

Institution: University of Hertfordshire		
Unit of Assessment: 3 – Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Changing policy and practice to improve patient experience and quality of life for people with advanced kidney disease		
Period when the underpinning research was undertaken: 2008 – 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Ken Farrington	Professor	2010 to date
David Wellsted	Reader in Health Research Methods	2002 to date
Enric Vilar	Senior Clinical Lecturer	2013 to date
Shivani Sharma	Senior Lecturer	2006 to date
Period when the claimed impact occurred: 2014 – 31 December 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact (indicative maximum 100 words)		
<p>Patient-centred research at the University of Hertfordshire (UH) has provided a body of evidence to support an increase in treatment options for people with advanced kidney disease and enhance opportunities for more personalised care. This has resulted in the adoption of new guidelines, recommendations and resources that have changed clinical practice, improving patient experience and quality of life outcomes. These include:</p> <ul style="list-style-type: none"> - National and international clinical practice guidelines which advocate offering conservative management as an alternative to dialysis, thereby increasing patient choice. - NICE guidance that specifies the need for clinicians to offer patients the choice of conservative management and the need to consider alternative renal replacement therapies, thus tailoring dialysis prescription to individual patients. - New resources and toolkits that increase the involvement of chronic kidney disease (CKD) patients in their own care. - The development, validation and analysis of a pioneering national Patient Reported Experience Measure for kidney patients to improve patient experience and reduce variation in how services are delivered across the NHS. 		
2. Underpinning research (indicative maximum 500 words)		
<p>The population of patients with moderate and severe advanced kidney disease is growing. An estimated 2.6m people aged 16 years and older in England have stage 3-5 kidney disease and this figure is expected to rise to 4.2m by 2036, according to Public Health England's Chronic Kidney Disease prevalence model. Frail and older patients comprise an increasing proportion.</p> <p>A programme of research led by Farrington at UH's Centre for Health Services and Clinical Research (CHSCR), involving collaboration with clinicians at East and North Hertfordshire NHS Trust, has sought to increase available treatment options for the management of advanced CKD and personalise care. Combining clinical experience with expertise in clinical study design, statistics and psychology, the Centre has adopted a holistic, patient-centred approach that has produced a large body of evidence for policy, guideline and practice changes to improve patient experience and quality of life. There are three interlinked research strands.</p> <p><u>Increasing patient choice.</u> Patients with advanced CKD experience a high burden of physical and psychosocial symptoms and costs of care are high. In many cases, an arduous course of dialysis does not improve these symptoms or quality of life outcomes, particularly for elderly and frail patients. Research at CHSCR has demonstrated the viability of a novel conservative management approach as an alternative to dialysis; this approach is based on careful symptom control, full medical treatment short of dialysis, and continuing multidisciplinary support in liaison with palliative care services when appropriate. Evaluation in a large retrospective cohort confirmed that for people with multimorbidity who are over 75, survival from entry into stage 5 CKD was similar in patients receiving conservative management or dialysis [3.1]. Further work found that patients treated conservatively tend to maintain quality of life as renal function</p>		

declines, whilst for those starting dialysis, life satisfaction deteriorates [3.2]. A qualitative study explored patients' reasons for choosing either conservative management or dialysis [3.3]. It found that patients at renal units with a more established conservative management pathway were more aware of the approach, less often believed that dialysis would guarantee longevity and more often had discussed their future with staff. Farrington was co-investigator on a randomised control trial (RCT), beginning in 2017, to establish the clinical and cost effectiveness of preparing for conservative care compared with dialysis in relation to quality and length of life in multi-morbid, frail, older people with failing kidneys [G1].

Individualising haemodialysis. In-centre haemodialysis (HD) is traditionally a 'one size fits all' treatment: four-hour sessions thrice weekly, whether the patient has just started treatment and retains considerable residual kidney function, or whether they are dialysis veterans with no kidney function. The prescribed treatment is the same irrespective of age, sex, comorbidity and physical activity levels. CHSCR research demonstrated four benefits of individualising treatment. 1) Residual kidney function potentially allows a safe reduction in the amount of dialysis received and an incremental approach helps preserve residual kidney function [3.4]. 2) The amount of dialysis required depends on sex, body size and physical activity. 3) Some patients, particularly those with minimal residual kidney function, may need more frequent dialysis to avoid the long gap at weekends, associated with increased mortality [3.5]. 4) Haemodiafiltration (HDF) may be associated with survival benefit compared with HD [3.6]. Farrington was co-investigator on an RCT, beginning in 2017, to compare the clinical and cost effectiveness of HDF vs HD [G2].

Improving patient experience. Research at CHSCR demonstrated a high prevalence of depression among patients undergoing demanding dialysis treatment; this has adverse outcomes, including poor survival [3.7]. Studies also highlighted difficulties in diagnosing depression in patients of South Asian origin, who are over-represented in the UK dialysis community. The three-year SELFMADE study [G3] used action research to demonstrate that a designated facilitator can help people to effectively self-manage their condition and enable staff to better facilitate a self-management approach. This body of work led to a collaboration with the UK Renal Registry, Kidney Care UK and NHS England in the Transforming Participation in Chronic Kidney Disease (TP-CKD) programme. It established the feasibility of routinely collecting Patient Activated Measures and Patient-Reported Outcome Measures from kidney patients to improve care [3.8].

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

These eight underpinning outputs are representative of a wider body of published research involving UH researchers on the management and treatment of advanced kidney disease.

3.1 Chandna SM, Da Silva-Gane M, Marshall C, Warwicker P, Greenwood RN, **Farrington K**. Survival of elderly patients with stage 5 CKD: comparison of conservative management and renal replacement therapy. *Nephrology Dialysis Transplantation*. 2011;26(5):1608-1614. <https://doi.org/10.1093/ndt/gfq630>

3.2 Da Silva-Gane M, **Wellsted D**, **Greenshields H**, Norton S, Chandna SM, **Farrington K**. Quality of life and survival in patients with advanced kidney failure managed conservatively or by dialysis. *Clinical Journal of the American Society of Nephrology*. 2012;7(12):2002-9. <https://doi.org/10.2215/CJN.01130112>

3.3 Tonkin-Crine S, Okamoto I, Leydon GM, Murtagh FE, **Farrington K**, Caskey F et al. Understanding by older patients of dialysis and conservative management for chronic kidney failure. *American Journal of Kidney Diseases*. 2015; 65(3):443-50. <https://doi.org/10.1053/j.ajkd.2014.08.011>

3.4 **Vilar E**, **Wellsted D**, Chandna SM, Greenwood RN, **Farrington K**. Residual renal function improves outcome in incremental haemodialysis despite reduced dialysis dose. *Nephrology, dialysis, transplantation*. 2009;24(8):2502-10. <https://doi.org/10.1093/ndt/gfp071>

3.5 Fotheringham J, Fogarty DG, El Nahas M, Campbell MJ, **Farrington K**. The mortality and hospitalization rates associated with the long interdialytic gap in thrice-weekly hemodialysis patients. *Kidney International*. 2015;88(3):569-75. <https://doi.org/10.1038/ki.2015.141>

3.6 Vilar E, Fry AC, **Wellsted D**, Tattersall JE, Greenwood RN, **Farrington K**. Long-term outcomes in online hemodiafiltration and high-flux hemodialysis: a comparative analysis. *Clinical Journal of the American Society of Nephrology*. 2009;4(12):1944-53

<https://doi.org/10.2215/CJN.05560809>

3.7 Chilcot J, **Guirguis A**, **Friedli K**, Almond M, Day C, Da Silva-Gane M, Davenport A, **Fineberg N**, Spencer B, **Wellsted D**, **Farrington K**. Depression Symptoms in Haemodialysis Patients Predict All-Cause Mortality but Not Kidney Transplantation: A Cause-Specific Outcome Analysis. *Annals of Behavioural Medicine*. 2018;52(1):1-8.

<https://doi.org/10.1007/s12160-017-9918-9>

3.8 Gair R, Stannard C, Van der Veer S, **Farrington K**, Fluck R. Transforming participation in Chronic Kidney Disease. Is it possible to embed Patient-reported Outcome Measures to make a difference to care and perception of care? *British Journal of Renal Medicine* 2019, 24 (1), 10-13.

Key grants

G1 NIHR Health Technology Assessment. The Prepare Multi-Morbid Older People for End-stage Kidney Disease Trial (PrepareME), 2017-2021, £2.8m (Farrington Co-applicant).

G2 NIHR Health Technology Assessment. The High-flux Haemodialysis vs High-dose Haemodiafiltration Registry Trial (H4RT) 2017-2020. £1.2M (Farrington Co-applicant).

G3 NIHR Research for Patient Benefit. Facilitation of Self-Management in a Haemodialysis Unit: An Evaluation (SELMMADE), 2011-2014, £235,000 (Farrington Chief Investigator).

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

Research at UH has developed new patient-centred strategies for the management of advanced CKD. It has changed clinical guidelines and practice, resulting in the greater availability of conservative management as an alternative to dialysis should patients choose it, and wider clinical uptake of alternative dialysis modalities including incremental haemodialysis and haemodiafiltration over standard haemodialysis. It has increased patients' involvement in the management of their own care, delivering improvements in patient experience.

Changing clinical practice to increase patient choice

CHSCR research has significantly increased the uptake of conservative management as an alternative to dialysis for older, frailer patients. This is evidenced by citations in new national and international clinical guidelines published during the impact period and peer-reviewed studies describing changes in clinical practice. Research in **3.1** and **3.2** informed a key recommendation in the UK Renal Association's practice guideline *Planning, Initiating and Withdrawal of Renal Replacement Therapy* (2014): '*We recommend that patients with advanced kidney disease (CKD Stage 4 & 5) who opt not to dialyse should undergo conservative kidney management [5.1].*' Kidney Disease: Improving Global Outcomes (KDIGO) is a charity that develops and implements evidence-based clinical practice guidelines. In 2015, it published *Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care*; Farrington was a member of the KDIGO consensus group. It cited **3.1** as evidence that '*the survival advantage of dialysis disappears in patients ≥ 75 years of age with high levels of comorbidity and/or poor functional status*'. It recommended: '*For patients unlikely to benefit, positive alternatives to dialysis, in the form of comprehensive conservative care, should be provided [5.2].*'

Based on his research in **3.1-3.3**, Farrington was asked by NHS Improving Quality to co-author (with one other author) *End of Life Care in Advanced Kidney Disease: A Framework for Implementation* (2015). The Framework focused on patients opting for conservative kidney management and those deteriorating despite dialysis. Its overarching aim is to enable people to make informed choices about their care needs and achieve high quality end of life care. A key section of the Framework reads: '*It should be emphasised that a 'no dialysis' option is not a 'no treatment' option: conservative management can relieve many symptoms, and maximise the person's health during the remainder of their life [5.3].*' A year later, in 2016, the official guideline body European Renal Best Practice published its *Clinical Practice Guideline on management of*

older patients with chronic kidney disease stage 3b or higher; Farrington was committee co-chair. Citing four papers authored by UH researchers, including 3.1 and 3.2, it stated that conservative management is a viable treatment option for some patient groups, which may not adversely affect survival or quality of life. It read: '*Choosing CM (conservative management) over dialysis might avoid unwanted outcomes such as hospital admissions and improve outcomes such as access to palliative care and receiving care in a preferred place [5.4].*' It concluded: '*We recommend that the option for CM be discussed during the shared decision-making process on different management options for ESKD (end-stage kidney disease) [5.4].*'

In October 2018, NICE published its guideline NG107: *Renal replacement therapy and conservative management*. Its aim was to improve quality of life by making recommendations on planning, starting and switching treatments, and coordinating care. The supporting evidence reviews cited five UH-authored papers [including 3.1 and 3.3] relating to offering certain patients the choice of conservative management [5.5]. One of the guideline's key recommendations read: '*Offer a choice of Renal Replacement Therapy or CM to people who are likely to need RRT [5.5].*' It also recommended an RCT of CM versus RRT in older people with a poor prognosis, which led directly to the PrepareME trial [G1] [5.5].

Taken as a whole, CHSCR research and the resulting new guidelines have increased the penetration of conservative management as a viable treatment for older frailer patients. This is evidenced by peer-reviewed papers, published during the impact period, demonstrating frequent use and wide acceptance of the role of conservative management in the UK [5.6a; cites 3.1-3.3], the Netherlands [5.6b; cites Farrington research], Canada and Australia [5.6c; cites 3.1-3.3].

Individualising haemodialysis treatment for better patient outcomes

The benefits of residual kidney function in HD patients [3.4] were highlighted in the *Renal Association Clinical Practice Guideline on Haemodialysis* (2019); Farrington and Vilar sat on the guideline committee. The guideline is for doctors and nurses in dialysis units and related areas in the UK. In line with UH research, it highlighted the advantages of incremental haemodialysis. It read: '*The practice of incremental HD is consistent with a concept of progressively increasing therapy (as residual renal function declines) over time, which may include augmented schedules at a later stage [5.7].*' Citing 3.4, it read: '*Preservation of residual function is of clinical importance since it provides significant solute and fluid removal, and is associated with improved quality of life and survival.*' And citing 3.7, it read: '*... patients with complex comorbidities can improve with more frequent therapy, more tailored to their needs [5.7].*' It also cited UH research to recommend that treatment should be adapted for '*women and smaller patients*' [5.7].

In line with UH research, NICE NG107 guidance [5.5] cited evidence suggesting that in-centre HDF was more effective than in-centre HD. It recommended that dialysis units should '*... consider HDF rather than HD for in-centre dialysis.*' Note was taken by the guideline committee of the on-going RCT of high-volume HDF versus high-flux HD [G2].

Implementing new methods and measures to improve patient experience

Having demonstrated the value of a designated facilitator for self-management of CKD, the SELFMADE study [G3] led to the creation of the new role of part-time peer support worker at East & North Hertfordshire NHS Trust. This study, combined with the research on depression that demonstrated the need for more effective self-management approaches [3.7], led to the appointment of Farrington as a programme board member for the joint UK Renal Registry/NHS England project *Transforming Participation in CKD* (TP-CKD). He co-chaired the Interventions group, which published the *Think Kidneys* 'Tools for Change' in September 2016. This practical toolkit enables patients and health professionals to work together to improve the knowledge, skills and confidence of patients with kidney disease (stage 3b or higher) [5.8].

The key output from this body of work was the development of the Patient Reported Experience Measure for Kidney Care (Kidney PREM), first published by the Renal Association and Kidney

Care UK in 2016 [5.9]. Through TP-CKD, Farrington played a key role in the initial development of the PREM and the wider CHSCR team led the validation and analysis of the instrument [5.9, 5.10]. Its publication led the chair of NHS England's renal services clinical reference group to call it 'a watershed moment with the formal recognition of patient experience as a quality marker in renal care' [5.9]. CHSCR leads the data analysis and production of the annual kidney PREM report. In 2019, 70 adult renal centres across the UK participated in the survey, with 16,469 patients from 297 units providing responses (up from 8,162 in 2016) [5.9]. According to the Renal Association and Kidney Care, Kidney PREM is seen as 'an official tool to reduce the variation in how kidney services are delivered across the NHS and promote the sharing of best practice to improve patient care' [5.9]. The data is used by local renal teams and patient groups to improve patient care across the country [5.9] and has been 'adopted as a key element of service review' by NHS England's improvement initiative *Getting It Right First Time* [5.9]. The Chief Executive of the Renal Association confirmed that research at UH had allowed the refinement and validation of the instrument [5.10]. He wrote: 'The tool is now used to provide insight into patient experience across the UK on annual basis with results used by national programmes to assess hospital performance [5.10].'

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

- 5.1** UK Renal Association Clinical Practice Guideline: Planning, Initiating and Withdrawal of Renal Replacement Therapy (January 2014). <https://renal.org/sites/renal.org/files/planning-initiation-final506a031181561659443ff000014d4d8.pdf> (page 27).
- 5.2** KDIGO guidance: Supportive Care in Chronic Kidney Disease (September 2015). [https://www.kidney-international.org/article/S2157-1716\(15\)32202-4/fulltext](https://www.kidney-international.org/article/S2157-1716(15)32202-4/fulltext) (citation 68)
- 5.3** NHS Improving Quality: End of Life Care in Advanced Kidney Disease: A Framework for Implementation (2015). <https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Advanced-kidney-disease.pdf> (page 7).
- 5.4** European Renal Best Practice: Clinical Practice Guideline on management of older patients with chronic kidney disease stage 3b or higher (November 2016). <https://doi.org/10.1093/ndt/gfw356> (citations 6, 163, 165, 187).
- 5.5** NICE guideline NG107: Renal replacement therapy and conservative management (October 2018). <https://www.nice.org.uk/guidance/ng107/resources/renal-replacement-therapy-and-conservative-management-pdf-66141542991301> (pages 18, 23). Nine UH authored papers cited in the supporting evidence reviews: <https://www.nice.org.uk/guidance/ng107/evidence/>
- 5.6 a)** A national study of practice patterns in UK renal units in the use of dialysis and conservative kidney management to treat people aged 75 years and over with chronic kidney failure, NIHR Journals Library (2015). <https://www.journalslibrary.nihr.ac.uk/hshr/hshr03120> (citations 11 and 13, and acknowledgements)
- b)** Conservative care as a treatment option for patients aged 75 years and older with CKD stage V: a National survey in the Netherlands, *European Geriatric Medicine* (2018). Doi: [10.1007/s41999-018-0031-9](https://doi.org/10.1007/s41999-018-0031-9) (citation 13)
- c)** Supportive Care: Comprehensive Conservative Care in End-Stage Kidney Disease, *CJASN* (2016). <https://doi.org/10.2215/CJN.04840516> (citations 19, 20, 38)
- 5.7** Renal Association Clinical Practice Guideline on Haemodialysis (2019). <https://doi.org/10.1186/s12882-019-1527-3> (citations 54, 61, 215, 223)
- 5.8** Think Kidneys Transforming Participation in Chronic Kidney Disease: Tools for Change. <https://www.thinkkidneys.nhs.uk/ckd/tools-for-change/>
- 5.9** Reports from Kidney Care UK and the Renal Association corroborating the impact of Kidney PREM and UH's involvement. <https://www.kidneycareuk.org/news-and-campaigns/news/2019-kidney-prem-results/> (impact of KPREM 2019); <https://www.thinkkidneys.nhs.uk/ckd/wp-content/uploads/sites/4/2018/04/PREM-report-final-2.pdf> (foreword by NHS England clinical reference group); <https://www.kidneycareuk.org/news-and-campaigns/news/2019-kidney-prem-results/> (adoption of KPREM by NHS Improvement's Getting It Right First Time initiative).
- 5.10** Corroborating statement on Kidney PREM from the Chief Executive, Renal Association.