



## **Supporting Information**

### **Supplementary material**

**This appendix was part of the submitted manuscript and has been peer reviewed.  
It is posted as supplied by the authors.**

Appendix to: Naidu P, Paolucci (Muran-Iwaidja) O, Luta (Kaurareg) R, Hughes (Wagadagam) JT.  
Optimisation during transition to dialysis commencement. *Med J Aust* 2024; doi: 10.5694/mja2.52347.

## **Supporting Information**

### **Appendix 1:**

Storying, deeply rooted in Indigenous cultures, serves as a powerful method of knowledge sharing and preservation, extending beyond traditional academia to disseminate knowledge in a humanising manner.<sup>1</sup> As stated by Blaze Kwaymullina referenced in Phillips et al:<sup>1</sup> “Stories spoken from the heart hold a transformational power, they are a way for one heart to speak to another. They are a means for sharing knowledge, experience and emotion. A story spoken from the heart can pierce you, become a part of you and change the way you see yourself and the world. Listening to a heart story is a way of showing respect, a silent acknowledgement of what the speaker has lived through and where they have come from. Sharing the past can ease old pains, soothe deep hurts and remind you of old joys, hopes and dreams.” This approach fosters understanding, empathy, and respect across cultural boundaries. By privileging storying, we acknowledge and magnify voices and ways of knowing that are often marginalised or overlooked with biomedical science reporting, where Indigenous peoples have been positioned as source of anthropologic enquiry by a scientist outside their culture, and arbitrarily, though not necessarily accurately from the perspective of studied person, considered as arbiter of truths or goodness.<sup>1</sup> Additionally, within Aboriginal and Torres Strait Islander cultures, storying is intentionally employed as an educational tool, and is useful here for healthcare providers and individuals navigating similar health journeys, demonstrating its value in fostering cross-cultural understanding and challenging dominant narratives.<sup>1</sup>

1. Phillips L, Bunda T. Research through, with and as storying. Oxon Routledge 2018.

## CONSIDER Statement

Guest Editors of the 2024 *Indigenous Health Special Issue* acknowledge the Indigenous expertise that informed the establishment of the CONSolidated critERtia for strengthening the reporting of health research involving Indigenous Peoples (CONSIDER) statement.

Authors should indicate how they have supported ethical publishing and reporting practices by providing the details of the research practices aligned with this publication in accordance with the CONSIDER statement. The reporting should not exceed two pages. This reporting will be published as online supplementary information. Detailed items can be accessed in the publication:

<https://bmcmmedresmethodol.biomedcentral.com/articles/10.1186/s12874-019-0815-8>

<b>Governance</b>
The case report was initiated following consent from Miss Luta, who is the owner of her health story, and she chose to be named as author, and its story form, over time would benefit families of the Torres Strait, if it could be accessible in journal form and interacted with as a learning resource to explain living with and making decisions about kidney disease. The audit and reporting of the clinical journey was approved the hospitals Human Research Ethics Committee, including the Aboriginal Ethics Subcommittee, and the hospitals Research Governance Office. Miss Luta and her family, including her two daughters, reviewed each stage of the manuscript with Hughes, the senior clinician involved in her care, and they provided approval, guidance, and edits that ensured its accuracy. This collaborative writing prioritised Miss Luta’s wellbeing and respected her leadership in managing the communication of her health journey.
<b>Prioritization</b>
The direction of the report was borne from Miss Luta’s health journey and lessons gleaned from her storying.
<b>Relationships (Indigenous stakeholders/participants and Research Team)</b>
Usual health care was received by Miss Luta, from Naidu (an advanced trainee in renal medicine), Hughes (nephrologist), and Paolucci (an Aboriginal and Torres Strait Islander Health Practitioner). Clinicians routinely undertake audit and reflection cycles, and invited Miss Luta to consent for Naidu and Hughes to follow her health journey within a written case report (as audit) until she commenced home haemodialysis training. The study

embodies the Torres Strait Islander ethical principle of collaboration for the advancement rather than loss of the Torres Strait community. It demonstrates a health journey marked by health optimisation, which has countered negative stereotypes, and emphasises the central role of patients and families as primary healers, supported by caregiving systems and reciprocal learning. We acknowledge our cultural reference point in this collaboration: Naidu (India), Hughes (Koike of Medicine of Wagadagam tribe of Torres Strait), Miss Luta (a Kaurareg nation elder), and Paolucci (Muran-Iwaidja).

### **Methodologies**

The case report adopts an Indigenous methodological approach in storying, and characteristic of Torres Strait Island culture, it has fostered mutual understanding, empathy, and respect across cultural boundaries. Storying has privileged Indigenous voices and ways of knowing, and mitigates potential for Othering, which may occur when story is told by those who exist outside the culture, and then reproduced in harming ways to ‘othered’ peoples in case-reporting histories. Storying allows the person autonomy to choose their preferred method of inclusion in the narrative, highlighting factors essential to their life and survival, such as cultural celebrations, employment, and recovery from illness. This approach aligns with the community's values, practices, and an understanding of power dynamics, acknowledging the broader political and social structures influencing Indigenous health.

### **Participation**

Miss Luta actively led the case report process, by providing her formal consent and confirmed the integrity of the written form as an identified co-author. It therefore speaks to the participation of all authors in collaborative care in health delivery and summarising the health journey in a way that others can relate to and learn from. The inclusion of her family at her request, in the telling of the summarised health journey, leveraged her professional skills as a teacher within her own family and demonstrates Torres Strait family-led caring. The collaborative effort of all authors facilitated reciprocal learning which aids understanding of roles of carer and cared-for, and to understand the impact of care outcomes.

### **Capacity**

The authors from the clinical team are members of a teaching hospital and undertake periodic learning and teaching. Naidu was invited to participate in a family group education event in 2021, to learn about collaborative learning and knowledge sharing, that was led by Paolucci. Reflection on the outcomes of health care was routinely prioritised within the Renal Home Therapies care program led by Paolucci and Hughes and which Naidu also contributed.

### **Analysis and interpretation**

The case report gave opportunity to summarise the care journey, signposting by health optimisation activity, and her own experience of care. That summation, revealed a health journey marked by safe deferral of symptomatic kidney failure with dialysis, and showed how intentional health optimisation was woven to ensure patient-important outcomes of self-dialysis, without permanent relocation and other social and cultural deprivation. Storying has presented the patient's health journey in her own voice, and was delivered from a strengths-based approach of research analysis, and is a form of teaching and opportunity for all listeners to learn.

### **Dissemination**

The published paper will be disseminated within the local renal service and shared with health workers and practitioners in the Australia and New Zealand Society of Nephrology, and its journal publication format will confirm patients as teachers to the health care industry. Copies will also be shared with the elders of Badu Island and nearby Torres Strait Islands to support their advocacy for a proposed dialysis unit. The model of care has presented demonstrated culturally safe clinical care was effectively delivered in very remote Australia. Such insights are particularly relevant for national priorities such as assisted haemodialysis in very remote areas, the National Indigenous Kidney Transplant Taskforce, and initiatives aimed at preventing CKD progression using novel renal-cardioprotective medicines. Culturally safe teams and practical models of care are essential for realising these objectives. Reporting case studies provides real-world data that can support the implementation of proposed care models, as demonstrated by the findings of this study.