

<b>Institution:</b> London South Bank University		
<b>Unit of Assessment:</b> 3 - Allied Health Professions, Dentistry, Nursing and Pharmacy		
<b>Title of case study:</b> Early Identification, Self-Management and Patient and Public Involvement/Engagement in Chronic Kidney Disease		
<b>Period when the underpinning research was undertaken:</b> 2012 – 2020		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Professor Nicola Thomas	Professor of Kidney Care	March 2013 – present
<b>Period when the claimed impact occurred:</b> August 2013 – December 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> N		
<p><b>1. Summary of the impact</b> (indicative maximum 100 words)</p> <p>Chronic kidney disease (CKD) is a long-term condition, affecting 6% of UK adults, with people of Black, Asian and minority ethnic (BAME) heritage five times more likely to develop the condition. Research carried out by Thomas, specifically with underserved groups, has focused on reducing these health inequalities by delivering wide-ranging impacts in three areas: (1) increasing the numbers of people with CKD in the UK being identified (coded) to well-above national rates and ensuring evidence-based management; (2) changing delivery and impact of self-management programmes for CKD; and (3) integrating meaningful patient and public involvement/engagement (PPI/E) activities, including robust peer support, into local and national programmes.</p>		
<p><b>2. Underpinning research</b> (indicative maximum 500 words)</p> <p>One million people in the UK have undiagnosed CKD, due in part to non-recognition in primary care. In addition, few people with CKD know what they can do to slow down the progression of their condition, so early facilitation of self-management is vital. Meaningful patient and public involvement, alongside robust peer support, complements these interventions and ensures research focuses on what matters to people living with kidney disease.</p> <p><b>1. EARLY IDENTIFICATION OF CKD</b></p> <p><b>Improving recognition (coding) and management of CKD in primary care.</b> This study [R1] (2017-2019) developed one part of a complex intervention for the East London Community Kidney Service, across three Clinical Commissioning Groups (CCGs). Half of the population in these CCGs is recorded as being of non-white ethnic origin, and all fall in the lowest 10% for social deprivation in England. Coding (formal identification and recording by Read code) of CKD is variable across the UK. Absence of coding is associated with poorer blood pressure control and management of cardiovascular risk; observational data also demonstrate higher rates of unplanned hospital admission among uncoded cases, as well as double the mortality rates of people who are coded (national CKD Audit 2018). Thomas undertook renal-specific clinical facilitation with Practices in the lowest decile of CKD coding, which focused on the importance of CKD coding and cardiovascular and blood pressure management, alongside renal education and case discussions for practice nurses. Practices showed significant coding improvement over a 1-year period following the intervention, with the CCG with highest coding rates increasing from 76–90% of CKD cases coded; the lowest coding CCG increased from 52–81%. In addition, combined data from all practices in the intervention CCGs showed a significant increase in the proportion of cases with blood pressure achieving target levels (difference in proportion <math>P&lt;0.001</math>) over the 2-year study period.</p> <p>Another intervention [R2] in the same three CCGs in East London explored the use of trigger tools that notify GP practices of falling kidney function in individual patients. Built from data in the</p>		

electronic health record (EHR), the trigger tools alerted clinicians to review patients with progressive CKD and invited clinical review, a referral option, and written reflection on management. Thomas undertook interviews to identify practitioner perceptions of trigger tool use and the research team compared them with reflections on clinical management in >1900 records. Results showed that building electronic trigger tools from the EHR can identify patients with falling kidney function, thereby prompting review of the management plan. In addition, the use of trigger tools was found to support patient safety and encourage learning about CKD management.

**Alerting GPs to progressive CKD (ASSIST-CKD).** This intervention (2016-19) facilitated early identification of kidney disease in 21 laboratories (serving 11-12,000,000 (11-12m) people) and aimed to identify people with progressive CKD to reduce their late referral to secondary care. The ASSIST-CKD software extracted biochemical data from laboratory databases and generated graphs of estimated kidney function (eGFR) over time. Where a graph showed progressive kidney disease it was sent to GPs prompting them to re-review patient care and if necessary, refer to renal services. Thomas led the mixed-method evaluation [R3], with five renal units, to understand drivers and barriers to widespread implementation and adoption. The study concluded that drivers included the intervention's low cost, ease of understanding, a sense of local ownership on the part of the GP and its perceived impact; barriers included nephrologists' perceived increase in new referrals.

## 2. SELF-MANAGEMENT OF CKD

**Care Bundle for CKD (ENABLE-CKD).** 13 GP practices in England/Wales implemented a Care Bundle for CKD to improve staff knowledge, management and patient awareness of CKD. Care Bundle components comprised urine testing, prescription of BP medication, cardio-vascular risk assessment and offer of a self-management programme. The self-management component was co-developed by Thomas in collaboration with people living with kidney disease. Thomas facilitated Care Bundle implementation in 9 Practices, alongside education of clinicians and patients (co-delivered with people living with kidney disease) and evaluation [R4]. The Care Bundle was undertaken with 1310 patients: 69.3% agreed to the self-management component. The reliability of the Bundle at project end was 100%. 826 new cases of CKD were identified by Practices participating in the project.

**East London Community Kidney Service (2016-20).** Another part of the complex intervention in East London, delivered an innovative, practical, sustainable way to deliver health education about CKD. Thomas worked with a nurse specialist and patients to develop and evaluate a suite of innovative, evidence-based learning materials in a variety of formats that suited differing health literacies and languages, including short films, translated into local languages [R5].

## 3. PPI/E IN CKD QUALITY IMPROVEMENT AND RESEARCH

Thomas developed and has led the **Kidney Research User Group (KRUG)** at LSBU since 2015. This Group informed the development of co-produced studies in kidney care, including: a multi-centre co-designed study on **Peer Support** in kidney care [R6]; Thomas's appointment of a **Patient Editor** (2018) for the Journal of Renal Care whilst she was Editor; and Thomas's input as a founder member of the national **Kidney Patient Involvement Network (KPIN)**. KPIN is a network of kidney organisations, charities and individuals committed to quality PPI/E who are working collaboratively on initiatives to improve standards and develop patient leaders of the future.

### 3. References to the research (indicative maximum of six references)

*All research is published in peer-reviewed journals. R1 and R3 are submitted as outputs for REF2021 in UoA 03.*

#### EARLY IDENTIFICATION OF CKD

[R1] Hull, S, Rajabzadeh, V, **Thomas, N**, Hoong, S, Dreyer, G, Rainey, H and Ashman, N (2019) Improving coding and primary care management for people with Chronic Kidney Disease: an observational controlled study in east London. *British Journal of General Practice* 2019; 69

(684): e454-e461. <https://doi.org/10.3399/bjgp19X704105>

**[R2] Thomas, N**, Hull, S and Rajabzadeh, V (2019). Using chronic kidney disease trigger tools for safety and learning: a qualitative evaluation in East London primary care. British Journal of General Practice. 69 (687), pp. e715 - e723. <https://doi.org/10.3399/bjgp19X705497>

**[R3] Thomas, N.**, Woolnough, L., Nation, M. and Gallagher, H. (2020). Quality improvement at scale: evaluation of the drivers and barriers to adoption and sustainability of an intervention to reduce late referral in chronic kidney disease. BMJ Open Quality. 9, p. e001045. <https://doi.org/10.1136/bmjopen-2020-001045>

### SELF-MANAGEMENT OF CKD

**[R4] Thomas, N**, Gallagher, G and Jain, N. (2014) A quality improvement project to improve the effectiveness and patient-centredness of management of people with mild-to-moderate kidney disease in primary care. BMJ Quality Improvement Reports 2014; u201337.w825 <https://bmjopenquality.bmj.com/content/bmjopen/3/1/u201337.w825.full.pdf>

**[R5] Rainey, H**, Hussain, S and **Thomas, N** (2020). Innovative education for people with chronic kidney disease: an evaluation study. Journal of Renal Care. <https://doi.org/10.1111/jorc.12325>

### PPI/E IN QUALITY IMPROVEMENT AND RESEARCH

**[R6] Trasolini, A.**, Wood, E. and **Thomas, N**. (2020). Peer Support Barriers and Facilitators in Kidney Care. Journal of Renal Care. <https://doi.org/10.1111/jorc.12350>

### GRANTS

Development and evaluation of a renal learning health system in east London. The Health Foundation. £74,922. (Thomas: project team member)

ASSIST-CKD. A programme to spread eGFR graph surveillance for early identification support and treatment of people with progressive chronic kidney disease: The Health Foundation, £604,971. (Thomas: co-investigator)

ENABLE. Enhancing care and saving lives of people with CKD: The Health Foundation £399,703. (Thomas: co-investigator)

Development and evaluation of the East London Community Kidney Service (patient education): Barts Health Kidney Patient's Association £9000. (Thomas: PI)

The experience of older people in the shared decision-making process in advanced kidney care: East Kent Hospitals NHS Trust. £37,965 (Thomas: co-PI)

Maximising the uptake and impact of peer support in kidney care: Kidney Care UK £42,249. (Thomas: PI)

Feasibility of using smartphone technology for home urine testing in people with diabetes and/or chronic kidney disease in East London. Burdett Trust £54,983 (Thomas: PI)

### AWARDS

Awarded to Thomas 2014: Lifetime member award from the European Dialysis and Transplant Nurses Association/European Renal Care Association

Awarded to Thomas and research team 2016: Commended for patient involvement by the National Centre for Public Engagement

Awarded to East London Community Kidney Service 2017: Runner up Health Service Journal awards (acute sector)

Awarded to East London Community Kidney Service 2018: Winner of Barts Health/QMUL Innovation award

Awarded to Thomas 2018: Donna Lamping Award (British Renal Society) for Outstanding Research in Kidney Care

## 4. Details of the impact (indicative maximum 750 words)

### 1. An increase in numbers of people with CKD being identified and appropriately managed

Based on a complex intervention developed by Thomas and colleagues **[R1, R2, R5]**, the East London Community Kidney Service (ELCKS), serving 1,200,000 (1.2m) people and covering 4

CCGs, has further developed this system-wide change in both intervention and control CCGs. The significant coding improvement seen during the intervention period has been sustained. In July 2020, the three intervention CCGs still have 86.1% of people with CKD coded and the control CCG now has 84.6% people with CKD coded, up from 52.3% in January 2018 [S1]. This is important as those who are not coded for CKD have double the mortality rates of people whose are coded, alongside a significant increase in unplanned hospital admissions and in rates of acute kidney injury (CKD Audit 2018). Combined data from all practices in three CCGs in 2020 showed a sustained level in the proportion of cases with blood pressure achieving NICE targets (65.2%). Additional impacts of the ELCKS include reduction of wait time for consultation, and only 20% referred patients requiring a hospital appointment [S2]. The ELCKS has been included as a case study in the NHS Long-Term Plan (2019) as an example of the transformation of outpatient services [S3]:

*“The new service supports timely provision of advice from the hospital specialist to the GP, to enable better management of the patient either in the community or with more specialist care where needed. A single pathway from primary to secondary care with rapid access to specialist advice provided by consultant led e-clinics have transformed the way the outpatient service is delivered. Since the e-Clinic began in December 2015, 50% of referrals are managed without the need for a hospital appointment. The average waiting time for a renal clinic appointment has fallen to five days, from 64 days in 2015.”*

The ASSIST-CKD intervention [R3] which commenced in 21 laboratories (serving an estimated 11-12,000,000 (11-12m) people across all Home Nations) during 2015-18, had by December 2020 been sustained in 13 regions, despite the impact of COVID-19 on laboratory workload. Late referral data for 2019 are available for the impact of the intervention on two evaluation sites (two other evaluation sites have missing data, and another has not continued with the intervention). In these two sites, late referral rates to secondary care (referral within three months of requiring dialysis/transplant), dropped from 21.4% and 21.2% in 2015 to 14% and 15.8% in 2019 respectively [S4]. One clinician, when reflecting on reduced referral rates from 2015-2018, said: “over that period we haven't changed anything else, we haven't introduced any other initiatives in that period, so it's possible that [the decrease in late referral rates is due to] ASSIST.” This is important as late referral is associated with poorer outcomes, such as prolonged hospitalisation, increased mortality, as well as a lower likelihood of planned vascular access or pre-emptive kidney transplantation. In addition, a Renal Association report in 2020 [S5] identified five factors which are key to the successful scaling-up of an intervention. ASSIST-CKD was cited as an exemplar and further, the report showcased useful resources employed in the programme, such as the business case infographic (p.111).

## 2. Changes to delivery and impact of self-management programmes for CKD

The ENABLE-CKD project [R3] led to the development of a Package of Innovation: a series of materials available online (for 3 years post-project) for download to assist with managing kidney disease in primary care. After the project finished, the Welsh Renal Network (the Network Manager was part of the project team) championed the intervention as a means for improving consistency of care across Wales. In both England and Wales, the advice of the project team was sought to influence policy and guidelines development, including what advice should be given to patients with CKD. The response was included in Welsh GP guidelines. [S6]. The work in East London by Thomas and colleagues [R5] delivered a practical, sustainable way to deliver health education about CKD, via development of innovative educational materials for self-management of CKD. Since development, the educational resources have been shared with three other London NHS Trusts who have used the resources as a foundation to their own self-management programmes. Self-management has also been enhanced by a home urine testing using smartphone technology, being piloted in Tower Hamlets. Following a grant secured by Thomas in 2019, early impact is showing 9% of patients with diabetes who tested their own urine (n=247) had abnormal results, meaning their care pathway is changed (according to local evidence-based guidelines) [S7].



**3. Delivery of meaningful PPI/E in quality improvement and research.**

A variety of impacts have resulted from the initiation of the Kidney Research User Group (KRUG), including a co-produced study that was awarded a commendation (see awards). Thomas was the Editor of the Journal of Renal Care (2012-19) - the Journal was the first kidney journal to appoint a patient editor in 2018. The Patient Editor chooses a paper in each issue [S8], writes a lay summary and then sends out the summary to 25 kidney patient organisations across the world. Specific impact from issue 4/20 was where the chosen paper informed the development of policy in renal conservative management in Scandinavia.

The success of KRUG demonstrated the value of PPI/E. KRUG initiatives such as development of a role description and a training programme for every PPI/E representative on research groups, informed similar developments in the national Kidney Patient Involvement Network (KPIN). KPIN was selected by NIHR to test standards for PPI/E in research in 2019 and now has 107 patient and 39 health care professional members. The KPIN website [S9] provides opportunities for learning. Three recent webinars (co-facilitated by Thomas) were attended by 82 attendees; there have been 29 opportunities for patient involvement in research posted by KPIN since launch. Feedback from clinicians/researchers has been very positive *"15 patients contacted me. I would definitely consider KPIN in the future and also have recommended it to colleagues."*

The results of the peer support project [R6] resulted in the development of a Peer Support Toolkit, which has been promoted by Kidney Care UK [S10] and has led to > 200 downloads of different documents before end 2020 with three renal units enquiring about initiating a peer support programme. One renal unit said of the Toolkit *"it has provided a great foundation to build the York Hospital Peer Support Programme."* The National Kidney Federation (for UK Kidney Patient Associations) has a national peer support programme plan which draws upon this work and has asked Thomas to facilitate training of peer supporters using the Toolkit.

**5. Sources to corroborate the impact** (indicative maximum of 10 references)

- [S1] Queen Mary University of London Clinical Effectiveness Unit July 2020 data
- [S2] Development and evaluation of a renal learning health system across inner east London. <https://www.health.org.uk/sites/default/files/2019-05/IFI%20R6%20Queen%20Mary%20final%20report.pdf>
- [S3] East London Community Kidney Service in NHS Long-term Plan (p.28) <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan-june-2019.pdf>
- [S4] 22<sup>nd</sup> Renal Registry report (2020) Chapter 1 p.18 [https://renal.org/sites/renal.org/files/22nd\\_UKRR\\_ANNUAL\\_REPORT\\_Ch1.pdf](https://renal.org/sites/renal.org/files/22nd_UKRR_ANNUAL_REPORT_Ch1.pdf)
- [S5] Report for Closing the Gap through Clinical Communities (ENABLE-CKD) (2012)
- [S6] Kidney services – improving at scale [Kidney Services: Improving At Scale – A QI learning report | The Renal Association](#)
- [S7] East London CKD guidelines [CKD- Chronic Kidney Disease \(clarity.co.uk\)](http://clarity.co.uk)
- [S8] Patient Editor for Journal of Renal Care [https://onlinelibrary.wiley.com/page/journal/17556686/homepage/patient\\_editor.html](https://onlinelibrary.wiley.com/page/journal/17556686/homepage/patient_editor.html)
- [S9] Kidney Patient Involvement Network <https://kpin.org.uk/>
- [S10] Peer Support Toolkit <https://www.kidneycareuk.org/health-professionals/peer-support-toolkit/>