated higher by patient experience questionnaires also perform better on clinical metrics [20, 23]. However, evidence of generalisation of use is very limited; this is a shortfall as PREMs can benchmark hospital performance and identify areas of service provision that require improvement [20]. PREM data may also be used to calculate incentive payments and produce reports which are made publicly available to enable patients make informed choices about their care [24].

PROMs and PREMs in CKD

Patients with CKD require long term care, the quality of which may have a significant impact on their HRQOL. PROMs/PREMs provide patients with an opportunity to describe the impact of disease and treatment on HRQOL, symptoms and the quality of care they receive from their perspective.

Selection of measures: evidence from systematic reviews

There are numerous PROMs/PREMs available [25]. To ensure that appropriate measures are selected, it is vital that the purpose of measurement, the target population, the psychometric evidence supporting the measures under consideration, and the setting are carefully considered [26]. Systematic reviews of PROMs/PREMs may provide psychometric evidence which may facilitate the selection process.

A systematic review recently conducted at the Centre for Patient-Reported Outcomes Research (CPROR), University of Birmingham, found evidence to support the use of the Kidney Disease Quality of Life-36 (KDQOL-36) for pre-dialysis patients; the KDQOL-36 & KDQOL-SF for dialysis patients; and the End Stage Renal Disease-Symptom Checklist Transplantation Module (ESRD-SCLTM) for transplant patients on immunotherapy [27*]. The Integrated Patient Outcome Scale-Renal (IPOS-Renal) is a new renal-specific tool that is currently being piloted by the UK Renal Registry. Its validation is on-going [28]. See Table 1 for a description of all the PROMs referred to in this review.

A recent review by Beattie et al. [20] found evidence to support the use of a number of generic PREMs and recommended the use of the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) for purposes relating to research or financial remuneration; the Quality from the Patients' Perspective Shortened (QPPS) to assess the effectiveness of quality improvement at a local level; and the Quality improvement in low-income settings (I-PAHC) for low-income settings [20]. The Care Experience Feedback Improvement Tool (CEFIT) is a new measure intended for quality improvement based on patient experience [36]. The majority of PREMs identified by Beattie et al. were designed for use after discharge from hospital and varied widely in terms of purpose, the domains assessed and timing of administration making it difficult to recommend any for use in CKD. There is therefore a need to validate generic PREM tools in renal disease-specific settings or develop new tools that may be more relevant.

The validated renal-specific PREMs available are limited to dialysis and comprise:

1. CAPHS In-Center Haemodialysis Survey [37, 38]
2. Consumer Quality Index for chronic dialysis [39, 40]

The validation of the UK Renal Registry (UKRR) National PREM survey was recently completed by the research team at University of Hertfordshire. Early reports of its psychometric properties are encouraging and the full report is due to be published shortly [31]. See Table 2 for a description of all the PREMs referred to in this review.

PROMs in CKD clinical trials and research

A clinical trial by Garg et al. used PROMs to evaluate the differences in HRQOL in patients on different haemodialysis treatments. They found that patients who receive frequent shorter hours daily haemodialysis reported better HRQOL compared to those on conventional haemodialysis [45*].

The Dialysis Outcomes and Practice Patterns Study (DOPPS) administers the KDQOL-36 to its cohort of haemodialysis patients annually. The study has reported associations between PROMs and clinical outcomes including mortality rates, even after adjusting for potential confounders. The researchers concluded that PROMs could be used as prognostic markers [46*].

PROMs in CKD routine clinical practice

Recent international developments suggest that the use of ePROMs may help tailor care to individual patient needs and improve patient outcomes. Pittman et al. [47**] recently demonstrated that it is not only feasible to collect electronic PROMs (ePROMs) but that ePROMs could be sensitive enough to detect clinically relevant changes in PROs in both short and longer term. They reported significant correlations between PROM data and clinical parameters, such as haemoglobin and eGFR, at levels of change that have not been previously described [47**]. They also suggested that ePROMs may be of use in pre-dialysis or dialysis patients by providing “early warning” prompts for issues such as fluid status and failure to thrive [47**].

A generic ePROM system, AmbuFlex, was developed in Denmark for the collection of PRO data to support symptom assessment and clinical decision making in outpatient settings [48*]. By 2015, a total of 13,135 outpatients from 15 clinics were individually referred for remote ePROM follow-up and up to 18,912 questionnaires were collected [48*]. An automated algorithm analyses PRO data collected for nine diagnostic groups, including renal failure, and decides whether patients require an outpatient consultation or not [48*]. The completion of an ePROM led to an overall decrease of up to 50% in hospital visits for the follow-up cases analysed. This could potentially lead to more efficient use of resources by freeing up appointment slots for patients who need to be seen in clinic [48*].

A recent pilot study at two outpatient dialysis clinics in Canada, using electronic versions of the KDQOL-36 and the Edmonton Symptom Assessment Scale (ESAS), confirmed that the collection of ePROMs may be feasible and acceptable to patients in routine practice [49, 50]. Whilst emerging evidence of use of ePROM systems in a US oncology setting suggests that real-time monitoring and clinical response to ePROM data may reduce hospitalizations, improve HRQOL and even improve survival [11**]. CPROR are currently undertaking feasibility and pilot work of a similar ePROM system.

PROMs and PREMs in renal registries

There are up to 144 renal registries worldwide [51] but their collection and use of PROM/PREM data is very limited. A review by Breckenridge et al. [40] reported that in Europe, only registries in Austria and France collected PROMs/PREMs [40]. In 2015, the UKRR, in partnership with NHS England, commenced the 'Valuing

Individuals: Transforming Participation in Chronic Kidney Disease' (TP-CKD) programme to assess the feasibility and sustainability of routine collection of PROMs and PREMs from patients with CKD [44]. The UKRR, in conjunction with the British Kidney Patient Association (BKPA), also developed a national strategy for an annual PREM survey to facilitate the benchmarking of kidney patient experience and inform service improvement for individual renal teams [52].

Challenges for PROMs and PREMs in CKD

While there are clear benefits of using PROMs/PREMs, there are also challenges associated with their implementation. While the implementation of PROMs/PREMs in clinical trials has been extensive, in clinical practice it has been relatively slow [53] despite the significant methodological advances in instrument development and psychometric testing. Specific areas that require attention include:

Implementation strategy

A number of guides and frameworks have been developed [53-56*] but it is unclear whether these have made any impact on the implementation of PROMs/PREMs in clinical practice or trials [57*]. Challenges with the NHS PROMs initiative illustrate the importance of introducing PROMs in a staged manner, and piloting the utility of a PROM in a defined clinical setting before generalising into mainstream clinical practice [57*].

The successful implementation of PROMs/PREMs requires a robust implementation strategy backed by strong and effective leadership [58]. Appropriate infrastructure relating to technological capability and data security need to be sorted out before the process is commenced [49, 50]. PROMs/PREMs collection and utilisation need to be integrated with existing clinical pathways and data collection methods to facilitate their adoption by clinicians [59-61]. There is a need for clear guidelines on how to effectively aggregate and incorporate patient-level PROM data into routine care in CKD [62, 63].

For clinical trials, implementation strategies are required to ensure uniform administration of PROMs/PREMs across trial sites and address the current tendency

for data collected with these measures to be compromised by high levels of missing data (a potential source of bias) [64].

Clinician scepticism

Although the use of PROMs in clinical trials has increased significantly in the past few years [65], clinician doubts about the benefits of PROMs and PREMs in clinical practice have persisted and remain an important challenge to the implementation of PROMs/PREMs. A taskforce was recently convened by CPROR and Birmingham Health Partners to assess the evidence and reflect on the UK National PROMs programme. One of its conclusions was that clinicians who traditionally rely on quantitative clinical data to inform clinical decisions are still unconvinced by the evidence supporting the use of PROMs to inform service change [57*]. Rotenstein et al. [66] have stressed the importance of clinician buy-in to ensure the success of any implementation plan [66].

Interpretation and presentation of data

For PROMs/PREMs data to be of any value, it has to be accurately interpreted and translated into actionable information that can be used to inform and drive quality improvements within the healthcare system. After interpreting PROMs/PREMs data, the findings have to be presented in a format that will make sense to stakeholders and decision makers [63, 66]. It has been suggested that one of the reasons the NHS PROMs programme has had no appreciable impact to date may be due to the poor presentation quality of data [62]. Different approaches might be required when presenting PROM data to patients and clinicians [67]. A review by Bantug et al. [68*] reported that patients prefer simple line graphs and interpret them with the highest accuracy. Clinicians were found to prefer similar graphs but valued greater detail

[68*, 69]. There is an urgent need for more work needs to be done to establish standards for PROM data interpretation and presentation [67].

The future of PROMs and PREMs

At present, the most common method of collecting PROM/PREM data is by the administration of paper-based questionnaires. However, this is changing rapidly as access to the internet improves and more people embrace the use of technological innovations such as smartphones, tablet devices and mobile phone applications [49, 70]. The ePROM system researchers at CPROR and University Hospitals Birmingham NHS Foundation Trust are currently working on may assist with the remote monitoring of symptom deterioration between scheduled clinic appointments and provide clinicians the opportunity to intervene promptly. It may also encourage patients to become more engaged with their care and potentially facilitate shared decision making between patients and clinicians, an integral principle of patient-centred care [14*].

Computer adaptive testing (CAT) is an algorithm-based method of PROM administration whereby the most relevant items (questions) from an item bank are automatically selected and administered sequentially, based on a respondent's prior responses with the aim of maximizing the information obtained about the respondent [71*]. Using a CAT simulation of the World Health Organization Quality of Life (WHOQOL)-100 questionnaire, Gibbons et al. [71*] recently demonstrated that electronic item banks could provide accurate measurements that are significantly shorter and often more reliable than paper-based versions [71*]. The significant progress in the development of open-source platforms mean that it is possible for researchers and clinicians to deploy cloud-based CATs directly to patients via the Internet and mobile phone applications [72].

Current technological innovations may also assist with the integration of PROM data with other routinely collected electronic health data such as laboratory test results. This integrated data also referred to as 'Big Data' has the potential to facilitate the delivery of high quality care that is "*personal and tailored*" to individual patients, development of diagnostic algorithms, and enhanced clinical audit [73, 74].

Conclusion

The drive for improvement in quality of renal care requires the adoption of a patient-centred approach to the provision of renal care and the measurement of its quality for significant progress to be achieved. Health providers need to design and properly implement robust strategies, which put the patient at the heart of service provision. This requires effective leadership and significant cultural and organisational changes.

The use of PREMs and PROMs may facilitate this process by giving patients the avenue to provide actionable information about their health and encouraging shared decision making between patients and their healthcare providers/clinicians. Recent advances in technology could lead to PROMs/PREMs playing a significant role in transforming health care delivery in future.

Key points

- PROMs and PREMs have applications in research; clinical trials and routine clinical practice, and may facilitate a patient-centred approach to renal care.
- PROMs may be used to evaluate quality of life from a patient perspective.
- PROMs could potentially complement clinician-reported outcomes in the clinical management of CKD patients.
- PREMs may be used to evaluate quality of care from a patient perspective.
- PREMs may facilitate quality improvement in renal care services.

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Conflicts of interest

There are no conflicts of interest.

References

Papers of particular interest, published within the annual period of review, have been highlighted as:

* of special interest

** of outstanding interest

1. * Hill NR, Fatoba ST, Oke JL, et al. Global Prevalence of Chronic Kidney Disease - A Systematic Review and Meta-Analysis. *PLoS One*, 2016. 11(7): p. e0158765.

This review presents the current global prevalence of chronic kidney disease.

2. Mills KT, Xu Y, Zhang W, et al. A systematic analysis of worldwide population-based data on the global burden of chronic kidney disease in 2010. *Kidney Int*, 2015. 88(5): p. 950-7.
3. * Levin A, Tonelli M, Bonventre J, et al. Global kidney health 2017 and beyond: a roadmap for closing gaps in care, research, and policy. *The Lancet*, 2017.

This study discusses the key themes that need to be addressed in managing kidney disease globally.

4. * Hsu RK, Powe NR. Recent trends in the prevalence of chronic kidney disease: not the same old song. *Current Opinion in Nephrology and Hypertension*, 2017. 26(3): p. 187-196.

This paper reports the current trends in the prevalence of chronic kidney disease.

5. Fraser SDS, Blakeman T. Chronic kidney disease: identification and management in primary care. *Pragmatic and Observational Research*, 2016. 7: p. 21-32.
6. Meyer T, Hostetter T. Medical Progress: Uremia. *The New England Journal of Medicine*, 2007. 357(13): p. 1316-25.
7. Almutary H, Bonner A, Douglas C. Symptom burden in chronic kidney disease: a review of recent literature. *Journal of Renal Care*, 2013. 39(3): p. 140-50.
8. Donabedian A. Evaluating the Quality of Medical Care. *The Milbank Quarterly*, 2005. 83(4): p. 691-729.
9. Pakhomov SV, Jacobsen SJ, Chute CG, Roger VL. Agreement between patient-reported symptoms and their documentation in the medical record. *Am J Manag Care*, 2008. 14(8): p. 530-9.
10. Department of Health and Human Services, Food and Drug Administration (US). Patient-reported outcome measures: use in medicinal product development to support labeling claims. Guidance for industry. [Internet]. 2009. [cited 2017 June 2]. Available from: <https://www.fda.gov/downloads/drugs/guidances/ucm193282.pdf>
11. ** Basch E, Deal A, Kris M, et al. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. *Journal of Clinical Oncology*, 2016. 34(6): p. 557-565.

This trial provides evidence for the potential utilities that may be derived from the implementation of PROMs.

12. Llanwarne NR, Abel GA, Elliott MN, et al. Relationship between clinical quality and patient experience: analysis of data from the English Quality and Outcomes Framework and the National GP Patient Survey. *Ann Fam Med*, 2013. 11(5): p. 467-72.
13. Department of Health. High Quality Care For All. NHS Next Stage Review Final Report. [Internet]. 2008. [cited 2017 June 2] Available from: <https://www.gov.uk/government/publications/high-quality-care-for-all-nhs-next-stage-review-final-report>
14. * Coulter A. Measuring what matters to patients. *Bmj*, 2017. 356: p. j816.

This paper highlights the importance of incorporating patient voices in clinical decision making.

15. * Kyte D, Ives J, Draper H, Calvert M. Current practices in patient-reported outcome (PRO) data collection in clinical trials: a cross-sectional survey of UK trial staff and management. *BMJ Open*, 2016. 6(10).

This paper highlights the challenges with the collection of PROMs in clinical trials.

16. Health and Social Care Information Centre. Finalised Patient Reported Outcome Measures (PROMs) in England, April 2014 to March 2015. [Internet]. 2016. [cited 2017 June 2]. Available from: <http://content.digital.nhs.uk/searchcatalogue>
17. Greenhalgh J, Meadows K. The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: a literature review. *J Eval Clin Pract*, 1999. 5(4): p. 401-16.
18. Snyder CF, Aaronson NK, Choucair AK, et al. Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations. *Qual Life Res*, 2012. 21(8): p. 1305-14.
19. Valderas JM, Kotzeva A, Espallargues M, et al. The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. *Qual Life Res*, 2008. 17(2): p. 179-93.
20. Beattie M, Douglas MJ, Atherton I, Lauder W. Instruments to measure patient experience of healthcare quality in hospitals: a systematic review. *Systematic Reviews*, 2015. 4: p. 97.
21. Richards N, Coulter A. Is the NHS becoming more patient-centred? Trends from the national surveys of NHS patients in England 2002-07. Picker Institute Europe, 2007.
22. Cleary PD, Edgman-Levitan S, Roberts M, et al. Patients evaluate their hospital care: a national survey. *Health Aff (Millwood)*, 1991. 10(4): p. 254-67.
23. Luxford K. What does the patient know about quality? *Int J Qual Health Care*, 2012. 24(5): p. 439-40.
24. CMS.gov. [Internet]. Centers for Medicare and Medicaid Services 2017. [cited 2017 June 2]. Available from: <https://www.cms.gov/>
25. Bryan S, Davis J, Broesch J, et al. Choosing your partner for the PROM: a review of evidence on patient-reported outcome measures for use in primary and community care. *Healthc Policy*, 2014. 10(2): p. 38-51.
26. Snyder CF, Watson ME, Jackson JD, Cella, D. Patient-reported outcome instrument selection: designing a measurement strategy. *Value Health*, 2007. 10 Suppl 2: p. S76-85.
27. * Aiyegbusi OL, Kyte D, Cockwell P, et al. Measurement properties of patient-reported outcome measures (PROMs) used in adult patients with chronic

kidney disease: a systematic review protocol. *BMJ Open*, 2016. 6(10): p. e012014.

This review presents the psychometric evidence to support the use of PROMs in patients with CKD.

28. Palliative care Outcome Scale. [Internet]. [cited 2017 June 2]. Available from: <https://pos-pal.org/>
29. Devlin N, Appleby J. Getting the most out of PROMs: Putting health outcomes at the heart of NHS decision-making. London: Kings Fund and Office of Health Economics, 2010.
30. Chao S, Yen M, Lin TC, et al. Psychometric Properties of the Kidney Disease Quality of Life-36 Questionnaire (KDQOL-36). *West J Nurs Res*, 2016. 38(8): p. 1067-82.
31. Ricardo AC, Hacker E, Lora CM, et al. Validation of the Kidney Disease Quality of Life Short Form 36 (KDQOL-36TM) US Spanish and English versions in a cohort of Hispanics with chronic kidney disease. *Ethnicity and Disease*, 2013. 23(2): p. 202-209.
32. Hays RD, Kallich JD, Mapes DL, et al. Kidney Disease Quality of Life Short Form (KDQOL-SF) Version 1.3: A manual for use and scoring. RAND, 1995.
33. Hays RD, Kallich JD, Mapes DL, et al. Development of the kidney disease quality of life (KDQOL) instrument. *Qual Life Res*, 1994. 3(5): p. 329-38.
34. Franke GH, Reimer J, Kohnle M, et al. Quality of life in end-stage renal disease patients after successful kidney transplantation: development of the ESRD symptom checklist - transplantation module. *Nephron*, 1999. 83(1): p. 31-9.
35. Davison SN, Jhangri GS, Johnson JA. Cross-sectional validity of a modified Edmonton symptom assessment system in dialysis patients: a simple assessment of symptom burden. *Kidney International*, 2006. 69(9): p. 1621-5.
36. Beattie M, Shepherd A, Lauder W, et al. Development and preliminary psychometric properties of the Care Experience Feedback Improvement Tool (CEFIT). *BMJ Open*, 2016. 6(6): p. e010101.
37. In-Center Hemodialysis CAHPS Survey. [internet]. [cited 2017 June 2]. Available from: <https://ichcahps.org/>
38. Wood R, Paoli CJ, Hays RD, et al. Evaluation of the Consumer Assessment of Healthcare Providers and Systems In-Center Hemodialysis Survey. *Clinical Journal of the American Society of Nephrology: CJASN*, 2014. 9(6): p. 1099-1108.
39. van der Veer SN, Jager KJ, Visserman E, et al. Development and validation of the Consumer Quality index instrument to measure the experience and priority of chronic dialysis patients. *Nephrol Dial Transplant*, 2012. 27(8): p. 3284-91.
40. Breckenridge K, Bekker HL, Gibbons E, et al. How to routinely collect data on patient-reported outcome and experience measures in renal registries in Europe: an expert consensus meeting. *Nephrol Dial Transplant*, 2015. 30(10): p. 1605-14.
41. Giordano LA, Elliott MN, Goldstein E, et al. Development, Implementation, and Public Reporting of the HCAHPS Survey. *Medical Care Research and Review*, 2009. 67(1): p. 27-37.
42. Larsson BW, Larsson G. Development of a short form of the Quality from the Patient's Perspective (QPP) questionnaire. *J Clin Nurs*, 2002. 11(5): p. 681-7.

43. Webster TR, Mantopoulos J, Jackson E, et al. A brief questionnaire for assessing patient healthcare experiences in low-income settings. *Int J Qual Health Care*, 2011. 23(3): p. 258-68.
44. UK Renal Registry (UKRR). Valuing Individuals - Transforming participation in Chronic Kidney Disease (CKD) Programme. [Internet]. 2015. [cited 2017 June 2]. Available from: <https://www.renalreg.org/projects/transforming-participation-in-chronic-kidney-disease-programme/>
45. ** Garg AX, Suri RS, Eggers P, et al. Patients receiving frequent hemodialysis have better health-related quality of life compared to patients receiving conventional hemodialysis. *Kidney Int*, 2017. 91(3): p. 746-754.

This trial reports that patients who receive frequent shorter hours daily haemodialysis may have significantly better quality of life compared to those on conventional haemodialysis.

46. * Port FK, Morgenstern H, Bieber BA, et al. Understanding associations of hemodialysis practices with clinical and patient-reported outcomes: examples from the DOPPS. *Nephrol Dial Transplant*, 2017. 32(suppl_2): p. ii106-ii112.

This article discusses the associations between HD facilities, clinical outcomes and PROs.

47. ** Pittman ZCL, John SG, McIntyre CW. Collection of daily patient reported outcomes is feasible and demonstrates differential patient experience in chronic kidney disease. *Hemodialysis International*, 2016.

This CKD trial provides evidence that PROMs could detect clinically significant changes in patient reported outcomes. Also reported significant correlations between PROMs and clinical parameters.

48. * Schougaard LM, Larsen LP, Jessen A, et al. AmbuFlex: tele-patient-reported outcomes (telePRO) as the basis for follow-up in chronic and malignant diseases. *Qual Life Res*, 2016. 25(3): p. 525-34.

This study provided evidence that the use of an ePROM could lead to a significant decrease in hospital visits for follow-up patients.

49. Schick-Makaroff K, Molzahn A. Brief communication: patient satisfaction with the use of tablet computers: a pilot study in two outpatient home dialysis clinics. *Canadian Journal of Kidney Health and Disease*, 2014. 1: p. 22.
50. Schick-Makaroff K, Molzahn A. Strategies to use tablet computers for collection of electronic patient-reported outcomes. *Health and Quality of Life Outcomes*, 2015. 13: p. 2.
51. Liu FX, Rutherford P, Smoyer-Tomic K, et al. A global overview of renal registries: a systematic review. *BMC Nephrology*, 2015. 16: p. 31.
52. British Kidney Patient Association. National Patient Reported Experience Measure (PREM) Survey receives 8,000 replies from patients. [Internet]. 2016. [cited 2017 June 2]. Available from: <http://www.britishkidney-pa.co.uk/news/80-national-patient-reported-experience-measure-prem-survey-receives-8000-replies-from-patients>
53. Antunes B, Harding R, Higginson IJ. Implementing patient-reported outcome measures in palliative care clinical practice: A systematic review of facilitators and barriers. *Palliative Medicine*, 2014. 28(2): p. 158-175.
54. Osoba D. Translating the science of patient-reported outcomes assessment into clinical practice. *J Natl Cancer Inst Monogr*, 2007(37): p. 5-11.
55. Aaronson N, Elliott T, Greenhalgh J, et al. User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice. International Society for Quality of Life Research, 2015.

56. * Porter I, Gonçalves-Bradley D, Ricci-Cabello I, et al. Framework and guidance for implementing patient-reported outcomes in clinical practice: evidence, challenges and opportunities. *Journal of Comparative Effectiveness Research*, 2016. 5(5): p. 507-519.

This study presents a framework for the implementation of PROMs in clinical practice.

57. * Kyte D, Cockwell P, Lencioni M, et al. Reflections on the national patient-reported outcome measures (PROMs) programme: Where do we go from here? *J R Soc Med*, 2016. 109(12): p. 441-445.

This paper discusses the issues facing the NHS PROMs programme.

58. Davies E, Shaller D, Edgman-Levitan S, et al. Evaluating the use of a modified CAHPS survey to support improvements in patient-centred care: lessons from a quality improvement collaborative. *Health Expect*, 2008. 11(2): p. 160-76.
59. Bennett AV, Jensen RE, Basch E. Electronic patient-reported outcome systems in oncology clinical practice. *CA Cancer J Clin*, 2012. 62(5): p. 337-47.
60. Jensen RE, Rothrock NE, DeWitt EM, et al. The role of technical advances in the adoption and integration of patient-reported outcomes in clinical care. *Med Care*, 2015. 53(2): p. 153-9.
61. Malhotra K, Buraimoh O, Thornton J, et al. Electronic capture of patient-reported and clinician-reported outcome measures in an elective orthopaedic setting: a retrospective cohort analysis. *BMJ Open*, 2016. 6(6).
62. Black N, Burke L, Forrest CB, et al. Patient-reported outcomes: pathways to better health, better services, and better societies. *Qual Life Res*, 2016. 25(5): p. 1103-12.
63. Wahl ER, Yazdany J. Challenges and Opportunities in Using Patient-reported Outcomes in Quality Measurement in Rheumatology. *Rheumatic Disease Clinics*, 2016. 42(2): p. 363-375.
64. Kyte DG, Draper H, Ives J, et al. Patient reported outcomes (PROs) in clinical trials: is 'in-trial' guidance lacking? a systematic review. *PLoS One*, 2013. 8(4): p. e60684.
65. Vodicka E, Kim K, Devine EB, et al. Inclusion of patient-reported outcome measures in registered clinical trials: Evidence from ClinicalTrials.gov (2007-2013). *Contemp Clin Trials*, 2015. 43: p. 1-9.
66. Rotenstein LS, Agarwal A, O'Neil K, et al. Implementing patient-reported outcome surveys as part of routine care: lessons from an academic radiation oncology department. *J Am Med Inform Assoc*, 2017.
67. Brundage MD, Smith KC, Little EA, et al. Communicating patient-reported outcome scores using graphic formats: results from a mixed-methods evaluation. *Qual Life Res*, 2015. 24(10): p. 2457-72.
68. * Bantug ET, Coles T, Smith KC, et al. Graphical displays of patient-reported outcomes (PRO) for use in clinical practice: What makes a pro picture worth a thousand words? *Patient Educ Couns*, 2016. 99(4): p. 483-90.

This paper reviews the evidence on the presentation format of PROM data.

69. Mcnair AGK, Brookes S, Davis CR, et al. Communicating the Results of Randomized Clinical Trials: Do Patients Understand Multidimensional Patient-Reported Outcomes? *Journal of Clinical Oncology*, 2010. 28(5): p. 738-743.
70. Pouwer F, Snoek FJ, van der Ploeg HM, et al. A comparison of the standard and the computerized versions of the Well-being Questionnaire (WBQ) and

- the Diabetes Treatment Satisfaction Questionnaire (DTSQ). *Qual Life Res*, 1998. 7(1): p. 33-8.
71. * Gibbons C, Bower P, Lovell K, et al. Electronic Quality of Life Assessment Using Computer-Adaptive Testing. *J Med Internet Res*, 2016. 18(9): p. e240. This study demonstrates the potential capabilities of computer-adaptive testing.
72. Scalise K, Allen DD. Use of open-source software for adaptive measurement: Concerto as an R-based computer adaptive development and delivery platform. *British Journal of Mathematical and Statistical Psychology*, 2015. 68(3): p. 478-496.
73. Calvert M, Thwaites R, Kyte D, Devlin N. Putting patient-reported outcomes on the 'Big Data Road Map'. *J R Soc Med*, 2015. 108(8): p. 299-303.
74. Association of the British Pharmaceutical Industry. Big data road map. [Internet]. 2013. [cited 2017 June 2]. Available from: <http://www.abpi.org.uk/our-work/library/industry/Documents/ABPI%20big%20data%20road%20map.pdf>

Figure titles and legends

Figure 1. Inter-relationships between PROMs, PREMs, elements of high-quality care and Patient-centred care (P.C.C).

