

Chronic Kidney Disease Integrated Care Pathway

March 2024

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Glossary of Terms

Chronic Kidney Disease (“CKD”)

A condition in which the kidneys are damaged and cannot filter blood as well as they should. Because of this, excess fluid and waste from blood remain in the body and may cause other health problems, such as heart disease and stroke.

Hypertension

High blood pressure, a common cause and consequence of CKD. It can further damage the kidneys and worsen kidney disease.

Haemodialysis

A procedure where blood is filtered using a dialysis machine to remove waste products and excess fluid from the body when the kidneys can no longer perform this function adequately.

Peritoneal Dialysis

A type of dialysis where a special fluid (dialysate) is introduced into the abdominal cavity to filter waste products and excess fluid across the peritoneal membrane.

Kidney Transplant

A surgical procedure to replace a diseased kidney with a healthy kidney from a living or deceased donor.

National Digital Health Strategy (“NDHS”)

A comprehensive plan to harness the power of digital technologies to strengthen Bermuda’s health system.

Integrated Care Pathway

An Integrated Care Pathway is a plan for delivering care that is comprehensive and integrated, meaning it covers patient care from the beginning to the end. An Integrated Care Pathway defines what happens, when it happens, and who is responsible at each stage. The objective is to improve patient experience, clinical outcomes, and operational performance. The CKD Pathway includes all care available to CKD patients. It includes services related to the prevention, presentation, diagnostics, diagnosis, treatment, and discharge or end of life.

Service Map

A visual representation that illustrates the various components and interactions of a medical service, highlighting the processes, stakeholders, and touchpoints involved. It helps to identify areas of improvement and optimise service delivery.

Journey Map

A visual representation that outlines the entire patient journey across different stages of a medical service. It provides insights into patient perspectives, needs, and pain points, enabling health providers to enhance patient satisfaction and outcomes.

Non-communicable disease (NCD)

A non-infectious, often long-term health condition caused by factors like lifestyle, genetics, and environment.

Referral Process

The systematic process of transferring a patient from one health provider to another, typically based on the need for specialised services or expertise.

PEARL (Patient Electronic & Administrative Records Log)

BHB-wide electronic medical record system.

Mid-Atlantic Wellness Institute (MWI)

Mid-Atlantic Wellness Institute (MWI) is the only psychiatric hospital in Bermuda.

King Edward VII Memorial Hospital (KEMH)

Bermuda’s hospital.

Health Insurance Committee (HIC)

Oversees the Health Insurance Fund and the FutureCare Fund.

Bermuda Health Council

Regulatory body that works to enhance and coordinate the delivery of health services.

Office of the Chief Medical Officer (OCMO)

The leading authority responsible for healthcare policies and practices, safeguarding public health, and improving health services on the Island.



Abstract

Results of CKD Care Pathway mapping efforts show that Bermuda should focus on prevention.

Objective: to map the journey of CKD patients in Bermuda and formulate future improvements

- This report presents the findings of a 12-week project conducted to **assess and map existing CKD-related health services** in Bermuda.
- The Report highlights **challenges** in the CKD Pathway.
- The Report also suggests **short term, medium-term, and long-term intervention opportunities for improvement.**

Approach: mapping the CKD Care Pathway using a multi-pronged approach

- This report is the result of contributions and engagement from more than **40 stakeholders**, including patients, health service providers, and insurers.
- Their perspectives and insights helped define the current state of CKD-related health services, identify the main challenges, and prioritise recommendations to enhance CKD-related health services in Bermuda.
- Through an extensive literature review, **more than 35 stakeholder interviews**, a survey, and two workshops, this report identifies **five challenges** and **17 opportunities for improvement** along the CKD Pathway.

The case for change: Bermuda should prioritise prevention to mitigate the burden of CKD

- CKD heavily burdens Bermuda, **impacting** patients with decreased quality of life, increased morbidity, and higher mortality.
- However, patients generally express **a high-level of satisfaction with the care they receive** in Bermuda.
- CKD treatment **strains Bermuda's finances**, but prevention could reduce costs, improve health, and benefit the health system.
- International research and the results of this pathway mapping project suggest that **investing in prevention, early detection, and education can significantly improve health outcomes for patients and reduce costs.**

“We are doing well delivering CKD care to patients that need it most. But the point is that we start delivering it too late. We really need to focus on preventing people from getting to the stage where they need us the most.”

- interviewed Kidney Care Professional



Methodology

The main objective of this project was to map the journey for CKD patients in Bermuda.

Between May and July 2023, a multidisciplinary team mapped the current care pathway for CKD patients in Bermuda. The objectives and key lines of enquiry are listed below.

Objectives

- a) **Map the CKD Integrated Care Pathway** by engaging stakeholders across the full continuum of care.
- b) **Propose improvements for a future state**, which include people-centred design options for the Pathway and reflect best-practice standards.
- c) **Identify any expected/projected efficiencies** to be achieved with the future state CKD Integrated Care Pathway.

Key Lines of Enquiry

- a) **Service provider** roles and responsibilities.
- b) **Service touchpoints**, processes, and handovers of care between service providers.
- c) **Patient** experiences and their care journey involvement.
- d) **Areas of overuse and/or duplication** or redundancy of services and inefficiencies in their provision.
- e) **Current State of CKD prevention**, promotion, and wellness activities.

Definition

In the context of this Care Pathway mapping effort, we understand CKD to be a condition in which the kidneys are damaged and cannot filter blood as well as they should. Because of this, excess fluid and waste from blood remain in the body and may cause other health problems. Broadly, CKD progresses along five stages. In the early stages, CKD is initially asymptomatic, making detection challenging. The five stages of CKD, which are briefly described in Table 1, are characterised by progressive kidney damage and declining filtration ability.

Stage I CKD	Stage II CKD	Stage III CKD	Stage IV CKD	Stage V CKD
<i>Kidney damage with normal kidney function</i>	<i>Kidney damage with mild loss of kidney function</i>	<i>Mild to severe loss of kidney function</i>	<i>Severe loss of kidney function</i>	<i>Kidney failure</i>
People in early-stage CKD may not know they have CKD as they often feel well and show no symptoms.		People are often diagnosed with kidney disease in the mid-stage, with many people still asymptomatic, as waste in the body builds and blood pressure rises.		Patients with kidney failure require dialysis or a kidney transplant to stay alive. Some may undergo palliative care instead.

Table 1: Overview of CKD stages and disease progression.

This effort was led by a multidisciplinary CKD Working Group.

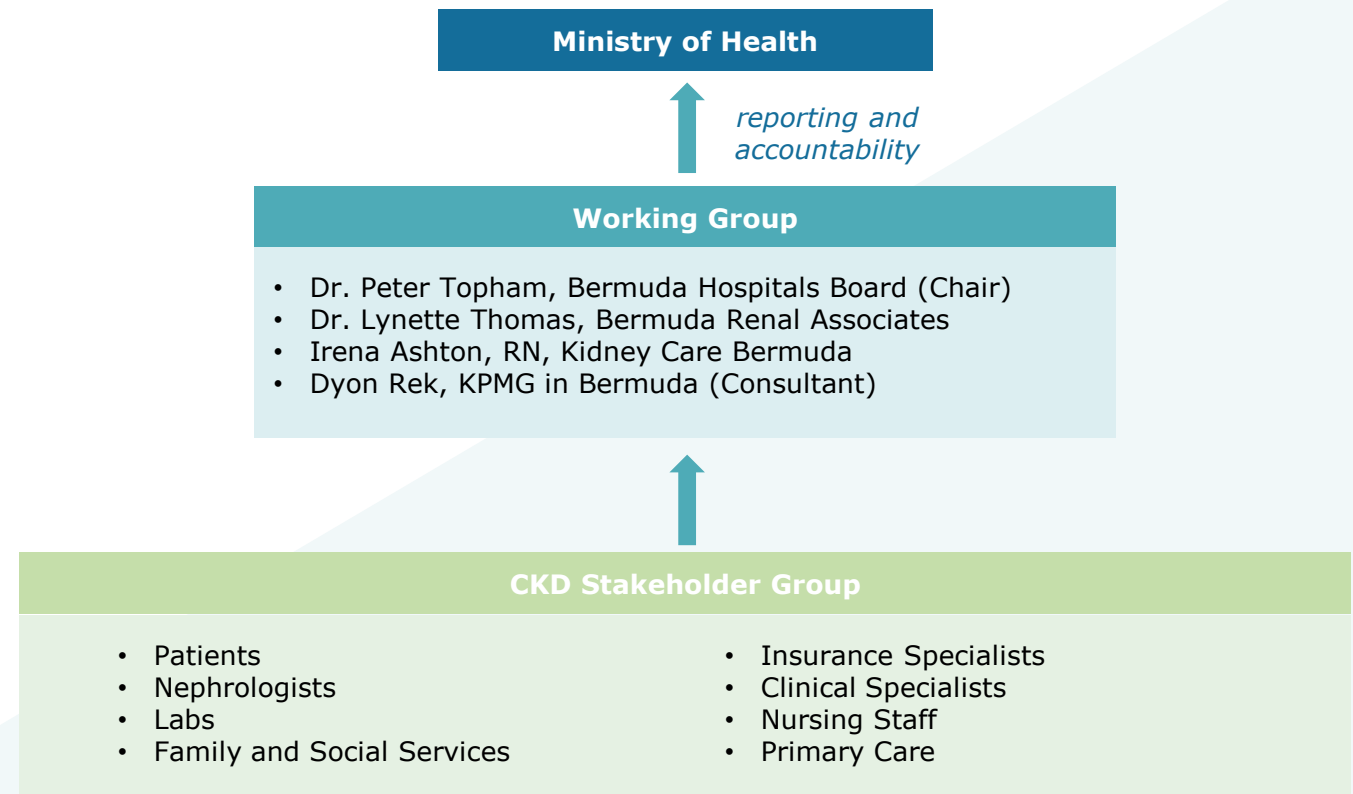


This Care Pathway mapping effort was led by the CKD Working Group (the Working Group). The multidisciplinary nature of the Working Group ensured that the Care Pathway mapping project incorporated diverse perspectives and accounted for the complexities of healthcare delivery.

The project governance structure comprised three levels:

1. The Working Group was responsible for gathering and analysing the materials, producing comprehensive reports, and recommendations.
2. The Stakeholder Group served as an essential source of information, providing valuable insights.
3. Representatives from the Ministry of Health provided guidance where needed.

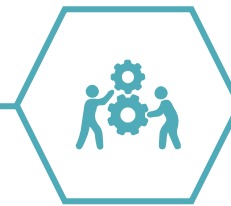
The Working Group would like to acknowledge the contributions and expertise provided by the wider CKD Stakeholder Group throughout the duration of this project.



Appendix 5 provides the detailed list of stakeholders (excluding patients and patient representatives for confidentiality reasons).

Previous work on CKD, both from Bermuda and abroad, formed the starting point of the mapping effort.

The Care Pathway mapping effort began with a thorough review of existing work in four categories:

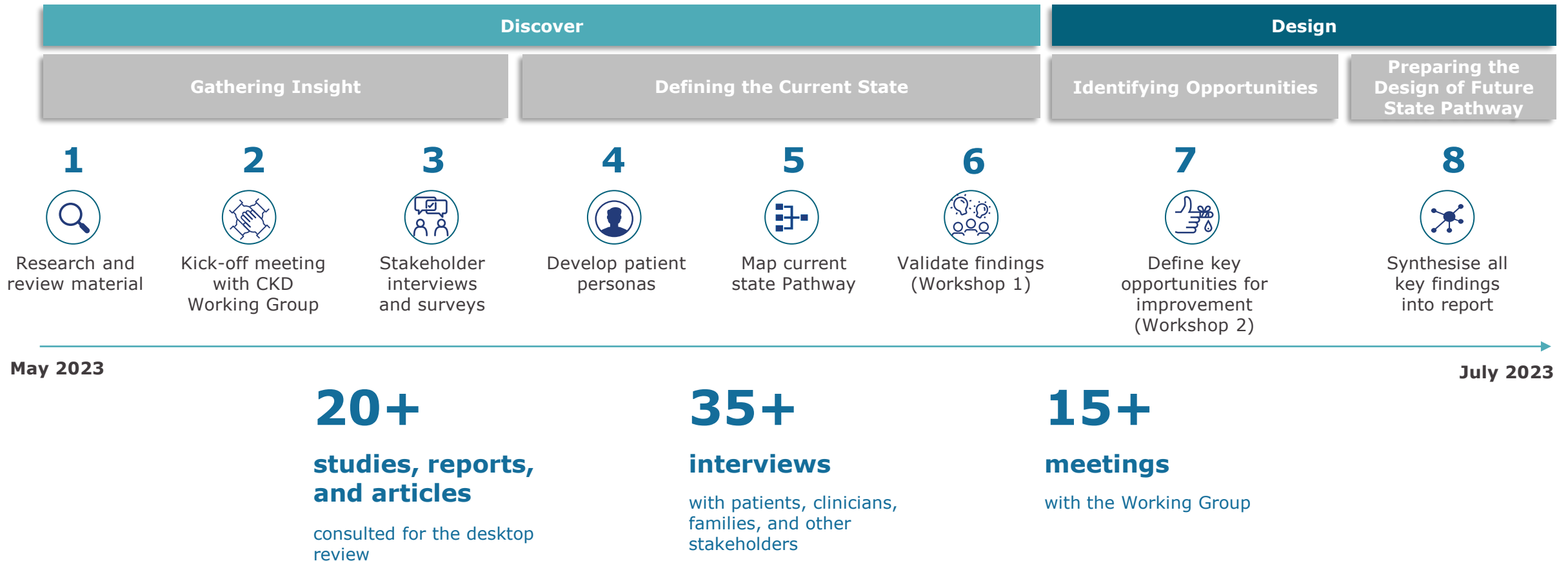


Scientific Literature	Clinical Guidelines and Best Practices	Initiatives and Organisations	Policies and Strategies
<ul style="list-style-type: none"> • Much of the literature attests to the added value of developing Integrated Care Pathways. • Literature emphasises the need for prevention and early detection. 	<ul style="list-style-type: none"> • Regular monitoring of patients can improve patient outcomes. • Patient education is crucial to the optimal delivery of CKD-related health services in Bermuda. 	<ul style="list-style-type: none"> • Other than treatment locations such as dialysis centres, there are no specific CKD-focused organisations in Bermuda at present. • Some initiatives focus on related conditions and causes of CKD, but do not have a specific focus on CKD. 	<ul style="list-style-type: none"> • Limited policy attention for CKD in Bermuda. • Bermuda Health Strategy (both 2014–2019 and 2022–2027) mention the prevalence and need to prevent CKD but no concrete measures are named.

Appendix 4 contains the summary of the literature studied.

Extensive stakeholder engagement and desktop review have led to a validated Care Pathway map for CKD in Bermuda.

The timeline below presents an overview of the mapping efforts conducted between May and July 2023, which were aimed at understanding and improving the CKD Pathway. This timeline highlights the key milestones and activities throughout the mapping process.





Current State

CKD forms a significant burden on Bermuda's health system.



Our kidneys act as a vital filtering system, balancing fluids and electrolytes and maintaining stable blood pressure. When they fail, waste accumulates, imbalances arise, and blood pressure becomes unstable, leading to serious health complications. Kidney disease, often silent and underdiagnosed, affects people of all ages and is recognised as a global concern: it is currently the tenth biggest killer worldwide and is projected to be the fifth highest cause of life years lost by 2040.¹ Bermuda faces an even more dire situation. Available data shows the disproportionate impact of CKD on Bermuda, stemming from two factors: 1) the high prevalence and 2) the high costs associated with the treatment of CKD.²

1. High prevalence of CKD

In addition to the significant cost difference, Bermuda also has a higher number of dialysis patients per 1000 individuals compared to the other countries in the region. The prevalence of CKD in Bermuda, as illustrated in Table 2, demonstrates its relative position in comparison to neighbouring countries.

2. High cost of CKD in Bermuda

Bermuda experiences a significant average annual cost per patient, with health service providers consulted during this project estimating expenses ranging from \$150,000 to \$200,000 per year per patient.

Country	CKD Prevalence, %
Virgin Islands (U.S.)	14.44
Bermuda	13.86
Barbados	13.63
United States	12.75
St. Vincent and the Grenadines	11.65
Trinidad and Tobago	11.46
St. Lucia	11.17
Antigua and Barbuda	10.79
Jamaica	10.67
Canada	10.25
Bahamas	9.93

Table 2: Prevalence of CKD by country

1. *Kidney Research UK, 2023: Kidney disease: A UK public health emergency. The health economics of kidney disease to 2033.*
 2. *The Global Kidney Health Atlas, International Society of Nephrology, 2020.*

CKD's high prevalence in Bermuda constitutes a major health crisis.

As mentioned, the prevalence of kidney disease in Bermuda is particularly high. According to data from the Bermuda Health Council that outlines how many health insurance claims were submitted in the 2022 fiscal year, 917 people were diagnosed with CKD.³ The data reflects claims with the primary diagnosis of CKD. The actual prevalence of CKD could be higher, however, with the potential of certain CKD patients not being included in these figures due to three reasons:

1. Patients without adequate insurance coverage may not be accounted for in these insurance claims statistics.
2. Patients who are not aware of their illness or who are not visiting a doctor when symptoms arise won't show in the insurance data.
3. If health providers did not include the appropriate ICD-10/9 codes (alphanumeric codes used in healthcare to classify and identify specific diagnoses, symptoms, and medical procedures) in their records, these patients will not show up in the statistics.

Other sources estimate that CKD affects a substantial portion (14%) of Bermuda's population. This percentage rises considerably to over 30% among individuals aged 65 and older. The presence of other underlying health problems further increases the risk of developing CKD.⁴ Furthermore, it is widely anticipated that CKD will continue to grow on a global scale. As a result, Bermuda may also experience an increase in CKD cases.⁵

The causes behind the growing prevalence in CKD cases in Bermuda are multifactorial. Uncontrolled diabetes, hypertension, obesity, and probable underlying genetic predispositions, coupled with a lack of awareness and preventive measures, contribute to the escalating prevalence of this disease. Additionally, lifestyle factors, such as poor diet choices and sedentary habits, further compound the risk of developing CKD.

Diagnosis	FY22	FY21	FY20	FY19	FY18
CKD, unspecified	212	214	348	329	318
CKD, Stage III	341	316	264	295	169
CKD, Stage IV	116	91	88	99	62
CKD, Stage V	38	35	32	38	18
End-stage renal disease	210	198	211	243	223

Disclaimers:

1. This data is provided is provided by the Bermuda Health Council and contains claims data submitted by insurers for local and overseas claims related to CKD in Bermuda (Note: this excludes local hospital and subsidy claims but includes overseas hospitals.).
2. Fiscal year (FY) is 1 April to 31 March.
3. Data included from Argus, BF&M, CG, GEHI, HIP and FTC.

Table 3: Distribution of CKD claims per stage based on available claims data.

3. The Health Council, *Data Analytics on CKD Services*. Received 30 June 2023 in reply to specified data request.
4. Vos, T. & Bikbov, B. (2020). *Global, regional, and national burden of chronic kidney disease, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017*. *GBD Chronic Kidney Disease Collaboration*, DOI: 10.1016/S0140-6736(20)30045-3.
5. Couser, W., Remuzzi, G., Mendis, S., & Tonelli, M. (2011). *The contribution of chronic kidney disease to the global burden of major non-communicable diseases*. *Kidney International*, 80 (12), 1258-1270.

The current CKD care model puts a considerable financial strain on Bermuda.

Recent data suggests that the current model of CKD care in Bermuda is financially unsustainable due to the combination of the high prevalence and high treatment costs. Table 4 provides an overview of the total insurance claims and paid services in Bermuda for 2021. It highlights that CKD ranks amongst the highest medical expenses on the Island.⁶

2021 Rank	Diagnosis	Total Insurance Claims	Total Paid for Claimed Services
1	Cancer	33,520	\$12,137,916
2	CKD	16,673	\$5,158,560
3	Diabetes	43,930	\$3,517,749
4	Heart Disease	7,165	\$3,393,479
5	Low Back Pain	17,159	\$1,722,873

Table 4: Top five diagnoses in Bermuda by total paid for claimed services

Bermuda Health Council does not make any guarantees or provide third-party validation for the data source. It is recognised that whilst being the nearest proxy to system-wide data, it excludes claims rejected by insurers and out-of-pocket payments. This excludes utilisation data from those without health insurance and contains a bias towards those services covered in insurance schedules of benefit. One patient may generate several claims. There is also anecdotal evidence from discussions with clinicians that there is considerable variation in coding for insurance claims. This is due to the system being primarily designed to facilitate payments rather than as a tool for disease surveillance.

6. Bermuda Hospitals Board, *Dialysis Service Review, February 2021.*

7. Bermuda Health Council. (2021). *Total insurance claims paid for leading causes of disease 2021.*

8. *Kidney Research UK, 2023: Kidney disease: A UK public health emergency. The health economics of kidney disease to 2033.*

Multiple factors contribute to the high costs of the provision of CKD-related health services in the present situation:

High cost of dialysis treatments

The expenses associated with dialysis equipment, maintenance, staffing, and supplies contribute to the overall financial burden.

Reliance on high-cost medication

Bermuda heavily depends on a multitude of expensive drugs, many of which lack a procurement contract and could potentially be substituted with more affordable alternatives available in the market.⁷

Limited availability of medical goods in the region

Costs for treating CKD are driven up further in the region due to the limited availability of medical supplies.

The economic burden of managing CKD is heightened further by the lost productivity of patients, particularly from the mid-stage of the disease onwards.⁸ As CKD progresses, patients experience a decline in health and physical functioning, limiting their ability to work and contribute to the workforce.

Also, the lack of preventative care often results in delayed diagnosis and intervention for CKD. This leads to its progression, which necessitates more costly treatment such as dialysis, kidney transplantation, or other intensive medical interventions, driving up the overall healthcare expenses for CKD management.

Patients experience barriers to accessing CKD care.

Based on interviews and workshops conducted as part of this Care Pathway mapping project, three primary barriers to care for CKD have been identified:

Financial Barriers



One of the significant barriers to accessing CKD health services is financial constraints. CKD requires ongoing medical care, including regular consultations, diagnostic tests, and medications. These treatments can be costly, especially for individuals without adequate health insurance or limited financial resources. The expenses associated with CKD management may deter individuals from seeking appropriate health services, leading to delayed or inadequate treatment.

Cultural Barriers



Cultural factors can also act as barriers to accessing CKD healthcare services. Some segments in the community may have cultural beliefs or practices that discourage seeking medical help or delay healthcare-seeking behaviour until the condition worsens. For example, in certain cultures, there may be a tendency to rely on home remedies, traditional healers, or spiritual practices rather than seeking professional medical assistance.

Informational Barriers



Lack of awareness and education about CKD can pose a significant barrier to accessing health services. Many individuals may be unaware of the early signs and symptoms of CKD or the importance of preventive measures. This lack of knowledge can lead to delayed diagnosis and intervention, resulting in the progression of the disease. Moreover, inadequate health literacy can prevent individuals from understanding the available healthcare resources, treatment options, and self-management strategies necessary for effective CKD management.

Patients generally express a high level of satisfaction with the care they receive in Bermuda.

Results of the survey, interviews, and workshops show that CKD patients in Bermuda are generally quite positive about the provision of their health services for the following reasons:



1. Patients feel they receive enough education and information

According to patients, CKD providers spend a lot of time and attention on patient education, empowering them to engage and make informed decisions. Patients value this.



2. Patients value the compassionate and caring attitude of health service providers

CKD healthcare staff demonstrate empathy, understanding, and provide emotional support, establishing a strong rapport with patients.



3. Patients value that health service providers go the extra mile

Patients value healthcare staff who go the extra mile to ensure their well-being and satisfaction.

The elements patients appreciate in their care are explained in more detail on the following pages.

One reason patients appreciate the care provided is because they feel well-informed about their condition and treatment.

1. Patients feel they receive enough education and information.

2. Patients value the compassionate and caring attitude of health providers.

3. Patients value that health service providers go the extra mile.

1

Patients feel they receive enough education and information

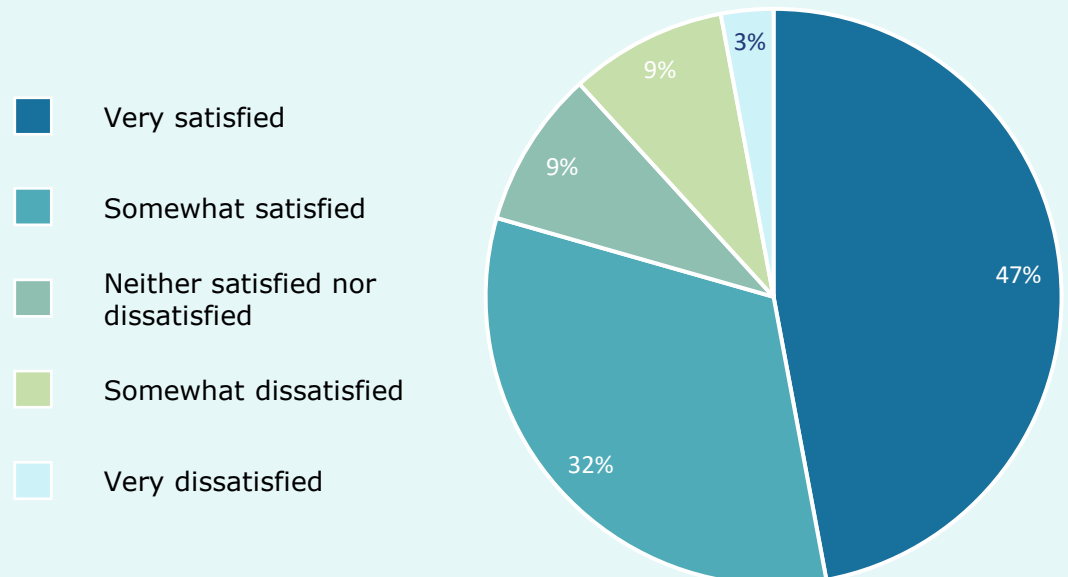
CKD health service providers indicated in interviews that they prioritise patient education and empowerment, offering information about the condition, treatment modalities, self-management techniques, and lifestyle modifications. This approach enables patients to actively engage in their care, make informed decisions, and take proactive measures to maintain their health. Importantly, this approach seems to be working: several patients in the interviews and a large portion of the survey respondents indicate they value the education and information they receive about their care. This indicates that patients appreciate being equipped with the knowledge necessary to understand their condition.

It is important to note that this only accounts for patients that have received a diagnosis. Those who are undiagnosed are still expected to be quite unaware of CKD, its risks, and its consequences.

"The dialysis training sessions were very helpful and informative. Care was taken to ensure that I learnt everything very well. I love the wrap-around services offered by my Nephrologist office."

- Interviewed Patient

Survey question: How satisfied are you with the information you currently receive about your care?



79% of respondents are **satisfied** with the information they received about their care.

N = 35

Patients value health service providers' compassionate and caring attitude.

1. Patients feel they receive enough education and information.

2. Patients value the compassionate and caring attitude of health providers.

3. Patients value that health service providers go the extra mile.

2

Patients value the compassionate and caring attitude of health service providers

Healthcare staff who work with CKD patients demonstrate a compassionate and caring attitude. They understand the challenges and emotional impact that CKD can have on patients' lives. By showing empathy, providing emotional support, and demonstrating genuine care, staff members establish a strong rapport with patients and make them feel valued and well-cared for.

"The amazing nurses at the dialysis unit kept my spirits up."
- Interviewed Patient

"The dialysis folks are amazing."
- Interviewed Patient

"My Doctor is very informative in relation to my after-transplant care and medications, and ensuring I have no complications."
- Interviewed Patient

Patients appreciate their health service providers' willingness to go above and beyond.



1. Patients feel they receive enough education and information.

2. Patients value the compassionate and caring attitude of health providers.

3. Patients value that health service providers go the extra mile.

3

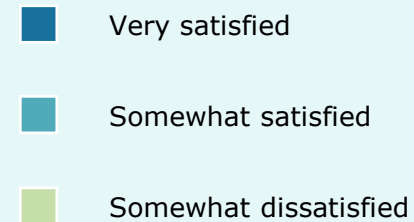
Patients value that health service providers go the extra mile

Patients appreciate when healthcare staff go above and beyond their regular responsibilities to ensure their well-being. This includes arranging additional appointments, helping with paperwork and insurance, coordinating with other professionals, or providing additional resources and information. Such kindness and willingness to go the extra mile leave a lasting positive impression on patients.

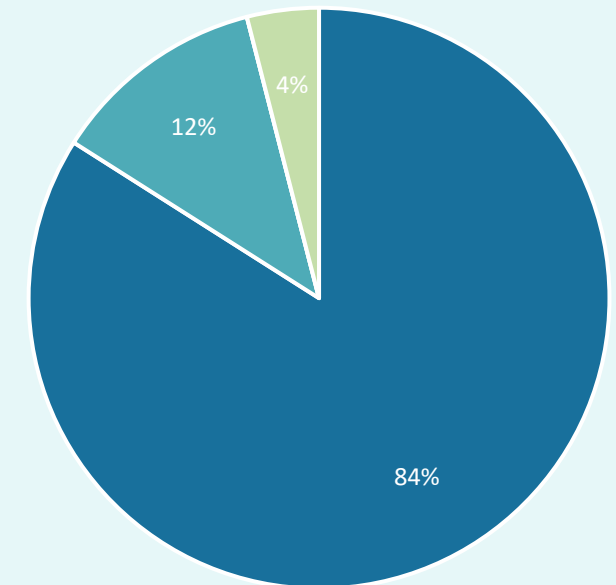
"The nurses and the doctors make me feel they really care about me. They always go beyond and above the call of duty."
- Interviewed Patient

"I just really want to thank everyone that is involved in my care from the bottom of my heart. You are so accommodating and always step up to the job. Thank you."
- Interviewed Patient

Survey question: How satisfied were you with the care that you received from your healthcare provider(s) during your most recent healthcare experience?



96% of respondents are **satisfied** with the care they received.



N = 35

Based on the Current State Assessment, this project helped inform a CKD Service Map and a Journey Map.

A Service Map depicts the ecosystem of healthcare services and relationships between different health service providers.

Based on stakeholder feedback, the desktop review, and the clinical experience of the Working Group, a comprehensive CKD Service Map has been developed. It depicts the ecosystem of healthcare services and encompasses various stages in the patient journey:

Prevention: Promoting healthy lifestyles and implementing interventions to prevent CKD development or progression.

Presentation: Recognising symptoms that indicate potential kidney health issues, leading individuals to seek medical attention or further evaluation.

Diagnostics: Conducting various tests and assessments to evaluate kidney function and identify the underlying cause of symptoms.

Diagnosis and Discussion of Treatment Options: Providing a diagnosis of CKD, discussing its implications, and appropriate treatment plans.

Treatment and Ongoing Care: Administering recommended interventions in accordance with the CKD stage, tailored to patient needs.

Discharge/End of Life: Addressing end-stage renal disease or advanced CKD through dialysis, kidney transplantation, and/or palliative care.

A Journey Map is a visual representation that outlines the various stages and touchpoints in a patient's experience.

Building from the insights gained from the Service Map, we developed a comprehensive healthcare Journey Map. A healthcare journey map is a visual representation or diagram that outlines the various stages and touchpoints in a patient's healthcare experience. The CKD Journey Map highlights:

Journey Phase and Touchpoints: Key interactions or points of contact throughout the patient journey.

The Emotional Journey: An illustrative line to track the movements in the patient's emotional journey across the touchpoints.

Personas: A character that represents the typical patient, helping us understand and design for their needs.

Challenges: Points at which interactions with health service providers or other stakeholders are not optimal in ensuring the highest quality care.

Opportunity for Improvement: Points at which improvements can be made to enhance patient health outcomes and efficiency.

Appendices 1 and 2 contain the complete Service Maps and Journey Maps.



Care Pathway Challenges

Five challenges for the provision of CKD-related healthcare services were identified by stakeholders.

This project has identified several significant challenges in the provision of CKD-related health services in Bermuda. They are listed below and explained in more detail on the following pages.

- 1 No strategies for prevention and early detection**
Prevention and early detection of CKD are hindered by the lack of CKD prevention strategies and a structured screening programme in Bermuda. This results 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, health service providers feel public knowledge and awareness about CKD in Bermuda is low. This can hinder prevention, identification, and management of the disease.
- 3 Insufficient coordination and communication between health service providers in the Care Pathway**
Inadequate coordination and communication among health 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 to access CKD-related healthcare services for individuals with CKD.
- 5 No comprehensive policy around organ donation**
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.

Insufficient prevention and education worsen CKD health outcomes for patients.

1 | No strategies for prevention and early detection

One of the key challenges is the lack of CKD prevention strategies in Bermuda. The absence of targeted efforts to prevent CKD and the lack of a national register lead to delayed diagnoses and missed opportunities for early intervention. Without proactive screening programmes and awareness campaigns, individuals at risk may not be identified in a timely manner, leading to delayed treatment initiation and progression of the disease.

*"I wished that my medical doctor would have identified and referred me to the Nephrologist much sooner, rather than wait until I reached Stage V. I believe that preventive intervention could have taken place much sooner. This was upsetting to me."
- Survey respondent*

2 | Lacking education and awareness among patients and service providers

Despite patients feeling adequately informed after receiving a diagnosis, health service providers in Bermuda believe that there is a low level of public knowledge and awareness about CKD. This lack of understanding poses a significant obstacle to preventing, identifying, and effectively managing the disease.

Insufficient public knowledge and awareness about CKD present a considerable challenge. Without proper understanding of CKD, individuals may fail to recognise early warning signs or grasp the importance of managing risk factors like diabetes and hypertension. This lack of awareness hampers proactive measures and self-management among individuals at risk, thereby impeding the prevention and management of the disease.

Furthermore, certain stakeholders express concerns regarding the limited understanding of signs and risks associated with CKD among general practitioners (GPs). This lack of awareness among GPs can lead to hesitancy in referring patients to specialists, consequently exacerbating health outcomes for individuals with CKD.

*"I really wish I was informed more when my GP first mentioned CKD."
- Survey respondent*

Insufficient coordination and communication among health service providers leads to inefficiencies in the Care Pathway.

3 | Insufficient coordination and communication between health service providers in the Care Pathway

Inadequate coordination and communication among healthcare providers poses challenges to delivering seamless care for CKD patients. The fragmented care delivery system often leads to disjointed treatment plans and a lack of efficient exchange of crucial patient information. This challenge is particularly evident between primary care physicians, specialists, and support services. The absence of robust coordination mechanisms and interoperability of electronic health record systems further complicates communication and collaboration among healthcare providers.

*"We never received a diagnosis as to the cause of kidney disease."
- Survey respondent*

*"I would have liked to receive more information about kidney disease and how it may affect other systems."
- Survey respondent*

*"I wish I got more acknowledgement on things that went wrong in my treatment."
- Survey respondent*

Several barriers to access and a lack of comprehensive donor policy can hinder adequate CKD treatment.

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

Financial, cultural, and informational barriers present significant challenges to accessing CKD care in Bermuda. High costs associated with CKD care and limited insurance coverage create affordability barriers that impede access to essential treatments. Cultural factors, such as a reluctance to seek medical help and reliance on alternative remedies, delay healthcare-seeking behaviour. Additionally, a lack of awareness and education about CKD hinders early diagnosis and intervention. Limited health literacy further prevents individuals from understanding available healthcare resources and self-management strategies.

"I have been denied by all major medical companies. I take care of my health and my condition is due to a genetic anomaly out of my hands and I still am unable to get insurance."
- Survey respondent

5 | No comprehensive policy around organ donation

The scarcity of organ donations and the absence of comprehensive transplant facilities pose obstacles in providing timely and accessible organ transplantation services for individuals with end-stage renal disease. There are a lot of ongoing initiatives, but they are currently not tied together in a comprehensive way. Therefore, there is still a limited availability of suitable organs, which hampers the treatment options available to patients in need of a transplant.

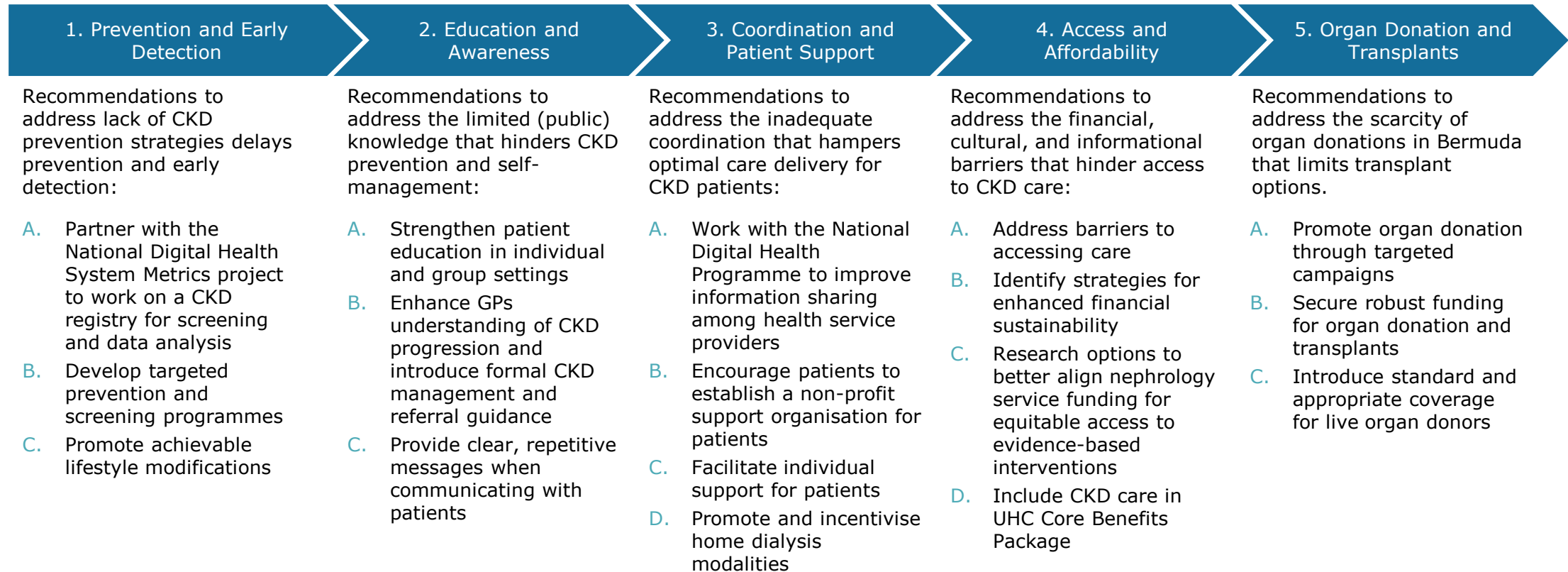
Moreover, the absence of comprehensive transplant facilities in Bermuda requires patients to travel abroad for transplant procedures, creating logistical challenges and potential delays in accessing necessary care. Enhancing organ donation awareness, promoting organ donor registration, and exploring partnerships with international transplant centres are potential avenues to address this challenge.

"A lot is going on around donor transplants in Bermuda, we just need to tie it all together."
- Stakeholder respondent



Care Pathway Opportunities

A synthesis of findings suggests 17 opportunities for improvement to address the five key challenges.



Collation of the results from the Pathway mapping effort has resulted in 17 opportunities for improvement in five areas. These opportunities for improvement are explained on the following pages. Where applicable, solutions are plotted for the following timeframes:

Short term



0-6 months

Medium term



6 months – 1 year

Long term



1 year – 2+ years

Each recommendation contains a suggested stakeholder to spearhead the efforts in the box called '*proposed initiator*'.

Realising registries for screening and data analysis can help identify at risk population and monitor patients.

1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

A Partner with the National Digital Health System Metrics project to work on a CKD registry for screening and data analysis

The lack of targeted efforts to prevent CKD results in delayed diagnoses and missed opportunities for early intervention. To effectively address these issues, it is important to establish a registry that can screen the patient population for CKD markers and continuously monitor their progression. The national registry should be accessible for any health provider with CKD health information to contribute to the registry, clinicians looking for CKD-related information to inform clinical decision making for their patients, and any healthcare stakeholder looking to analyse and understand national CKD outcomes. Such a registry will be most effective if it focuses on non-communicable diseases (“NCDs”) as a whole. National screening programmes that target NCDs such as hypertension and diabetes tend to be more efficient in managing CKD, because these registries encompass related conditions like hypertension and diabetes. This allows for integrated data and the provision of comprehensive care and improved patient monitoring.

Given these needs, there is an opportunity to partner with the National Health System Metrics project, part of the UHC Programme, to seek support in developing a registry. Once a registry is well established, it can be connected to the national digital health platform which is being developed by the National Digital Health Program. The purpose of the platform is for providers across Bermuda’s health system to connect digital health data sources to a central platform to allow providers and patients across Bermuda to have access to national health system trends.

Other Considerations

Innovations in the field of patient screening may prove useful in realising more screening and data analysis of the population – especially those at risk.

One such innovation is the Carna Health Bermuda initiative, which aims to transform the management of CKD in Bermuda. The project focuses on early disease identification and empowering individuals through the Carna blood testing device that is connected with an online platform for data analysis and identification of those at risk. Carna Health has been awarded a Bermuda Health Council Innovation Programme grant to implement their solution in Bermuda using a phased approach that will commence late 2023.

► Proposed Initiator: Ministry of Health

Bermuda can improve its offering of CKD-related health services through a prevention and screening programme.

1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

B Develop targeted prevention and screening programmes

Despite the increasing prevalence of CKD in Bermuda, there is a lack of targeted sustainable prevention programmes to address the risk factors associated with the disease. There is evidence suggesting that focusing on CKD prevention and early identification significantly improves health outcomes for patients, as well as costs:

- A UK study supported the importance of targeted interventions for CKD management. It assessed four interventions: early/improved diagnosis, improved CKD management, use of SGLT-2 inhibitors, and increased transplantation rates. These interventions were projected to prevent 10,000 deaths, save 49,574 quality-adjusted life years, and cost £7,688 per quality-adjusted life year. The reduction in indirect costs outweighed the increase in NHS expenses, resulting in cost savings.⁹
- A February 2023 report on the economic benefits of early detection and treatment in Australia estimated that early detection and management of CKD would result in a net benefit of \$10.2 billion over 20 years, or \$25,457 per person detected. Implementing screening for early detection would cost \$227.8 million, which amounts to about 2.2 percent of the net benefits realised.¹⁰

For Bermuda to realise these benefits, it is crucial to develop targeted prevention and screening programmes that address the specific risk factors contributing to CKD. These programmes should focus on promoting healthy lifestyles, early detection and management of chronic conditions, and community engagement.

Proposed steps for the implementation of this improvement:

- In the short term, the Health Department & OCMO should take proactive measures to identify individuals at risk of CKD by instituting a screening programme. Given the well-established association between CKD and hypertension, it is prudent to integrate these efforts with existing hypertension screening initiatives such as the HEARTS in the Americas initiative. These actions should harmonise closely with the outlined objectives of establishing a CKD registry, as detailed in Recommendation 1A.
- In the medium term, a targeted prevention programme should be developed and implemented. These initiatives should encompass a public awareness campaign aligned with previous efforts (i.e., the *Well Bermuda Campaign* that aimed at increasing CKD awareness, screening, and monitoring the population). This approach will be most effective when anchored in primary care. Primary care should play a pivotal role in the prevention programme by advocating the prevention programme, actively counselling patients on CKD and providing timely access to appropriate CKD disease management medications. In this context, it is also recommended to consider providing CKD disease management medications free of charge, similar to the successful pilot programme that offered free blood pressure medication to Bermuda citizens.
- In the long term, ongoing evaluation and monitoring of the prevention programmes should be conducted to assess their effectiveness and identify areas for improvement. This may involve collecting and analysing data on programme outcomes, refining strategies based on lessons learned, and ensuring sustained funding and support for the initiatives.

► Proposed initiator: Health Department & Office of the Chief Medical Officer (“OCMO”)

9. *Kidney disease: A UK public health emergency. The health economics of kidney disease to 2033, Kidney Research UK, 2023*

10. *Kidney Health Australia, Changing the chronic kidney disease landscape: The economic benefits of early detection and treatment. February 2023*

Promoting achievable lifestyle modifications is key in the moderation of CKD progression.

1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

C Promote achievable lifestyle modifications

The existing health system in Bermuda does not place enough emphasis on encouraging practical lifestyle changes for individuals who have, or are at risk of developing, CKD. To address this problem, it is essential to promote achievable lifestyle modifications in Bermuda that are tailored to the local context and individual needs. This should also take other conditions into account, such as diabetes, hypertension, and periodontal disease.

To enhance effectiveness, this strategy should be integrated into primary care, as these health service providers can actively promote the prevention programme, offer counselling on CKD and ensuring timely access to suitable disease management medications. Proposed steps for the implementation of this improvement include:

- In the short term, the Health Department & OCMO should prioritise the acquisition of culturally sensitive educational materials, such as pamphlets and booklets sourced from other jurisdictions with comparable public health challenges, addressing practical lifestyle modifications for individuals with CKD. These materials should focus on both raising awareness about CKD risk factors, as well as upskilling individuals with life skills to be able to lead a healthier life. Additionally, a portion of these materials should be dedicated to educating primary care providers about the concept of Green Prescriptions or written recommendations to encourage physical activity and dietary improvements, ensuring comprehensive support for individuals in their journey toward better health.
- In the medium term, these resources should be disseminated at various healthcare facilities, including GP offices, BHB, and other clinics.

- In the long term, the Health Department & OCMO should prioritise sustaining and expanding these programs. This entails recognising and mitigating the commercial determinants of health in Bermuda. It is therefore crucial to explore incentives and partnerships with local businesses. This could involve recognising and rewarding businesses that actively support and promote healthy lifestyles among their employees and customers, thereby creating a positive synergy between public health goals and local business interests. Regular evaluations should continue to assess the impact of these efforts on CKD management and patient outcomes, with necessary adjustments made based on the outcomes of these assessments.

Other Considerations

*The Health Department's **Health Promotion Unit** has been actively engaged in a range of efforts aimed at fostering a healthier Bermuda. Initiatives such as the **Grow Eat Save** programme have been educating the public on cultivating nutritious foods, promoting healthier dietary and more affordable dietary choices. **Move More Bermuda** and the **Commit to Change** programmes have been working to encourage physical activity and lifestyle modifications. The **Take it to the Streets** screening programme, which addresses critical health indicators like hypertension, blood glucose, height, and weight, represents a crucial step toward early detection and intervention. However, limited staffing poses a challenge to sustaining and expanding these essential programmes.*

► Proposed initiator: Health Department & OCMO

Improvements to patient education can be made by organising education in individual and group settings.

1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

A Strengthen patient education in individual and group settings

The current provision of CKD-related health services in Bermuda faces challenges in effectively educating patients. Limited patient education can lead to low awareness and understanding of CKD and its risk factors. This lack of knowledge can hinder patients' ability to actively participate in their care, make informed decisions, and adhere to recommended treatment plans.

To address this, it is crucial to improve education for CKD patients and at risk groups, including those suffering from Hypertension, Diabetes or Periodontal Disease. This can be achieved by implementing comprehensive patient education programmes and organising education in group settings.

Proposed steps for the implementation of this improvement:

- In the short term, the Ministry of Health should develop and disseminate clear and culturally appropriate educational materials about CKD, its risk factors, and self-management strategies. These materials should be easily accessible to patients in different formats and languages.
- In the medium term, the Ministry of Health can collaborate with community organisations, patient advocacy groups, or social workers to establish structured group education programmes. In these group sessions, healthcare professionals can provide information on CKD-prevention, self-care strategies, medication adherence, and dietary modifications. Patients can also engage in discussions, ask questions, and share their personal experiences.

- In the long term, continuous evaluation and improvement of patient education programmes should be conducted based on patient feedback and outcomes data.

► **Proposed initiator: Ministry of Health**

Added value can be realised by enhancing GPs understanding of CKD and introducing formal CKD management guidelines.



1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

B Enhance GPs understanding of CKD progression and introduce formal CKD management and referral guidance

Currently, there is a need to enhance GPs' understanding of CKD progression and mobilise them to refer patients for specialist input at the correct time, given they are the primary point of contact for many patients and have a crucial role in early. Enhanced awareness and knowledge among GPs regarding CKD progression can lead to quicker referrals to specialists and more optimal management of the condition.

It is therefore essential to provide enhanced and comprehensive education to GPs on CKD progression and risk factors, as well as equipping them with formal management and referral guidance. Existing guidelines such as HEARTS (a package for cardiovascular disease management) are a good example.

Proposed steps for the implementation of this improvement are as follows:

- In the short term, the Ministry of Health should develop and deliver educational programmes for GPs that focus on CKD awareness and early detection. This should be based on available and internationally recognised referral guidelines. Workshops, seminars, and online resources can be utilised to enhance GP knowledge and skills in managing CKD patients.
- In the medium term, partnerships can be established between primary care networks and specialist clinics to facilitate timely referrals and promote collaboration. This can involve implementing referral Pathways, and establishing regular meetings or case conferences.

- In the long term, regular updates and refreshers on CKD management should be provided to GPs to ensure ongoing knowledge. Feedback mechanisms should be implemented to assess the effectiveness of GP education programmes and identify areas for improvement.

Other considerations

- *Traditionally, some laboratories have used calculations to adjust eGFR values for black patients; however, contemporary advances in medical science discourage this approach. Therefore, it is advisable to report eGFR results as singular values without race-based adjustments. This recommendation should be integrated into Bermuda's future CKD management and referral guidelines.*
- *An opportunity for synergy lies in the comprehensive inclusion of all newly diagnosed CKD patients in the national registry when General Practitioners (GPs) indicate CKD on insurance claims. To incentivise GPs in referring patients to Nephrology at earlier stages, a well-defined system of incentives based on clear and internationally recognised guidelines could be implemented. For instance, adhering to appropriate referral stages could ensure smoother insurance claim processing.*

► **Proposed Initiator: Ministry of Health**

Health service providers should focus on the delivery of clear messages to CKD patients.

1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

C Provide clear, repetitive messages when communicating with patients

There is a need to improve the clarity and repetition of key messages regarding CKD prevention and management. Complex medical information can be overwhelming for patients, especially when provided in a single encounter. Insufficient reinforcement of important messages can lead to confusion, misunderstanding, and suboptimal adherence to treatment plans.

Clear and consistent messaging is essential to ensure individuals are well-informed about CKD and adequately prepared for it. Education programs should emphasise both awareness and preparedness, guiding people on how to respond when symptoms arise or when they receive a CKD diagnosis. This includes recognising signs and seeking timely medical attention, both for themselves and for family members. Patients with diabetes, periodontal disease, a family history of CKD, or hypertension should also be educated about understanding their CKD numbers (lab values) and the significance of regular CKD screenings.

Proposed steps for the implementation of this improvement:

- In the short term, the Ministry of Health should review and revise their communication protocols to ensure the delivery of clear and concise messages to patients. This can involve the development of standardised patient education materials that use simple language and visual aids to reinforce key concepts.

- In the medium term, individual healthcare facilities should establish reminder systems, such as post-visit summaries, follow-up calls, or text message reminders, to reinforce important messages and ensure patients have a clear understanding of their treatment plans.
- In the long term, it is recommended to implement continuous campaigns to clearly and repetitively convey the message around the risks and consequences of CKD, such as the Know Your Kidney Health Campaign organised by the Bermuda Health Council in 2022.¹¹ This will help reinforce the importance of CKD awareness and encourage proactive actions among individuals.

► **Proposed initiator: health service providers**

Improving information sharing among health providers decreases lead times and enhances early intervention.

1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

A Work with the National Digital Health Programme to improve information sharing among health service providers

Limited communication and coordination among health service providers within the current CKD Pathway can lead to fragmented care and impede the timely and appropriate management of CKD. The absence of a standardised system for sharing patient information forces health service providers to operate in isolation, causing delays and missed opportunities for early intervention.

To effectively address this issue, it is important to enhance information sharing and break down barriers among health service providers. This is another opportunity to align with the mentioned ongoing efforts of the National Digital Health Programme. The CKD team should partner with the National Digital Health Programme to communicate their need for a national CKD registry (as suggested under recommendation 1A) and develop strategies for effective information sharing of CKD information in light of known barriers.

By aligning the work of the National Digital Health Programme with the CKD project, Bermuda can aim to establish a comprehensive and interconnected healthcare information sharing system that promotes more efficient and effective care coordination for CKD patients and beyond.

► **Proposed initiator: National Digital Health Strategy Interim Board**

Structured group support for patients can enhance their health outcomes and reduce emotional toll of CKD.

1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

B Encourage patients to establish a non-profit support organisation for patients

CKD can have a significant impact on patients' physical, emotional, and social well-being. However, many patients may face challenges in accessing the necessary support and resources to cope with their condition. The absence of a dedicated support organisation limits the availability of targeted assistance, education, and psychosocial support for CKD patients and their families.

The solution to this problem involves establishing a non-profit support organisation specifically designed to meet the needs of CKD patients in Bermuda. This should be a patient-driven organisation that serves as a central hub offering a range of services, including patient advocacy, educational programmes, peer support groups, counselling services, and assistance with navigating the health system.

Proposed steps for the implementation of this improvement:

- In the short term, a representative from health service providers should select a group of motivated patients to initiate the (re)establishment of a non-profit support organisation for CKD patients, like "Kidney Patients in Action." This collaboration will be essential for laying the foundation.
- In the medium term, patients should formally establish the organisation with a dedicated physical location and/or online platform, providing information, resources, and a platform for peer support.

- In the long term, the support organisation should focus on sustained engagement and provision of services to CKD patients. This may include regular support group meetings, educational workshops, and collaborations with health service providers to ensure a holistic and patient-centred approach to CKD care. Regular evaluations should be conducted to assess the impact and effectiveness of the support organisation and identify areas for improvement.

► **Proposed initiator: Health service providers**

A single point of contact for patients can reduce the sense of being overwhelmed and improve care coordination.

1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

C Facilitate individual support for patients

CKD involves various aspects, including medical treatments, lifestyle modifications, and emotional well-being. However, patients often find it challenging to navigate this complex landscape on their own. The absence of a designated case manager can leave patients feeling overwhelmed and unsure of where to seek guidance or support.

To address this issue, it is crucial to introduce a way to facilitate individual emotional and practical support for patients. An opportunity for this is arranging a case manager for CKD patients. This dedicated professional would serve as a central point of contact and guide patients through their CKD journey. The case manager would have a comprehensive understanding of the condition, available resources, and emotional support services.

Proposed steps for the implementation of this improvement:

- In the short term, the Ministry of Health should develop a dedicated CKD case manager profile and job description. This profile should encompass essential qualifications, including expertise in CKD management and prior experience in dealing with CKD either directly or indirectly. Also, the Ministry should set up a taskforce to research the demand and expectations of CKD patients regarding case workers. This research should aim to identify the number of patients who would benefit from having a dedicated case manager and gather insights into their specific expectations.

- In the medium term, such a taskforce should hire an appropriate number of case managers considering the number of patients and time required for effective support. When hiring the caseworkers, the expectations of patients regarding caseworkers identified in the previously mentioned research should be considered.
- In the long term, the role of case manager could be expanded to include regular reporting on patients' emotional and physical well-being. Collating this data will allow policymakers to identify opportunities for further improvement in the CKD Pathway based on patient feedback, as well as further adapting the role of the case manager to fit patient needs.

► **Proposed Initiator: Ministry of Health**

Promoting and facilitating the use of home dialysis modalities can yield significant benefits for patients.



1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

D Promote and incentivise home dialysis modalities

Home dialysis offers numerous benefits, including increased freedom and flexibility for patients, reduced burden on health service providers, and potentially improved patient outcomes. However, according to stakeholders, the utilisation of home dialysis modalities in Bermuda remains limited.

Therefore, actively promoting and incentivising home dialysis modalities as a viable and preferred option for suitable CKD patients in Bermuda can have great value.

Proposed steps for the implementation of this improvement:

- In the short term, the Ministry of Health should publish and distribute a comprehensive document outlining the advantages of home dialysis for CKD patients. This publication should be widely distributed to health service providers, including hospitals and clinics, to raise awareness about the benefits and feasibility of home-based dialysis.
- In the medium term, the Ministry should establish a dedicated task force with the objective of developing a programme of incentives for patients to choose home dialysis. This programme should focus on non-financial incentives, such as enhanced access to educational resources on home dialysis.

- In the long term, the task force should focus on implementing the non-financial incentives programme to encourage patients to opt for home dialysis. The Ministry should ensure effective implementation and monitor the impact of the incentives programme to continuously refine and optimise its effectiveness in promoting and supporting home dialysis modalities.

► **Proposed Initiator: Ministry of Health**

Patients experience several barriers to care that need to be addressed.



A Address barriers to accessing care

As previously mentioned, some barriers to care exist in the current CKD Care Pathway. Barriers identified so far are of financial, cultural, and informational nature. These barriers can impede timely access to CKD care, lead to delayed treatment initiation, and result in suboptimal health outcomes for affected individuals.

To address this problem, it is essential to implement strategies that aim to address and overcome barriers to care access in Bermuda.

Proposed steps for the implementation of this improvement:

- In the short term, the Ministry of Health, in collaboration with health insurers, should conduct a thorough assessment to identify the greatest barriers to care access. This assessment should include an evaluation of what health services are covered by insurers, such as the frequency of specialist visits allowed per year, and how these factors influence people's access to care.
- In the medium term, the Ministry of Health should establish a task force comprising representatives from community organisations, insurers, and local health service providers to develop effective solutions for the identified barriers. An opportunity for synergy arises here by linking this task force to the existing UHC Health Forums, which should expedite the process of identifying potential stakeholders. This collaboration will save time and streamline efforts in addressing the access challenges more efficiently.

- In the long term, the task force should implement these solutions to overcome the identified barriers. Continuous monitoring and evaluation of access barriers should be conducted to identify ongoing challenges and implement tailored interventions if needed. The collaboration between policymakers, patients, health service providers, and stakeholders should be maintained to advocate for policies that support equitable access to CKD care across Bermuda.

► **Proposed Initiators: Ministry of Health and the Bermuda Health Council**

The financial CKD landscape should be assessed to identify strategies for long-term financial sustainability.

1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

B Identify strategies for enhanced financial sustainability

As previously mentioned, the disproportionately high costs of CKD care place a significant burden on the health system. As a result, CKD care has become financially unsustainable.

Solving this involves conducting a detailed assessment of the financial CKD landscape in Bermuda to identify strategies for enhanced financial sustainability.

Proposed steps to address this issue include:

- In the short term, the Ministry of Health should focus on setting up a prevention and screening programme, in line with earlier recommendations in this report.
- In the medium term, the Ministry of Health should conduct a thorough analysis of the costs associated with CKD treatment to identify areas of disproportionality and potential opportunities for cost reduction. This analysis should involve reviewing pricing structures, conducting market research, and benchmarking against international best practices.

- In the long term, and linked with recommendation 4D, efforts should be made to act on cost reduction opportunities. This may include consolidating the procurement of high-cost drugs used in CKD treatment. Simultaneously, initiatives should be undertaken to review current fees associated with CKD management with a view to finding opportunities to reduce the patients' expense. It should also include a comprehensive review of the referral system, identifying and addressing financial incentives that discourage appropriate referrals to specialists. This might involve adjusting reimbursement models, implementing guidelines for appropriate referrals, and providing education and training to health professionals on the benefits of multidisciplinary care for CKD patients.

► **Proposed Initiator: Ministry of Health**

Review evidence-based funding models to promote competition, reduce costs and enhance patient outcomes.

1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

C Research options to better align nephrology service funding for equitable access to evidence-based interventions

The current provision of local CKD-related health services include challenges to the affordability of critical nephrology services. Affordability challenges can lead to inequitable access of needed services and exacerbate existing disparities in health, such as delayed diagnoses, limited treatment options, and suboptimal CKD management. A notable risk to affordability exists in funding model variability when comparing services delivered through public facility and private nephrology practices. Nephrologists providing care through the publicly funded BHB operate within funding schemes regulated by law. As a result, insured patients able to receive care through this provider have services covered at 100% of the regulated fee. In contrast, private nephrology practices determine their fees according to their own privately established clinical and operational models, which are not subject to legal regulation and may require co-payments of insured patients. Neither model adequately covers or funds care for those unable to obtain a health insurance policy. Variations in funding models, in addition to non-universal clinical standards, further complicate addressing care gaps and take focus away from preventing disease progression and ensuring optimal CKD patient outcomes. To determine the extent of the disparities being created from these challenges, an expansion of health and service data that can be statistically linked to outcomes is required.

A potential approach to address these challenges:

1. Measure current variation in access, cost, and outcomes for CKD patients
2. Define evidence-based interventions that should be available for all
3. Explore options for implementing value-based care models

The following steps are proposed to tackle this problem:

- In the short-term, a comprehensive assessment should be undertaken to expand on the Joint Strategic Needs Assessment (JSNA) and further baseline CKD in Bermuda, establishing variations in access to nephrology services and any related variation in patient outcomes. The assessment should consider factors such as comorbidities, biochemistry, demographic variables, family history, socioeconomic status, and health system engagement.
- In the medium-term, focus should be placed on defining the core evidence-based care interventions to help in the timely diagnosis and treatment of CKD patients. This should be informed by the findings of the population health assessment and aim to identify eligible health services, establish cost-benefit of these, and design equitable structures to improve the quality and outcomes of care.
- In the longer-term, and based on the preceding steps above, work should be undertaken to explore modern options for a cross-entity funding model that seeks to promote value-based comprehensive care that considers a competitive market and incentivises performance, cost reduction, and optimal patient outcomes. Considerable research, policy, and care improvement work has been undertaken internationally in this area and adapting and adopting such 'value-based kidney care' can be an ambition for Bermuda's health system.

► Proposed initiators: Bermuda Health Council and Government's Health Insurance Department

The inclusion of CKD care as a UHC Core Benefit could greatly enhance access to care and improve health outcomes.

1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

D Include CKD care in UHC Core Benefits Package

A significant enhancement to access to and affordability of CKD care in Bermuda could be made with the inclusion of CKD care in the UHC Core Benefits Package. This would ensure that individuals diagnosed with CKD have access to necessary services, treatments, and medications as part of UHC.

The following steps are proposed to include CKD care in the UHC Core Benefits Package:

- In the short term, a further costing analysis of the current CKD Care Pathway should be conducted to assess the financial implications of including CKD care in the UHC Core Benefits Package. This analysis should provide valuable insights into the potential costs, resource allocation, and financial feasibility of incorporating CKD care into the Core Benefits Package.
- In the medium term, an implementation plan for the inclusion of CKD care in the UHC Core Benefits Package should be developed, based on the costing analysis. This plan should outline the necessary adjustments to the Benefits Package based on the identified pathway and any opportunities for improvements. This could include specific treatments, medications, and support programmes for CKD management. It should also address the financial considerations and potential reimbursement mechanisms required to ensure sustainability and affordability.

- In the long term, CKD care should be implemented as a core benefit under UHC. This would involve updating policies, guidelines, and reimbursement structures to ensure that individuals with CKD can access necessary services and treatments without the current level of financial barriers. Ongoing monitoring, evaluation, and adjustments can be made to optimise the inclusion of CKD care in the UHC Core Benefits Package and ensure its long-term effectiveness and sustainability.

Other considerations

Including CKD care in the UHC Core Benefits Package is a key step towards improving access to essential services for individuals with CKD. However, it is important to acknowledge that covering CKD in all insurance packages may lead to rising premiums. To ensure financial feasibility and prevent premium increases, a significant focus on prevention measures becomes crucial. By prioritising preventive efforts such as early detection, education, and lifestyle interventions, Bermuda can mitigate the financial burden associated with CKD and maintain affordable premiums for individuals.

► **Proposed Initiator: Ministry of Health**

Promotion of organ donation through targeted campaigns can significantly increase the number of kidneys available.



1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

A Promote organ donation through targeted campaigns

Organ transplantation – both from live and deceased donors – is a critical treatment option for individuals with end-stage renal disease. However, in Bermuda the availability of organs for transplantation is limited. Globally, the lack of available organs leads to prolonged waiting times for those seeking a transplant and reduced access to life-saving transplants. Low public awareness and local misconceptions about organ donation contribute to the shortage of organs.

In Bermuda, significant efforts have already been made towards improving organ donation. For instance, the Bermuda Health Council conducted a comprehensive assessment to identify the specific needs and requirements related to organ donation in Bermuda. This assessment will play a crucial role in shaping future strategies and initiatives. Additionally, the Health Council is actively involved in several ongoing efforts, including:

- Working in partnership with New England Donor Services to support and enhance organ donation initiatives.
- Collaborating with Canadian organisations to develop joint programmes that further promote and advance organ donation efforts.
- Engaging with donor organisations and hospitals in the USA, UK, and Canada to gain insights into ongoing global organ donation activities and establish an overview of collective efforts.

- Working closely with a former member of the Bermuda Organ Donor Association to update the National Organ Donor Registry.

To build on the momentum following these efforts, the following is proposed:

- In the short term, the Health Council should continue its ongoing efforts to promote organ donation. Additionally, the ongoing public campaigns could be repurposed to run annually, ensuring a sustained and impactful awareness drive every year.
- In the medium term, the Health Council should continue its sustained efforts to establish an organ donation registry. This involves collaborating with hospitals, transplant centres, and Government agencies to develop and implement a centralised database for organ donation. The registry should contain comprehensive information about potential kidney donors, and regular updates and data maintenance should be prioritised to ensure accuracy and easy accessibility.
- In the long term, the Health Council should continue engaging with policymakers to develop legislation that supports organ donation. By advocating for supportive legislation, Bermuda can create an environment that encourages and facilitates organ donation, thereby increasing the availability of organs for transplantation and saving more lives. A conducive legal framework will play a crucial role in furthering the success of organ donation initiatives in the long run.

► Proposed initiator: Bermuda Health Council

Securing robust funding for organ donation and transplants will further enhance availability of donor organs.



B Secure robust funding for organ donation and transplants

The costs associated with kidney donation, overseas transplant surgeries, and post-operative care, can be substantial in Bermuda. The limited availability of robust funding poses a challenge in ensuring equitable access to organ donation and overseas transplantation services for CKD patients in Bermuda – especially for uninsured and underinsured individuals.

It is therefore crucial to secure robust funding for organ donation and transplants. Proposed steps:

- In the short term, the Bermuda Health Council, in coordination with the Health Insurance Committee, should continue actively aligning on their ongoing efforts to secure robust funding for organ donation and transplants.
- In the medium term, once funding is secured, it is important that the Health Council builds on the previously completed needs assessment to determine if the allocated funding is sufficient and financially sustainable for organ donation and transplants. This assessment should continue to consider the cost of kidney donation, overseas transplant surgeries, immunosuppressant medications, post-operative care, and long-term follow-up.

- In the long term, the Health Council should continue initiating research into alternative funding options for organ donation and transplants in Bermuda. This research is already underway and should continue to focus on innovative approaches, such as healthcare financing models, public-private partnerships, and potential collaborations with international organisations or research institutions. By exploring and implementing alternative funding strategies, the Health Council can contribute to the long-term financial sustainability of overseas organ transplantation services and improve access for CKD patients in Bermuda.

► **Proposed initiator: Bermuda Health Council**

Making sure donors are appropriately covered or reimbursed for their donation is key.

1. Prevention and Early Detection

2. Education and Awareness

3. Coordination and Patient Support

4. Access and Affordability

5. Organ Donation and Transplants

C Introduce standard and appropriate coverage for live organ donors

Kidney transplantation relies on organ donation, and it is crucial to support and promote individuals who are willing to donate their kidneys to save lives. However, the current system sometimes places financial burdens on donors, including expenses related to medical evaluations, travel, accommodation, and lost wages. This financial burden can deter potential donors and limit the availability of organs for transplantation.

A possible solution is providing adequate coverage for kidney donors in Bermuda. By ensuring that donors are not financially burdened by the process, more individuals can be encouraged to come forward.

Proposed steps:

- In the short term, the Bermuda Health Council should continue to collaborate with relevant stakeholders, including health service providers, insurers, and policymakers, to develop an overview of the expenses associated with the donation process, including medical evaluations, travel, accommodation, and any income loss during the recovery period.

- In the medium term, the Health Council and the Health Insurance Committee should establish a task force consisting of healthcare professionals, organ donation programmes from abroad, and representatives from insurance companies to develop a policy that ensures adequate coverage for kidney donors. This policy should cover all necessary expenses associated with the donation process, including medical evaluations, travel, accommodation, and any income loss during the recovery period.
- In the long term, the task force should oversee the implementation and administration of the policy for kidney donors. The task force should ensure that the policy is consistently applied, evaluate the financial impact on donors, and address any emerging challenges or concerns.

Other considerations

A consideration for this could be increasing access to live kidney donor transplantation in the United Kingdom (UK). This approach is based on the reasoning that British territories citizens, including Bermudians, can potentially avoid high international patient fees that are charged in other transplantation markets. By facilitating access to live kidney donor transplantation in the UK, Bermuda could offer a more affordable and accessible option for patients seeking kidney transplants, while also potentially reducing financial burdens associated with international organ transplantation.

► **Proposed initiator: Bermuda Health Council**

The World Health Organisation identifies six key building blocks for health system strengthening.

The World Health Organisation (WHO) has identified six key building blocks for health system strengthening. They are visualised in the diagram below. These building blocks serve as components to enhance the overall performance and effectiveness of a health system.

Stewardship & Governance

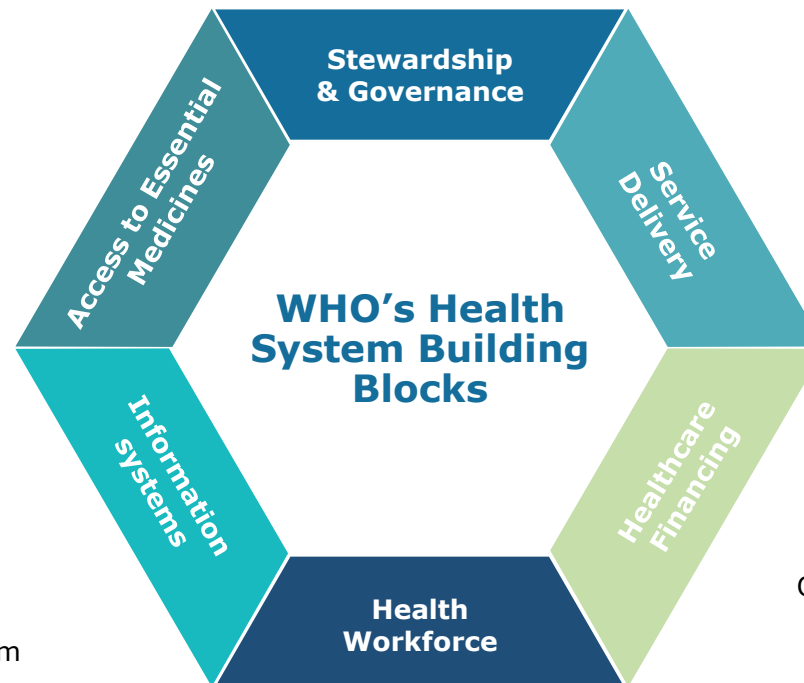
Ensuring the existence of policy frameworks combined with effective oversight, coalition building, regulation, attention to system design and accountability.

Access to Essential Medicines

Access to essential medicines of assured quality, safety, efficacy and cost-effectiveness, with scientifically sound and cost-effective use.

Information Systems

One that ensures the production, analysis, dissemination and use of reliable and timely information on health determinants, health system performance, and health status.



Service Delivery

Deliver effective, safe, quality personal and non-personal health interventions to those that need them, when and where needed, with minimum waste of resources.

Healthcare Financing

System raises adequate funds for health, in ways that ensure people can use needed services without financial catastrophe or impoverishment associated with payment.

Health Workforce

One that works in responsive ways, fair and efficient to achieve the best health outcomes possible, given available resources and circumstances.

The identified opportunities across the CKD Pathway align with four of WHO's six building blocks.

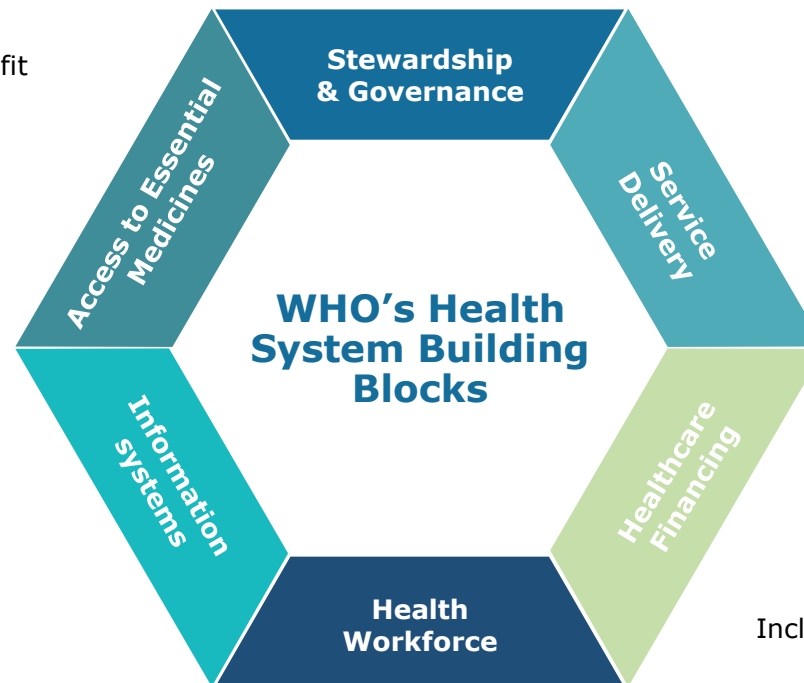
In the diagram below, we have plotted the mentioned points of improvement for the CKD Pathway along four of the building blocks that correspond with the recommendations: Stewardship & Governance, Information Systems, Service Delivery, and Healthcare Financing.

Stewardship & Governance

- 3B Encourage patients to establish a non-profit support organisation for patients
- 4A Address barriers to accessing care

Information Systems

- 1A Partner with the National Digital Health System Metrics project to work on a CKD registry for screening and data analysis
- 1B Develop targeted prevention and screening programmes
- 2B Enhance GPs understanding of CKD progression and introduce formal CKD management and referral guidance
- 2C Provide clear, repetitive messages when communicating with patients
- 3A Work with the National Digital Health Interim Governance Board to improve information sharing among health service providers
- 5A Promote organ donation through targeted campaigns



Service Delivery

- Promote achievable lifestyle modifications 1C
- Strengthen patient education in individual and group settings 2A
- Facilitate individual support for patients 3C
- Promote and incentivise home dialysis modalities 3D
- Research options to better align nephrology service funding for equitable access to evidence-based interventions 4C

Healthcare Financing

- Identify strategies for enhanced financial sustainability 4B
- Include CKD care in UHC Core Benefits Package 4D
- Secure robust funding for organ donation and transplants 5B
- Introduce standard and appropriate coverage for live organ donors 5C

Implementing the improvements will result in a future state CKD Pathway that focuses on prevention and awareness.



The 17 opportunities for improvement that have been identified through the Pathway mapping process span five key areas:

01 Prevention and Early Detection

04 Access and Affordability

02 Education and Awareness

05 Organ donation and Transplants

03 Coordination and Patient Support

While the range of improvements suggested may seem extensive, it is essential to implement these recommendations to create a more effective Pathway for preventing CKD, improving outcomes, enhancing financial sustainability around CKD spending, and promoting better health for CK - patients in Bermuda. Prioritisation to highlight the key improvements to be implemented first is therefore crucial.

By acknowledging the challenges and taking proactive steps towards change, we can work towards an ideal future state of CKD-related health services in which we focus on that which matters most: patient health outcomes.

Contact Us:

We'd love to hear from you! If you have any query or concern, reach out for a helping hand. Please find our contact details below:

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▶ More information and the latest updates can be found online at www.healthstrategy.bm

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Appendices

Appendix 1: Service Map

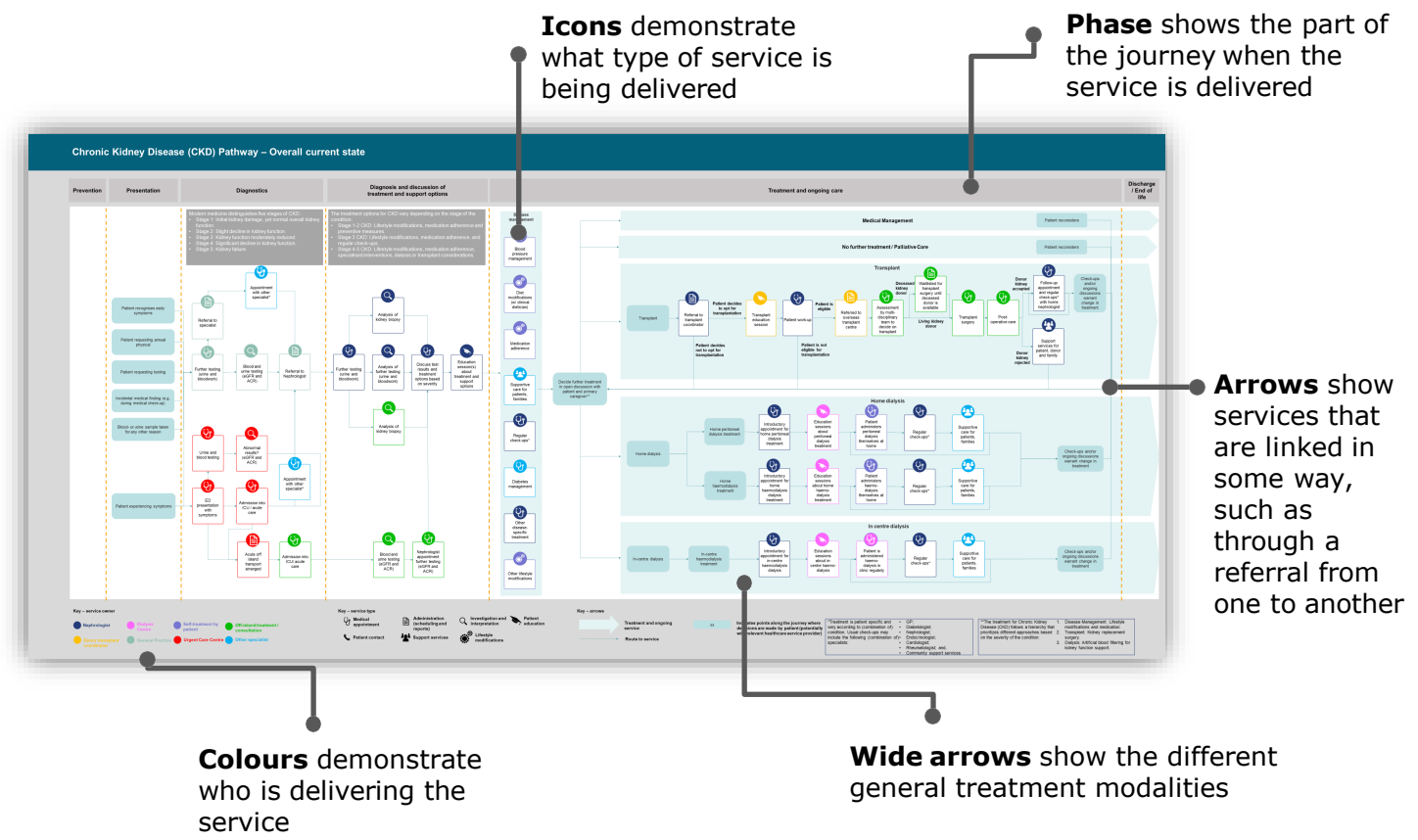
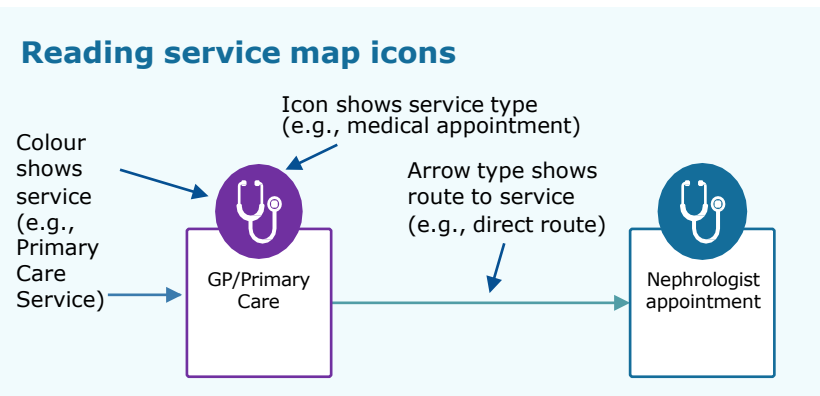
Current State and Future State

Service Maps outline the services available during a patient's journey.

A healthcare service map is a visual representation or diagram that outlines the various health services, providers, and resources available within a specific health system or community.

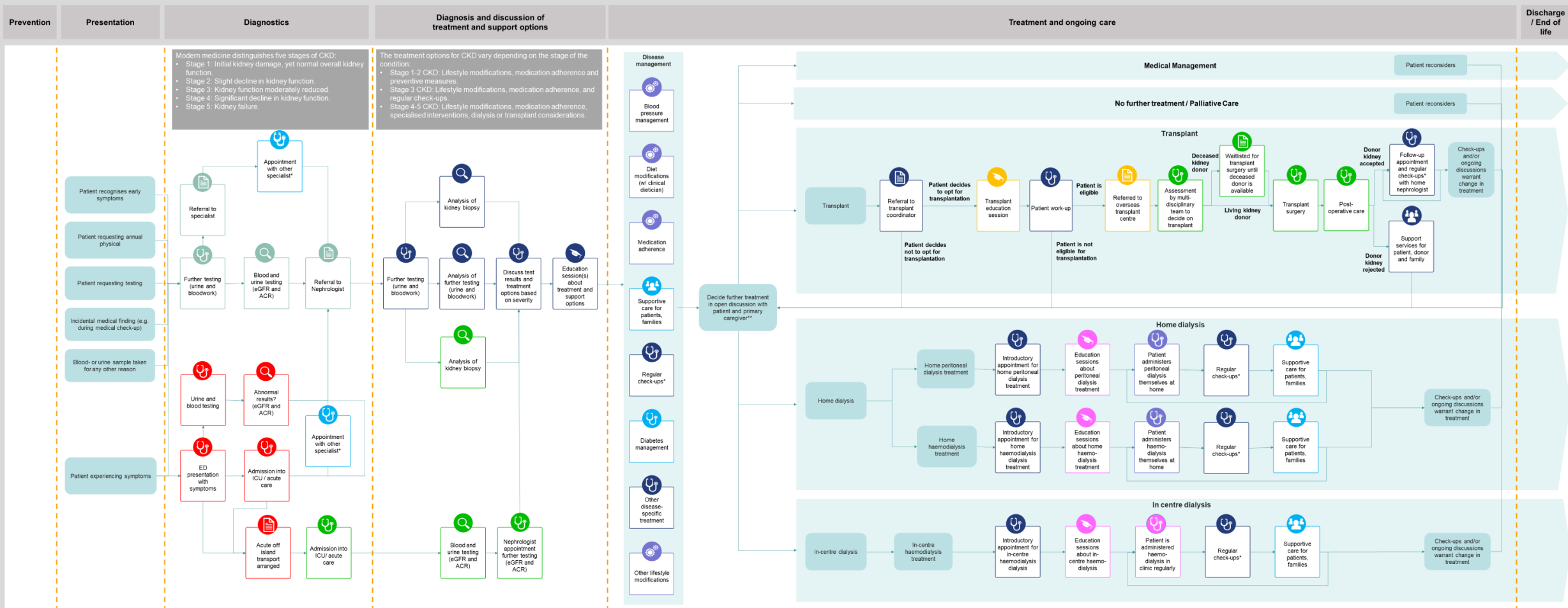
Why are Care Pathway service maps useful?

- ▶ A Service Map is a graphic depiction of the services available to patients across their journey.
- ▶ These are helpful communication tools. They align stakeholders on a 'single version of the truth' by providing a clear visual of the service landscape, routes to services, and any gaps or duplication in service delivery.



The overall Service Map encompasses health services available to all CKD patients, regardless of stage.

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:

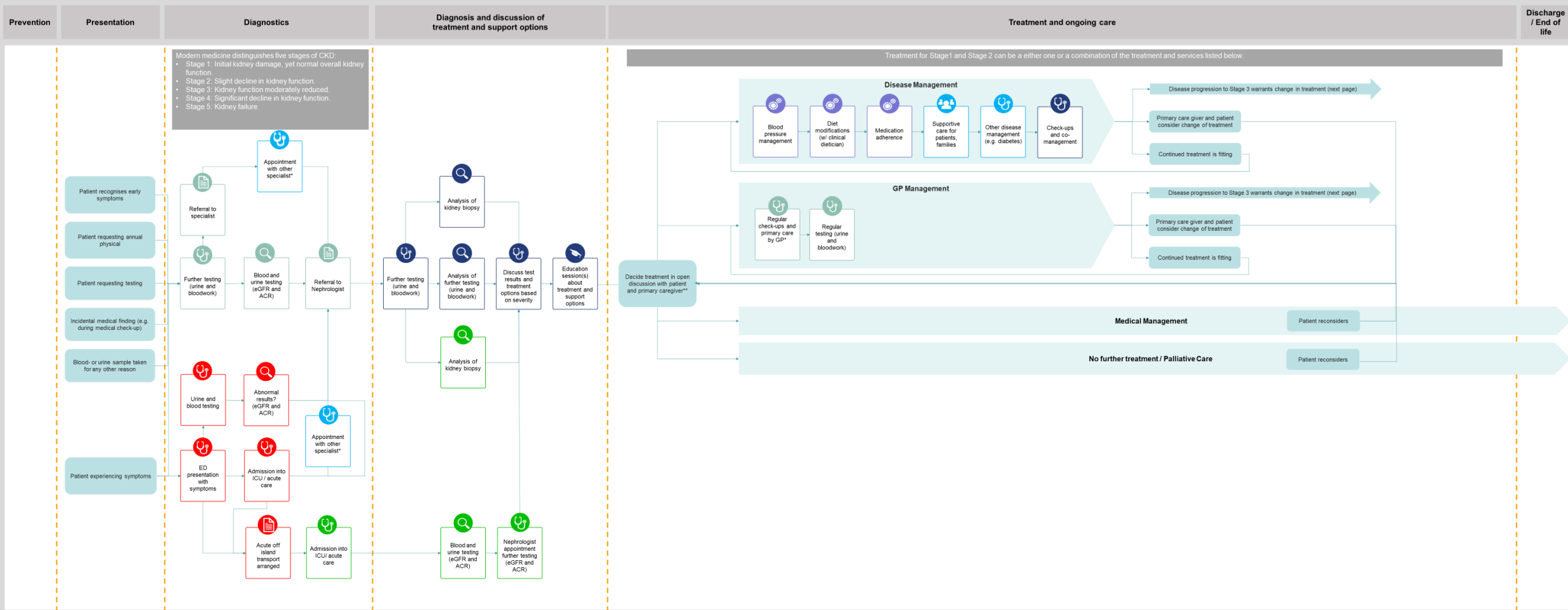
- GP
- Diabetologist
- Nephrologist
- Endocrinologist
- Cardiologist
- Rheumatologist and
- Community support services

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

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

The Service Map for Stage I and II patients focuses on disease management and primary care through GPs.

Chronic Kidney Disease (CKD) Pathway – Current state – Stage 1 and 2



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:

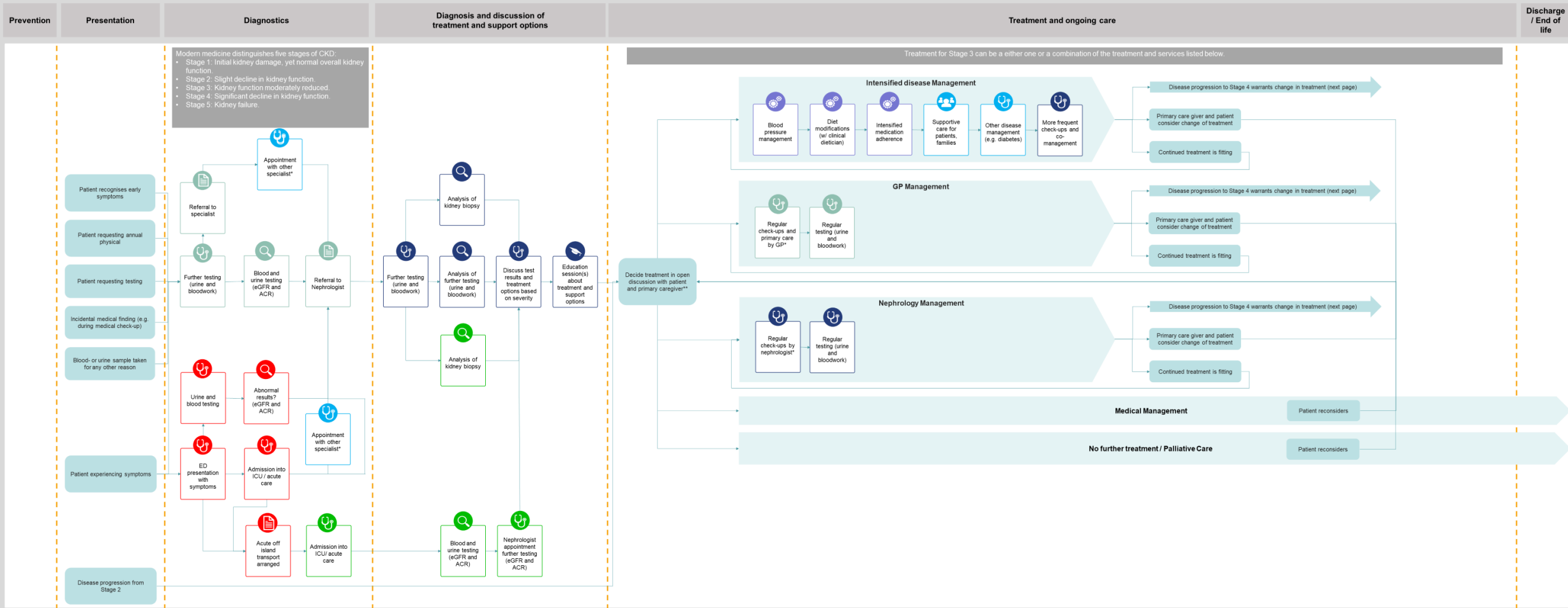
- GP;
- Diabetologist;
- Nephrologist;
- Endocrinologist;
- Cardiologist;
- Rheumatologist; and;
- Community support services

**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.

The Service Map for Stage III patients adds nephrology management.

Chronic Kidney Disease (CKD) Pathway – Current state – Stage 3



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:

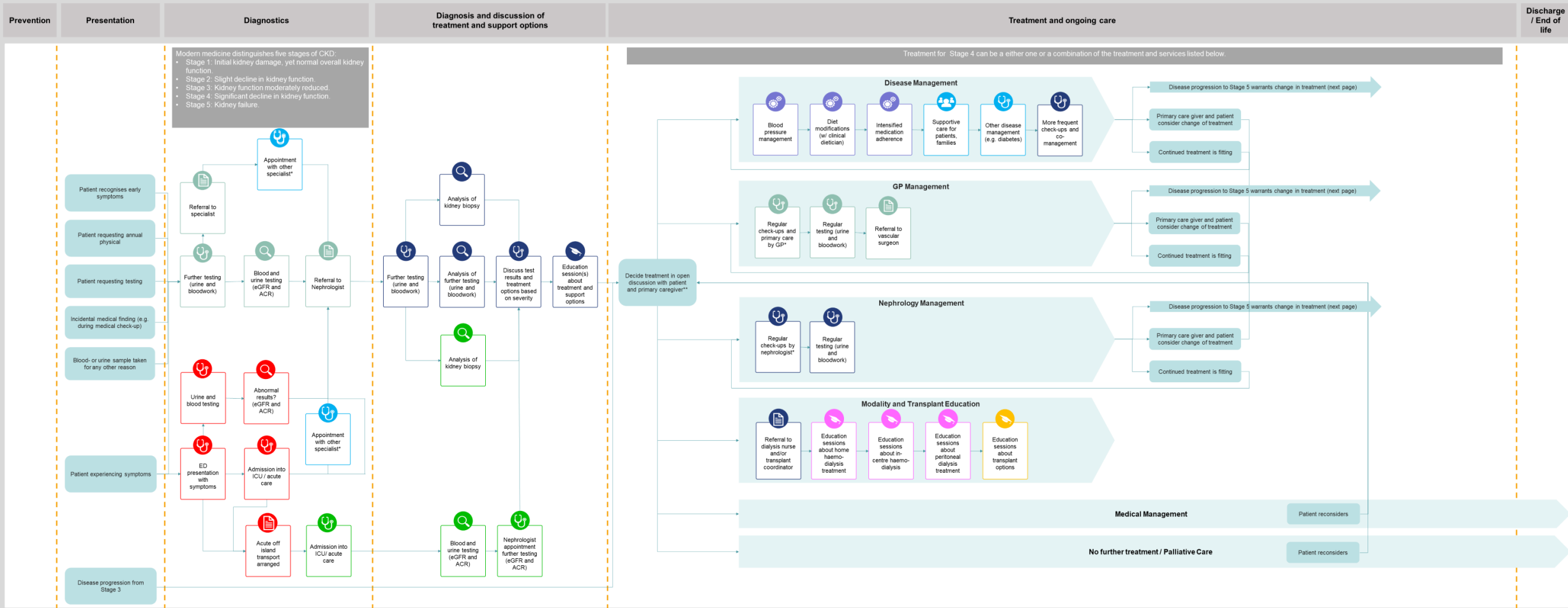
- GP;
- Diabetologist;
- Nephrologist;
- Endocrinologist;
- Cardiologist;
- Rheumatologist; and;
- Community support services

**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.

The Service Map for Stage IV adds dialysis modality and transplant education as patients prepare for end-stage.

Chronic Kidney Disease (CKD) Pathway – Current state – Stage 4



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:

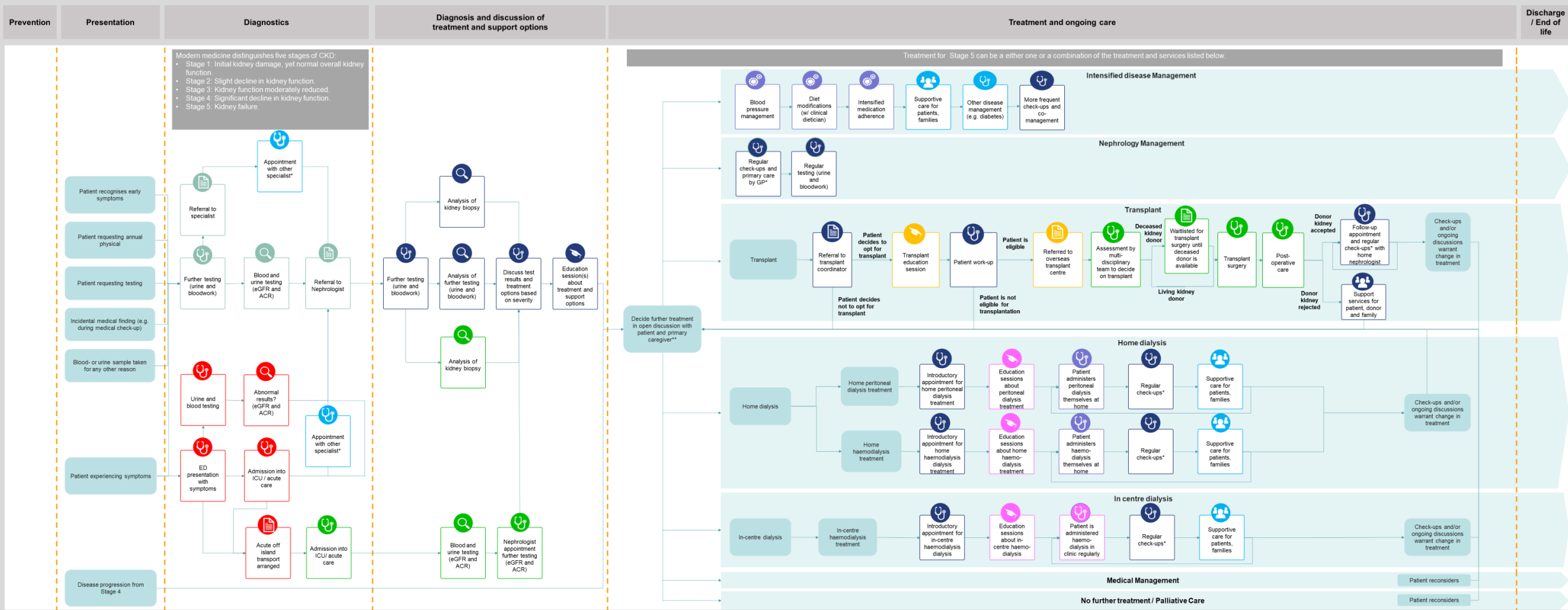
- GP;
- Diabetologist;
- Nephrologist;
- Endocrinologist;
- Cardiologist;
- Rheumatologist; and;
- Community support services

**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.

The Service Map for Stage V includes dialysis modalities and treatment services.

Chronic Kidney Disease (CKD) Pathway – Current state – Stage 5



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:

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

Appendix 2: Journey Map

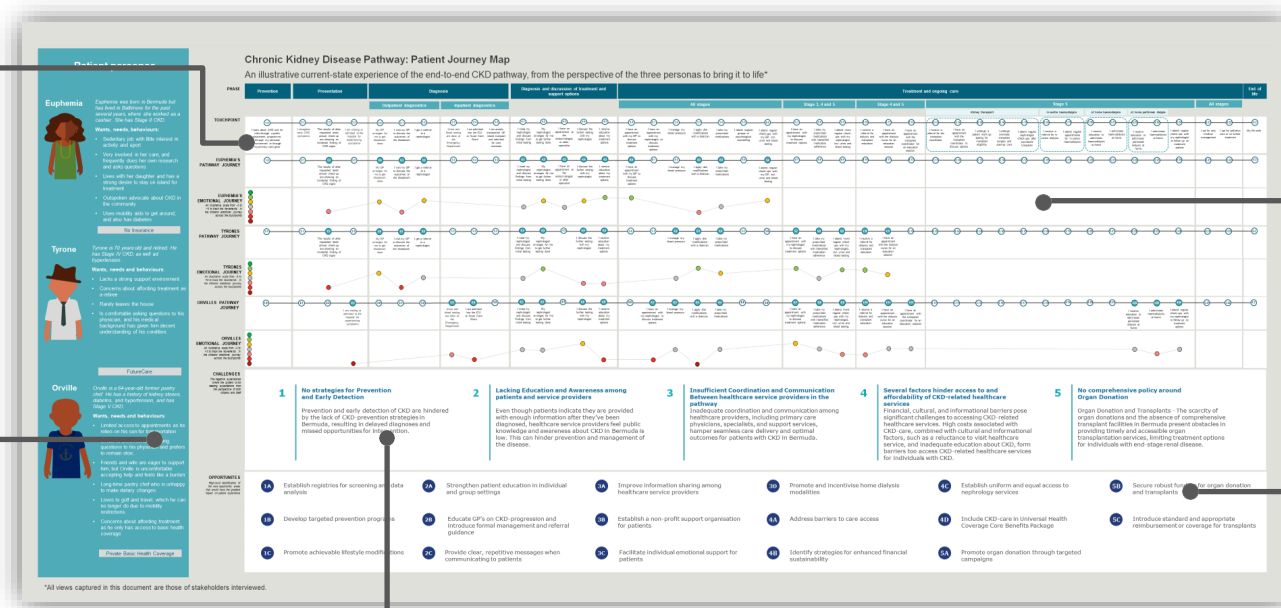
Journey Maps contain individual “touchpoints” patients have with health service providers.

A Journey Map breaks down patients’ experience into the specific, individual “touchpoints” they have with health service providers. Moving through the various touchpoints in the journey gives the organisation a first-person view of every interaction, from beginning to end. This brings to life the emotional experience and the pain and gain points encountered by users along their journey.

Journey Phase and Touchpoints Validated through workshops and interviews

Personas Overview of fictional patient profiles to bring to journey to life

Challenges
Aspects in the journey that could be better organised



The Emotional Journey
An illustrative line to track the movements in the patients’ emotional journey across the touchpoints

Opportunity Areas
High-level identification of the core opportunities that would have the greatest impact on patient experience



The Journey Map for CKD outlines the various stages and touchpoints in a patient's experience.

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 as 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

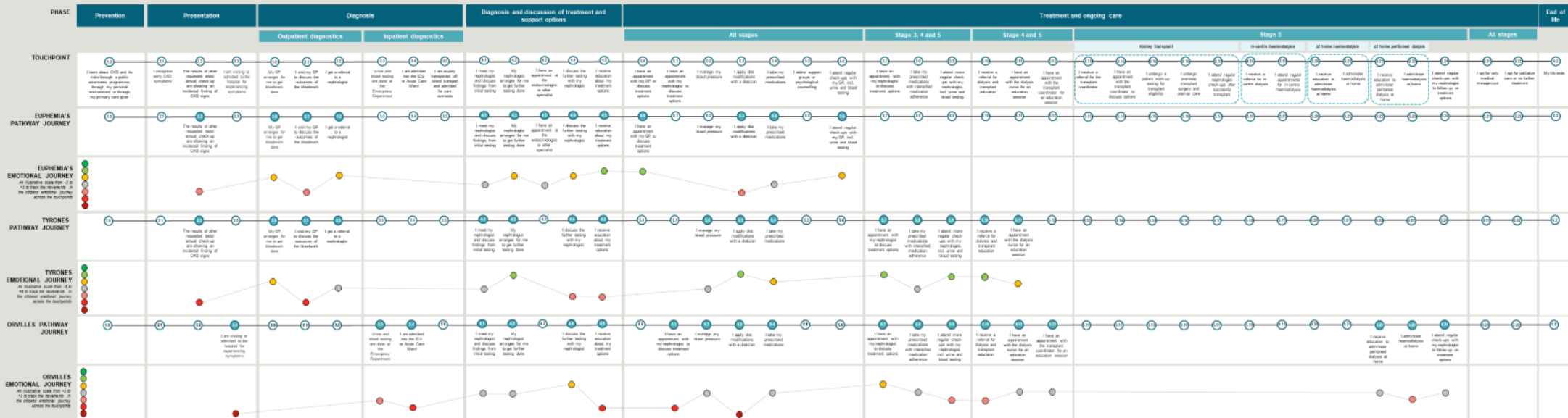
Orville is a 64-year-old former pastry chef. He has a history of kidney stones, diabetes, and hypertension, and has Stage V CKD.

- 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

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*



CHALLENGES
The biggest impediment to the care opportunity areas that most have the greatest impact on patient experience

OPPORTUNITIES
High-level identification of the care opportunity areas that most have the greatest impact on patient experience

- 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.
 - 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.
 - 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.
 - 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.
 - 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.
- 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
 - 4E 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.

Appendix 3: Patient Personas

Euphemia



Background and lifestyle

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

A few months ago, Euphemia moved back to Bermuda to be closer to her eldest daughter. Shortly thereafter, Euphemia was diagnosed with Stage II CKD.

She leads a very sedentary life and she has no strong feelings about living an active lifestyle. Having lived with CKD for a few months, Euphemia advocates for newly diagnosed patients in the community.

Euphemia worries a lot about her coverage, as she has no health insurance.

Pre-existing conditions:

Euphemia lost her leg in a car crash as a child and uses mobility aids to get around. She also has diabetes.

Diagnosis:

Stage II CKD – diagnosed through testing that was done because of her diabetes.

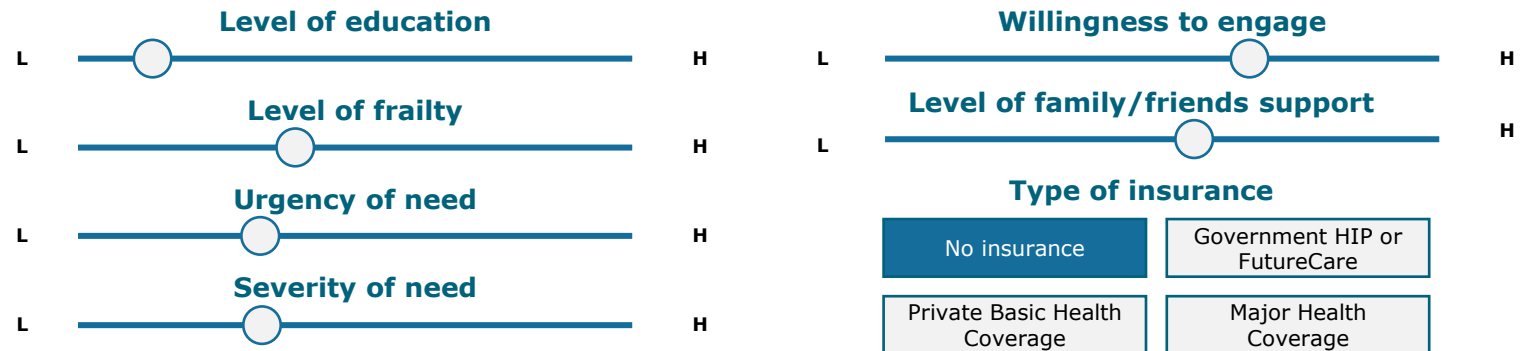
Access to support network:

Two of Euphemia's children live on island; her daughter is her primary source of support.

Behaviours:

- Strong Buddhist faith and desire to stay near her temple community and children in Bermuda.
- Lives with her daughter.
- Outspoken advocate about CKD in the community.

Key attributes:



Access to information:

Frequently does her own research at home and often requests pamphlets and resources from her clinicians.

Euphemia is very involved in her care and would like to know as much as she can about her treatment options.

What Euphemia needs from the Pathway



Detailed communication to meet her interest in remaining informed



Care on island, near her family



Involvement of her daughter in her treatment, who is her primary support



Information about how her CKD and its treatment may interact with her other pre-existing conditions

Tyrone



Background and lifestyle

Tyrone retired in 2014 after a career as a periodontist. He is now 70, and since retiring, he has become very interested in oil painting. He wants to spend the remainder of his life working on his art from his home studio.

Tyrone was recently diagnosed with Stage IV CKD. He is concerned about how he will afford his treatment now that he is retired.

Tyrone also worries about his insurance as he only has FutureCare, which limits the amount of medical appointments he can make.

Pre-existing conditions:

Tyrone prefers to avoid sitting for long periods of time as a result of his sciatica. Tyrone also has hypertension.

Diagnosis:

Stage IV – diagnosed through testing that was done because of his hypertension.

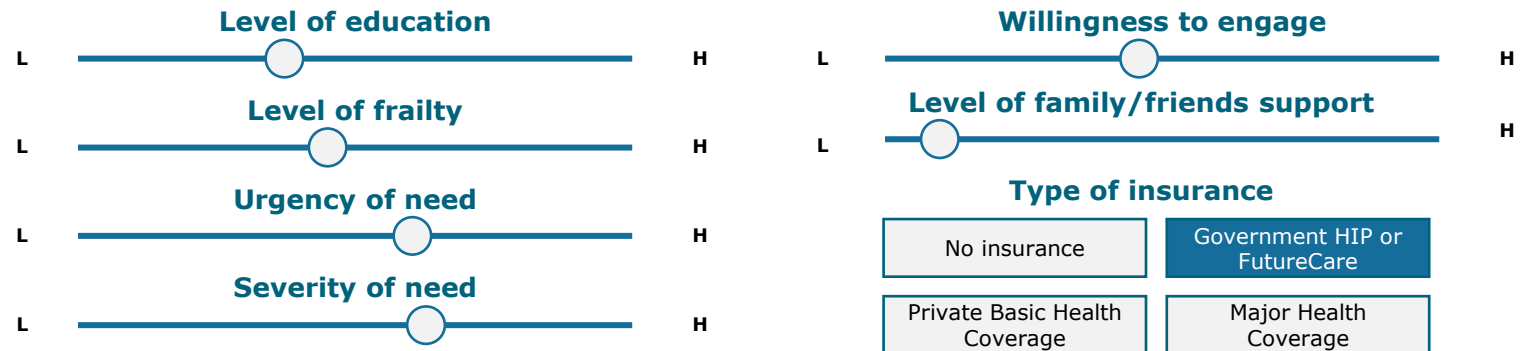
Access to support network:

Lacks a strong support environment.

Behaviours:

- Concerns about affording treatment as a retiree.
- He lives alone.
- Tyrone doesn't have a car and rarely leaves his house.

Key attributes:



Access to information:

Has joined a Facebook group about homeopathic remedies for his condition.

Is comfortable asking questions to his physician. His medical background has given him a decent understanding of his condition.

What Tyrone needs from the Pathway



Access to support groups and other social support



Clear explanations of payment options and costs of treatment



Respect for his interest in natural and holistic complements to his treatment



Tyrone prefers to stay in his home as much as possible, so he prefers home treatment.

Orville



Background and lifestyle

Orville is a 64-year-old pastry chef. He has suffered with kidney stones since his early adulthood and was diagnosed with Type II Diabetes in his early 40s. Orville's wife encourages him not to consume sugary foods, but he is unhappy to give those up.

Orville loves to golf and travels to the US with his friends on an annual golf trip. Last year, his doctor diagnosed him with Stage V CKD and for the first time, he was unable to travel for the annual golf trip due to mobility restrictions.

Although he can afford his treatment, Orville has been struggling to cope with his diagnosis and the limitations it has placed on his life. He is a bit reluctant to share about his condition and sometimes feels like a burden.

Pre-existing conditions:

Orville has been diagnosed with Type II Diabetes and has a history of kidney stones, diabetes, and hypertension.

Diagnosis:

Stage V – diagnosed through monitoring by his nephrologist because of his history of kidney stones.

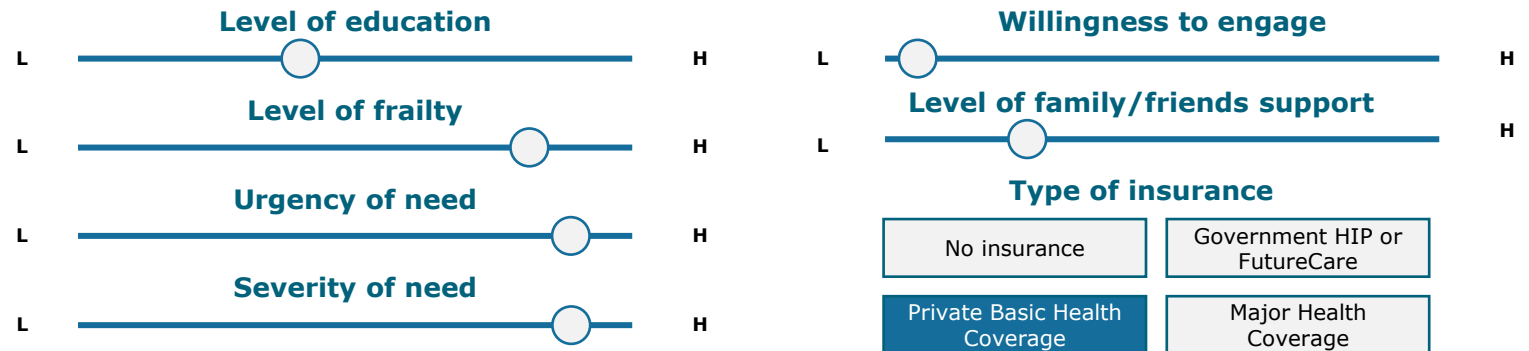
Access to support network:

Friends and wife are eager to support him, but Orville is uncomfortable accepting help and feels like a burden

Behaviours:

- 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.
- Feels a bit hopeless about his condition and as a result, is not enthusiastic about engaging with his treatment plan.
- Reliant on family for transportation.

Key attributes:



Access to information:

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.

What Orville needs from the Pathway



Access to care and support for his mental and social well-being



Clear communication of appointment times to arrange for transportation



Compassionate suggestions for lifestyle adjustments that account for his love of sweet foods



Help adjusting to his new mobility and lifestyle changes

Appendix 4: Desktop Review








This desktop review summarises available data on the state of the CKD Integrated Care Pathway in Bermuda.

The table below lists all the sources studied within four categories: 1) **scientific literature**, 2) **clinical guidelines and best practices**, 3) **initiatives and organisations**, and 4) **policies and strategies**. The summaries of the four categories are presented on the following pages. After this, each piece of work is discussed in more detail, outlining its basic premise and the implications for Bermuda's CKD Care Pathway.

1 Scientific Literature	2 Clinical Guidelines and Best Practices
<ul style="list-style-type: none"> CKD Care Pathway in the United Kingdom: Outcomes-Based Approach by Ayman Karkar and Muhammad Rafique. Healthcare Pathways for chronic kidney disease in primary care: a systematic review by Payne S.A., Kirby M., and Davies I. Development and Implementation of a Chronic Kidney Disease Care Pathway in a Primary Care Practice by Wiegand T.J., Albright R.C., and Pickett T.C. Chronic kidney disease management: a public health priority by El Nahas M. and Levin A. Quality improvement in chronic kidney disease: the role of care pathways by Zaza G., Squitieri S., and Di Iorio B. The Implementation of a Chronic Kidney Disease Care Pathway in a Canadian Primary Care Setting by Boucher N., Guerra L., and Ta A. Development of a Chronic Kidney Disease Care Pathway for a Primary Care Practice by Patel P., Stankus N., and Chen S.C. 	<ul style="list-style-type: none"> Chronic kidney disease in adults: Assessment and management by National Institute for Health and Care Excellence. NKF KDOQI clinical practice guideline for the evaluation and management of chronic kidney disease by National Kidney Foundation. Canadian Society of Nephrology commentary on the 2021 KDIGO Clinical Practice Guideline for the Management of Blood Pressure in Chronic Kidney Disease by Tangri N., et al.
3 Initiatives and Organisations	4 Policies and strategies
<ul style="list-style-type: none"> About us by Bermuda Renal Associates. Chronic Disease Innovation Programme (CDIP) by Bermuda Health Council. Healthy schools programme by Government of Bermuda. Dialysis by Bermuda Hospitals Board. About us by National Kidney Foundation. Chronic Kidney Disease (CKD) [Fact sheet] by WHO. Chronic Kidney Disease (CKD) surveillance system by Centres for Disease Control and Prevention. ISN Global Kidney Health Atlas by International Society of Nephrology. KDIGO 2020 clinical practice guideline for the management of chronic kidney disease by Kidney Disease: Improving Global Outcomes (KDIGO). 	<ul style="list-style-type: none"> Bermuda Health Strategy 2014 – 2019 by Ministry of Health, Bermuda. Bermuda Health Strategy 2022 – 2027 by Ministry of Health, Bermuda. National Health Insurance by Bermuda Health Council.

Based on the initial desktop review, seven areas relevant to CKD Pathway mapping were identified.

The table below lists the most important conclusions drawn from researching the current state.

<p>1 Much of the literature attests to the added value of Pathways. </p> <p>Introduction of Pathways can lead to improvements in key clinical outcomes, such as:</p> <ul style="list-style-type: none"> • earlier detection of CKD; • increased adherence to guidelines, and; • improved patient outcomes. 	<p>2 Literature emphasises prevention and early detection. </p> <ul style="list-style-type: none"> • Several articles attest to the value of early detection and diagnosis. • Early detection and diagnoses are associated with an increase in the quality of life and health outcomes for patients. • Clearly implemented Care Pathways are likely to improve the detection of CKD. 	<p>3 Regular monitoring of patients can improve patient outcomes. </p> <p>Monitoring and follow-ups are beneficial for patients as this:</p> <ul style="list-style-type: none"> • allows for prompt intervention and treatment; • helps health service providers manage symptoms and improve quality of life; • enables personalised treatment plans, and; • prevents hospitalisation. 	<p>4 Patient education is vital. </p> <p>Patient education is vital, since it:</p> <ul style="list-style-type: none"> • helps patients take an active role in their healthcare; • helps prevent complications and improve health outcomes; • improves compliance with treatment plans & medications; and, • enhances communication between patients and service providers.
<p>5 CKD mentioned in policy documents but not exhaustively covered. </p> <ul style="list-style-type: none"> • National Health Strategy (both 2014 – 2019 and 2022 – 2027) mentions the prevalence and need to prevent CKD. • Neither document mentions concrete measures to take in this regard. 	<p>6 Multiple Bermudian initiatives focus on CKD. </p> <ul style="list-style-type: none"> • Chronic Disease Innovation Programme: Government-led initiative that aims to improve the prevention and management of chronic diseases, including CKD. • Healthy Schools Programme: Government-led initiative that promotes healthy living among school-aged children in Bermuda. • Bermuda Diabetes Reversal Programme: Initiative that seeks to empower patients to understand, manage, control, and (in some cases) reverse their diabetes under the supervision of medical experts. 	<p>7 Several organisations in Bermuda focus on CKD. </p> <ul style="list-style-type: none"> • Bermuda Renal Associates • Kidney Care Bermuda • Bermuda Life Center 	

Karkar and Rafique recommend an outcomes-based approach to pathway mapping for CKD in the UK.



1	Scientific Literature	2	<i>Clinical Guidelines and Best Practices</i>
3	<i>Initiatives and Organisations</i>	4	<i>Policies and Strategies</i>

Methodology: Reviewing CKD Care Pathway in the UK

The methodology of this article is a review of the CKD Care Pathway in the UK. The authors discuss the different stages of the Pathway and the outcomes that are measured. They also provide an overview of the evidence base for the Pathway and its effectiveness in improving patient outcomes.

Conclusion: The authors conclude that implementing an outcomes-based CKD Care Pathway in the UK led to improvements in clinical outcomes and cost-effectiveness.

This article discusses the development of the CKD Care Pathway in the United Kingdom, which is an outcomes-based approach to managing CKD.¹² The authors conclude that this approach can lead to improvements in key clinical outcomes, such as earlier detection of CKD, increased adherence to guidelines, and improved patient outcomes, including reduced hospital admissions and improved survival rates. They also note that this approach can help to address some of the challenges associated with managing CKD in primary care, such as limited resources and lack of coordination between different healthcare providers.

The CKD Pathway is designed to identify and manage CKD at an early stage, before it progresses to end-stage renal disease. The authors describe the different stages of the Pathway and the outcomes that are measured, including:

1. Early detection and diagnosis of CKD
2. Assessment of CKD stage and risk factors
3. Implementation of interventions to manage CKD and its comorbidities
4. Monitoring and follow-up to evaluate treatment response and adjust management as needed
5. Referral to a specialist for advanced CKD or end-stage renal disease
6. Preparation for kidney replacement therapy (if necessary)
7. Provision of supportive care for patients and families

Reference:

12. Karkar, A., & Rafique, M. (2018). CKD Care Pathway in the United Kingdom: Outcomes-Based Approach. *International Journal of Nephrology and Renovascular Disease*, 11, 91–97. <https://doi.org/10.2147/ijnd.s158648>.

Payne, Morton, and Burton attest to improvement of patient outcomes as a result of Care Pathway implementation.

1	Scientific Literature	2	<i>Clinical Guidelines and Best Practices</i>
3	<i>Initiatives and Organisations</i>	4	<i>Policies and Strategies</i>

Methodology: Systematic Literature Review

The methodology of this article is a systematic review of the literature on healthcare pathways for CKD in primary care. The authors searched multiple databases for relevant studies and selected 15 studies that met their inclusion criteria. They analysed the data from these studies to evaluate the effectiveness of the pathways in improving patient outcomes.

Conclusion: CKD Pathways in primary care were effective in improving the detection of CKD, adherence to guidelines, and patient outcomes.

This systematic review aimed to assess the effectiveness of healthcare pathways for CKD in primary care.¹³ The Study found that healthcare pathways for CKD in primary care were effective in improving the detection of CKD, adherence to guidelines, and patient outcomes.

Specifically, the review identified that healthcare pathways for CKD in primary care resulted in increased identification and detection of CKD, improved adherence to guidelines for the management of CKD, and better patient outcomes, such as improved blood pressure control and slower progression of CKD.

Additionally, the Study highlighted that the use of electronic medical records and decision support tools could enhance the effectiveness of CKD pathways in primary care. The authors concluded that the implementation of healthcare pathways for CKD in primary care has the potential to improve the quality of care for patients with CKD and reduce the burden of CKD on the health system.

Reference:

13. Payne, S. A., Kirby, M., & Davies, I. (2019). Healthcare pathways for chronic kidney disease in primary care: a systematic review. *British Journal of General Practice*, 69(681), e813–e821. <https://doi.org/10.3399/bjgp19x706241>.

Wiegand, Albright, and Pickett demonstrate successful implementation of a CKD Pathway in primary care.

1	Scientific Literature	2	Clinical Guidelines and Best Practices
3	Initiatives and Organisations	4	Policies and Strategies

Methodology: Case study of a CKD Pathway in a US primary care practice

The methodology of this article is a case Study of the development and implementation of a CKD care pathway in a primary care practice in the United States. The authors describe the different components of the Pathway and how they were implemented in the practice. They also discuss the challenges they encountered and how they addressed these challenges.

Conclusion: Use of CKD Care Pathway in a primary care setting can lead to improved patient outcomes and adherence to guidelines.

The Study aimed to evaluate the development and implementation of a CKD Care Pathway in a primary care practice.¹⁴ Overall, the Study demonstrated the feasibility and effectiveness of implementing a CKD Care Pathway in a primary care setting, leading to improved patient outcomes and adherence to guidelines. This Study also measured improvements in CKD detection, adherence to guidelines and Centre patient outcomes such as blood pressure control and kidney function.

The Pathway they used was:

1. Patient identification and screening.
2. Confirmation of CKD diagnosis.
3. Staging of CKD based on glomerular filtration rate and albuminuria.
4. Assessment of comorbidities and complications.
5. Development of a personalised care plan for each patient.
6. Provision of patient education and self-management support.
7. Implementation of evidence-based interventions to manage CKD and its complications.
8. Regular monitoring of patients' kidney function, blood pressure, and other relevant parameters.
9. Referral to nephrologists or other specialists as needed.
10. Integration of primary care and specialist care to provide coordinated and continuous care for patients with chronic kidney disease.

Reference:

14. Wiegand, T. J., Albright, R. C., & Pickett, T. C. (2019). Development and Implementation of a Chronic Kidney Disease Care Pathway in a Primary Care Practice. *Journal of Primary Care & Community Health*, 10, 2150132719854402. <https://doi.org/10.1177/2150132719854402>.

El Nahas and Levin emphasise the importance of early detection and prevention strategies for managing CKD.

1	Scientific Literature	2	Clinical Guidelines and Best Practices
3	Initiatives and Organisations	4	Policies and Strategies

Methodology: Systematic Literature Review

In their article, El Nahas and Levin discuss the epidemiology and pathophysiology of CKD and they review the evidence on strategies for early detection and prevention. The authors conducted a narrative review of the available literature, which involved searching electronic databases such as PubMed and the Cochrane Library, as well as reviewing relevant guidelines and reference lists. Specifically, the authors reviewed studies and guidelines on the following topics:

1. Definition and classification of CKD.
2. Prevalence and incidence of CKD worldwide.
3. Risk factors for CKD, including age, ethnicity, diabetes, hypertension, and cardiovascular disease.
4. Screening and diagnostic tests for CKD, including estimated glomerular filtration rate (eGFR) and albuminuria.
5. Strategies for prevention and management of CKD, including lifestyle modifications and pharmacological interventions.

Reference:

15. El Nahas, M., & Levin, A. (2016). Chronic kidney disease management: a public health priority. *Nephrology Dialysis Transplantation*, 31(2), 201–203. <https://doi.org/10.1093/ndt/gfw352>

Conclusion: Early detection and prevention can lead to improved patient outcomes.

This article discusses the global burden of CKD and the need for effective management and prevention strategies.¹⁵ The authors highlight the importance of early detection and management of CKD, as well as lifestyle interventions to prevent the progression of the disease. They emphasise the importance of early detection and prevention strategies for managing CKD.

The outcomes of implementing these strategies include:

1. *Delaying or preventing the progression of CKD:* Early detection and treatment of CKD can help slow or halt the progression of the disease, preventing patients from reaching advanced stages of CKD or end-stage renal disease requiring dialysis or kidney transplantation.
2. *Reducing the burden of CKD:* CKD is a global health problem that is associated with high morbidity, mortality, and healthcare costs. Early detection and prevention strategies can help reduce the burden of CKD by preventing complications and improving outcomes.
3. *Improving quality of life:* Patients with CKD often experience symptoms and complications such as fatigue, pain, and anaemia, which can significantly affect their quality of life. Early detection and prevention strategies can help improve quality of life by addressing these symptoms and complications and providing supportive care.
4. *Decreasing healthcare costs:* CKD is associated with high healthcare costs. Early detection and prevention strategies can help decrease these costs by reducing the need for expensive treatments and hospitalisations.

Zaza, Squitieri, and Iorio suggest improving CKD management with Care Pathways.



1	Scientific literature	2	Clinical guidelines and best practices
3	Initiatives and organisations	4	Policies and strategies

Methodology: Systematic literature Review

This article is a literature review that discusses the role of care pathways in quality improvement initiatives for CKD management. The authors conducted a systematic review of existing research on the use of care pathways in CKD management and drew upon their own experience as health providers to identify key considerations for developing effective care pathways. They also discussed the principles of quality improvement that underlie effective care pathways.

Conclusion: Effective care pathways can improve patient outcomes.

The authors conclude that effective care pathways can improve patient outcomes, including delaying disease progression, reducing complications, and improving quality of life. They call for further research to identify best practices for the development and implementation of care pathways in CKD management.¹⁶ They identified several key considerations for developing effective care pathways, including:

- the need for patient-centred care;
- interdisciplinary care teams, and;
- continuous quality improvement.

Reference:

16. Zaza, G., Squitieri, S., & Di Iorio, B. (2021). Quality improvement in chronic kidney disease: the role of care pathways. *Journal of Nephrology*, 34(2), 399-408.

Boucher, Guerra, and Ta find use of a CKD Pathway in primary care settings leads to improvements for patients and providers.



1	Scientific Literature	2	Clinical Guidelines and Best Practices
3	Initiatives and Organisations	4	Policies and Strategies

Methodology: Retrospective Chart Review

The methodology of the Study involved a retrospective chart review and a before and after comparison of key outcomes to assess the effectiveness of a CKD Care Pathway in a Canadian primary care setting. The Study included 267 patients with CKD who were managed by primary care physicians. The researchers analysed data from electronic medical records to determine the proportion of patients who underwent CKD screening, were referred to specialists, and received appropriate medication management before and after the implementation of the Care Pathway. They also assessed the proportion of patients who achieved guideline-recommended blood pressure and glycaemic control targets.

Conclusion: Implementing CKD Pathways leads to improvements for providers and patients.

The outcomes of the Study showed significant improvements in CKD screening rates, referral rates, and medication management after the implementation of the Care Pathway.¹⁷ The Pathway used in the Canadian primary care setting comprised five steps:

1. **Screening:** Identify patients who are at risk for CKD through routine blood pressure measurements, urine dipstick tests, and blood tests to assess kidney function.
2. **Diagnosis:** Confirm the diagnosis of CKD through estimated glomerular filtration rate (eGFR) and albuminuria measurements.
3. **Treatment and Monitoring:** Provide appropriate treatment and monitoring for patients with CKD based on their stage of disease. This includes lifestyle modifications, medication management, and referral to a nephrologist as needed.
4. **Patient Education:** Educate patients about CKD, its risks, and the importance of adherence to treatment plans.
5. **Follow-up:** Schedule regular follow-up appointments to monitor patients' kidney function and adjust treatment plans as necessary.

The findings suggest that the implementation of a CKD Care Pathway in a primary care setting can improve patient outcomes by increasing the identification and management of CKD.

Reference:

17. Boucher, N., Guerra, L., & Ta, A. (2020). The Implementation of a Chronic Kidney Disease Care Pathway in a Canadian Primary Care Setting. *Canadian Journal of Kidney Health and Disease*, 7, 1-10.

Patel, Stankus, and Chen develop a patient-centred CKD Care Pathway in a primary care setting.

1	Scientific Literature	2	Clinical Guidelines and Best Practices
3	Initiatives and Organisations	4	Policies and Strategies

Methodology: Review of existing guidelines

The authors reviewed existing guidelines on CKD management and developed a patient-centred care pathway. The Care Pathway was implemented in a primary care practice and data was collected on the number of patients screened for chronic kidney disease, the number of patients referred to a nephrologist, and the number of patients with appropriate medication management. The authors analysed the data and compared outcomes before and after the implementation of the Care Pathway.

Conclusion: Implementing a CKD pathway leads to improvements for providers and patients

The authors found that the implementation of the CKD Care Pathway led to significant improvements in guideline adherence and patient outcomes.¹⁸ Specifically, there was an increase in the number of patients screened for chronic kidney disease, an increase in the number of referrals to a nephrologist, and an improvement in medication management. The authors note that the Care Pathway provided a structured approach to CKD management. The steps they propose in their pathway are:

1. *Screening and diagnosis*: Identify patients at risk for CKD and perform appropriate testing and diagnosis.
2. *Risk stratification*: Stratify patients based on their risk of progression to end-stage renal disease and other complications.
3. *Patient education*: Provide education to patients on chronic kidney disease, its management, and the importance of lifestyle modifications.
4. *Monitoring and management*: Implement regular monitoring and management of chronic kidney disease, including blood pressure control, medication management, and referral to nephrology as needed.
5. *Referral and coordination of care*: Coordinate care with nephrologists and other healthcare providers as needed to ensure optimal management of chronic kidney disease.
6. *Patient follow-up*: Schedule regular follow-up visits to monitor disease progression, manage comorbidities, and adjust management strategies as needed.

The implementation of the Pathway likely contributed to the improvements seen in patient care. Overall, the Study suggests that the development and implementation of a care pathway can lead to improved outcomes for patients with CKD in a primary care setting.

Reference:

18. Patel, P., Stankus, N., & Chen, S. C. (2020). Development of a Chronic Kidney Disease Care Pathway for a Primary Care Practice. *Journal of Primary Care & Community Health*, 11, 2150132720966482.

Several international guidelines on CKD Pathways exist that can be useful for informing a future state care pathway.

1	Scientific Literature	2	Clinical Guidelines and Best Practices
3	Initiatives and Organisations	4	Policies and Strategies

Various organisations have developed guidelines and recommendations for the management of CKD.

The National Institute for Health and Care Excellence (NICE) recommends several guidelines concerning prevention and treatment:¹⁹

- Early identification and diagnosis of CKD using estimated glomerular filtration rate (eGFR) and urinary albumin-to-creatinine ratio (ACR)
- Lifestyle interventions, such as smoking cessation, weight management, and regular physical activity
- Management of hypertension and diabetes to prevent and delay the progression of CKD
- Pharmacological treatments, such as renin-angiotensin-aldosterone system (RAAS) inhibitors and statins, to slow the progression of CKD
- Regular monitoring of kidney function and related health markers, as well as referrals to specialists as needed

National Kidney Foundation (NKF) focuses on comprehensive patient evaluation, management of complications, use of medications, and lifestyle modifications to slow the progression of CKD and improve patient outcomes:²⁰

- Comprehensive patient evaluation, including assessment of comorbidities and medication use

- Management of complications, such as hypertension and anaemia
- Use of medications, such as RAAS inhibitors, to slow the progression of CKD
- Lifestyle modifications, such as a low-protein diet, to manage CKD-related complications
- Referrals to specialists as needed, such as nephrologists and dietitians

Canadian Society of Nephrology (CSN) emphasises early identification, comprehensive evaluation, medication use, and lifestyle modifications:²¹

- Early identification and diagnosis of CKD using eGFR and ACR
- Comprehensive patient evaluation, including assessment of comorbidities and medication use
- Management of complications, such as hypertension, anaemia, and bone disease
- Use of medications, such as RAAS inhibitors and erythropoiesis-stimulating agents (ESAs), to slow the progression of CKD and manage related complications
- Lifestyle modifications, such as a low-protein diet, to manage CKD-related complications
- Regular monitoring of kidney function and related health markers, as well as referrals to specialists as needed

References:

19. National Institute for Health and Care Excellence. (2021). Chronic kidney disease in adults: Assessment and management. <https://www.nice.org.uk/guidance/ng157>
20. National Kidney Foundation. (2020). NKF KDOQI clinical practice guideline for the evaluation and management of chronic kidney disease. <https://www.kidney.org/content/nkf-kdoqi-guidelines>
21. Tangri, N., et al. (2021). Canadian Society of Nephrology commentary on the 2021 KDIGO Clinical Practice Guideline for the Management of Blood Pressure in Chronic Kidney Disease. *American Journal of Kidney Diseases*, 78(2), 266-268. <https://doi.org/10.1053/j.ajkd.2021.03.002>

Some initiatives related to CKD are in place in Bermuda.

1	Scientific Literature	2	Clinical Guidelines and Best Practices
3	Initiatives and Organisations	4	Policies and Strategies

Some Bermudian initiatives cover CKD:

1. Chronic Disease Innovation Programme (CDIP): The CDIP is a Government-led initiative that aims to improve the prevention and management of chronic diseases, including CKD. The Programme includes a range of initiatives, such as community-based education and screening programmes, training for healthcare professionals, and the development of clinical guidelines for CKD management. However, few updates can be found after 2019.²²
2. Healthy Schools Programme: A Government-led initiative that promotes healthy living among school-aged children in Bermuda. The programme includes a range of initiatives, such as nutrition education, physical activity programmes, and health screenings. By promoting healthy lifestyle habits at a young age, the programme aims to reduce the risk of chronic diseases such as CKD later in life.²³
3. Bermuda Diabetes Reversal Programme (DRP): The programme seeks to empower patients to understand, manage, control, and (in some cases) reverse their diabetes under the supervision of medical experts.²⁴

References:

22. Chronic Disease Innovation Programme (CDIP): Bermuda Health Council. (n.d.). Chronic disease innovation programme (CDIP). <https://www.bhec.bm/chronic-disease-innovation-programme/>
23. Healthy Schools Program: Government of Bermuda. (n.d.). Healthy Schools Program. <https://www.gov.bm/healthy-schools-program>

24. Fountain Health (n.d.). Diabetes Reversal programme. <https://www.fountainhealthbermuda.com/diabetes-reversal-programme>

Multiple organisations focus on treating CKD in Bermuda.

1	<i>Scientific Literature</i>	2	<i>Clinical Guidelines and Best Practices</i>
3	Initiatives and Organisations	4	<i>Policies and Strategies</i>

Multiple organisations in Bermuda are (partially) focused on CKD:

1. Bermuda Renal Associates: Non-profit private renal practice that specialises in the care of patients with various kidney disorders, hypertension and electrolyte disorders, whilst providing extensive patient education. The practice also provide public education and screening services on various topics related to kidney disease.²⁵
2. Kidney Care Bermuda: Offers specialised care for individuals with kidney disease, including dialysis treatments.²⁶
3. Bermuda Life Center: Provides support, resources, and dialysis to individuals living with kidney disease in Bermuda.²⁷

References:

25. *Kidney Care Bermuda: Kidney Care Bermuda. (n.d.). Home. Retrieved from <https://www.kidneycare.bm>*
26. *Bermuda Life Center (Jill Caines): Bermuda Life Center (Jill Caines). (n.d.). Retrieved from <https://bermuda-life-center.business.site/>*

WHO and CDC recommend prevention and integration of a CKD Pathway into the primary care system.

1	<i>Scientific Literature</i>	2	<i>Clinical Guidelines and Best Practices</i>
3	Initiatives and Organisations	4	<i>Policies and Strategies</i>

Overall, global health organisations recognise the importance of early detection and effective management of CKD. They provide resources and guidance for health providers, policymakers, and individuals to address this important public health issue. The highlights are summarised here:

WHO recommends a comprehensive approach to CKD care that includes the following strategies: ²⁸

- Primary prevention of CKD through the control of risk factors such as diabetes, hypertension, and obesity
- Early detection of CKD through regular monitoring of kidney function in high-risk populations, such as people with diabetes or hypertension
- Effective management of CKD through a multidisciplinary team approach that includes physicians, nurses, dietitians, and social workers. Treatment options may include lifestyle modifications, medication, and, in severe cases, renal replacement therapy such as dialysis or kidney transplantation
- Integration of CKD services into primary care systems, to ensure that CKD care is accessible and affordable to all individuals, regardless of their socioeconomic status or geographic location.

The CDC provides guidelines for CKD screening and diagnosis, which include the following recommendations: ²⁹

- Screen high-risk individuals for CKD, such as those with diabetes or hypertension, using laboratory tests such as serum creatinine and estimated glomerular filtration rate (eGFR).
- Confirm the diagnosis of CKD using repeated laboratory tests over a period of at least three months.
- Stage CKD according to the level of eGFR and the presence of proteinuria, which can help guide treatment decisions and predict outcomes.
- Refer individuals with CKD to nephrology specialists or multidisciplinary care teams for further evaluation and management.

References:

28. WHO. (2019). *Chronic kidney disease (CKD) [Fact sheet]*. World Health Organization. [https://www.who.int/news-room/fact-sheets/detail/chronic-kidney-disease-\(ckd\)](https://www.who.int/news-room/fact-sheets/detail/chronic-kidney-disease-(ckd))

29. Centers for Disease Control and Prevention. (2021). *Chronic kidney disease (CKD) surveillance system*. <https://www.cdc.gov/ckd/surveillance.html>

CKD-specific NGOs recommend strategies aimed at reducing the global burden of CKD.

1	Scientific Literature	2	Clinical Guidelines and Best Practices
3	Initiatives and Organisations	4	Policies and Strategies

The ISN Global Kidney Health Atlas provides recommendations for improving CKD care and reducing the global burden of kidney disease, which include the following strategies:³⁰

- Enhance CKD surveillance and monitoring systems to better understand the epidemiology and impact of CKD in different regions of the World
- Increase public awareness of CKD and its risk factors to promote early detection and prevention
- Strengthen health systems and workforce capacity for CKD prevention, detection, and management, including the development of national CKD guidelines and standards of care
- Promote research and innovation in CKD diagnosis, treatment, and prevention, to improve outcomes and reduce the burden of disease

The Kidney Disease: Improving Global Outcomes (KDIGO) clinical practice guidelines provide specific recommendations for the evaluation and management of CKD:³¹

- Screen high-risk individuals for albuminuria using spot urine tests and confirm with a 24-hour urine collection if needed
- Manage blood pressure in individuals with CKD to a target of less than 130/80 mm Hg, using medication and lifestyle modifications as needed
- Use angiotensin-converting enzyme (ACE) inhibitors or angiotensin receptor blockers (ARBs) to manage hypertension and reduce proteinuria in individuals with CKD
- Consider referral to a nephrologist or multidisciplinary care team for individuals with advanced CKD

References:

30. International Society of Nephrology. (2017). *ISN global kidney health atlas*. <https://www.theisn.org/global-kidney-health-atlas>
31. *Kidney Disease: Improving Global Outcomes (KDIGO)*. (2020). *KDIGO 2020 clinical practice guideline for the management of chronic kidney disease*. *Kidney International Supplements*, 10(1), e1-e137. <https://doi.org/10.1016/j.kisu.2020.04.001>

Few CKD-related policies and strategies are in place in Bermuda.

1	Scientific Literature	2	Clinical Guidelines and Best Practices
3	Initiatives and Organisations	4	Policies and Strategies

Only a few policies and strategies related to CKD are in place in Bermuda:

- Bermuda Health Strategy 2014-2019 outlines the Government's priorities and goals for improving healthcare in Bermuda. One of the key areas of focus is the prevention and management of chronic diseases, including CKD. The strategy emphasises the importance of early detection and treatment of CKD, as well as the need for effective management of risk factors such as diabetes and hypertension.³²
- In the state of Bermuda's health, the National Health Strategy 2022 – 2027 mentions CKD prevention and treatment as a priority:³³

"In order to manage the Island's limited financial means, we need to understand what our priority health needs are, including both physical and mental health. The growth in chronic preventable non-communicable diseases like heart disease, kidney disease, cancer, and diabetes has strained Bermuda's health system capacity, particularly as our population ages. Urgent change is needed to address this pressing challenge. We must establish a clear and accurate picture of what these health needs are and implement ways to monitor and manage them."

- Health Insurance: Bermuda has several health insurance programmes that cover a range of medical services, including treatment for CKD.³⁴

References:

32. Bermuda Ministry of Health. (2022). Bermuda National Health Strategy 2014-2019. Retrieved from: <https://www.gov.bm/sites/default/files/2019-01/Bermuda-Health-Strategy-2014-2019.pdf>
33. Bermuda Ministry of Health. (2022). Bermuda National Health Strategy 2022-2027. Retrieved from: <https://www.gov.bm/sites/default/files/MoH%20Bermuda%20Health%20Strategy%202022-2027%20v10.pdf>
34. Bermuda Health Strategy 2014-2019: Ministry of Health, Bermuda. (2014). Bermuda health strategy 2014-2019. <https://www.gov.bm/sites/default/files/2019-01/Bermuda-Health-Strategy-2014-2019.pdf>

Appendix 5: Consulted Stakeholders

This project was completed in partnership with stakeholders across Bermuda.



The involvement of all stakeholders played a pivotal role in shaping this project's outcomes and we are grateful for their participation and support.

Thank you!

Ashley Rodgers, Project Manager, Data and Innovation, Bermuda Health Council

Brenda Dale, AVP Wellness, BF&M

Chris Merritt, General Manager, Atlantic Medical International

Diane Gordon, Disaster Manager, Bermuda Red Cross

Dr. Danielle Farrington, Consultant Nephrologist, Kidney Care Bermuda

Dr. Dean Okereke, Chief of Emergency, BHB

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This project also owes its success to the invaluable contributions of many highly engaged patients, whose names remain undisclosed to protect their privacy.

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We'd love to hear from you! If you have any query or concern, reach out for a helping hand. Please find our contact details below:

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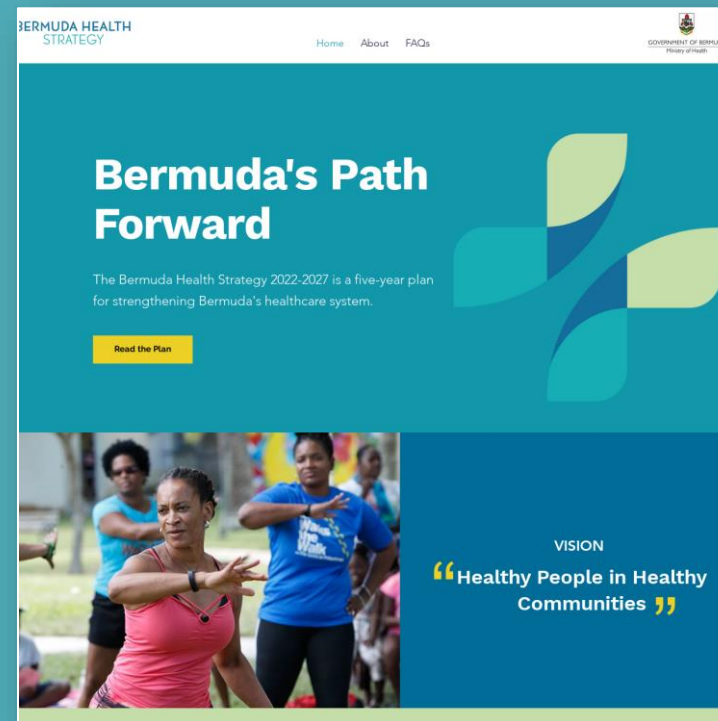
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