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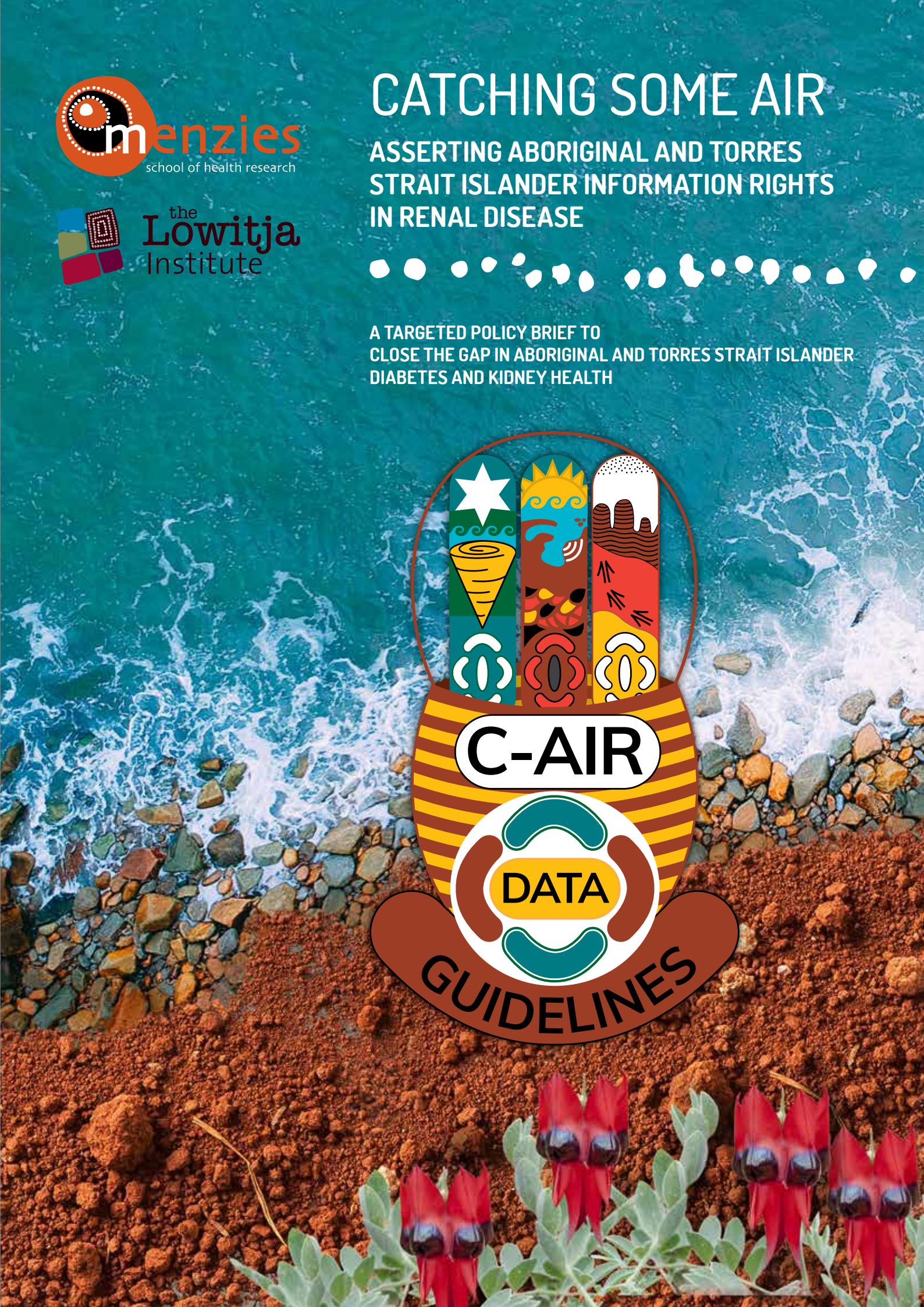
CATCHING SOME AIR

ASSERTING ABORIGINAL AND TORRES STRAIT ISLANDER INFORMATION RIGHTS IN RENAL DISEASE

A TARGETED POLICY BRIEF TO
CLOSE THE GAP IN ABORIGINAL AND TORRES STRAIT ISLANDER
DIABETES AND KIDNEY HEALTH



In the spirit of respect, Menzies School of Health Research acknowledges the people and elders of the Aboriginal and Torres Strait Islander nations who are the traditional owners of the land and seas of Australia.

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The policy brief was presented in December 2018 to the Hon Warren Snowden MP, and Hon Ken Wyatt AM MP. On May 3rd 2019, Catching Some Air entered into an agreement with Kidney Health Australia to submit this document unaltered as an appendix to the National Strategic Action Plan for Kidney Disease within the Compendium Stocktake document to the Government.

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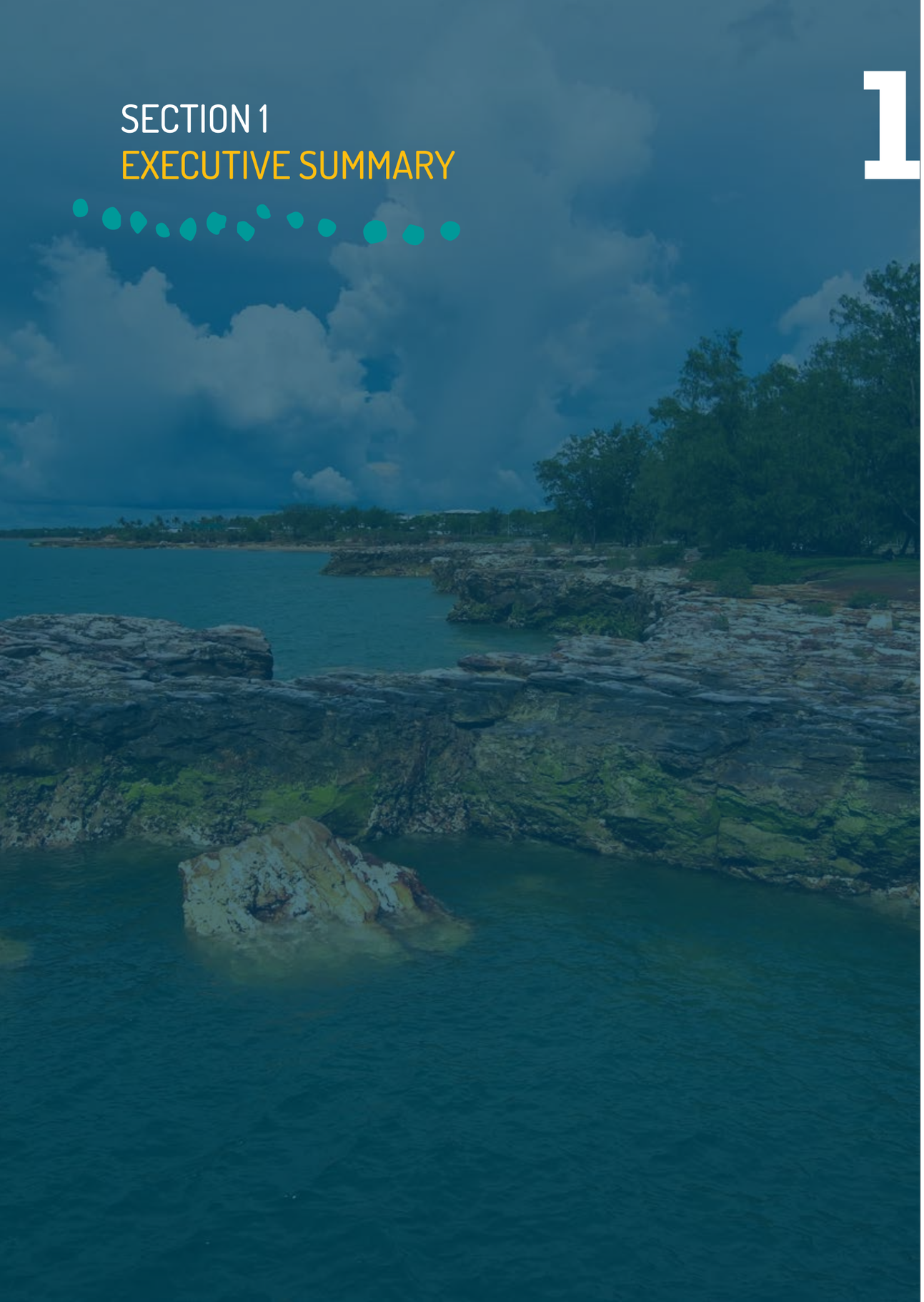

SECTION 1
EXECUTIVE SUMMARY

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We momentarily pause, take a breath ('catch some air'), reflect, plan and advocate for targeted action to improve kidney health for Aboriginal and Torres Strait Islander peoples in northern and central Australia.

The Indigenous-led CATCHING SOME AIR (C-AIR) project team have comprehensive expertise spanning culture and community, community development, health promotion, Indigenous training, primary and tertiary health care, research, evaluation and policy. Informed by an intensive 12-month community-consultation, we present strategic multi-level activities which require sustainable implementation for diabetes and kidney health advancement. This policy brief was invited by Hon Ken Wyatt AM MP, Minister for Indigenous Health and invited by Hon Warren Snowden, Member for Lingiari following targeted feedback led by Dr Jaqui Hughes to these parliamentarians on November 29th 2018.

Aboriginal and Torres Strait Islander diabetes and kidney disease - devastating yet preventable

Diabetes and chronic kidney disease (CKD) occur more frequently and at younger ages among Aboriginal and Torres Strait Islander people compared to non-Indigenous Australians[1]. Undiagnosed and poorly controlled diabetes and progressive CKD contribute to excess hospital care for Aboriginal and Torres Strait Islander people, and have devastating impacts on individuals, families, communities and economies. Early clinical markers of diabetes and CKD often co-exist with overweight, cardiovascular disease risk markers[2] and chronic infections[3-5] and inflammation[6], and low socio-economic status[7, 8]. Episodes of chronic infection[9] and acute infection with sepsis[10] may contribute to acute kidney injury and explain rapidly progressive CKD and dialysis initiation[11]. Improving communication about kidney health and health treatments is a high priority identified by health care providers and Aboriginal and Torres Strait Islander health care users and communities[12-15].

In Darwin, Thursday Island and Alice Springs, the C-AIR project invited community members with lived-experiences of diabetes and CKD to recommend best practice for kidney health in relation to 1) clinical care and 2) the collection and use of kidney health data[12, 13, 15]. The consultation meetings have confirmed that data and clinical care are powerfully linked, yet Aboriginal and Torres Strait Islander peoples have been excluded from processes which determine health action priorities, modalities and models of service delivery, decision-making processes and accountability for policy decisions. This feedback is consistent with advice obtained at the 2017 Indigenous Patients Voices Symposium[16].

Consultation approach and key recommendations

A consultation process led by Aboriginal and Torres Strait Islander people engaged with patients living with diabetes and kidney disease, carers and family members. The consultation articulated the urgent and unmet need for a community-level focus on prevention/health education, early intervention and brief interventions.

A new paradigm involving a broader investment is required across the continuum of care in primary, secondary and tertiary health care for our mob at risk of kidney disease. The new paradigm must encompass community-identified priorities for Aboriginal and Torres Strait Islander diabetes and kidney health in regional and remote Australia, and acknowledge the complex matrix of stakeholders.

Investment Required

We believe action is needed now to close the gap in renal health. This requires urgent and targeted investment including:

1) Fund activities to identify and map the cross-sector silos which impact Aboriginal and Torres Strait Islander renal health in North and Central Australia
2) Agree on a set of measurable key performance indicators which target and demonstrate Closing the Gap in Aboriginal and Torres Strait Islander renal disease, and a financial investment to collect, monitor and evaluate health outcomes
3) We ask for financial investment and commitment to implement, evaluate and upscale a multi-disciplinary community-based Indigenous kidney health workforce servicing rural and remote communities

Our Commitment

We invite a strategic partnership at the Federal level to engage us to progress the business case aligned to the required investment with stakeholders (State and Territory governments, local government, community controlled health sector, higher education and vocational education and training institutions, research institutes, and health services and other relevant stakeholders).

Policy Challenges (risks)

To address and resolve renal disease within Aboriginal and Torres Strait Islander communities is challenging in its own right. During our consultation and preparation for this policy brief, a number of pertinent issues and concerns (referred now as challenges) were identified ***(TABLE 1)***. These challenges cannot be addressed in isolation of the broader context to Close the Gap in Aboriginal and Torres Strait Islander renal health.
The challenges require urgent attention, either alone or collectively.

Action Outcomes

We have identified the three most urgent key priorities (investment required) and the policy recommendations (items). We anticipate some of the above challenges can be addressed and incorporated within the investment required and the policy recommendations.

Policy Items (recommendations)

The key policy recommendations (Items) are referenced to Aboriginal and Torres Strait Islander community-informed and expressed priorities for best practice for health, in particular for diabetes and kidney health. The issue, impact, proposed solution and potential funding requirements are discussed for each item.

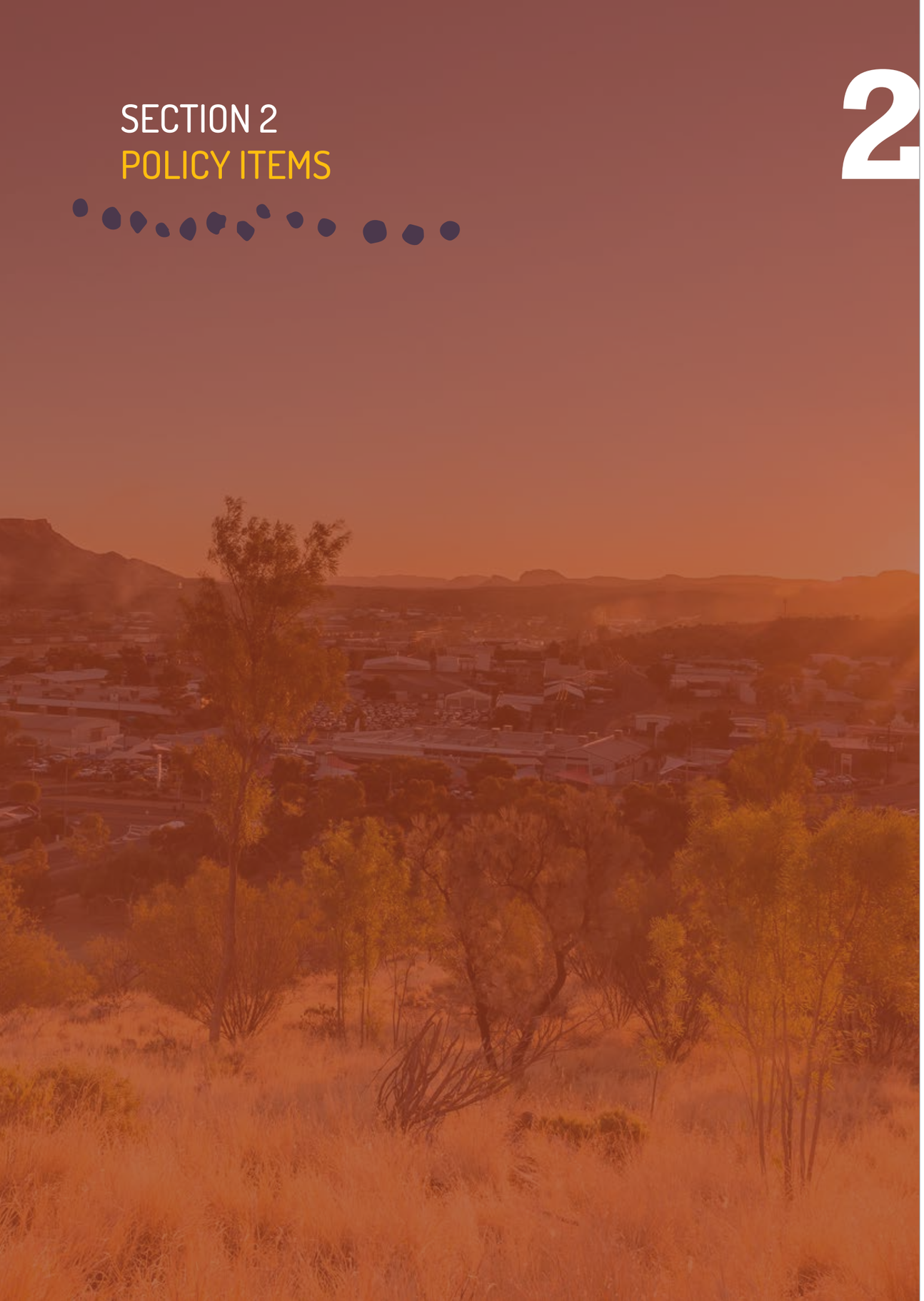
- Coordinated and economically sustainable strategies to address renal health across all levels of government
- Meaningful knowledge sharing for the Aboriginal and Torres Strait Renal Patient Community
- Preventative Health Care
- Sustainable Workforce

Table 1. Challenges in Closing the Gap in Aboriginal and Torres Strait Islander renal health

1. Silos
2. Funding
3. Changes in government policy at all levels of government
4. Shifting sign posts
5. Lack of specific renal health targets and performance indicators
6. Leadership
7. Racism
8. Poverty
9. Transparency
10. Support for Indigenous workforce
11. Readiness of community
12. Training and support to sustain succession planning and Indigenous workforce
13. Data, monitoring and evaluation systems
14. Lack of treaty
15. Indigenous ownership of renal current and future directions
16. Reciprocity of shared priority agenda
17. Urban vs Rural vs Remote Aboriginal and Torres Strait Islander communities
18. Cross cultural knowledge sharing

SECTION 2
POLICY ITEMS

2



Item 1

Coordinated and economically sustainable strategies to address renal health across all levels of government

The Issue

Lack of coordination of policy and planning of urban, rural and remote renal health services have adverse effects on the health and wellbeing of renal patients, their carers/families and the wider community. Renal health services planning has been heavily weighted towards a centralised service model which has been necessary to meet the needs of end stage kidney disease, with insufficient engagement of renal patients in the design, development and implementation of these services.

The Impact

The absence of strategic policy to address issues associated with renal prevention/health promotion has been detrimental to Aboriginal and Torres Strait Islander communities. The present renal service planning model detracts from the community-defined and mandated priority of simultaneously delivering health maintenance and preventive health care.

The Proposed Solution

The greatest health impact requires coordination and integration of health services and programs that work cohesively and accountably toward closing the renal health gap within thirty years. Guided by agreed key performance indicators for optimal kidney health, a consortium of cross-sector agencies must be identified to collaborate with renal patients and carers. These agencies include Federal, State, Territory, Local government, Aboriginal Medical Services, Private and Public Renal Services.

Collective and integrated solutions should be developed, implemented and evaluated to test their ability to achieve predefined key performance indicators for optimal kidney health within a culturally appropriate and cultural competent framework for kidney health and illness prevention.

Proposed funding requirement

- Fund a cross-border executive level program leader and team to oversee in key pilot sites and which has authority to direct priorities across agencies. The executive team manages a coordinated implementation of strategies across all levels of governments, health services and with rural and remote stakeholders
- Design, implement and evaluate an Indigenous-led renal workforce model for rural and remote communities.
- Upfront commitment to fund the upscaling of successful models across regions in Northern and Central Australia where progressive kidney disease and ESKD are most profoundly impacting Australians

We believe sustainability in this proposed solution will achieve a cost benefit through reduced expenditure on acute care evacuations, and costly management of diabetes and end stage kidney failure. An employed local workforce drives local economies, improves the standard of living for the Indigenous workforce, and creates health hubs with a focus on health maintenance.

Item 2
Meaningful knowledge sharing for the Aboriginal and Torres Strait Renal Patient Community

The Issue
Australia's health care system advantages Australians living close to centralised and metropolitan services, and disadvantages those living further away. There is a physical divide between biomedical knowledge keepers (health expertise) who can assist access to biomedical treatments, and the Aboriginal and Torres Strait Islander peoples living in Australian regions which have the highest burden of diabetes and progressive CKD (health care users).

The Impact
Aboriginal and Torres Strait Islander patients and families want information for personal positive health, and personalised action plans which promote health and wellness. This divide diminishes accurate, relevant, efficient and effective knowledge sharing, and manifest as **profound knowledge gaps.**

Profound knowledge gaps may arise due to
1. Staff having low knowledge of effective methods of biomedical knowledge sharing between culturally distinct groups (the health carer and remote living Indigenous peoples)
2. Reduced time for effective knowledge sharing (competing clinical duties of understaffing)
3. Low workforce participation of Indigenous people who have knowledge of bicultural ways of working
4. Systems of health care which favour those who can access mainstream and centralised services, and
5. Models of care designed to meet the needs of service providers, rather than Aboriginal patients.

The Proposed Solution
Fit for purpose **biomedical knowledge sharing processes and methods** are required to address the **profound knowledge gaps** and to advance health of Aboriginal and Torres Strait Islander peoples. These processes will address key priority areas recognised by clinicians and patients and community and include: overweight, diabetes, heart and kidney health, and risks associated with chronic infection and inflammation.

Proposed Funding Requirement
1. Fund the development of a health curriculum developed in partnership with community, clinical leaders and adult learning specialists. The curriculum should be suitable for adult learners, people of variable education base and Indigenous learning strengths
2. Funding to develop mixed-media resource packages suitable for individual patient and family use, in group meetings and use with a clinician. Resource packages will need to be modified for local learning and knowledge strengths
3. Funding knowledge exchange events, appropriately facilitated by an Indigenous person and incorporating technical experts from well-patients and clinicians. We believe there is value in upscaling Kidney Yarning Circles: Pathways to My Home and the group meetings we have hosted as part of Catching Some Air.

We believe the funding request align to Closing the Gap in Indigenous health funding.

Item 3
Preventative Health Care

The Issue
There is no comprehensive preventive kidney health care model which is suitable for Aboriginal and Torres Strait Islander people living in rural and remote areas known to have high risk of diabetes and progressive CKD.

The Impact
Undiagnosed and poorly controlled diabetes and progressive CKD contribute to excess end stage kidney disease (requiring dialysis), hospital care and excess mortality. These largely preventable conditions have devastating impacts on individuals, families, communities and economies in Northern Australia.

The Proposed Solution
A preventive care model is required and must work for Aboriginal and Torres Strait Islander people living with and at risk of developing diabetes and CKD. The model will require ground up design with adaptations from existing models (such as Deadly Choices), and requires funding of an Indigenous workforce in rural and remote communities.

Community based health prevention workers will comprise this innovative workforce, which will be locally recruited and trained. Their training expertise will include health promotion/prevention/health education. They will be linked into regional, state/territory wide and commonwealth hubs.

Commonwealth and Territory/State and Local governments and Aboriginal Community Control sectors must have a partnership agreement with renal patients within local communities/ regional areas to discuss options for funding.

Proposed Funding Requirement
1. Financial support to expand the Deadly Choices health promotion program nationally, with emphasis on Indigenous employment
2. Financial support to implement and evaluate the impact on kidney health maintenance and reduced CKD progression of an Indigenous renal health curriculum within the Deadly Choices program
3. Funding to support primary health care staff training and competency in renal health

Item 4
Sustainable Workforce

The Issue
The current renal workforce across metropolitan, urban, regional, rural, remote and very remote communities is predominantly comprised of non-Indigenous staff. In rural and remote communities the skill mix is concentrated around generalist clinical skills.

The Impact
Aboriginal and Torres Strait Islander patients living with diabetes and kidney disease require highly accessible and safe health care. Clients report fear and mistrust of health systems oriented to non-Indigenous populations. Fear impedes health access and confidence.

The present workforce models in rural and remote communities suffer from chronic understaffing, recruitment challenges following retirement or high staff turnover, and a reliance on fly-in temporary staff. These factors significantly impact on the quality and continuity of care and trust for patients, carers and communities, and lead to poorer health outcomes.

The Proposed Solution
Strategic activities to increase the Indigenous health workforce in rural and remote areas are required, and should include:

- An Indigenous-led multidisciplinary team model of care which invests in building the professional capacity of the community based workforce and the primary health care sector.
- Training opportunities for local people as carer assistants for people with advanced co-morbid conditions and disability.
- Training program development to support local Indigenous people to access employment as health workers, practitioners and nurses within the MBS 13105 item for assisted dialysis in very remote Australia.
- Local community infrastructure to host health promotion and health maintenance activities
- Accommodation for the new workforce
- Affordable and reliable transport infrastructure to enable professional capability enhancement and networking with renal services

Proposed Funding Requirement
Funding to support development, implementation and evaluation of the impact of Indigenous-led work units
Funding training pathways and programs for community members to be trained and employed within the workforce
Funding capital investment in rural and remote communities to host health promotion activities, and safe and affordable housing for Indigenous workforce

These funding requirements are aligned to the National Aboriginal and Torres Strait Islander Health Worker Association plan, National Strategic Framework for Chronic conditions, Local Government Association, State and Territory workforce.

ABBREVIATIONS

C-AIR	Catching Some Air - Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease
CKD	Chronic Kidney Disease
MBS	Medicare Benefit Schedule

Ms Norma Benger designed the Catching Some Air Project logo, which represents Aboriginal and Torres Strait Islander authority in message sticks to guide recommendation standards for data and clinical care for kidney health. The artwork is not to be reproduced.

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