Chronic Kidney Disease Pathway: Patient Journey Map

An illustrative current-state experience of the end-to-end CKD pathway, from the perspective of the three personas to bring it to life*

Patient personas

Euphemia

Euphemia was born in Bermuda but has lived in Baltimore for the past several years, where she worked as a cashier. She has Stage II CKD.

Wants, needs, behaviours:

- Sedentary job with little interest in activity and sport
- Very involved in her care, and frequently does her own research and asks questions
- Lives with her daughter and has a strong desire to stay on island for treatment
- Outspoken advocate about CKD in the community
- Uses mobility aids to get around, and also has diabetes

No Insurance

Tyrone

Tyrone is 70 years old and retired. He has Stage IV CKD, as well ad hypertension.

Wants, needs and behaviours:

- Lacks a strong support environment
- Concerns about affording treatment as a retiree
- Rarely leaves the house
- Is comfortable asking questions to his physician, and his medical background has given him decent understanding of his condition.

FutureCare

Orville

Orville is a 64-year-old former pastry chef. He has a history of kidney stones, diabetes, and hypertension, and has Stage V CKD.

Wants, needs and behaviours:

- Limited access to appointments as he relies on his son for transportation.
- Orville is uncomfortable asking questions to his physician and prefers to remain stoic.
- Friends and wife are eager to support him, but Orville is uncomfortable accepting help and feels like a burden
- Long-time pastry chef who is unhappy to make dietary changes.
- Loves to golf and travel, which he can no longer do due to mobility restrictions.
- Concerns about affording treatment as he only has access to basic health coverage.

Private Basic Health Coverage

CHALLENGES

The negative experiences where the system is not meeting expectations from the perspective of both citizens and staff

1 No strategies for Prevention and Early Detection

Prevention and early detection of CKD are hindered by the lack of CKD-prevention strategies in Bermuda, resulting in delayed diagnoses and missed opportunities for intervention.

2 Lacking Education and Awareness among patients and service providers

Even though patients indicate they are provided with enough information after they've been diagnosed, healthcare service providers feel public knowledge and awareness about CKD in Bermuda is low. This can hinder prevention and management of the disease.

3 Insufficient Coordination and Communication Between healthcare service providers in the pathway

Inadequate coordination and communication among healthcare providers, including primary care physicians, specialists, and support services, hamper seamless care delivery and optimal outcomes for patients with CKD in Bermuda.

4 Several factors hinder access to and affordability of CKD-related healthcare services

Financial, cultural, and informational barriers pose significant challenges to accessing CKD-related healthcare services. High costs associated with CKD-care, combined with cultural and informational factors, such as a reluctance to visit healthcare service, and inadequate education about CKD, form barriers too access CKD-related healthcare services for individuals with CKD.

5 No comprehensive policy around Organ Donation

Organ Donation and Transplants - The scarcity of organ donations and the absence of comprehensive transplant facilities in Bermuda present obstacles in providing timely and accessible organ transplantation services, limiting treatment options for individuals with end-stage renal disease.

OPPORTUNITIES

High-level identification of the core opportunity areas that would have the greatest impact on patient experience

- **1A** Establish registries for screening and data analysis
- **1B** Develop targeted prevention programs
- **1C** Promote achievable lifestyle modifications
- **2A** Strengthen patient education in individual and group settings
- **2B** Educate GP's on CKD-progression and introduce formal management and referral guidance
- **2C** Provide clear, repetitive messages when communicating to patients
- **3A** Improve information sharing among healthcare service providers
- **3B** Establish a non-profit support organisation for patients
- **3C** Facilitate individual emotional support for patients
- **3D** Promote and incentivise home dialysis modalities
- **4A** Address barriers to care access
- **4B** Identify strategies for enhanced financial sustainability
- **4C** Establish uniform and equal access to nephrology services
- **4D** Include CKD-care in Universal Health Coverage Core Benefits Package
- **5A** Promote organ donation through targeted campaigns
- **5B** Secure robust funding for organ donation and transplants
- **5C** Introduce standard and appropriate reimbursement or coverage for transplants

*All views captured in this document are those of stakeholders interviewed.

Chronic Kidney Disease (CKD) Pathway – Overall current state

Key – service owner

- Nephrologist
- Dialysis Centre
- Self-treatment by patient
- Off-island treatment / consultation
- Donor transplant coordinator
- General Practice
- Urgent Care Centre
- Other specialist

Key – service type

- Medical appointment
- Administration (scheduling and reports)
- Investigation and interpretation
- Patient education
- Patient contact
- Support services
- Lifestyle modifications

Key – arrows

- Treatment and ongoing service
- Route to service

xx — **Indicates points along the journey where decisions are made by patient (potentially with relevant healthcare service provider)**

*Treatment is patient specific and vary according to (combination of) condition. Usual check-ups may include the following (combination of) specialists:

- GP;
- Diabetologist;
- Nephrologist;
- Endocrinologist;
- Cardiologist;
- Rheumatologist; and,
- Community support services

**The treatment for Chronic Kidney Disease (CKD) follows a hierarchy that prioritizes different approaches based on the severity of the condition:

1. Disease Management: Lifestyle modifications and medication.
2. Transplant: Kidney replacement surgery.
3. Dialysis: Artificial blood filtering for kidney function support.