Queensland Human Rights Commission

CASE NOTE:

Inquest into RHD Doomadgee Cluster

Court/tribunal	Coroners Court of Queensland
Type of proceeding	Inquest into health care deaths
Application of *Human Rights Act 2019*	Section 58 (conduct of public entities)
Rights engaged	Right to life (s 16) Right to privacy and reputation (s 25) Right to protection of families and children (s 26) Cultural rights - Aboriginal peoples and Torres Strait Islander peoples (s 28) Right to health services (s 37)
Outcome	Findings and recommendations made
Commission intervened?	Yes
Date of decision	30 June 2023

About Rheumatic Heart Disease (RHD)

RHD is entirely preventable. It is almost exclusively a disease of poverty and social disadvantage and was eradicated from white Australia many decades ago. There are currently 3600 active clients on the Queensland RHD Register and Control Program; of those, 68% of clients identify as Aboriginal or Torres Strait Islander.

RHD starts as a sore throat from strep infections that are most common in childhood. Repeated strep infections can lead to rheumatic fever, which causes inflaming and scarring of the heart valves. RHD results from damage to the heart valves due to one or several episodes of rheumatic fever. Rheumatic fever and RHD predominantly affect children, adolescents and young adults. Prognosis of RHD is relatively poor and treatment can include regular and painful antibiotic injections, blood thinning medications and monitoring, and heart surgery.

RHD is prevented by the most simple and basic measures of health and hygiene including washing of hands, washing of clothes, regular showering / bathing, and early treatment of sores and fever.

Background

The inquest investigated the deaths of three young women. At the request of family, they are referred to in the Coroner's written findings as Betty (age 18), Ms Sandy (age 37) and Kaya (age 17).

All are Aboriginal women who lived in Doomadgee, and died from RHD or complications from RHD, within 12 months of each other.

The women variously received treatment and care for their conditions from Doomadgee Hospital, Gidgee Healing (an Aboriginal Community Controlled Health Organisation providing primary health care in Doomadgee), other community and hospital services within North West Hospital and Health Service, and Alice Springs Hospital.

The issues examined at inquest included:

- the adequacy of primary health services provided to the women by Gidgee Healing;
- the adequacy of care provided by Doomadgee Hospital to the women, with particular emphasis on the six months before their deaths; and
- the adequacy of screening RHD and the public health, education/prevention and follow up provided in Doomadgee regarding acute rheumatic fever (ARF) and RHD.

The Coroner found inadequate primary health care had been provided to Betty and Ms Sandy, and that Doomadgee Hospital had not provided appropriate follow up care to Betty and Ms Sandy. Doomadgee Hospital also failed to act on Kaya's mother's reasonable concerns for her daughter.

The Coroner additionally found that adequate screening of RHD has yet to be achieved in Doomadgee, that there was and remains poor knowledge in Doomadgee regarding the cause and prevention of ARF and RHD in the community, there is an inability to provide effective culturally safe care due to hurdles in recruiting and retaining Indigenous Health Workers and Indigenous Liaison Officers in Doomadgee, and there had been a general breakdown in trust in the community regarding the provision of health care services provided in Doomadgee (paragraphs [694]-[695] of the Coroner's written findings at https://www.courts.qld.gov.au/__data/assets/pdf_file/0006/770109/cif-booth-sandy-george-20230630.pdf).

A summary of factors that coalesced and contributed to the outcomes for Ms Sandy, Betty and Kaya are at paragraph [124].

The Coroner made 19 recommendations in accordance with section 46 of the Coroners Act 2003.

Application of the Human Rights Act to the inquest

The Coroner found that holding an inquest and making findings and recommendations to prevent deaths is an administrative function of the court, and therefore subject to the obligations on a public entity under section 58 of the Human Rights Act 2019 [125]. This means that the Coroner must:

a. conduct the inquest in a manner that is compatible with human rights (including the right to life, the right to a fair hearing, equality before the law, and the cultural rights of Aboriginal peoples and Torres Strait Islander peoples);

b. undertake a thorough and effective investigation that takes into account all surrounding circumstances, in accordance with the right to life. This may include making findings on failures by public entities to comply with the Human Rights Act that may have caused or contributed to the deaths. If the relevant acts or decisions occurred before the Human Rights Act commenced, human rights are relevant to the Coroner's power to comment on matters to prevent deaths from happening in the future, given that these public entities have human rights obligations going into the future;

c. give proper consideration to human rights, and to make decisions, findings, and comments that are compatible with human rights;

d. in making recommendations, take into account the protection of human rights, including a consideration that recommendations should be designed to protect human rights (such as the right to life, the right to health services and cultural rights) and should not disproportionately limit human rights (such as the right to privacy) [132].

The Coroner accepted that Queensland Health, the North West Hospital and Health Service, and the Doomadgee Shire Council, as well as their staff and executive officers, are all public entities within the meaning of the Human Rights Act [126].

Gidgee Healing accepts that it is likely to be a public entity under the Human Rights Act. However, even if it is not a public entity, the Coroner noted that it does not affect the function of the Coroner to make comments or recommendations [127]-[128].

Health records and information sharing

The Coroner found that the barriers to an unimpeded flow of medical records and health information across all relevant health services and facilities in Doomadgee represented a serious systemic failure. She said:

> *The siloing of critical health records and the inability to share the information across all platforms was known by all entities and yet continued and continues without complete rectification. The inability of health providers and professionals to gain a full clinical picture at crucial times impacted the care and treatment of Betty, Kaya and Ms Sandy [107].*

In relation to human rights, the Coroner observed:

> *The complexity of medical record keeping, also includes a consideration of data sovereignty. It is a fundamental human right for all people to control and protect personal data and to expect organisations to control and protect that data, which in turn increases First Nations access to control decisions and the narratives that affect them and their communities [102].*

The Coroner recommended developing (or refining) guidelines for information sharing between Gidgee Healing and North West Hospital and Health Service.

Doomadgee Hospital and the right to access health services

The Coroner accepted the Commission's submission that:

> The Doomadgee Hospital appears on relevant occasions to have failed to provide patients and their families with sufficient information about their health care and treatment, to enable them to fully understand their health conditions and the benefits of treatment, and to appropriately involve families in the provision of health care. In addition, the failure to adequately communicate with Gidgee Healing about shared

patients appears to have led to a breakdown in providing adequate follow-up. These factors have impacted on the protection of patients' health by limiting the right to life and the right to health services.

At times the Hospital did not deliver culturally safe services, and there appears to have been at least a perception among some patients of racism and, more generally, in their interactions with health workers affecting the right to equality, the right to health services, and cultural rights [651]-[652].

The Coroner's recommendations go towards addressing these issues.

Cultural rights and considerations

In her decision, the Coroner outlined the history of Doomadgee, and noted the people of Doomadgee were placed in that location by a State government only relatively recently.

The Coroner considered the cultural safety of health services being provided in Doomadgee, including the training being provided to clinicians, the use of prejudicial language in health records, and the limited knowledge of practitioners of the Queensland Health Guideline '*Sad News, Sorry Business'*.

Noting the issues that had been raised around cultural safety, the Coroner expressed concern that Ms Sandy's nonadherence and disengagement with the health services in Doomadgee may have been a direct result of the medical overwhelm experienced by her over many years of prior treatment for her condition [648].

The Coroner found that cultural rights are preserved by the existence of Gidgee Healing in Doomdagee in that it:

- supports community identity, such as employing local community members and/or Aboriginal or Torres Strait Islander people more broadly;
- ensures that there is observance of language and cultural expression;
- recognises kinship ties and how those relationships might be impacted, such as local staffing, patient interactions and genuine immersion of staff in the community;
- ensures that Aboriginal and Torres Strait Islander people are not forced to assimilate, for example by allowing autonomy of choice to use a mainstream service such as the Doomadgee Hospital; and
- is governed by a predominately First Nations Board of Directors and CEO, including a number of Directors with close cultural connections to Doomadgee [722].

The Coroner observed that it is essential that racism in all its forms be identified, measured and monitored. Self-reporting and subjective assessment is not sufficient or appropriate in a mature society. Tools are available to assist with the objective assessment of racism. Language matters and is at the forefront of societal change [729].

The Coroner also indicated that adoption of any of the recommendations must be implemented with the community of Doomadgee and not just for the benefit of the Doomadgee community [728].

The Coroner's recommendations relevant to cultural safety included:

- appointing an independent Community Liaison Officer who can promote local recruitment,
- developing a 'guardian angel service' to support patients in times of acute illness,
- that health services consider adopting or adapting a tool such as the Matrix for Identifying, Measuring and Monitoring Institutional Racism within Public Hospitals and Health Services (Marrie, A. and Marrie, H. 2014) ;
- that health services consider whether improvements could be made with respect to the recording of clinical notes to avoid implicit negative cultural and racial connotations, and
- that a program be co-designed with the Doomadgee community to ensure all clinicians and staff have appropriate training in understanding cultural safety and communicating in a culturally safe way with patients with an understanding of cultural matters specifically relevant to the Doomadgee community.

Rights of the child

In line with the submissions of the Commission the Coroner found that adequate screening for RHD is yet to be achieved in Doomadgee. She further accepted that rheumatic fever, which leads to RHD, is most commonly seen in children aged 5 to 14 years, and that any limitation to strategies for prevention limits the rights of children [695]-[696].

The Coroner recommended that Queensland Health take steps to determine the most effective approach to identify ARF and RHD in Doomadgee and other First Nations communities where there is high prevalence.

Read the Coroner's findings in full: https://www.courts.qld.gov.au/__data/assets/pdf_file/0006/770109/cif-booth-sandy-george-20230630.pdf.