CORONERS COURT

OF NEW SOUTH WALES

Inquest:	Into the death of Ivan Leo Goolagong
File number:	2017/225703
Hearing dates:	1-5 March 2021
Date of findings:	22 October 2021
Place of findings:	Coroners Court, Lidcombe
Findings of:	Deputy State Coroner E Truscott
Catchwords:	Coronial Law - Cause and manner of death - First Nations Person- palliative care - death in corrections custody – Justice Health - care and treatment
Representation:	Counsel Assisting: Mr W de Mars instructed by Ms L Nash of Crown Solicitor's Office Priscilla Goolagong and Ivan Goolagong Jnr: Self-represented Department of Corrective Services NSW: Ms C Melis instructed by Ms H Aitken of Department of Communities and Justice Justice Health and Forensic Mental Health Network: Mr P Rooney instructed by Ms O Sclavenitis of McCabes Dr J Grimsdale: Mr S Beckett instructed by Mr J Vijayaraj of Avant Law Dr V Sze: Ms Liarne McCarthy of HWL Ebsworth

Findings	**Identity**	**Ivan Leo Goolagong**
	Date of Death	**23 July 2017**
	Place of Death	**Long Bay Hospital Medical Subacute Unit**
	Cause of death	**Metastatic Pancreatic Adenocarcinoma**
	Manner of death	**Ivan Leo Goolagong was a Wiradjuri man who died of natural causes whilst in the custody of Corrective Services NSW**
Non-Publication Orders	1. That the following information contained in the brief of evidence tendered in the proceedings not be published under section 74(1)(b) of the Coroners Act 2009 (NSW): a. The names, addresses, phone numbers and other personal information that might identify any family and/or person who visited Mr Goolagong while in custody, other than legal representatives or visitors acting in a professional capacity; b. the names, personal information and master index numbers known as the MIN, relating to any persons in the custody of Corrective Services NSW other than Mr Goolagong; c. the direct contact details of Corrective Services NSW staff; d. the closed-circuit television, CCTV footage and CCTV images and any stills of images captured at the Long Bay Hospital nursing station.	
Non-Access Orders	2. Pursuant to section 65(4) of the Coroners Act 2009 (NSW), a notation be placed on the Coroner's file that if an application is made under section 65(2) for access to any Corrective Services NSW documents on the Coroner's file, that material shall not be provided until Corrective Services NSW has had an opportunity to make submissions in respect of that application.	
Recommendations	**<u>Early release under s. 160 *Crimes (Administration of Sentences) Act 1999*</u>** **To the NSW Commissioner of Corrective Services**	

1. That CSNSW develops a policy to give guidance to Services and Programs Officers, Regional Aboriginal Programs Officers, psychologists and any other relevant staff, in relation to the advice and assistance that such staff should provide inmates who express a desire to seek early release on medical grounds, and that such policy be aimed at helping to facilitate and expedite such applications without the need for inmates engaging legal assistance.

2. That, in the interim, CSNSW takes action to ensure that relevant staff (including Services and Programs Officers, Regional Aboriginal Programs Officers and psychologists) who are asked by inmates for assistance in connection with early release applications on medical grounds:

    - Are aware of the potential need for such matters to be expedited;
    - Are aware that they can and should contact relevant CSNSW project officers for further potential advice and assistance as to how the matter might best be progressed; and
    - Are aware that it is not the case that such applications can only proceed by means of the inmate engaging legal assistance.

To the Commissioner of Corrective Services and the CEO of the Justice Health Forensic and Mental Health Network

That CSNSW and Justice Health formalise a policy, as soon as possible, with the aim of helping inmates suffering from a terminal illness who wish to apply for early release, or their families, to do so in a manner that minimises delay and does not require applicants to seek recourse to external legal representation to obtain medical reports from Justice Health or to advance their application.

To the CEO of the Justice Health Forensic and Mental Health Network

That Justice Health take action to ensure that any relevant staff with reporting obligations under cl. 285 CAS Regulation are aware of their obligations under that clause.

Telephone access for inmates during end of life care

To the Commissioner of Corrective Services and the CEO of the Justice Health Forensic and Mental Health Network

That a CSNSW and Justice Health working party in relation to the operation of the MSU is established to develop practices, so as to:

- Ensure that terminally ill inmates receiving end of life care in the MSU are permitted phone access to contact family members at any hour of the day and that requests for phone access by such prisoners are allowed and not delayed;
- Make phone access for terminally ill inmates more streamlined so that clinical staff are permitted to provide relevant phone access to patients without the need for permission to be obtained from CSNSW; and
- Consider any other measures that might be implemented to make the environment in the MSU for terminally ill inmates less restrictive.

Palliative Care Needs of First Nations prisoners

To the Commissioner of Corrective Services and the CEO of the Justice Health Forensic and Mental Health Network

1. That relevant senior officers of CSNSW and Justice Health review the report prepared for the court by Associate Professor Williams with a view to determining how some of the policy suggestions outlined at pages 28 to 31 might be implemented in their organisations.

2. That a CSNSW and Justice Health working party consult with Associate Professor Williams to consider the feasibility of:
   - Introducing peer support programs for terminally ill First Nations prisoners in the MSU; and
   - Enabling access to Long Bay Hospital by "in-reach" services offered by of appropriate community based First Nations Health organisations.

To the NSW Commissioner of Corrective Services

That CSNSW takes action to provide greater support for, and numbers of, Regional Aboriginal Programs Officers, and Aboriginal Support and Programs Officers, so they at least reflect the proportion of NSW inmates who are First Nations.

To the CEO of the Justice Health Forensic and Mental Health Network

1. That Justice Health employs at least two First Nations health care workers, nurses or medical officers as part of the complement of clinical staff at the MSU, and looks to employ greater numbers of First Nations staff generally, and that in doing so Justice Health ensures that such additional staff are provided with adequate support to perform their work effectively.

2. That MSU clinical staff receive immersive training in provision of health care to First Nations patients within a First Nations' community health organisation setting.

Provision of palliative care to terminally ill inmates at the MSU more generally

To the CEO of the Justice Health Forensic and Mental Health Network

1. That Justice Health develops a care planning protocol for all patients in the MSU who are diagnosed with a terminal illness, so that a clear multi-disciplinary plan is devised, followed up and regularly re-evaluated, commencing as soon as an inmate is identified as having a terminal diagnosis.

2. That the positions responsible for devising, overseeing and evaluating such care plans are clearly identified and known by clinical staff at the MSU.

3. That the role and responsibilities of the Cancer Care Nurse Coordinator so far as it relates to MSU patients is clearly delineated, made known to clinical staff in the MSU and audited for its effectiveness.

4. That Justice Health urgently prioritise providing immersive forms of training of MSU clinical staff involving placements over a number of days with outside Palliative Care providers such as the Program of Excellence in the Palliative Approach ("PEPA").

	5. That further training of MSU staff in Palliative Care emphasises the importance of early identification of the psychosocial needs of inmates and skills in rapport development.

IN THE CORONERS COURT
LIDCOMBE
NSW

Section 81 *Coroners Act 2009*

REASONS FOR DECISION

Introduction

1. Ivan Leo Goolagong was a proud Wiradjuri man born in Condobolin, NSW in 1949. His two eldest children, Priscilla and Ivan (Jnr), attended each day of this inquest. Through Counsel Assisting they generously shared with the court some details about Ivan Leo Goolagong's early life.

2. Ivan Leo Goolagong grew up on Country in and around Condobolin. He commenced his working life at the age of 13 after leaving school aged 12 with rudimentary literacy and numeracy skills. His main work was labouring and stock work. He married young and had nine children. By his late teens, he had become a talented rugby league player. The Goolagong family moved to various towns (such as Albury in the south) and later settled on the Central Coast as their father pursued his football career. Later Ivan Leo Goolagong developed an art practice and became a clothing print designer. The family frequently travelled back to Country and to visit their large extended family, who remained in and around Condobolin.

3. By his mid to late 30's, Ivan Leo Goolagong had developed diabetes type II. He had been struggling with alcohol for some time and, to preserve his health, he stopped drinking. He entered custody in 2011 at the age of 61 years, by which time he had additional health problems including ischaemic heart disease, asthma, anaemia and chronic pancreatitis. While in prison, he had numerous ongoing health issues requiring review by various health services. In December 2016, Ivan Leo Goolagong was diagnosed with pancreatic cancer. On 31 January 2017 Ivan Leo Goolagong underwent a Whipple's Procedure, which is a significant surgery to remove the bulk of the pancreas. On 20 February 2017 he was admitted into the Long Bay Prison Hospital Medical Subacute Unit ("MSU"). Apart from two occasions when he was transferred to Prince of Wales Hospital ("POWH") for treatment relating to his cancer, he remained there until his death on

23 July 2017. Upon his admission to the MSU, Ivan Leo Goolagong should have been referred to the Cancer Care Nurse Coordinator ("CCNC"). The CCNC is employed by Justice Health at Long Bay to coordinate care for prisoners diagnosed with cancer. Ivan Leo Goolagong did not receive any such care or support. On two or three occasions, at his request, Ivan Leo Goolagong saw a psychologist employed by Corrective Services NSW ("CSNSW"), which is a separate organisation and which is siloed from Justice Health. Within a couple of days of his admission into the MSU (in February 2017), the family of Ivan Leo Goolagong sought assistance to apply for his early release on parole pursuant to s. 160 of the *Crimes (Administration of Sentences) Act 1999* ("CAS Act") so that he could return to Country for end of life care and to be with his family. They sought the assistance of CSNSW program officers who were employed to assist Aboriginal prisoners. After their request was not progressed, approximately a further month passed, at which time the family sought assistance again. The family were incorrectly advised that they needed to instruct a lawyer to make this application, notwithstanding that Justice Health was under a statutory obligation to advise CSNSW that because of illness, Ivan Leo Goolagong would not survive his sentence. Justice Health failed to properly notify CSNSW regarding same.

4. Ivan Leo Goolagong's family instructed Legal Aid to submit his early release application to the State Parole Authority. Unfortunately, to obtain the information about his medical condition to provide to the State Parole Authority, Ivan Leo Goolagong's solicitor was required to submit a Freedom of Information Application to CSNSW and Justice Health, and to seek a letter from his oncologist regarding his life expectancy and trajectory of his illness. All of this could and should have been provided to the family without the need for such a time-consuming and costly process.

5. As a result of the Whipple's procedure, Ivan Leo Goolagong had significant difficulties consuming food and maintaining his weight. This was also compounded by the progression of his disease. Those difficulties were marked by a lack of appetite, difficulty swallowing, and aversion to certain foods he received in custody. Ivan Leo Goolagong lost a significant amount of weight as a result of his disease, and by July 2017, when he was scheduled to have palliative chemotherapy, he was deemed too frail for it to proceed.

6. Ivan Leo Goolagong's application for early release on parole was submitted to the State Parole Authority in late June 2017, and while CSNSW input was being

sought, Priscilla was making the necessary arrangements to facilitate Ivan Leo Goolagong's release from the MSU. Initially, it was hoped that Ivan Leo Goolagong could be cared for at home by his family, however these plans were abandoned, as it became apparent that his health had gravely deteriorated. Arrangements were being facilitated to have Ivan Leo Goolagong admitted into Condobolin Hospital. Unfortunately, Ivan Leo Goolagong passed away before the State Parole Authority hearing regarding his early release had been heard (which had been listed for 1 August 2017).

7. On the night of 22 July 2017, he requested to speak with Priscilla on the telephone but this was declined by CSNSW, who apparently told him that the call could wait until morning. Unfortunately, Ivan Leo Goolagong passed before then.

8. The inquest is required pursuant to ss. 27(1) and s. 23 of the *Coroners Act 2009* (the "Act") as Ivan Leo Goolagong was in lawful custody at the time of his death.

9. Given the constraints of the provisions of the Act, an inquest is confined to the manner and cause of a person's death and cannot be too far removed from the events that led to a person's ultimate passing. As Ivan Leo Goolagong had suffered from a variety of health issues whilst in custody prior to his diagnosis with pancreatic cancer, his family were concerned about the overall healthcare treatment that their father received during that entire time, not just during the final months of his life. Their invaluable First Nations perspective on the challenges that First Nations inmates face in receiving culturally appropriate healthcare is acknowledged and greatly appreciated. However, the Act requires consideration only of matters sufficiently connected to a person's death. It was therefore not appropriate that this inquest inquired into matters removed from Ivan Leo Goolagong's cancer diagnosis. Accordingly, the inquest explored the palliative care and treatment provided to Ivan Leo Goolagong, with a focus on the scope for improvements that might assist towards providing inmates in custody with a standard of care similar to that afforded to persons diagnosed with a terminal illness in the general community.

10. I acknowledge and regret that this limitation will undoubtedly sadden and cause despair to Ivan Leo Goolagong's loved ones. I extend my sincere condolences to the Goolagong family and especially acknowledge their sadness at knowing that their father, Ivan Leo Goolagong, a proud Wiradjuri man, died in custody, alone, rather than being given an opportunity for early parole to travel back to Country

and be with his family engaging in appropriate Aboriginal Ceremony. This fact has been traumatic, particularly for Priscilla, who feels strongly that her father's spirit is yet to go back to Country and be at rest. An inquest itself is often difficult and traumatic for family and loved ones, and I accept that this inquest has been no exception. I hope however that in some way, the inquest and these findings provide some relief and peace to Priscilla, Ivan Jnr and the extended Goolagong family.

Issues at the inquest

11. The issues identified in the coronial investigation to be explored in the inquest were as follows:

    1. Did Ivan Leo Goolagong receive adequate and appropriate treatment from the time of his transfer to the MSU on 20 February 2017 until his death on 23 July 2017?
    2. In particular were the palliative care, dietary and psychosocial needs of Ivan Leo Goolagong adequately met during this period when he was at the MSU?
    3. Following his discharge from Prince of Wales Hospital on 29 June 2017, should Ivan Leo Goolagong have been transferred back there at some stage prior to his death on 23 July 2017?
    4. Was Ivan Leo Goolagong's application for early release based on his terminal illness being appropriately acted upon by Corrective Services NSW and Justice Health?
    5. To what extent, if any, are services specific to the needs of First Nations inmates in custody with terminal illnesses, available to inmates such as Ivan Leo Goolagong?

Cancer diagnosis and treatment

12. In August 2016, Ivan Leo Goolagong was an inmate at Junee Correctional Centre when he developed jaundice. A CT scan taken on 1 September 2016 reported *"[l]arge likely intra-ductal calcification at the head of the pancreas causing moderate to marked pancreatic and bile duct dilation, on a background of*

scattered calcification in the pancreas consistent with chronic pancreatitis".[1] He was transferred to the MSU and then to POWH where stents were placed in the common bile duct. On 8 September 2016, he was transferred back to the MSU, however he was then readmitted to POWH on 8 October 2016 with cholangitis, septicaemia with atrial flutter. The biliary stents were blocked. They were replaced, and Ivan Leo Goolagong was transferred back to the MSU until 26 November 2016, when he was transferred back to Junee Correctional Centre (with four days at Bathurst Correctional Centre in the interim).

13. On 7 December 2016 Ivan Leo Goolagong had another CT scan at Wagga Wagga Base Hospital which indicated an enlarged pancreatic mass with lymphadenopathy and hypodensities in the liver. On 13 December 2016, Ivan Leo Goolagong was transferred to Royal Prince Alfred Hospital ("RPAH") for a Whipple's Procedure and investigation of the suspected cancer. The procedure was delayed as Ivan Leo Goolagong had hyperkalaemia (excessive potassium levels) which required treatment prior to the procedure being able to be undertaken. On 10 January 2017, he was transferred to and remained in the MSU until his transfer back to RPAH on 31 January 2017 for his Whipple's procedure. He underwent surgery, and after a period of recovery he returned to the MSU on 20 February 2017. A histopathology report dated 7 February 2017 indicated the following:

- A 70mm pancreatic adenocarcinoma with margins;
- Metastatic adenocarcinoma in 6/18 lymph nodes with extra nodal spread and tumour deposits; and
- Metastatic adenocarcinoma in liver.[2]

14. Professor David Goldstein, Ivan Leo Goolagong's treating oncologist, noted in correspondence dated 9 March 2017:

> *"Given his pathology, Ivan has T3 N1 M1 stage IV pancreatic adenocarcinoma. We explained that he is at high risk of recurrence at 80% given the high-risk features on his pathology and foci of metastatic disease in his liver. There are 2 possible options of management for Mr Goolagong. The first being whether we would view his case as a subgroup of pancreatic cancer patients who are*

[1] Discharge Referral Note dated 8 September 2016, Justice Health medical records (Volume 4), Volume 2, Tab 25, p. 121.
[2] Histopathology Report by Dr Catriona McKenzie dated 7 February 2017, Justice Health medical records (Volume 5), Volume 2, Tab 26, p. 160.

potentially rendered with no evidence of disease after surgery despite his focus of liver metastasis and subsequently treat with "adjuvant chemotherapy comprising of ESPAC-4 protocol. The second management option would embrace a palliative approach with surveillance and then institute palliative chemotherapy at the time of recurrence. We will discuss his case at our next gastrointestinal multidisciplinary team meeting. In the meantime, I have advised Mr Goolagong to continue to improve his fitness and nutrition. We will follow him up in 2 weeks' time and will keep you informed of his progress."[3]

15. On 19 April 2017, Ivan Leo Goolagong underwent a CT scan, which was reviewed by Professor Goldstein on 27 April 2017. He noted:

> *"CT scan shows no evidence of disease progression at this point in time although it was a non- contrast because of difficult venous access. The plan is to continue with surveillance at present and not initiate palliative chemotherapy until there is good evidence of disease progression.*
>
> *Accordingly he will be seen again in a month's time".*[4]

16. On 23 May 2017, Professor Goldstein reviewed Ivan Leo Goolagong again and noted:

> *"He remains asymptomatic but somewhat depressed because of the knowledge that he does have metastatic disease. There is nothing new to find on physical examination. His liver function tests are stable though his albumin is somewhat low and his CA19-9 continues to slowly elevate. Given the absence of any physical symptoms and the normal CT previously, further surveillance is reasonable and he will be seen again in one month's time."*[5]

17. On 23 June 2017 a contrast CT scan report indicated "*multiple new hypodense liver lesions…highly suspicious for progressive metastatic disease*".[6]

Ivan Leo Goolagong's understanding of his diagnosis and wish to seek early release on parole

18. It was not until the histopathology report was received following the Whipple's surgery that it was confirmed that Ivan Leo Goolagong's cancer had metastasised, although the results of a December PET scan conducted at Wagga Wagga Base Hospital were highly suggestive of this eventual diagnosis. At that

[3] Letter from David Goldstein to A/Prof Charbel Sandroussi dated 9 March 2017, Justice Health medical records (Volume 4), Volume 2, Tab 25, p. 179.
[4] Letter from David Goldstein to A/Prof Charbel Sandroussi dated 27 April 2017, Justice Health medical records (Volume 4), Volume 2, Tab 25, p. 186.
[5] Letter from David Goldstein to A/Prof Charbel Sandroussi dated 23 May 2017, Justice Health medical records (Volume 5), Volume 2, Tab 26, p. 170.
[6] Final Report on CT Chest and Abdomen dated 23 June 2017, Justice Health medical records (Volume 7), Volume 2, Tab 28, p. 64.

time, it appears that Ivan Leo Goolagong was expecting that the Whipple's Procedure would mean that all of the cancer had been removed, and that he would therefore be cancer free. It is unclear whether Ivan Leo Goolagong had been informed that it was known, or at least suspected, that the cancer had metastasised to his liver, and was aware of the seriousness of his disease. Professor Goldstein's reference to the recurrence of cancer in his letter of 9 March 2017 tends to support that Ivan Leo Goolagong was under the impression that the surgery had removed all of the cancer. In reality, it had only removed the cancer from the pancreas; it had metastasised to his liver as well. The fact that Ivan Leo Goolagong did not understand this is perhaps unsurprising given the terminology used.

19. Whether Ivan Leo Goolagong had been advised of the histopathology results (which confirmed his terminal condition) is unclear. It was recorded in Ivan Leo Goolagong's medical notes on 24 February 2017 that he remarked that he was "*cancer free now*". The writer of that note had placed in brackets *"(?told in RPAH)"*. Again, this entry is supportive of the fact that Ivan Leo Goolagong did not fully appreciate the nature of his diagnosis.

20. This notwithstanding, on 22 February 2017, Ivan Leo Goolagong had a telephone conversation with the CSNSW Manager of Security ("MoS"), Cheryl Wood, together with his daughter Priscilla, in which they discussed a possible early release to parole due to his terminal condition. The following day (23 February 2017), CSNSW Aboriginal case workers Catherine Ryan and Kristy Ohlsen also visited Ivan Leo Goolagong in relation to his desire to seek early release on parole.

21. On 24 February 2017, Ivan Leo Goolagong saw MSU doctor, Dr Mica Spasojevic. She queried Ivan Leo Goolagong's understanding about being "*cancer free*". As a result of that meeting, Dr Spasojevic reviewed the February 2017 histopathology report and the December 2016 PET scan. She then spoke with Ivan Leo Goolagong again on 28 February 2017 and discussed the results of the histopathology report with him. Ivan Leo Goolagong asked to see a psychologist, which occurred the following day on 1 March 2017. The psychologist's notes indicate that Ivan Leo Goolagong had been informed that his cancer remained.

22. On 30 March 2017, Ivan Leo Goolagong attended Professor Goldstein and on his return to the MSU he remarked that his "*cancer ha[d] returned"* to his liver.[7] His

[7] Case Note Report dated 31 March 2017, Justice Health medical records (Volume 5), Volume 2, Tab 26, p. 171.

medical notes record that Ivan Leo Goolagong was frustrated at being told that he still had cancer in his liver, having previously been told that it was in remission.

23. It would appear that when Ivan Leo Goolagong returned to the MSU on 20 February 2017, his understanding as to the nature of his disease may have been limited. He had been advised that at that stage there was no cancer to treat but that there was a high chance that in the future there would be. This is consistent with Professor Goldstein's letter of 9 March 2017. From a medical perspective however, having no signs or evidence of cancer that requires immediate treatment is different to not having cancer at all. A lay person may have difficulty understanding this distinction. The fact that this distinction had apparently not been successfully communicated to Ivan Leo Goolagong meant that he may not have had an adequate understanding of his disease and its likely progression, which is most regrettable. This miscommunication was no doubt compounded by the fact that such a misunderstanding occurred with the context of Ivan Leo Goolagong holding an understandable mistrust towards medical providers in regards to the information and treatment that they provided. As such, it appears that he felt cheated by his medical providers and his treatment remained an ongoing cause of understandable, yet preventable, distress to Ivan Leo Goolagong.

24. As early as February 2017, Ivan Leo Goolagong understood that his medical condition was serious because at that time, he had discussions about the prospects of an early release due to his diagnosis. He reiterated this desire again on 30 March 2017 when he said he "*would like assistance from welfare because he wants to appeal his sentence on medical grounds*".[8]

25. Ms Ohlsen, Aboriginal Services and Programs Officer, again saw Ivan Leo Goolagong on 3 April 2017. He told her his cancer had returned and he wanted to action an appeal against his sentence. This was confirmed in a telephone call between Ms Ohlsen and Priscilla on 6 April 2017. On or around 27 April 2017, Ivan Leo Goolagong was presumably informed of the results of the CT scan of 19 April 2017. He was presumably told that medical providers would continue to monitor his condition rather than commence treatment. Again, on 3 May 2017, Ivan Leo Goolagong told a CSNW psychologist that he wanted assistance regarding an early release from prison application. These repeated requests indicate that Ivan Leo Goolagong understood that his condition was terminal.

[8] Case Note Report dated 31 March 2017, Justice Health medical records (Volume 5), Volume 2, Tab 26, p. 171.

26. There does not appear to have been a scan in May 2017 and Ivan Leo Goolagong was apparently asymptomatic at this time. He had a contrast scan on 23 June 2017 which showed progressive disease. He arranged to see a lawyer to arrange his financial affairs, power of attorney and last will and testament. Although Ivan Leo Goolagong wanted to have chemotherapy treatment and he was conveyed to POWH on 7 and 13 July 2017, on each occasion chemotherapy did not proceed as he had become so frail that he felt unable to cope with chemotherapy and its side effects.

The Medical Subacute Unit, Long Bay Prison Hospital

27. Counsel Assisting made the following submission:

> *"The evidence suggests that the clinical staff in the MSU have little if any specific training in the psycho-social aspects of Palliative Care. The evidence also suggests that they had little or no interaction with Ivan Snr aimed at establishing an understanding of his social or cultural background. In short, they do not appear to have been well equipped to attempt to develop rapport and empathy with a First Nations man with a terminal illness. By contrast, some of the more specialist staff at POWH (for example the psychiatry medical officer) exhibited an understanding of how this might be done, however their opportunity to interact with Ivan Snr was limited in the circumstances".*

28. The Goolagong family adopted this submission and remain highly upset that Ivan Leo Goolagong died in such circumstances.

29. Justice Health did not take issue with Counsel Assisting's submission, preferring to focus their submissions on the medical care that Ivan Leo Goolagong received after 30 June 2017 and the changes that had been made more recently in regard to the palliative care services provided by Justice Health in the MSU.

30. Likewise, CSNSW did not take issue with Counsel Assisting's analysis. Rather their closing submissions focussed on the routines in the MSU, Ivan Leo Goolagong's application for early release on parole, the refusal of Ivan Leo Goolagong's request for a telephone call to his daughter on the night prior to his death and the recommendations put forward by Counsel Assisting.

31. The MSU has 29 beds in one and two bed cells. The numbering system commences at number 16 (cells 1 – 15 are part of the Aged Care and Rehabilitation unit at Long Bay Hospital). The MSU accommodates prisoners

who have been discharged from hospital and require ongoing medical care. The current Governor of Long Bay Hospital (which supervises the MSU) is Mr Jason Hodges (in 2017 he was working in the correctional facility at Broken Hill). He provided two statements which were included in the coronial brief of evidence, and he gave oral evidence at the inquest. He identified that CSNSW officers working in the MSU have a number of functions, including facilitating health providers' access to inmates, facilitating inmates to exercise outside of their rooms, interacting with prisoners and reporting and recording matters as they arise on shift.

32. The MSU is subject to a routine similar to any hospital. This includes meal service throughout the day: 7:30am breakfast, a 10am morning tea, a 12pm lunch, a 2pm afternoon tea, and a 5.30 pm dinner.

33. However, as the MSU patients are prisoners, their cells are locked from 2:30pm to 8am each day as well as 11.30am - 12.30pm to allow CSNSW to have lunch breaks. From time to time, lockdowns may be imposed due to reduced staff levels, for example, when officers are redeployed to escort prisoners during unplanned transfers to an (outside) hospital or where there is a serious incident in a relevant corrections facility. Prisoners have access to the dialysis unit in the MSU until 7pm.

34. Medical staff, who are employed by Justice Health, require a CSNSW staff member to accompany them if they are attending a patient in their cell. When a patient has an appointment to see a medical practitioner, a CSNSW staff member is required to escort them to and from the cell. The CSNSW staff member is also required to be present during the appointment. Although Mr Hodges said that locking the cells does not hamper medical staff accessing a patient, the evidence from medical staff was that their access to prisoners is very limited given the hours that prisoners are regularly locked in their cells and additional lockdowns that would occur from time to time, and that generally, prisoners are unavailable when the cells are locked.

35. Mr Hodges also stated that the locked cell system does not interfere with food service. That is because food service is either via a door hatch or the door being opened or closed in any event. Mr Hodges stated that when a prisoner is in end of life care, the CSNSW MSU staff facilitate family members to visit regardless of lock-in times. He also stated that when requested by nursing staff, a MoS can

authorise a patient's cell door to remain unlocked to enable nursing staff direct access to a patient, which allows them to provide *"comfort and care"* to a patient whose health is precarious and/or deteriorating.

36. CSNSW staff provide corrections services for a secure facility at POWH known as the "Annex". This is a seven bed unit for inmates requiring hospitalisation outside of the relevant medical unit of a correctional facility. The hospital visiting regime applies to the Annex and CSNSW are able to accommodate a degree of flexibility so that visitors can attend the Annex outside of regular visiting hours. More recently, due to the COVID-19 restrictions affecting visitation to correctional facilities, CSNSW has arranged for computer tablets to be located at its hospitals to facilitate video-call visits between prisoners and their family and friends.

37. Dr Spasojevic is a senior career medical officer at Justice Health. She has worked at the MSU as its full-time medical officer since 2008. She explained that care of MSU patients is provided under the guidance of appropriate specialists from POWH or other referring hospitals. She provided a statement as part of the coronial investigation, in which she described the MSU's role thus:

> … *"providing care to patients with chronic and subacute medical conditions, post-surgical care, spinal patients care, infectious disease, oncology patient care, palliative care and end of life care.*
>
> *For patients with a terminal illness, medical care is provided under oncology and palliative care specialists, their guidance and follow ups".*[9]

Ivan Leo Goolagong's Health Management Plan

38. On 20 February 2017, when Ivan Leo Goolagong was received into the MSU from RPAH following his Whipple's procedure, a form called a Health Management Plan ("HMP") was commenced and kept on his file. It is a two-page document with each side expressing a statement that *"this is a multi-disciplinary plan with an expectation that all professionals involved in care contribute".*[10] The HMP's design identifies a patient's needs, the strategies and interventions for each of those needs, the person or service responsible for addressing those needs and the target and review dates, as applicable.

[9] Statement of Dr Mica Spasojevic dated 18 August 2020 at [8]-[9], Volume 1, Tab 21A, p. 2.
[10] See for example, Health Management Plan, Justice Health medical records (Volume 4), Volume 2, Tab 25, p. 214.

39. The HMP should have provided for a comprehensive palliative care plan for Ivan Leo Goolagong. The progression of the cancer, and whether palliative chemotherapy treatment was required, necessitated close monitoring and good communication amongst the MSU medical staff. Importantly, the HMP should have focused on Ivan Leo Goolagong's nutrition, in particular the requirement to be on a pancreatic enzyme replacement (Creon), which arose from his Whipple's procedure. Every time Ivan Leo Goolagong ate, he was required to take Creon. He was required to eat a diabetic diet, which the inquest learned was no different to a normal CSNSW-mandated diet. Due to his poor appetite, Ivan Leo Goolagong was also provided with the meal replacement "Ensure Plus" for supplemental nutrition. Due to his diabetes, his blood sugar levels required especially close monitoring and were often deranged. Ivan Leo Goolagong experienced significant difficulty with his appetite and receiving palatable food. This required ongoing monitoring and communication.

40. The HMP was completely inadequate, both in its content and use as a multi-disciplinary communication device to ensure that Ivan Leo Goolagong was appropriately managed. Dr Spasojevic said it was not a form that she dealt with, identifying it as one which the nurses were required to complete. Registered Nurse ("RN") Christine Maher said that she commenced the HMP, entering the words *"weight loss"*. She gave evidence that she otherwise did not complete the form, as it was not a form with which she was familiar. The HMP provides for the identification of a patient as Aboriginal or Torres Strait Islander. RN Maher stated that she did not think that Ivan Leo Goolagong identifying as Aboriginal held any relevance (regarding patient care) beyond that the HMP required that information to be completed.

41. The inquest heard evidence from Paul Grimmond, who is the Director of Nursing and Midwifery Services at Justice Health. In his statement, he said that all patients who have a life limiting illness are referred to the CCNC. This is required to occur if the patient identifies that they have cancer when they are received into the custody of CSNSW or if they are diagnosed at any time during their incarceration. The CCNC position is full-time and located at Long Bay Hospital. The CCNC also provides services to other CSNSW facilities. The position was occupied at the time when Ivan Leo Goolagong was a prisoner. According to Mr Grimmond's statement, Ivan Leo Goolagong was not referred to or seen by the CCNC at any time. He should have been. According to Mr Grimmond's statement that was because Ivan Leo Goolagong required input from the palliative care

team. That team was based at POWH.

42. Given that the referral to the CCNC was supposed to have occurred at the time of Ivan Leo Goolagong's diagnosis and there was a five month gap before the community palliative care team attended upon him (on 18 July 2017), this evidence does not provide an adequate explanation as to why Ivan Leo Goolagong was not referred to the CCNC, in circumstances where as at the end of February 2017, it was known that Ivan Leo Goolagong had pancreatic cancer that had metastasised to his liver.

43. Mr Grimmond said that the explanation as to why Ivan Leo Goolagong was not referred to the CCNC was provided to him by the After Hours Nurse Manager who, like Mr Grimmond, worked in the Integrated Care Service at Long Bay Hospital. On the last day of the inquest Mr Grimmond gave further evidence that he had recently spoken to the CCNC about Ivan Leo Goolagong and the CCNC told him that she had seen Ivan Leo Goolagong at one point but that he had declined her services. Mr Grimmond was unable to say when this interaction occurred and agreed that there is no reference to such a conversation between Ivan Leo Goolagong and the CCNC in any of the Justice Health records or in any other location that he was aware of.

44. Further, in Ivan Leo Goolagong's Justice Health medical and nursing records there is not a single reference to the CCNC at any point. Nor did any of the staff who made statements or gave evidence to the inquest at any time mention the position or role of the CCNC at the MSU. This evidence establishes that not only did the CCNC play no role in Ivan Leo Goolagong's care or coordination of care, the staff at the MSU did not contemplate this as a possibility.

45. The lack of coordinated cancer care resulted in a poor delivery of the already meagre palliative care services that were available to Ivan Leo Goolagong, which negatively impacted on his and his family's involvement in his end of life care.

The Cancer Care Nurse Coordinator

46. A document dated May 2020 and titled "Business Rules" was produced to the inquest during Mr Grimmond's evidence. It was not possible to discern during the inquest, whether the rules relating to the CCNC's role existed in that form since 2016 (when the role was commenced), or whether they were more recently

created. In any event, the role descriptor does give an indication of what care Justice Health expects a prisoner with a cancer diagnosis to receive from its staff. The key aspects of the role are as follows:

- Guiding the patient to information and services that foster independence;
- Awareness of consultation, treatment plans and treatment outcome;
- Coordination of the implementation of care plans including the provision of information and referral to appropriate services; and
- Single point of contact for cancer services development and education of staff regarding appropriate referral pathways and documentation; and release planning.

47. Ivan Leo Goolagong's HMP being barely completed could be explained by the fact that it was likely to have been an appropriate task to be carried out by the CCNC. This, of course, did not occur as no appropriate referral had been made. Mr Grimmond said that the CCNC had taken leave in January, February, March and July 2017 but that she had known Ivan Leo Goolagong when he was in another prison as she used to give him insulin. She apparently told Mr Grimmond that, at some stage in 2017 when she was in a meeting, she heard that Ivan Leo Goolagong was in the MSU. She subsequently went to the MSU to see him and introduce herself and talk about the service. She told Mr Grimmond that she knew him well and he responded to her with *"[u]s Black Fellas, we do our own things our own way".*[11]

48. If that is accurate, it would seem that the CCNC took that comment as dismissive (to the extent she didn't even write a note), rather than considering there might be a person other than herself, who could have a conversation with Ivan Leo Goolagong about what his cultural needs (which he raised) were. The CCNC was unable to tell Mr Grimmond when this conversation occurred, and she said she was surprised that she hadn't made a note of it.

Palliative care

49. The coronial investigation included the obtaining of expert review of the custodial

11 Transcript of Hearing Day 5 (5 March 2021), T129.50-130.1 (Paul Grimmond).

Palliative Care Services provided to Ivan Leo Goolagong. A report prepared by Associate Professor Ghauri Aggarwal was served, and Justice Health obtained a report prepared by Dr David Gorman. Both Associate Professor Agarwal and Dr Gorman are palliative medicine and pain specialists. Associate Professor Aggarwal is currently the Head of Department at the Concord Centre of Palliative Care.

50. Associate Professor Aggarwal and Dr Gorman gave their evidence in conclave. They concurred that the following definitions provided by Palliative Care Australia relevantly explain what Palliative Care and End of Life Care is and what such care seeks to provide:

> ***"Palliative Care** is person and family-centred care provided for a person with an active, progressive and advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.*
>
> *…. is care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness*.
>
> *…. identifies and treats symptoms which may be physical, emotional, spiritual or social. Because palliative care is based on individual needs, the services offered will differ but may include:*
>
> *(a) Relief of pain and other symptoms e.g. vomiting, shortness of breath;*
>
> *(b) Resources such as equipment needed to aid care at home;*
>
> *(c) Assistance for families to come together to talk about sensitive issues;*
>
> *(d) Links to other services such as home help and financial support;*
>
> *(e) Support for people to meet cultural obligations;*
>
> *(f) Support for emotional, social and spiritual concerns;*
>
> *(g) Counselling and grief support; and*
>
> *(h) Referrals to respite care services*.
>
> ***…**is a family-centred model of care, meaning that family and carers can receive practical and emotional support*.
>
> ***End-of-life care** is the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death. The needs of patients and their carers is higher at this time. This phase of palliative care is recognised as one in which increased services and support are essential to ensure quality, coordinated care from the health care team is being delivered. This takes into account the terminal phase or*

when the patient is recognised as imminently dying, death and extends to bereavement care".[12]

First Nations palliative care needs

51. Associate Professor Megan Williams is a Wiradjuri woman but from Country distant to that of Ivan Leo Goolagong's Country. As far as she is aware, they are not related. In any event, when she gave her evidence in the inquest, her expertise and independence was not subject to any challenge. Amongst other appointments and responsibilities, she is a member of the Commonwealth funded 'National Palliative Care in Prisons Project' and chairs its Aboriginal and Torres Strait Islander ("ATSI") Community Engagement Strategy Working Group. Associate Professor William's assertion that a prisoner had a right to equivalent health care in prison as a person in the community was likewise not contentious.

52. Associate Professor Williams adopted the Nelson Mandela Rules for prison management. She noted that prisons throughout the world have engaged Indigenous Elders and professionals to guide appropriate cultural protocols and programs of support and engagement with Indigenous prisoners. She explained that palliative care, like any health care for a First Nations person, requires a holistic understanding and practice taking into account matters ranging from contextual societal factors to spiritual factors. Specifically for palliative care she addressed the following:

- Cultural connection
- Cultural identity and identification
- Aboriginal and Torres Strait Islander cultural knowledges respected
- Cultural rights
- Aboriginal definition of health
- Respecting the context of health, wellbeing and healing
- Addressing multiple needs
- Earlier engagement with end-of-life care
- Cultural safety
- Social support
- Cultural support
- Personal support and gendered business

[12] See Expert Report of Dr David Gorman dated 1 February 2021, Volume 7, Tab 54A, [8.1]-[8.5].

- Right to equivalent care in the community
- Effective and timely access to support and palliative care
- Access to information
- Death and dying
- Intergenerational responsibilities and family care.

53. From material contained in the brief of evidence, Associate Professor Williams noted that although Ivan Leo Goolagong was recorded as being from Condobolin and that he was an Aboriginal man, the records did not identify him to be Wiradjuri. There was reference to Ivan Leo Goolagong having been impacted by the Stolen Generation, however, there was a complete absence of any detail about this to inform care planning. She noted that it appeared that at no time was information about Ivan Leo Goolagong's cultural identity and community probed for, named or recorded by any of the care providers who saw him in the MSU. Without such information, any care planning results in a lack of engagement by care providers with the patient regarding their cultural needs.

54. Given that there are over 300 Aboriginal nations in Australia, had there been some information about Ivan Leo Goolagong's cultural identity and community, it would have allowed for engagement with Local Traditional Owners and Elders, who could provide guidance (relevant to care planning), that appropriately acknowledged Ivan Leo Goolagong's Country and community.

55. Associate Professor Williams noted that most CSNSW and Justice Health forms had an option to select Aboriginal and/or Torres Strait Islander Identity. She identified the time when such forms are completed by CSNSW and Justice Health staff as an opportunity to prompt a First Nations prisoner for meaningful details, as well as establishing or improving trust and rapport.

56. Associate Professor Williams made it clear that despite the First Nations peoples' experience of colonisation, the removal of land, separation of their families and communities and the consequent loss of cultural knowledge, it should not be assumed that all knowledge, such as knowledge relating to *"end-of-life"*, has been lost or destroyed. Indeed, the Goolagong family's submissions refer to their Mortuary Lore and their distress that such Lore was not respected when Ivan Leo Goolagong was dying, as well as after his death.

57. Associate Professor Williams asserted that it is well known that disrespect for

First Nations peoples' knowledge, processes, rights and needs, prevails in health workplaces. She observed that in prisons, a skilled and respectful prison workforce is required to ensure that First Nations cultural knowledge is respected. She indicated that this workforce should include both corrections staff and health service staff. Associate Professor Williams identified poor adherence to the United Nations Declaration on the Rights of Indigenous People occurring in the context of provision of palliative care in prison. In particular, she identified poor adherence to the need for non-discrimination based on Indigeneity and identity, the right of Indigenous people to be actively involved in developing and determining health and social programmes affecting them and the need for Indigenous people to, as far as possible, administer such programmes through their own institutions.

58. Associate Professor Williams report puts forward an Aboriginal definition of health as one that is:

> *"not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole Community in which each individual is able to achieve their full potential as a human being thereby bringing about the total wellbeing of their Community. It is a whole of life view and includes the cyclical concept of life-death-life. (National Aboriginal Community Controlled Health Organisation (NACCHO), 2011, pp. 5-6)."*[13]

59. The report points to the difficulty (if not impossibility) of achieving holistic health when health and other services and systems are each siloed. The Goolagong family submissions speak to a lack of ongoing psychological care for Ivan Leo Goolagong, noting that there was no apparent communication between the prison psychologist and the POWH psychiatrist, Dr Bautovich. Dr Bautovich spoke with Ivan Leo Goolagong during his June admission at POWH. Additionally, the prison psychologists are employed by CSNSW rather than Justice Health. Accordingly, their files do not form part of the Justice Health file. This siloing of services prevents good continuity of care, effective communication and effective delivery of health services.

60. Associate Professor Williams conveyed the importance of understanding First Nations holistic health and healing and explained that "*health extends to wellbeing as well as healing rather than [just] treatment and recovery of physical equilibrium. Healing in a range of domains of life can occur even if a return to*

[13] Expert Report of Associate Professor Megan Williams dated 26 February 2021, Volume 7, Tab 54E, p. 8.

physical health is not possible".[14] Palliative Care service providers need to be capable of cross-cultural work and contribute to (and engage with) culturally responsive systems.

61. In doing so, there needs to be an understanding of the numerous socio-cultural factors which adversely impact workplace practices and that these, together with other subjective factors, impact on patient and family capacity to engage with palliative care. Associate Professor Williams reminds us that rolling out palliative care funding staff and programs without a workforce that has understanding, respect and engagement with First Nations people's holistic health needs, will be both ineffective and unsustainable.

62. She pointed out the many reasons behind First Nations people's lack of engagement with formal health care. These range from individual and community experience, ineffective assessment and services, lack of availability of services, mainstream services not changing their model of care and not engaging staff skilled to provide culturally safe care to meet the needs of Aboriginal people and the lack of investment of funds from government.

63. In order for a prisoner to have their needs and beliefs respected, not only the person working for the service provider, but also the system in which they work, needs to know what those needs and beliefs are and act appropriately in relation to them. I suspect that at this point in time, this will not be achieved in the context of a non-First Nations workforce and probably not until it is incorporated in a real sense by the government institutions involved in the imprisonment of First Nations persons. The severe over-representation of First Nations persons in custody is problematic in and of itself. It is also accepted that First Nations people have poorer health outcomes in the community than non-First Nations people. The fact that First Nations people in custody do not have equivalence of care to those First Nations people in the community, presents as a triple disadvantage. Not only are First Nations people more likely to go to prison, but once they are there, they tend to have poorer health outcomes when compared to other First Nations people in the community (who are already disadvantaged when compared to non-First Nation community members).

64. In relation to Ivan Leo Goolagong, it is readily apparent that, even though by

[14] Expert Report of Associate Professor Megan Williams dated 26 February 2021, Volume 7, Tab 54E, p. 8.

December 2016 (or the latest February 2017) CSNSW and Justice Health knew that his illness was terminal with a short prognosis, there was no consideration given to his palliative care needs at all, except for his direct medical needs. Aside from Dr Sze's attendance on the one occasion on 18 July 2017, there was no proper palliative care assessment and no timely palliative care provided to Ivan Leo Goolagong. No one sought to engage First Nations Health care providers and no one sought to broker his engagement with a culturally appropriate person or organisation external to the MSU. There is no evidence that any person who was involved with Ivan Leo Goolagong's care, either from CSNSW and Justice Health, sought cultural guidance locally or elsewhere, so as to afford Ivan Leo Goolagong the opportunity to engage with cultural end of life protocols. That this time was an especially significant time for Ivan Leo Goolagong, his family and community seems to have gone unnoticed by those involved with his care in prison. Ivan Leo Goolagong's family needs did not receive due regard or support. This lack of regard has unfortunately, and unnecessarily, proved to be traumatic for Ivan Leo Goolagong's children Priscilla and Ivan Goolagong Jnr. It has no doubt been traumatic for other family and community members as well.

65. The evidence in the brief of evidence suggests that Ivan Leo Goolagong had social, financial, emotional, mental, physical and spiritual needs and that these needs were not appropriately met. If those who failed to engage with Ivan Leo Goolagong failed to do so because they had no understanding of his needs, or they felt it was culturally inappropriate for them to personally do so, then they should have sought guidance in order to secure a person or persons with whom Ivan Leo Goolagong could engage with in a culturally appropriately manner. This did not occur.

66. Associate Professor Williams and Aunty Glendra Stubbs gave evidence about the need for First Nations people's spirits to be respected so that they can continue their perpetual life-death-life cycle. They gave evidence as to the consequences when this does not occur; to both the passed spirit, as well as to the family. Families experience the long-term effects of sadness and worry. This then perpetuates the ongoing trauma of First Nations peoples.

67. Cancer Australia's document *"The optimal care pathway for Aboriginal and Torres Strait Islander People with cancer"* (2018), lists key considerations which Associate Professor Williams outlines in her report:

- *"The health care provider must understand the patient, including their cultural identity;*
- *Care coordination is required for each person, informed by their culture, gender, socio-economic status and family connections*
- *An expert in Aboriginal and Torres Strait Islander health care must be included in provision of services and support such as an Aboriginal Hospital Liaison Officer or Aboriginal and Torres Strait Islander health worker*
- *Plain English must be used with guidance on using Aboriginal cultural languages and expressions;*
- *Take time to build rapport;*
- *Involve family in care planning and appointments*
- *Appropriate engagement including touching".*

68. Cancer Australia include what they call 'evidence-based' principles related to tumour-specific pathways but do not detail what evidence they have drawn on from an Aboriginal and/or Torres Strait Islander perspective. Their principles are:

- patient-centred care
- safe and quality care
- multidisciplinary care
- supportive care
- care coordination
- communication
- research and clinical trials

69. Prevention and early detection are also identified as necessary and relevant to end of life care, as is screening, immunisation, risk reduction for other illnesses and investigation of co-morbidities. Step seven of the Optimal Care Pathway relates to end of life care. This recommends:

- *A return to Country*
- *Multidisciplinary palliative care*
- *Pain management*
- *Cultural practices for death and dying discussed with local Aboriginal and Torres Strait Islander personnel and communities."*[15]

70. Associate Professor Williams set out the numerous barriers incarceration presents for meeting the health needs of First Nations people – none of which

[15] Expert Report of Associate Professor Megan Williams dated 26 February 2021, Volume 7, Tab 54E, pp. 17-18.

would be insurmountable if there was sufficient care, understanding and resources allocated to address them.

71. I recommend the reading of Associate Professor's Williams report and to facilitate her recommendations, I attach it to these findings.

72. Aunty Glendra Stubbs is a Wiradjuri woman. She is an Aboriginal Elder with the Youth Koori Court and has been supporting the healing and recovery of members of the Stolen Generation and their families and communities for over 40 years. This work has included occupying roles with numerous State and Federal organisations. She is currently the CEO of Link-Up, an organisation for the support of members of the Stolen Generation. She worked for nearly a decade as an advisor for Knowmore Legal Centre, working with the Royal Commission into Institutional Responses to Child Sexual Abuse. This involved extensive engagement with prisoners over a long period of time. The Commissioner sought to ensure that everybody in prison had the opportunity to say if they were a victim of childhood institutional abuse. Many of the prisoners, both men and women, were Aboriginal people.

73. Aunty Glendra explained that the forced separation of First Nations people has caused a deep fear, anxiety or reluctance to seek medical treatment. This is because First Nations people were sometimes removed in a hospital or when attending a medical appointment. She said that trauma and distrust of anybody in a position of power flows down through the generations. Accordingly, the experience of many would be to not attend any medical services and/or have very limited engagement when they did attend.

74. Aunty Glendra spoke about being involved in interviewing many hundreds of prisoners for the "*Bringing them Home*" Report. She identified that the biggest fear for a First Nations person who has had their family removed is the fear of dying in an institution. She said that their *"memories of the institution were embedded in their psyche about bad behaviours and so they thought they would be having the same treatment in their old age that they had in their youth. Places such as Chinchilla Boys and Cootamundra Girls (Homes) were not places that anyone would want to live".*[16]

[16] Transcript of Hearing Day 4 (4 March 2021), T73.15-20 (Aunty Glendra Stubbs).

75. In relation to prisons in particular, she said that prisons were obviously not *"homely places where people (visitors) feel welcomed...it's a cold institution and its punitive…there's nothing therapeutical, healing…is missing because kindness goes a long way….You've got to book, you've got to travel…it's expensive to get to places…people aren't put in prisons where their family is, they are usually put in other places…only days you (can) choose from (to visit)…like there's lockdowns all the time and people will travel and then get there and they can't see their loved ones".*[17]

76. In relation to First Nations people's end of life preparation and burial rights, she wrote that it is important for an Aboriginal person to spend the end of their life on Country because it gives their family assurance that their loved one's spirit will be calm. The importance of peace and being surrounded by loved ones is as important for the person passing as it is for their family and community. She wrote of the importance of the spirit entering the right place and she said in her evidence, *"you want to hope that your family go back to their family… there'll be people there that they know and be welcomed and that the spirit leaves the body and doesn't get caught up with bad stuff…that's why we do smoking ceremonies and spend a lot of time… not rushing ceremony at the end of life… you'll say your respects and two days later you're back at work… well we can't do it that way we have to take a long time to make sure that everybody's needs are being met...we spend as much time as we need with each other".*[18]

77. Additionally, going to back to Country is important for passing on knowledge to the community. Aunty Glendra said that Ivan Leo Goolagong was an elder and elders can pass a lot of knowledge and stories on their death bed and there needs to be those opportunities to tell the stories to their community.

78. Aunty Glendra reminded us that we all want to have somebody that cares about us there at the time we're leaving and it is really important in palliative care: "*as a community we need to look after our most vulnerable and that's at your most vulnerable stage, when you're leaving this earth".*[19] She was saddened that Ivan Leo Goolagong did not have his request for a telephone call with Priscilla granted. She also pointed out that just because a worker finishes at 5pm, the family's worry and care does not. She suggested that there be a 24 hour call centre

[17] Transcript of Hearing Day 4 (4 March 2021), T73.26-40 (Aunty Glendra Stubbs).
[18] Transcript of Hearing Day 4 (4 March 2021), T74.1-12 (Aunty Glendra Stubbs).
[19] Transcript of Hearing Day 4 (4 March 2021), T75.5-7 (Aunty Glendra Stubbs).

facility available for prisoners whose families could not be with them at these critical times.

79. Associate Professor Aggarwal's report emphasised the psychosocial needs of patients receiving palliative care. She expressed concern about the level of care provided to Ivan Leo Goolagong regarding his psychological care needs. She was also concerned about MSU not enabling adequate family engagement. She queried whether Ivan Leo Goolagong's spiritual, cultural and psychological care was adequately considered during the last days of his life. Associate Professor Aggarwal said in her evidence:

> *"I think the principle of not dying alone is a really important one, as a society, we need to value and as the delivery of palliative care I think it's part of the concept and so really having Ivan Senior's ability to contact his family…his worries and concerns may have been assisted with having some contact with family members and I think that's implicit in the delivery of good palliative care in any setting."*

80. Both Associate Professor Aggarwal and Dr Gorman were of the view that palliative care should have been introduced to Ivan Leo Goolagong earlier than it occurred. As palliative care involves both medical and psychosocial care, a review of Ivan Leo Goolagong's medical care as part of his palliative care treatment needed to be examined.

Medical palliative care provided to Ivan Leo Goolagong

81. Dr Gorman was of the view that, given the histopathology report of February 2017, a referral to the palliative community team (which attended the MSU) could have appropriately been made when Ivan Leo Goolagong was received into the MSU in February 2017. Referring to Professor Goldstein's letter of 9 March 2017, Dr Gorman said it was evident that the intended approach for Ivan Leo Goolagong was to embrace a palliative approach with surveillance and chemotherapy at time of recurrence. Dr Gorman agreed it was clear that Ivan Leo Goolagong's cancer was considered to be terminal at that point. He said in his evidence that the oncology team could have referred Ivan Leo Goolagong to the palliative team in March so that he could receive emotional, social and spiritual support. Dr Aggarwal pointed out that there are differing pathways from different services and perhaps the fact that Ivan Leo Goolagong was in custody rather than in the community made the referral pathway more complex. It seems that the MSU was

responsible for a referral and that it was done at a time when the Community palliative care team did not have a consultant to attend the MSU and by the time Dr Sze did attend, Ivan Leo Goolagong was leaving the palliative care period and entering end of life care.

82. Ivan Leo Goolagong had rapid weight loss due to the surgery and the cancer. His food intake was poor and he had pain. He had episodes of hypoglycaemia and so regular insulin therapy ceased on 28 February 2017. He attended POWH for oncology review with Professor Goldstein and also attended the Diabetes Centre there. His oral intake and hydration remained problematic and on 15 May 2017 he was transferred to POWH for an overnight stay for hypokalaemia treatment. On 6 June 2017 he was readmitted to POWH as he had developed an extensive deep venous thrombosis of his right leg, and commenced Clexane therapy.

83. On 8 June 2017 at the MSU, Dr Spasojevic noted that he was *"frail, weak, unable to mobilise"* and when asked how he felt he said *"good"*.[20] He was receiving OxyContin for pain and he told Dr Spasojevic that he wanted active CPR measures performed. Dr Spasojevic identified that Ivan Leo Goolagong should be reviewed by a Palliative Care Service. She said in evidence that she considered that a review was necessary as Ivan Leo Goolagong's health was declining and he had complex issues. She telephoned Ms Cindy Grundy, the Sacred Heart Hospital's Clinical Nurse Consultant ("CNC") to request that someone from the service attend Ivan Leo Goolagong. As a result of that telephone call Dr Spasojevic made a file note that *"Palliative team will kindly review"*.[21] In her evidence Dr Spasojevic said that she did not complete any paper referral and was not advised to do so. She expected that somebody would attend the MSU in the following one to two weeks to review Ivan Leo Goolagong.

84. Identifying the need for palliative review appears to have also triggered a welfare referral, because Ivan Leo Goolagong was attended to on the same date by both Ms Ryan and Ms Ohlsen. Both made a file note that they had been advised that Ivan Leo Goolagong's health had deteriorated, that he required assistance with daily living and that this information had been passed on to a family member (Dorothy Towney, as she was listed as next of kin).

85. Dr Spasojevic went on leave from the MSU from 9 to 21 June 2017. On her

[20] Progress Note by Dr Mica Spasojevic dated 8 June 2017, 9:00, Volume 1, Tab 24, p. 75. Progress
[21] Note by Dr Mica Spasojevic dated 8 June 2017, 9:00, Volume 1, Tab 24, p. 75.

return she again attended Ivan Leo Goolagong and learned that the palliative care referral had not resulted in Ivan Leo Goolagong being visited by community palliative care. She noted that Ivan Leo Goolagong's health had further declined in that he was *"very frail; complained of epigastric pain on swallowing food; minimal oral intake; weight loss; decreased mobility."*[22] Dr Spasojevic then sent a written referral by facsimile to Ms Grundy and she arranged for Ivan Leo Goolagong to be transferred to POWH for management of his weight loss, diabetes and cancer.

86. Ivan Leo Goolagong remained at POWH from 22 to 29 June 2017. On 23 June he had a dietician review which noted *"Mr Goolagong is well known to the dietician from previous admissions for poor oral intake and malnutrition on the background of metastatic pancreatic cancer. He has excellent appetite in hospital however very poor compliance in gaol due to dislike of food which is a long-standing issue. Mr Goolagong has had extensive involvement with the food service manager and doctors at Long Bay to organise appropriate meals but reports ongoing issues with delivery".*[23] The dietician determined that a nasogastric tube was not required whilst in hospital because *"currently able to meet over 100% of nutritional requirements".*[24]

87. Dr Bautovich from the POWH mental health team undertook a psychiatric review and noted that Ivan Leo Goolagong had developmental vulnerabilities citing that he *"was raised in rural NSW and had witnessed repercussions of stolen generation…remains in contact with his children, continues to be connected to culture – speaks indigenous language…played rugby league at a high level and had loss of consciousness on several occasions during games…he was able to eat food at the hospital but is frustrated at the limited choice in gaol…denies thoughts of wanting to hasten death".*[25] Dr Bautovich determined that *"there was no evidence of pervasive mood disorder that would account for his poor oral intake".*[26]

88. On 23 June Ivan Leo Goolagong had a contrast CT scan (the first contrast CT, as

[22] Progress Note by Dr Mica Spasojevic dated 21 June 2017, 10:30, Volume 1, Tab 24, p. 86.
[23] Dietician – Initial Assessment Progress Note dated 23 June 2017, 14:48, Prince of Wales Hospital medical records, Volume 3, Tab 31, p. 42.
[24] Dietician – Initial Assessment Progress Note dated 23 June 2017, 14:48, Prince of Wales Hospital medical records, Volume 3, Tab 31, p. 43.
[25] Mental Health Progress Note dated 23 June 2017, 16:44, Prince of Wales Hospital medical records, Volume 3, Tab 31, p. 14.
[26] Mental Health Progress Note dated 23 June 2017, 16:44, Prince of Wales Hospital medical records, Volume 3, Tab 31, p. 14.

the earlier CT in April was non-contrast) and he saw the POWH palliative care team. The review identified that he had no specialist palliative care needs but stated that the hospital team would link with community (palliative care) to follow his progress. There is no reference in the palliative care team's notes of that day to suggest that they had reviewed the CT scan. However, the notes indicate that members of the palliative care team spoke with Ivan Leo Goolagong about his understanding of metastatic cancer because he told them that he *"feels like people just want him to die"*.[27] There were notes about his frustration with his diet.

89. When Ivan Leo Goolagong was informed that he would be transferred back to Long Bay Hospital, it seems that he may not have understood that he would be going directly back to the MSU because, according to Priscilla, when she spoke to him by telephone he was very defeated. On her account, he said words similar to *"may as well dig me a hole because I'll be dead by the time I get back to the MSU".*

90. The notes made upon Ivan Leo Goolagong's transfer back to the MSU on 30 June 2017 indicated that he reported that he *"feels fine"*. The notes also record that Ivan Leo Goolagong met with Dr Grimsdale and the catering manager. The latter said that he could have a "finger food diet" and that he would have Creon directly before meals, as per the POWH discharge summary.

91. Ivan Leo Goolagong continued to deteriorate, he became less mobile, was eating very little and was given nightly Endone for abdominal pain management. He experienced episodes of shortness of breath. Ivan Leo Goolagong had been taken from the MSU to POWH on 5 and 7 July 2017 for chemotherapy but declined to proceed with it.

92. Despite Dr Spasojevic's telephone call on 8 June 2017, a further referral on 21 June 2017 and the POWH referral on 23 June 2017, the community palliative care team did not see Ivan Leo Goolagong until 18 July 2017. The reason for this is that Dr Sze was a newly appointed member of the team commencing on 19 June 2017. He did not become aware of the referral till considerably later and only had approval to commence visits to Long Bay from 11 July 2017. His appointment was such that he was only able to attend the correctional centre one day a week. Ivan Leo Goolagong was his first patient in the corrections facility in his role with the

[27] Progress Note dated 23 June 2017, 12:21, Prince of Wales Hospital medical records, Volume 3, Tab 31, p. 17.

community team.

93. By the time Dr Sze saw Ivan Leo Goolagong, the planned palliative chemotherapy had not proceeded because Ivan Leo Goolagong was too weak from the progression of the disease and his poor nutritional intake. The palliative care provided was limited to pain management. It did not encompass other aspects such as psychosocial and cultural matters.

94. Dr Aggarwal commented that she thought it would have been preferable that Dr Sze prescribed Ivan Leo Goolagong with slow release OxyContin twice a day rather than 10 mg per day. She also thought that an anti-neuropathic agent might have been prescribed. Dr Sze said that he discussed the medication with Ivan Leo Goolagong and Ivan Leo Goolagong was content with the approach taken. However, it is difficult to measure Ivan Leo Goolagong's understanding and agreeability given his apparent despondency and belief that no-one particularly cared about what was happening with him. Though he was able to articulate that he had been made aware at POWH that without chemotherapy treatment he only had a few months to live, he did not seem able to articulate to Dr Sze that he felt his time of death was much closer. Dr Sze appeared to have appreciated that Ivan Leo Goolagong was at the end of life stage as he also prescribed morphine in the event Ivan Leo Goolagong would be unable to swallow the OxyContin tablet and/or needed assistance with breathing.

95. Associate Professor Aggarwal and Dr Gorman were both of the view that there were an inadequate number of medical reviews by MSU doctors during June and July 2017. Some of this time coincided with Dr Spasojevic's period of leave from the MSU. It also coincided with Ivan Leo Goolagong's admission to POWH and transfers for treatment. Prior to this, Dr Spasojevic had reviewed Ivan Leo Goolagong regularly and made notes approximately every one to three days. After Ivan Leo Goolagong's return from POWH to the MSU on 30 June 2017, he was reviewed by Dr Joanne Grimsdale. He was again reviewed by Dr Grimsdale on 21 July 2017, after the palliative specialist review of 18 July 2017. Dr Grimsdale was not on duty from 6 to 21 July 2017. In relation to the last three weeks, Dr Gorman said that he did not think that Ivan Leo Goolagong's care was compromised by the lack of medical input *"although in a sub-acute unit medical input and notes every few days would be ideal."*[28]

[28] Expert Report of Dr David Gorman dated 1 February 2021, Volume 7, Tab 54A, [9.6(b)].

96. Dr Gorman commented in his report that *"many patients who die in the community for the last weeks of life have no medical input – the family and the palliative care nursing staff manage the "comfort" care".*[29]

97. This is no criticism of Dr Grimsdale. Mr Beckett correctly pointed out that she had limited rostered shifts during this period and on the occasions she did attend Ivan Leo Goolagong she made detailed notes about each attendance. I agree with Mr Beckett's submissions that any lack of note-making is not a comment applicable to Dr Grimsdale. Indeed, her evidence at the inquest helpfully clarified both the treatment of Ivan Leo Goolagong and the practices and procedures of the MSU.

98. There is no evidence to suggest that Ivan Leo Goolagong's pain management was not appropriately prescribed or that it should have been reviewed more regularly. I note that Associate Professor Aggarwal would have prescribed slow release OxyContin twice daily and considered an anti-neuropathic agent. However, it appears that the medication prescribed and administered to Ivan Leo Goolagong was adequate to manage his pain and symptoms.

99. That Ivan Leo Goolagong passed away much sooner than the few months that had been suggested is particularly sad because Ivan Leo Goolagong's family had insufficient time to secure his early release or spend time with him. Ivan Leo Goolagong's rapid decline in July 2017 was not due to any lack of care and treatment but rather a consequence of his illness.

Services provided to Ivan Leo Goolagong in the MSU

100. Dr Gorman, whilst agreeing with Associate Professor Aggarwal, remarked that psychological and spiritual support are essential components of comprehensive Palliative care. Dr Gorman said that such care is not always available in the community, particularly in regional areas. Dr Gorman said he was unable to determine the degree of Ivan Leo Goolagong's contact with family and other support services (such as Aboriginal liaison services) from the material provided to him. However, he said that he hoped that these were available. He was of the opinion that there were no major deficiencies in his care, nor did he believe that Ivan Leo Goolagong suffered because of a lack of expertise or resources. With

[29] Expert Report of Dr David Gorman dated 1 February 2021, Volume 7, Tab 54A, [9.6(b)].

respect, in that regard, I disagree with Dr Gorman's position.

101. Ivan Leo Goolagong did not have a case worker who coordinated his care. He did not receive culturally appropriate psychological or emotional and spiritual support. He was denied a phone call to his daughter despite it being evident he was dying. Ivan Leo Goolagong was very much on his own, although he was obviously not well enough to deal with his situation on his own. Had there been some coordination, someone might have considered asking whether a family or community member could attend his monthly reviews with Professor Goldstein at POWH. Given that the purpose of the review was to monitor and discuss Ivan Leo Goolagong's disease progression, it would have been supportive and helpful for him to have someone with him. This would have enabled him to be supported in asking any questions about his scans, his prognosis and any treatment options.

102. Despite the lack of a coordinated care approach (by, for example, the CCNC who could have overseen his HMP), Ivan Leo Goolagong did seek the assistance of psychologists and Aboriginal welfare officers. This was an attempt to obtain some level of support for progressing his application for early release. Ultimately, they were of little assistance to him. The fact that Ivan Leo Goolagong did not share or discuss any personal concerns or share his knowledge with Aboriginal welfare officers may be attributable to him presuming or realising that they were not able to provide the type of support he required.

103. The assistance provided to Ivan Leo Goolagong was disappointing in its lack of communication, delivery and follow up. It is unclear to what extent, if any, the situation would have changed had there been a coordinated care approach. Service program officers or Aboriginal welfare officers are not trained in palliative care or providing social/cultural support to people who are in or near their end of life. There was no such person available to Ivan Leo Goolagong.

104. Of the documented issues, aside from metastatic cancer, it was Ivan Leo Goolagong's diet and nutritional needs which caused him (from a medical perspective) the greatest difficulty. While there were some attempts to provide him with food which he could manage better, he lost a very significant amount of weight over the five months at the MSU. Had Ivan Leo Goolagong been able to arrange other food options, his weight loss may not have been so profound and thus he may have been able to have the planned chemotherapy.

105. In relation to Ivan Leo Goolagong's medical needs, I note that Dr Gorman questioned the benefit of palliative chemotherapy at that stage of his treatment. Though, again from a medical perspective, I agree with that position, given the (cultural) need for Ivan Leo Goolagong to return to Country, the treatment may have afforded him additional time to do so.

106. Ms Ryan gave evidence at the inquest and Ms Ohlsen was excused from doing so. In 2017, Ms Ryan had been working for CSNSW for over 20 years. At that time she said that (as the regional Aboriginal welfare officer) she was responsible for Aboriginal prisoners in the Metropolitan East (the other regional Aboriginal welfare officer is responsible for Metropolitan West). As such, the correctional centres she was responsible for, include the Long Bay complex, Dawn de Loas, and the Silverwater complex. She said *"[s]o basically my role is to support and provide advice and cultural support for Aboriginal offenders and also to corrective services management and other staff with regards to Aboriginal inmates…I assist them if they are placed on segregation…advocate on their behalf…".*[30] She said that if there is a death in Aboriginal death in custody she would assist and work in with the Aboriginal Support and Planning Unit. Other duties include working with Aboriginal inmates and the program pathways to reduce their risk of re-offending, engage in therapeutic programs and other programs to help Aboriginal inmates stay connected to their culture whilst in prison. She is involved in the organisation of numerous NAIDOC events and activities at each correctional centre. This involves an engagement with internal/external stakeholders, engaging with elders, writing submissions for funding, working with state-wide disability services for inmates, and with the prisoner's case management unit in relation to programs for prisoners. She also provided assistance to the Acute Crisis Management Unit at Long Bay giving advice to psychologists and psychiatrists.

107. Ms Ryan indicated that, in 2017, she was giving assistance to two to four hundred prisoners, just in the Long Bay Prison Complex. In 2017 Ms Ohlsen was the sole welfare officer for Aboriginal prisoners in the Long Bay complex. Ms Ryan was not Ms Ohlsen's supervisor, although she was aware of what this role entailed: "…*they assist with a lot of crisis intervention. They assist with fundamental support. They assist with programs. They run EQUIPS programs…they provide the day-to-day services…like with their reintegration*

[30] Transcript of Hearing Day 4 (4 March 2021), T80.5-15 (Catherine Ryan).

or...contacting family...welfare type stuff…they would assist with any death in families with providing an application to apply to attend a funeral…if …something's not going to plan, that's where...they would come to me and …then I would meet with management and advocate further".[31]

108. Ms Ohlsen reported to a senior welfare officer who, in turn, reported to the Manager of Offender Service Programs. Each day she would assess the referrals she had received and prioritise her day's work accordingly. A referral can be created by either a custodial or non-custodial staff member (other than Justice Health) and is placed on the Offender Information and Management System ("OIMS"). This, in turn, generates a support service line which is accessible to all staff. The comment section of the referral will indicate the nature of the prisoner's requests, including whether he wants to see the Aboriginal SAPO.

109. If a Justice Health staff member working in the hospital, such as a nurse, wanted to assist a prisoner by communicating their request to see welfare, they would do so by asking a CSNSW officer to place a referral on OIMS.

110. It appears from Ms Ohlsen's statement that she had limited contact with Ivan Leo Goolagong and most of it was in relation to his application for early release. She first saw him on 3 and 6 April 2017, but his application did not progress as a consequence. She appears to have had no contact with him after that, until 8 June 2017. At this time, she had received information that Ivan Leo Goolagong had deteriorated and wanted to know what was happening with his lawyer and early release application. It does not appear that either saw him after that date though Ms Ohlsen was fielding inquiries between Priscilla and the parole State Parole Authority. On 19 May 2017, at the request of Ms Ryan, Ms Ohlsen obtained from Priscilla Ivan Leo Goolagong's lawyer's contact details so that the lawyer could visit Ivan Leo Goolagong in the MSU.

111. Ms Ohlsen was then on leave. On 8 June 2017, she and Ms Ryan attended Ivan Leo Goolagong as they had received information that he had deteriorated. Ivan Leo Goolagong said that although he had seen his solicitor, he did not know what was happening with the application for early release and he had not heard from the solicitor. He also had not had any contact with his next of kin or Priscilla.

[31] Transcript of Hearing Day 4 (4 March 2021), T82.46 - 83.5 (Catherine Ryan).

112. On 9 June 2017, Ms Ohlsen and Priscilla spoke about Priscilla organising visits and legal bookings. On 16 June 2017, Ivan Leo Goolagong was given a message that his solicitor would see him on 22 June 2017 so that Priscilla could hold a power of attorney. Ms Ohlsen provided her own details to Ivan Leo Goolagong's solicitor as a message had been left for her to do so. On 13 July 2017 Ms Ohlsen spoke with the solicitor and made arrangements for him to call Ivan Leo Goolagong on 14 July 2017. Ivan Leo Goolagong spoke with his solicitor on 14 July 2017.

The involvement of Aboriginal Special Program Officer Ohlsen with the s 160 application for early release.

113. On 22 February 2017 Ms Woods and Priscilla had a telephone conversation in which they discussed whether Ivan Leo Goolagong should or could apply for early release due to his prognosis. Priscila spoke to Ivan Leo Goolagong on the telephone about this. File notes identify that Ivan Leo Goolagong was visited on 23 February 2017 by Ms Ryan and Ms Ohlsen. In her evidence, Ms Ryan was taken to an OIMS entry dated 22 February 2017 referring Ivan Leo Goolagong to see Aboriginal welfare for an early release application. The entry also indicated that Ms Ryan saw Ivan Leo Goolagong (with Ms Ohlsen) on that day in relation to an early release application. Although Ms Ryan agreed that she did see Ivan Leo Goolagong, she made no note of it and had no recollection of meeting with him. She was taken to a note setting out his complaint about the food he was being provided. Ms Ryan then recollected that Ivan Leo Goolagong had told her: "*[t]hey're not giving me the right diet*" so she spoke with the doctor who told her the diet was correct but he was finding it hard to eat due to having surgery.

114. Ms Ohlsen likewise had not included in her statement to the inquest that she and Ms Ryan had met with Ivan Leo Goolagong on 22 February 2017. She says in her statement that Ivan Leo Goolagong first spoke to her about such an application on 3 April 2017.

115. On 6 April 2017 Ms Ohlsen again saw Ivan Leo Goolagong and spoke with Priscilla over the telephone about the early release application. Ms Ohlsen advised Priscilla that Ivan Leo Goolagong would need to instruct a solicitor. In her statement Ms Ohlsen said her role "*did not include assisting with compassionate early release*". In her evidence at the inquest, Ms Ryan confirmed

that the welfare officers roles did not include being involved in a prisoner's early release applications.

116. It would appear that Ivan Leo Goolagong did not appreciate that Ms Ohlsen was not assisting him with the application because on 3 May 2017 Ivan Leo Goolagong told the CSNSW psychologist again that he wanted to see Aboriginal Welfare in relation to his early release application.

117. From reading the file notes and correspondence, it would also appear that Priscilla was not aware that Ms Ohlsen was not assisting with the application because on 19 May 2017, Ms Ryan sent an email to Ms Ohlsen asking that she contact Priscilla in relation to the application…as "*from your previous conversation you are assisting Ivan with this*". The content of that email shows that Ms Ryan did not question Ms Ohlsen's involvement with the application, but her evidence was that they advised the family to obtain a solicitor. In her evidence, Ms Ryan said that she was aware that both sentence administration and Justice Health would be involved in such an application.

118. Of the welfare officer role, Ms Ryan said that they "*can facilitate phone calls or follow things up or send an email but just not the actual lodging of an application. We can, you know, like advocate for them...like Parole you need to go and see this particular inmate…in regards to their...early release or an email – a phone call can be made, assisted to be made, with the inmate…to see if they've got ground to apply*".[32]

119. Ms Ohlsen attended Ivan Leo Goolagong on 9 June 2017. This was to follow up a telephone call from Ms Wood, MoS, to Ms Towney (next of kin) on 8 June 2017. Ms Wood was advising Ms Towney that his health was deteriorating and that he had been admitted into POWH (it is CSNSW policy to advise the next of kin when a prisoner is admitted to a hospital outside the prison complex).

120. On 27 June 2017 the Legal Aid Commission received a letter from Professor Goldstein supporting Ivan Leo Goolagong's application for early release. This was sent with the application on 28 June 2017 to the State Parole Authority. It was emailed on 28 June 2017 to Mr Neil McNamara and on 29 June 2017 he sent an email to Justice Health Clinical Operations seeking information as to Ivan

[32] Transcript of Hearing Day 4 (4 March 2021), T86.36-42 (Catherine Ryan).

Leo Goolagong's mobility, whether he would have better access to more medical services outside the prison, what his post release treatment would involve and whether he would live with family or be in hospital. He asked for a response within two weeks.

121. On 5 July 2017 Ms Katherine McCullock, who was the Senior Community Corrections Officer at the Long Bay Parole Unit, was tasked with completing a pre-release report in relation to Ivan Leo Goolagong's application for early release. The report was required by 1 August 2017. In preparation of the report, Ms McCullock was required to organise a home visit to carry out an assessment of the proposed accommodation and inform the State Parole Authority of any risks Ivan Leo Goolagong presented, how those risks would be addressed and how he would be managed on parole.

122. Priscilla was arranging Ivan Leo Goolagong to live with family, with the palliative care unit at Condobolin Hospital as back up. Ms McCullock needed to identify where Ivan Leo Goolagong would be living and an assessment of what would need to be carried out by another parole officer. On 5 July 2017 she emailed Ms Ohlsen to contact Ivan Leo Goolagong's family to ascertain the accommodation. She also sent an email to the Serious Offenders Board to provide their input into his application.

123. On 12 July 2017, Ms Ohlsen sent an email to Ms McCullock saying that Priscilla had been calling to obtain an update about what was happening with parole. Ms McCullock advised her by email that a home visit would need to be arranged, so asked her to contact the family in relation to Ivan Leo Goolagong's proposed accommodation. Ms Ohlsen provided Ms McCullock with Priscilla's contact details though Ms McCullock did not contact Priscilla as it appears she thought that Ms Ohlsen was doing so.

124. On 17 July 2017, Priscilla called Ms Ohlsen to advise that the Condobolin Hospital required Ivan Leo Goolagong's medical information. Ms McCullock also needed to know what Ivan Leo Goolagong's diagnosis and prognosis was. Ms Ohlsen then contacted the MSU Nursing Manager who apparently advised Ms Ohlsen that Justice Health did not deal with these issues because they related to parole.

125. On 19 July 2017 Ms Ohlsen emailed Ms McCullock telling her that Justice Health

would not be involved in the application, and she asked "*Do you know what happens from here? I have no clue*!" Priscilla was contacted and it was clarified that the plan was for Ivan Leo Goolagong to go to Condobolin Hospital. After becoming aware of this, Justice Health then indicated that there would be no difficulty with Justice Health providing information to the hospital.

Section 160: "The Early Release Scheme"

126. Section 160 of the CAS Act provides that:

> *(1) The Parole Authority may make an order directing the release of an offender on parole who (but for this section) is not otherwise eligible for release on parole if the offender is dying or if the Parole Authority is satisfied that it is necessary to release the offender on parole because of exceptional extenuating circumstances.*
>
> *(2) The Parole Authority is not required to consider an application for a parole order under this section, or to conduct a hearing, if it decides not to grant such an application.*
>
> *(3) Divisions 2 and 3 do not apply to a parole order under this section.*
>
> *(4) This section does not apply in respect of an offender serving a sentence for life*

127. Part 18 cl. 285 (c) of the *Crimes (Administration of Sentences) Regulation* 2014 ("CAS Regulation") places an obligation upon a "prescribed health officer" to report to a "prescribed CSNSW officer" that, because of illness, an inmate will not survive sentence or is totally and permanently unfit for correctional centre discipline (*emphasis added).*

128. "Prescribed health officer" and "prescribed CSNSW officer" are defined in cl. 3 of the CAS Regulation as follows:

> *"A prescribed health officer, in relation to a provision of this Regulation, means—*
> *(a) the Chief Executive, Justice Health and Forensic Mental Health Network, or*
> *(b) a medical officer or other member of staff of Justice Health and Forensic Mental Health Network authorised by the Chief Executive, Justice Health and Forensic Mental Health Network, to exercise the functions of a prescribed health officer for the purposes of the provision.*
>
> *A prescribed CSNSW officer means –*

(a) the Commissioner, or

(b) a correctional officer or departmental officer authorised by the Commissioner to exercise the functions of a prescribed CSNSW officer for the purposes of the provision."

129. Both CSNSW and Justice Health concede that the CAS Regulation was not complied with in relation to Ivan Leo Goolagong.

130. Justice Health policy number 1.170 "*Early Release for Health related Reasons*" dated 4 April 2016 was in operation in 2017. That policy relevantly states under the heading "Mandatory Requirements**"**:

> *"Senior staff of Justice Health & Forensic Mental Health Network (JH&FMHN) may identify patients for whom it is considered appropriate to apply for early release. For this purpose, senior staff are Nurse Managers, Nursing Unit Managers (NUM), Health Managers, Executive Directors, treating Medical Officer(s) and Clinical Directors. …… Conditions that would meet the criteria for consideration for early release include, but are not limited to terminally ill patients, patients whose health is deteriorating rapidly or a person whose condition is such that he or she should be cared for in a setting other than a correctional centre or detention centre, for example, a hospice or long-term rehabilitation unit.*
>
> *In addition to the above policy requirements, the Crimes (Administration of Sentences) Regulation 2014, clauses 285 (a), (b) and (c) create a mandatory requirement when a JH&FMHN health officer has formed an opinion that:*
>
> - *the mental or physical condition of a patient constitutes a risk to life of the patient or to the life, the health or welfare of any other person;*
> - *the life of a patient will be at risk if the patient continues to be detained in a correctional centre; or*
> - *because of illness, a patient will not survive sentence or is totally and permanently unfit for correctional centre discipline,*
>
> *that the JH&FMHN prescribed health officer must report their opinion and the reasons for the opinion to a prescribed CSNSW Officer. The requirements of clause 285 apply to both sentenced and unsentenced patients".*

131. Justice Heath indicated in submissions that it accepted that the policy was not complied with, but submitted that "*no individuals involved in the care of Mr Goolagong should be criticised in these proceedings*". The evidence establishes that those who gave evidence in the inquest did not know of Justice Health policy 1.170 or the mandatory requirement under cl. 285 CAS Regulation. Given the numerous individuals in the MSU who fell within the category identified in Justice

Health policy 1.170, namely "Nurse Managers, Nursing Unit Managers ("NUM"), Health Managers, Executive Directors, treating Medical Officer(s) and Clinical Directors", I extend my criticism to those persons who occupied those positions during the time Ivan Leo Goolagong was in the MSU from 20 February to 23 July 2017, for failing to discharge their obligations pursuant to cl. 285 of the CAS Regulation. The MSU is involved in palliative care and the fact that its personnel do not know about the obligation and policy is, frankly, astounding. I similarly extend my criticism to those in Justice Health who failed to ensure that a prescribed health officer is aware of such an obligation, although it should be noted that Justice Health conceded it needs to train its staff in relation to the cl. 285 CAS Regulation obligations.

132. CSNSW conceded in their submissions that their pathway to making a s. 160 early release application is vague. Further, they conceded it was not necessary for Ivan Leo Goolagong's family to engage a legal representative or make a Freedom of Information application to obtain information relevant to the application. CSNSW also conceded that neither Ms Ryan nor Ms Ohlsen appears to have understood that such an application could be made directly to the CSNSW Senior Programs Officer. The CSNSW Senior Programs Officer would then prepare and provide the relevant information and a submission to the Commissioner to obtain a recommendation from the Commissioner to be submitted to the State Parole Authority. Ms Ryan was unable to indicate where the idea that the family needed to instruct a lawyer came from. Given the positions they occupy and the ease of obtaining the necessary information, the fact that neither Ms Ryan nor Ms Ohlsen made such inquiries (so that they could at least give correct information about the early release application process) to assist Ivan Leo Goolagong and his family in early 2017 is highly regrettable.

133. Mr McNamara provided a statement and gave oral evidence at the inquest. In his statement he said that s. 160 applications can be made by a prisoner or anyone else on their behalf. In his evidence he said an application was usually made by the prisoner or by a family. He said that once the application is received, the process of getting the information to the State Parole Authority is *"pretty good"*.[33] Ivan Leo Goolagong's application was received on 5 July 2017 and provided to Ms McCulloch that day. A hearing date of 1 August 2017 was listed for less than a month after the application. Had Justice Health policy 1.170 and cl. 285 CAS

[33] Transcript of Hearing Day 3 (3 March 2021), T66.34 (Neil McNamara).

Regulation been complied with, and had the Goolagong family been advised correctly, it is likely that a hearing date would have occurred much more proximate to 22 February 2017, when the family first raised their desire to make a s.160 application. Had the application been successful, Ivan Leo Goolagong would have returned to Country and would no doubt have passed in accordance with his Culture and Lore, surrounded by those who loved him.

134. The inquest received evidence that very few s. 160 applications are received by the State Parole Authority and of these a little under a third are granted (which amounts to about three applications granted per annum). Counsel Assisting suggested in submissions that those figures are unsurprising given the lack of adherence to policy, lack of knowledge of pathways and the giving of uninformed, and incorrect, advice that results in significant and unnecessary delays. Often, time simply runs out prior to an application being processed. Although CSNSW sought to argue against such submission, it really is not surprising at all that disenfranchised prisoners and their families do not obtain timely access to the early release scheme. It is highly evident that both CSNSW staff and Justice Health Staff need training about this scheme and need to be compelled to discharge their duties accordingly.

135. Mr McNamara's email of 29 June 2017 seeking information from the Clinical Director of Primary Care at Justice Health ("Clinical Director") was a task delegated to Dr Grimsdale. Dr Grimsdale was a rostered medical officer working in the MSU on 30 June 2017. The first time she had met Ivan Leo Goolagong was upon his return from POWH. Dr Grimsdale appropriately telephoned the POWH and spoke with a registrar to obtain information additional to her own observations. The Clinical Director relied on this information and prepared a markedly brief letter for the consideration and signature of the CEO of Justice Health. The letter contained a conclusion that "*Mr Goolagong is receiving adequate care and management while in custody and his condition can continue to be managed whilst in custody, in a manner comparable to the care he would receive in the community".* That position is somewhat contradicted by the evidence in this inquest.

136. Mr McNamara confirmed that there was no formal arrangement in place with Justice Health as to notifications regarding inmates who were seriously medically ill. He said that Justice Health would notify him of such a prisoner so that he could ask for a medical report or contact their family or a legal representative.

This would be to notify them of the s. 160 provisions so they could consider making an application. He said that the submission to the Commissioner included information relating to the following:

- *The inmate's condition and likely prognosis;*
- *The offence and the circumstances surroundings its commission;*
- *Time remaining to be served;*
- *Conduct whilst in custody;*
- *Governor or General Manager comments if provided;*
- *Relevant Judge's Remarks on Sentencing (which are obtained when a prisoner comes into custody);*
- *Parole Officer's report in relation to post release arrangements;*
- *Other relevant information (e.g. supporting documents from relatives etc.)*

137. Mr McNamara had indicated in his email of 29 June 2017 that the application did not seem *"super urgent"* but that a response was required within two weeks (the application had included Professor Goldstein's letter indicating that Ivan Leo Goolagong may have 4-5 months to live or up to 12 months, with treatment). On 18 July 2017, Mr McNamara sent a second email to Justice Health asking if there was any progress with his request. Consistent with Ms Ohlsen's involvement, the palliative care arrangements that Priscilla was making at that time were aimed at placing Ivan Leo Goolagong at Condobolin Hospital. However, that had yet to be confirmed, as the hospital was also waiting for Justice Health to provide it with information. According to Ms Ohlsen they were unwilling to provide this information at the request of the family rather than at the request through the parole system.

138. The lack of published policy and information for CSNSW staff and prisoners and their families about s. 160 applications and Justice Health's failure to comply with cl. 285 CAS Regulation, caused Ivan Leo Goolagong to lose an opportunity to have his application considered by the State Parole Authority. Whether or not the application would have been granted is unknown, but I would hope that from this inquest it has been learned that when an application is made to the State Parole Authority, as part of *"other relevant information",* an application for early release should specifically include information regarding a prisoner's cultural identity and beliefs and end of life protocols, especially for First Nations persons. This is critical information that should be taken into account by the State Parole Authority, and may require separate criteria to be developed. Associate Professor Williams' report would be a useful document for such prisoners to refer

to in any such application.

Ivan Leo Goolagong's request to telephone his daughter Priscilla

139. Registered Nurse ("RN") Christine Maher gave evidence that she worked at the MSU from 7pm on 22 July to 7 am on 23 July 2017.

140. RN Maher's notes indicate that at about 8.45 pm on 22 July 2017 Ivan Leo Goolagong complained of severe pain. As Ivan Leo Goolagong had already had his regular pain relief, RN Maher decided to commence the subcutaneous morphine that had been charted by Dr Grimsdale in accordance with Dr Sze's notes. Ivan Leo Goolagong wanted to sit in a chair rather than be in bed and RN Maher and the enrolled nurse who was on duty assisted him out of bed and he sat in the bedside chair. He remained there for 30 minutes and they then assisted him back to bed and he complained of breathlessness, so RN Maher placed him on nasal prong oxygen.

141. In her evidence RN Maher said that she was aware that Ivan Leo Goolagong was deteriorating and that a decision had been made to leave his cell door unlocked and open. She thought that had occurred prior to her coming on shift that night but was not sure. Ivan Leo Goolagong's cell was door was only a metre from the nursing station so she had ready access to him without having to ask a CSNSW officer to open it.

142. In her statement Nurse Maher stated that Ivan Leo Goolagong had:

> *"requested on the night of the 22nd of July 2017 to speak with his daughter and this was relayed to DCS. The Senior in Charge said that she would contact the daughter on the morning of 23rd July 2017 regarding his request and that contact with the family for a visit/phone call for Mr Ivan Goolagong would be organised as soon as possible".*[34]

143. It is unclear at what time this request was made by Ivan Leo Goolagong or when RN Maher conveyed his request to the senior CSNSW officer, as the note made by RN Maher in the Justice Health file does not indicate the time nor who the senior CSNSW officer was. In her evidence, she said she thought it was at about

[34] Statement of Christine Maher dated 30 August 2017, Volume 1, Tab 17, [9].

2 or 3 o'clock in the morning (23 July 2017) that Ivan Leo Goolagong said that he wanted to speak with his daughter.

144. RN Maher gave evidence that she did not have access to any next of kin phone numbers even though the Justice Health admission form required that information to be completed. In any event she said she had no *"jurisdiction about contacting family. I am not allowed to"*. She said she contacted the senior CSNSW officer on duty. It is unclear what she actually said to the senior CSNSW officer. During the inquest, RN Maher was asked by counsel assisting the parameters of what she was able to do to facilitate this call, to which RN Maher replied, *"inform [the senior CSNSW officer] and have them – and then it was up to them to follow up from there".*

145. When asked whether she could have taken some initiative to explain to the senior CSNSW officer the urgency of the request, RN Maher replied:

> "*I did. I said it needed to be done as soon as possible and I had been informed by the senior it would be done first thing in the morning. And there was nothing more I could do…. I probably indicated to the officer that there wasn't a lot of time, and that it needed to be – that's why I said them it needed to be done as soon as possible and I was assured that it would be done in the morning*".

146. RN Maher accepted in evidence that it was evident that his death was imminent. She stated that she told her supervisor that it was imperative that they contact Ivan Leo Goolagong's daughter as soon as possible as he was particularly unwell. She said she probably said that there wasn't much time. Despite this information she said that the supervisor indicated that Ivan Leo Goolagong's daughter would be contacted in the morning and was not prepared to do any more.

147. The senior CSNSW officer RN Maher spoke to has not been further identified by her or by CSNSW. Ms Melis did in her examination of RN Maher suggest that the senior CSNSW officer on duty that night was a man and not a woman. RN Maher replied that her note referring to *"she"* was probably correct. There is no record of the request made by Ivan Leo Goolagong or of the discussions RN Maher had with any other person anywhere within CSNSW records that have been produced to the Court.

148. Mr Hodges in his evidence agreed that, in the circumstances, permission should have been granted so that Ivan Leo Goolagong was able to speak with his

daughter at the time he requested to do so. He indicated that procedures available at the MSU were flexible enough to enable such a call to be made outside of normal hours. In such circumstances, however, they would require nursing staff to relay the request to a CSNSW Senior Corrective Services Officer so that arrangements could be made via the MoS or relevant senior officer.

149. Whilst it is not clear why a decision was made to not allow Ivan Leo Goolagong to have immediate contact with Priscilla, an arrangement should be in place whereby such calls can be facilitated as a matter of course. The emotional distress caused to Priscilla, knowing that her father wanted to speak to her in his final hours, but was not permitted to, was completely unnecessary and avoidable.

150. Counsel assisting submits that this raises questions as to:

- The extent to which relevant staff have a proper appreciation of the end of life psychosocial needs of inmates; and
- The effectiveness of a system that requires permission for a phone call between a patient (at such an end stage of their lives as Ivan Leo Goolagong was) and a family member to go through a formal decision-making process involving both Justice Health and CSNSW, and whether there should instead be greater flexibility and discretion for such calls to be facilitated by Justice Health staff when an inmate's death appears imminent.

151. CSNSW submitted that *"wherever possible, CSNSW is, to use RN Maher's words, "usually very accommodating", in the MSU"*. Further, it was submitted that CSNSW will set up extra family visits so that the family can say their goodbyes to an inmate who may be dying. Even though the MSU still forms part of the Long Bay Correctional Centre, "*there are adjustments made to correctional routine to accommodate the inmates it houses, namely, inmates who may be stepping down from a hospital and recovering or ill patients."* Those submissions may be correct but RN Maher's evidence ultimately resiled from them. She refrained from stating that she knew what formal arrangements were made for family members. RN Maher noted that in her experience, which was considerable given RN Maher has worked at Long Bay Hospital since 2008, the only familiarity she had with extra family visits is that sometimes when she came on shift she was told that a patient had been visited by a family member.

152. It is important that prisoners and their families are aware of any visiting entitlements and arrangements available at the MSU rather than stumbling upon such latitude or learning of it when it is too late. If CSNSW is prepared to make such changes so that families can say their goodbyes then it is essential that there are published policies and good communication between Justice Health and CSNSW. This also requires appropriate training to relevant staff and standardised application, to ensure that visiting arrangements and entitlements are permitted systematically rather than haphazardly.

Current arrangements at the MSU

153. Justice Health do not contest that in order to meet First Nations prisoners' palliative care needs, there needs to be upskilling of medical, nursing, and other staff. Despite conceding that the palliative care needs of First Nations prisoners are not being met, Justice Health point to Dr Gorman's evidence to note that he did not find any major deficiencies with the care provided to Ivan Leo Goolagong and that he believed that Ivan Leo Goolagong did not suffer because of any lack of expertise or resources. I accept that overall Ivan Leo Goolagong's pain management was adequate, notwithstanding Associate Professor Aggarwal's comment that slow release Oxycontin twice daily with an anti-neuropathic agent would have been preferable. However, this assessment does not accurately assess the holistic care that was provided to Ivan Leo Goolagong.

154. Between July 2019 and August 2020, there was apparently no Palliative Care Specialist employed at Justice Health, as there was no funding for that position (which had been occupied by Dr Sze in 2017). From August 2020, a Specialist Palliative Care Service has been funded which allows POWH to service those prisoners not only in the MSU, but throughout the entire Long Bay Correctional Centre. Dr Gorman remarks in his report that this should enable earlier involvement in the care of terminally ill prisoners. Whether or not a Palliative Care Consultant Clinic of 1 day per fortnight adequately meets the needs of those prisoners was not a matter that the inquest inquired into. However, I note that there are significant challenges in attending to a certain number of prisoners on any given day when taking into account planned and unplanned lockdown periods. There appears to be difficulty in maintaining that position as the first occupant resigned after four months and at the time of the inquest the position remained vacant.

155. However, Justice Health now has a Palliative Care Team at Long Bay Correctional Centre. The team has a full-time position of a "Palliative Care Transitional Nurse Practitioner" who is the clinical lead of the Network Palliative Care multi-disciplinary team which includes the POWH Palliative Care Consultant Physician.

156. The team also has a full-time Palliative Care Aboriginal Health worker position. That position seems to be responsible for State-wide correctional centres. The extent to which the occupant of that position has direct clinical involvement with MSU patients must be limited because they are based in Wellington in regional NSW. As at the date of the inquest, though experienced in Aged Care, the occupant of this role still required palliative care training and support. I note Associate Professor Williams' evidence regarding cultural protocols involving *"gendered business"* and the strain placed on First Nations Health Workers to cater to the needs of First Nations prisoners, particularly where they are working without the support of proportionate representation. Whether one First Nations worker will be able to adequately cater to the needs of all First Nations prisoners, irrespective of location and gender, is questionable and may place an undue level of pressure on such a worker.

157. The team also has a Palliative Care Occupational Therapist (0.6 position) and a Palliative Care SocialWorker (0.4 position).

158. Mr Grimmond, the Director of Nursing and Midwifery Services at Justice Health, gave evidence about the development of Business Rules identifying the role or of the Cancer Nurse specialist at Long Bay Hospital, which will include:

- Guiding the patient to information and services that foster independence;
- Awareness of consultation, treatment plans and treatment outcomes;
- Coordination of the implementation of care plans including the provision of information and referral to appropriate services;
- Single point of contact for cancer services;
- Development and education of staff regarding appropriate referral pathways and documentation; and release planning.

159. Mr Grimmond gave evidence that Justice Health is an active partner in the National Palliative Care in Prisons Project led by the Centre for Improving Palliative, Aged and Chronic Care through Clinical Research and Translation

('IMPACCT"). Mr Grimmond said that the project aims to co-design a new national framework of palliative care for Australian prisoners, inclusive of national policies, workforce capacity, building strategies, clinical service models of care and a toolkit of resources, for ongoing use. Mr Grimmond indicated that Justice Health representatives participate as partners and investigators across the National Consortia Project Advisory Group, Correctional/Justice Health Services Working Group, and the Aboriginal and Torres Strait Islander Community Engagement Strategy Working Group.

160. Mr Grimmond gave evidence that Justice Health was, at the time of the inquest, drafting a Model of Palliative Care, which (as referred to in the Justice Health submissions) aims to provide:

- A centralised referral pathway including an electronic health record alert for 'Palliative Care' to clearly identify patients receiving palliative care;
- Regular multi-disciplinary palliative care team meetings to discuss patient care;
- Palliative care information for staff being developed and which is accessible on the intranet;
- Palliative care staff engaging with staff across the Justice Health network to raise the profile of the team, provide education on palliative care, and how their team can support patients and staff;
- A Justice Health network palliative care education forum; and
- For the development of a cross-organisational partnership between the palliative care team and CSNSW Chaplaincy services to ensure pastoral care is offered to all palliative care patients.

161. At the conclusion of the evidence at the inquest, it was recommended that the scheduled meeting of the Steering Committee responsible for the development of the Model of Palliative Care should involve consultation with palliative care and cultural experts including Associate Professor Aggarwal, Associate Professor Williams and Aunty Glendra Stubbs. Given their respective evidence at the inquest, Justice Health were very supportive of this course. The Steering Committee was apparently adjourned for a month to enable such consultation. At the time of writing its submissions, Justice Health noted that:

"On 28 April 2021 the Palliative Care Model of Care was supported by the Steering

Committee to begin piloting through PDSA (Plan Do Study Act) cycles in the coming weeks. PDSA cycles enable testing with patients and staff to ensure the Model of Care meets their needs. The cycles create a feedback loop to identify gaps, and make any changes or improvements as required. The Network are still awaiting comment from the palliative care and cultural experts, once received these will be reviewed and embedded into the Palliative Care Model of Care".

162. In relation to the issues identified at the outset of the inquest, those questions have been answered in these findings for the reasons already articulated:

a. Although Ivan Leo Goolagong received adequate and appropriate medical treatment, he did not receive timely or adequate non-medical, psychosocial, palliative care, from the time of his transfer to MSU on 20 February 2017 until his death on 23 July 2017. His dietary care could have been improved earlier.

b. There was no evidence received that consideration should have been given to transferring Ivan Leo Goolagong back to the Annex at POWH at any stage between his discharge on 30 June 2017 prior to his death on 23 July 2017.

c. It could not have been foreseen that Ivan Leo Goolagong would be denied the opportunity to speak with his daughter in the early hours of the morning of 23 July 2017. Information about Ivan Leo Goolagong's deteriorating health was provided to his family but, due to the lateness of the s. 160 application, the family's attention was on arranging palliative care at Condobolin Hospital in furtherance of the s. 160 application rather than arranging family members to visit Ivan Leo Goolagong.

d. Ivan Leo Goolagong's opportunity to apply to the State Parole Authority for early release was not appropriately acted upon by CSNSW and Justice Health. The family were given incorrect information by CSNSW personnel about the application process and Ivan Leo Goolagong's lawyers were required to engage in unnecessary applications to obtain information to support the application. Justice Health failed to

discharge its cl. 285 CAS Regulation obligations in February/March 2017. This failure was ongoing. Despite Ivan Leo Goolagong's continued and apparent deterioration and the progression of his terminal illness, no Justice Health member of the MSU gave consideration to cl. 285 CAS Regulation.

e. There were no services specific to the needs of First Nations prisoners with a terminal illness and accordingly no such services were available to Ivan Leo Goolagong. That situation has now changed since the development of a Model of Care and the employment of specialised First Nations personnel. It is hoped that such a programme successfully overcomes the deficiencies of care, and proper regard is given to the experience of Ivan Leo Goolagong, and his family, at the end of his life. Importantly, it is hoped that Associate Professor Williams' comments regarding the pressures faced by First Nations workers are properly considered and adequate supports implemented for such First Nations workers to ensure their success and the success of the Model of Care.

163. The Goolagong family have, in their submissions, supported the submissions of Counsel Assisting. They have also raised additional matters outside the statutory scope of this inquest, including a desire to relocate Ivan Leo Goolagong's body to Country, which would involve an application under the Act for exhumation (they are of course, at liberty to make such an application). The family, particularly Priscilla, is understandably highly traumatised by the circumstances surrounding the death of their father. As mentioned earlier, Pricilla's belief that Ivan Leo Goolagong died distressed and isolated, coupled with the denial of his opportunity to speak with her before his passing, has been particularly damaging and continues to be a source of continuing hurt and upset. The family is also angry that it was not until in the afternoon of 23 July 2017 that they learned of their father's passing rather than in the morning when he died (which was around 7:30am). Priscilla has found the coronial process exceptionally challenging. The difficulties in effectively engaging with CSNSW and Justice Health regarding her father's care and his possible early release, have understandably heightened the family's distrust of the coronial process.

164. Despite extensive efforts and assurances by this Court, this profound distrust has resulted in the family, particularly Priscilla, remaining to be convinced in relation to certain matters that were properly addressed throughout the coronial process, including:

    a. that the mortuary photographs shown to the family on numerous occasions are those of Ivan Leo Goolagong;
    b. that the CCTV footage from the MSU accurately captures the events on the morning of Ivan Leo Goolagong's death;
    c. that certain documentary errors in the police brief of evidence, for example, regarding the title of a document and Ivan Leo Goolagong's weight, were in fact errors as opposed to relating to a different person altogether; and
    d. that the smoking ceremony organised for Ivan Leo Goolagong at the MSU was not held in the correct cell.

165. This is most regrettable and it is a reminder to all of us, about the effect of generational, deeply entrenched institutional distrust and trauma that has often been experienced by First Nations families.

166. The family seek that I make recommendations in relation to matters that fall within the ambit of civil proceedings, and which relate to duty of care and compensation. A Coroner's statutory role is confined to matters set out in s. 81 of the Act. As such I am unable to make recommendations, including in relation to civil matters, that fall outside of my statutory powers.

167. Counsel Assisting has put forward a number of recommendations to the Commissioner of Corrective Services and the CEO of Justice Health. The agencies' response to these suggestions has in large part been met with agreeance. Indeed, many of the recommendations have been addressed or are currently on foot. I note that Associate Professor Williams submitted lengthy recommendations at my request and they have greatly assisted in advancing the introduction of improvements. For the sake of completeness, those recommendations are attached to her report annexed to these findings. However, I note that Justice Health submissions indicated that *"the challenge in facilitating 'closeness to family and closeness to Country ' is that the MSU at Long Bay Hospital is the only appropriate environment to provide the level of care required by patients with complex palliative care needs and whom are end of life"*.

168. I make the following recommendations on the basis that many of the recommendations are currently already on foot.

Early release under s. 160 *Crimes (Administration of Sentences) Act 1999*

To the NSW Commissioner of Corrective Services

1. That CSNSW develops a policy to give guidance to Services and Programs Officers, Regional Aboriginal Programs Officers, psychologists and any other relevant staff, in relation to the advice and assistance that such staff should provide inmates who express a desire to seek early release on medical grounds, and that such policy be aimed at helping to facilitate and expedite such applications without the need for inmates engaging legal assistance.

2. That, in the interim, CSNSW takes action to ensure that relevant staff (including Services and Programs Officers, Regional Aboriginal Programs Officers and psychologists) who are asked by inmates for assistance in connection with early release applications on medical grounds:

    - Are aware of the potential need for such matters to be expedited;
    - Are aware that they can and should contact relevant CSNSW project officers for further potential advice and assistance as to how the matter might best be progressed; and
    - Are aware that it is not the case that such applications can only proceed by means of the inmate engaging legal assistance.

To the Commissioner of Corrective Services and the CEO of the Justice Health Forensic and Mental Health Network

That CSNSW and Justice Health formalise a policy, as soon as possible, with the aim of helping inmates suffering from a terminal illness who wish to apply for early release, or their families, to do so in a manner that minimises delay and does not require applicants to seek recourse to external legal representation to

obtain medical reports from Justice Health or to advance their application.

To the CEO of the Justice Health Forensic and Mental Health Network

That Justice Health take action to ensure that any relevant staff with reporting obligations under cl. 285 CAS Regulation are aware of their obligations under that clause.

Telephone access for inmates during end of life care

To the Commissioner of Corrective Services and the CEO of the Justice Health Forensic and Mental Health Network

That a CSNSW and Justice Health working party in relation to the operation of the MSU is established to develop practices, so as to:

- Ensure that terminally ill inmates receiving end of life care in the MSU are permitted phone access to contact family members at any hour of the day and that requests for phone access by such prisoners are allowed and not delayed;
- Make phone access for terminally ill inmates more streamlined so that clinical staff are permitted to provide relevant phone access to patients without the need for permission to be obtained from CSNSW; and
- Consider any other measures that might be implemented to make the environment in the MSU for terminally ill inmates less restrictive.

Palliative Care Needs of First Nations prisoners

To the Commissioner of Corrective Services and the CEO of the Justice Health Forensic and Mental Health Network

1. That relevant senior officers of CSNSW and Justice Health review the report prepared for the court by Associate Professor Williams with a view to determining how some of the policy suggestions outlined at pages 28 to 31 might be implemented in their organisations.

2. That a CSNSW and Justice Health working party consult with Associate Professor Williams to consider the feasibility of:
    - Introducing peer support programs for terminally ill First Nations prisoners in

the MSU; and

- Enabling access to Long Bay Hospital by “in-reach” services offered by of appropriate community based First Nations Health organisations.

To the NSW Commissioner of Corrective Services

That CSNSW takes action to provide greater support for, and numbers of, Regional Aboriginal Programs Officers, and Aboriginal Support and Programs Officers, so they at least reflect the proportion of NSW inmates who are First Nations.

To the CEO of the Justice Health Forensic and Mental Health Network

1. That Justice Health employs at least two First Nations health care workers, nurses or medical officers as part of the complement of clinical staff at the MSU, and looks to employ greater numbers of First Nations staff generally, and that in doing so Justice Health ensures that such additional staff are provided with adequate support to perform their work effectively.

2. That MSU clinical staff receive immersive training in provision of health care to First Nations patients within a First Nations’ community health organisation setting.

<u>Provision of palliative care to terminally ill inmates at the MSU more generally</u>

To the CEO of the Justice Health Forensic and Mental Health Network

1. That Justice Health develops a care planning protocol for all patients in the MSU who are diagnosed with a terminal illness, so that a clear multi-disciplinary plan is devised, followed up and regularly re-evaluated, commencing as soon as an inmate is identified as having a terminal diagnosis.

2. That the positions responsible for devising, overseeing and evaluating such care plans are clearly identified and known by clinical staff at the MSU.

3. That the role and responsibilities of the Cancer Care Nurse Coordinator so far as it relates to MSU patients is clearly delineated, made known to clinical staff

in the MSU and audited for its effectiveness.

4. That Justice Health urgently prioritise providing immersive forms of training of MSU clinical staff involving placements over a number of days with outside Palliative Care providers such as the Program of Excellence in the Palliative Approach ("PEPA").

5. That further training of MSU staff in Palliative Care emphasises the importance of early identification of the psychosocial needs of inmates and skills in rapport development.

169. I now enter findings pursuant to s. 81:

Identity	**Ivan Leo Goolagong**
Date of Death	**23 July 2017**
Place of Death	**Long Bay Hospital Medical Subacute Unit**
Cause of death	**Metastatic Pancreatic Adenocarcinoma**
Manner of death	**Ivan Leo Goolagong was a Wiradjuri man died of natural causes whilst in the custody of Corrective Services NSW.**

170. I wish to thank all parties involved and particularly Associate Professor Williams and Aunty Glendra Stubbs for their generous sharing of their invaluable insights and experiences. I thank the Goolagong family for their participation in this inquest which I know has been extremely difficult and, I suspect, with insufficient outcome to meet their distress about their father's passing. I give my sincere condolences.

171. This inquest is now closed.

E Truscott
Deputy State Coroner
22 October 2021

THE UNIVERSITY OF SYDNEY

A[redacted]ssor Megan Williams Research Lead and Assistant Director
N[redacted] for Cultural Competence
P[redacted]Chancellor (IndigenousStrategy and Services)
M[redacted]stitute of Criminology

[redacted]
[redacted]

[redacted]

[redacted]
[redacted]
[redacted]

[redacted]

[redacted]

26 February 2021

Dear [redacted]

Inquest into the death of Mr Ivan Goolagong

Thank you for the opportunity to provide an expert report assisting Deputy State Coroner Truscott in the inquest into the death of Mr Ivan Goolagong.

I, Megan Williams, acknowledge for the purpose of Rule 31.23 of the Uniform Civil Procedure Rules 2005 that I have read the Expert Witness Code of Conduct in Schedule 7 to the said rules and agree to be bound by it.

In the preparation of my report, I have read:

- Annexure 1 detailed observations
- Seven volume Brief of Evidence reports.

As a member of the Wiradjuri Aboriginal nation, I respectfully acknowledge that the research for and writing of this report has occurred on the land of the Gadigal people of the Eora nation and I offer my respect to their ancestors and Elders as knowledge holders for business on this land.

Content of report

a) **Name and address** above

b) **Acknowledgement of Code of Conduct** above

c) **Qualifications to prepare the report**

I am qualified to prepare this report in several ways:

Work experience:

- I have focused on actions to improve the health and wellbeing of people in the criminal justice system for over 25 years, with particular attention on issues for Aboriginal and Torres Strait Islander people. I have contributed through program design and delivery, research and evaluation, policy reviews, tertiary curriculum design and delivery and workforce development initiatives
- I am a member of the Commonwealth-funded National Palliative Care in Prisons (PiP) Project - *Strengthening access to best evidence based care for people with palliative care needs in Australian prisons: A national co-design and capacity building* project, and Chair its Aboriginal and Torres Strait Islander Community Engagement Strategy Working Group
- At the University of Sydney, I am a member of the *Child Sexual Abuse Course Review Working Group*, leading the review and development of curriculum and education that implements recommendations of the *Royal Commission into Institutional Responses to Child Sexual Abuse*
- I am currently a Chief Investigator of the following justice and health projects:
    - *Banga-ma-la-nha collaborative throughcare program for young Aboriginal women transitioning from prison to community* developing a criminal justice system workforce capability framework, funded by the National Health and Medical Research Council (NHMRC)
    - NHMRC-funded Centre for Research Excellence *STRengthening systems for InDigenous healthcare Equity (CRE-STRIDE)*
    - Co-creation and evaluation of the *Indigenous mental Health Intervention Program (IMHIP) - Youth* funded by the Medical Research Futures Fund including to reduce risk of deaths in custody.
- I have been a facilitator for subject *Ageing and Endings* in the UNSW Medicine program
- I participate in collective healing program delivery and evaluation with Mibbinbah health promotion charity
- Through my early-career work I facilitated support groups for people with HIV/AIDS including during palliative care.

Tertiary education:

- My PhD research entitled *Connective Services* examined Aboriginal and Torres Strait Islander professionals' and family caregiver roles in assisting people to transition from prison to community life and reduce risk of death
- I completed Post-graduate studies in Indigenous research design and social sciences
- My undergraduate studies in social sciences had a focus on human rights and access to justice.

Aboriginal and Torres Strait Islander community connections and contributions:

- Director of Project 10%, an Aboriginal and Torres Strait Islander-led company

- Deaths in Custody Working Group, Queensland
- Prison visitor for family and community members.

I identify as Wiradjuri through paternal family.

d) Assumptions and material facts

"The greatest fear of all is losing a family member in the Intensive Care

I acknowledge my personal experience of the incarceration of family members producing profound experiences of grief, powerlessness, frustration and dismay across generations. My own family has experienced the sudden death in custody of a young man with poor mental health. I believe that a family member death in custody may be comparable, if not worse than a death in ICU, because family may have the choice to be present at a hospital in the community. That choice is greatly reduced when a member is in prison or prison hospital, with many barriers to visitation a reality (Williams, 2017).

I draw on Wiradjuri knowledges throughout my work and in this report. Wiradjuri understand Country to be foundational to one's existence, that has shaped Wiradjuri language, processes of knowledge development, how to understand the world, roles people have and spiritual principles for being in relationships including humility – because all humans depend on our environment (Minmia, 2007; Perkins & Langton, 2010; Sheehan, 2011).

Country is spelled with a capital C (Girra Maa, 2018) to signify its importance, and it refers to lands, waterways and atmosphere of one's ancestors of the past, family of the present and next several generations for whom one's life is to be dedicated (Arabena, 2015).

Annexure 1 p. 5 indicates Mr Goolagong is understood to be Wiradjuri, because he was born and grew up in Condobolin, NSW.

To the best of my knowledge, I am not related to Mr Goolagong; the Country of my ancestors and family is a different clan group some several hundred kilometres away.

I have a western health and social science education and am influenced by foundational documents:

- United Nations Declaration on the Rights of Indigenous Peoples (United Nations, 2007)
- Aboriginal and Torres Strait Islander ethical principles published by the National Health and Medical Research Council (NHMRC, 2018)
- Social determinants of health for Aboriginal and Torres Strait Islander peoples (Jackson Pulver, Williams, & Fitzpatrick, 2019)
- Ngaa-bi-nya Aboriginal program evaluation framework (said 'nar-bin-ya' in Wiradjuri) which identifies many concepts of good practice in health and social services for and by Aboriginal people (Williams, 2018)

Palliative care is defined in this document as 'person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life' (Palliative Care Australia, 2018, p. 3).

The NSW government generally refers only to 'Aboriginal people'. I use 'Aboriginal and Torres Strait Islander' in this document when making points or citing material that have relevance to all peoples identified as First Peoples of Australia. It is appropriate, however, to refer to Mr Goolagong as an Aboriginal person given he has not identified as having Torres Strait Islander heritage.

e) Use of literature and supportive material

I have drawn on a range of literature which is cited in text and identified in a reference list at Annexure 1.

f) Matters falling outside field of expertise

All questions and answers fall within my field of expertise. Given my qualifications arein public health with a focus on health in criminal justice contexts and not in law, I critique information and provide answers to questions in relation to rights to healthcare.

Please find attached my CV.

g) Examinations, tests or other investigations relied on

All literature drawn on is cited, with a reference list in Annexure 1.

h) Acceptance and identification of others' opinions

All opinions drawn on are cited, with a reference list in Annexure 1.

i) Declaration appropriate inquiries made

I declare that I have made inquiries of literature rather than other persons; no matters of significance have been withheld from the court.

j) Qualifications of opinions expressed

All statements are qualified with weight of evidence, citations or qualification as expert opinion.

k) Concluded opinions, insufficient research

Gaps in evidence are clearly noted where applicable.

l) Length and complexity of report

Each of the five expert report questions posed are addressed with themes identified and sub-points used for clarity.

Matters addressed

As per request dated 8 February 2021.

1. What are the unique cultural needs of Aboriginal people whilst receiving palliative care (in particular, their psycho-social needs) and those of their family?

This section addresses a range of needs, from contextual societal factors to spiritual factors:

- Cultural connection
- Cultural identity and identification
- Aboriginal and Torres Strait Islander cultural knowledges respected

- Cultural rights
- Aboriginal definition of health
- Respecting the context of health, wellbeing and healing
- Addressing multiple needs
- Earlier engagement with end-of-life care
- Cultural safety
- Social support
- Cultural support
- Personal support and gendered business
- Right to equivalent care in the community
- Effective and timely access to support and palliative care
- Access to information
- Death and dying
- Intergenerational responsibilities and family care.

Cultural connection

Each Aboriginal and Torres Strait Islander nation has its own language, cultural protocols, identity, and processes for engaging with death and dying. Knowing which Aboriginal nation a person identifies as belonging to is essential to make appropriate care plans.

Annexure 1 indicates Mr Goolagong was born on Wiradjuri Country, but this does not identify him to be Wiradjuri as such. Nor does material in the Brief of Evidence volumes, to the best of my understanding. Mr Goolagong is described as impacted by the Stolen Generations although no detail to inform care planning or its effectiveness inrelation to this is provided.

To the best of my understanding and review of Briefs of Evidence, at no time was information about the cultural identity and community of Mr Goolagong probed for, named or recorded.

Even where Aboriginal people's cultural identity has been disrupted by government's forcible removal of children, separation from homelands and other colonisation processes, most Aboriginal people are able to make some connections to other family or Country, and if not, might identify as Stolen Generations (Garvey, 2007).

One implication of lack of querying or clarification is a lack of documentation of such, and subsequently a lack of care planning that draws on culture, and lack of engagement by care providers about cultural needs (Dudgeon, Milroy, & Walker, 2014; Garvey, 2007; Haswell et al, 2014).

There is no one Aboriginal culture or identity to ascribe to in Australia. There are over 300 nations, and information, identity and protocols of one nation are not to be appropriated and applied to an Aboriginal person of another nation. This is ingenuine, causes identity confusion, undermines local Traditional Owners and Elders and reinforces processes of colonisation including denial. Local Traditional Owners and Elders are to be applied to and asked for their guidance, acknowledging their holdingof expertise for that Country and community and what it offers (Pascoe, 2018).

Prisons throughout the world have engaged Indigenous Elders and professionals to guide appropriate cultural protocols and programs of support and engagement with Indigenous prisoners (Marchetti & Nicholson, 2020). The Nelson Mandela Rules for prison management support this (United Nations (UN), 2015).

Cultural identity and identification

A foundational need is a workforce skilled in accurate and meaningful identification of prisoners who say they are an Aboriginal and/or Torres Strait Islander person.

Many Australian and NSW government documents recognise that Aboriginal and Torres Strait Islander people are diverse (Department of Prime Minister and Cabinet, 2018; NSW Public Service Commission, 2019). Given Corrective Services NSW (CSNSW) and Justice Health and Forensic Mental Health Network (JH&FMHN) are government organisations, this understanding of the diversity of Aboriginal and TorresStrait Islander people is relevant and appropriate for workforces to use in the care ofpeople such as Mr Goolagong.

Most CSNSW and JH&FMHN forms appear to have a general option to select Aboriginal and/or Torres Strait Islander identity.

It is my own professional experience that completing intake and assessment forms for and with Aboriginal and Torres Strait Islander people can be a timely opportunity to prompt for details about cultural identity and to be recorded if paperwork space and formatting allows. Engagement to prompt for cultural identity information can improve trust and rapport between service providers and clients (Bennett, Green, Gilbert, & Bessarab, 2013).

Accurate identification as an Aboriginal and/or Torres Strait Islander person – which nation/s they are connected to – requires:

- The opportunity for Aboriginal and Torres Strait Islander people to identify themselves, and not have others assume
- Adequate administrative processes to record cultural identity accurately
- Adequate skills of staff to understand and record cultural identity information
- Next steps – what does having this information mean, and how can rights and needs be achieved?

Aboriginal cultural knowledges respected

Aboriginal and Torres Strait Islander people have had highly developed knowledges for understanding end-of-life, and protocols for end-of-life care for countless millennia (Glaskin, Tonkinson, Musharbash, & Burbank, 2008), for at least 60 000 years of continuous cultures (Perkins & Langton, 2010).

If the assumption is made that Mr Goolagong is Wiradjuri, it is relevant to understand that from the early to mid-1800s, colonisation of Wiradjuri lands occurred and through massacres, forced removal of Wiradjuri from homelands and separation of families, some loss of cultural knowledges including about end-of-life occurred (Read, 1988).

There is an assumption, however, that Wiradjuri and other Aboriginal and Torres Strait Islander knowledges have been ‘lost’ or ‘destroyed’ (Cumpston, 2020) and in my experience this can be used as a reason by health care providers that Wiradjuri cultural knowledges are not drawn on.

However, much has been retained; Wiradjuri culture is best understood as a living culture (Minmia, 2007; Sheehan, 2011). Further, as has been Aboriginal and Torres Strait Islander cultural process and protocol since time immemorial, knowledges are shared and used between Aboriginal and Torres Strait Islander people (Arbon, 2008; Sheehan, 2011). In my experience, ways of understanding health and wellbeing are informed by a range of sources.

Mounting evidence indicates current health and justice workforces have limited access to and knowledge of Aboriginal and Torres Strait Islander cultures (Manton & Williams, in press). An increasing number of publications report widespread racism in health workplaces, with constant disrespect and disregard for Aboriginal and Torres Strait Islander people's knowledges, processes, rights and needs (Bargallie, 2020).

It is a cultural need and a right of Aboriginal and Torres Strait Islander people that their cultural knowledges are respected and used in prison settings (Haswell et al, 2014), and this extends in relation to palliative care, and in bereavement care for families (Glaskin et al, 2008; Ulrik, Foster, & Davis, 2011; Wanganeen, 2014).

Again, achieving this cultural need and right of Aboriginal and Torres Strait Islander people requires a skilled, respectful prison workforce.

Cultural rights

All Indigenous peoples have the following rights, which reflect Indigenous cultural protocols, values and aspirations (UN, 2007). Australia has come under scrutiny for not achieving these, particularly in relation to incarceration of Aboriginal and Torres Strait Islander peoples (Tauli-Corpuz, 2017). The following cultural rights and needs, ranging from using cultural traditions to determining health programs, are to be met, including in prisons:

Box 1: United Nations Declaration on the Rights of Indigenous Peoples relevant to palliative care in prison

Article 2: Freedom from discrimination based on Indigeneity and identity
Article 3: The right to self-determination including social and cultural development – whichcould contribute to improvements in palliative care for people in prisons
Article 4: The right to autonomy and self-government in internal and local affairs – therefore to have a role in criminal justice system decision making
Article 5: The right to maintain and strengthen political, legal, economic, social and culturalinstitutions – which could contribute to improvements in palliative care for people inprisons
Article 8(2): States shall provide effective mechanisms for prevention of, and redress for: (a) Any action which has the aim or effect of depriving them of their integrity asdistinct peoples, or of their cultural values or ethnic identities
Article 11: The right to practise and revitalize their cultural traditions and customs
Article 15: States shall take effective measures, in consultation and cooperation with theindigenous peoples concerned, to combat prejudice and eliminate discrimination
Article 16: Indigenous peoples have the right to participate in decision-making in mattersthat affect their rights
Article 23: the right to be actively involved in developing and determining health and social programmes affecting them and, as far as possible, to administer such programmes through

Aboriginal definition of health

NSW government has published a number of documents that indicate its awareness of and commitment to respecting Aboriginal people's cultures, including the NSW Aboriginal Health Plan (NSW Ministry of Health, 2012) and Communicating Positively guide (Centre for Aboriginal Health, 2019).

Palliative care occurs in the context of NSW's health system, and the Australian health system, and hence the above documents are relevant.

The Aboriginal definition of health to be achieved is:
not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole Community in which each individual is able to achieve their full potential as a human being thereby bringing about the total wellbeing of their Community. It is a whole of life viewand includes the cyclical concept of life-death-life. (National Aboriginal Community Controlled Health Organisation (NACCHO), 2011, pp. 5-6)

This definition signifies that Aboriginal and Torres Strait Islander people's understanding of health is holistic. It is broader than the biomedical focus of material inthe seven Brief of Evidence volumes relating to Mr Goolagong's death in custody.

Mainstream, non-Indigenous policy makers, service providers and researchers have consistently demonstrated an inability to engage with this holistic concept of health (Eckermann et al, 2010). Holistic health care is difficult to achieve with siloed services and systems (Jackson Pulver et al, 2019).

However, Aboriginal and Torres Strait Islander have the right to experience health according to their cultures (UN, 2007) and prisons and justice health services have a responsibility to ensure this occurs.

Respecting the context of health, wellbeing and healing

It is a cultural need and norm of Aboriginal people to be supported by effective systems that help achieve holistic health, wellbeing and healing.

As explained above, Aboriginal and Torres Strait Islander people do not define health as being only that of the individual. An individual's health, wellbeing and healing is inextricably related to that of their family. It is also reflected in the health of their local Aboriginal and Torres Strait Islander community and Country. Health extends to wellbeing, as well as healing rather than treatment and recovery of physical equilibrium. Healing in a range of domains of life can occur even if a return to physicalhealth is not possible.

Further, the health of an Aboriginal and Torres Strait Islander person is highly influenced by how the general Australian community relate to them - this very much shapes how health and other service providers deliver programs and care (Jackson Pulver et al, 2019) and extends to those in the community potentially placed to provide post-prison release care.

Adequate resourcing by governments to produce a workforce that is able to engage respectfully with Aboriginal and Torres Strait Islander culture knowledges and peopleis essential, and this includes addressing the persistent negative stereotyping of Aboriginal and Torres Strait Islander people and prisoners perpetuated by the

mainstream media (McCallum & Holland, 2010; Williams, Sweet, Finlay, & McInerney, 2017).

It is a cultural need, therefore, for service providers responsible for palliative care to both be capable of cross-cultural work and contribute to systems that are culturally responsive.

Meeting the cultural needs of an individual Aboriginal person is not possible without action at all layers in the diagram below, so that there is a supportive system that delivers palliative care in prison. The solution is in consistent, persistent workforce training about Aboriginal and Torres Strait Islander cultures, because workforce operate each of the levels in the diagram below that influence individual health (Jackson Pulver et al, 2019).

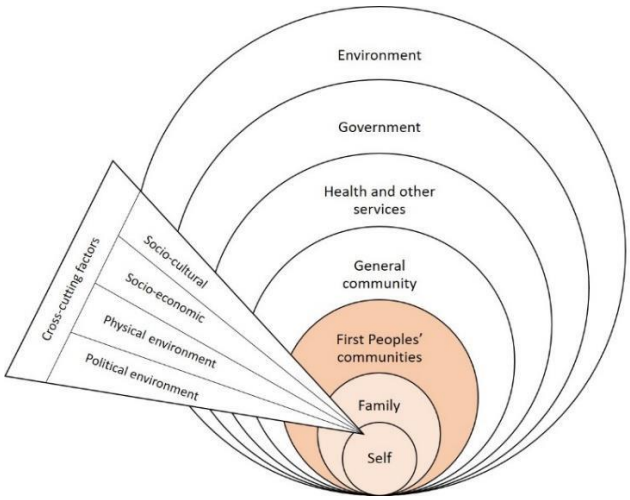

Figure 1: Multi-level empowerment framework (Jackson Pulver et al, 2019, p. 191)

Addressing multiple needs

The diagram above shows how it is a cultural need of Aboriginal and Torres Strait Islander people to not see health as being only that of an individual, but to see it as connected to and influenced by other people, services and environments.

Aboriginal and Torres Strait Islander people in prison are known to have many needs, health issues and underlying risk factors for poor health and wellbeing (Australian Institute of Health and Welfare, 2020).

There diagram above also indicates 'bigger picture' factors to also understand in assessing an Aboriginal and Torres Strait Islander person's level of care received.

In contemporary Australia, to understand Aboriginal and Torres Strait Islander people's wellbeing, it is a cultural need to identify and address a range of contextualissues including:

- Socio-cultural factors such as exclusion from decision making, invisibility of cultural identity, discrimination and lack of understanding of Aboriginal and Torres Strait Islander cultures by workforces with the power to influence wellbeing

- Socio-economic factors including income, employment and education which will impact on Aboriginal and Torres Strait Islander patient and family capacity to engage with palliative care
- Physical environmental factors including Aboriginal and Torres Strait Islander people being more likely to live in regional and remote areas of Australia than the general population, creating barriers to visiting prisons
- Lack of influence, participation and control Aboriginal and Torres Strait Islander people have in designing and leading systems of care to meet their needs (Jackson Pulver et al, 2019).

The diagram and list above does not mean that one palliative care provider has to address all of the levels of action required for effective health and wellbeing care. But, it signifies that 'rolling out' palliative care funding, staff and programs is short-sighted and unsustainable if contextual factors are not improved – lessons that other sectors have responded to including youth homelessness (Haswell et al, 2013) and Aboriginal and Torres Strait Islander post-prison release care (Haswell et al, 2014).

Without a system-wide assessment of need, and a plan to that address multiple needs Aboriginal and Torres Strait Islander prisoners have, the cultural needs of Aboriginal and Torres Strait Islander people will be difficult to meet in palliative care.

How a staff member engaged in palliative care enacts an holistic definition of health for and with Aboriginal and Torres Strait Islander people is discussed in section 5 below.

Earlier engagement with end-of-life care

It is well known that Aboriginal and Torres Strait Islander people consistently have poorer access to mainstream services than other Australians and that diagnoses for health issues occurs later than for others with poorer prognoses. However, Aboriginal and Torres Strait Islander people have the right to access care earlier, and that is effective. Again, quality care informed by culture is also a right (UN, 2007) anda commitment of governments to achieve (NSW Government Department of Aboriginal Affairs, 2013). Earlier engagement with supportive care has been found to result in better outcomes for individuals post-prison release (Conroy & Williams, 2017).

Reasons for lack of engagement by Aboriginal and Torres Strait Islander people earlier with formal care providers include:

- Personal, family and community experiences of racism and poor reputations of services
- Poor reputation of services and negative beliefs held by Aboriginal and Torres Strait Islander people about services
- Ineffective assessment from a western biomedical perspective
- Lack of availability of services to meet needs of Aboriginal and Torres Strait Islander people and families
- Reluctance of mainstream services to change their care provision to meet the need
- Lack of skills of mainstream services to provide culturally safe care
- Lack of investment by universities and governments to train and develop culturally safe workforces or achieve Aboriginal and Torres Strait Islander staff and student targets (for example Bennett et al, 2013; Fogliani, 2020; Haswell et al, 2014; Manton & Williams, in press; Williams, 2015)

Cultural safety

Some of the statements above highlight the power that the mainstream health and justice workforces have over the extent to which the cultural needs of individual Aboriginal and Torres Strait Islander people are able to be identified and met.

To guide organisations' actions, cultural safety frameworks are increasingly more common in government services, with leadership by the Australian Health Practitioner Regulation Agency (2020) and Aboriginal and Torres Strait Islander organisations such as Australian Indigenous Doctors' Association (2017).

A commonly accepted definition of cultural safety is:
an environment which is safe for people; where there is no assault, challenge ordenial of their identity, of who they are and what they need. It is about sharedrespect, shared meaning, shared knowledge and experience, of learning together with dignity, and truly listening (Williams, 1999, pp. 213-214).

Cultural safety frameworks and related workforce development are envisioned as a way of meeting Aboriginal and Torres Strait Islander people's cultural needs.

Social support

In Volume 5 p. 175 of the Brief of Evidence, Mr Goolagong was quoted as having a 'desire to interact with other inmates the Koori culture' and 'inmates whom are a similar cultural background as myself'.

This asking for support contrasts with Mr Goolagong being described as having 'underlying anxiety' (Vol 2, p. 476).

To the best of my understanding there were few actions to connect Mr Goolagong to social support or cultural support from people of a similar background, particularly that would assist with underlying anxiety.

Peer support has been found to be instrumental in meeting social, emotional, practical and instrumental needs among Aboriginal and Torres Strait Islander people (Conroy & Williams, 2017; Haswell et al, 2014; Williams, 2007; Williams, 2015).

Personal support and gendered business

It is possible Mr Goolagong may have had a need for 'gendered business' meaning his needs are best addressed in the context of other males or those he feels comfortable with (Bulman & Hayes, 2011).

Post-traumatic stress disorder has been fond at high rates among Aboriginal and Torres Strait Islander women in prison (Heffernan et al, 2012) and may be important to consider including in relation to whether touching is personally or culturally appropriate or not.

Right to equivalent care in the community

The Nelson Mandela Rules (UN, 2015) which set out the United Nation's minimum rules for the treatment of prisoners, state that prisoners have the right to have their individuals needs and beliefs respected.

Respected means these being known, and acted on appropriately.

Prisoners must not be cut off from the community, and prisons should mirror life in the community in prison. For Aboriginal and Torres Strait Islander people this means access to Aboriginal and Torres Strait Islander community-controlled services which are only very minimally available in prison (Pettit et al, 2019).

Prisons are to offer social, spiritual, moral supports - equivalent care as in the community. For Aboriginal and Torres Strait Islander people this means support groups e.g. for Stolen Generations, gender-based groups, Traditional Owner groups and cultural healing programs (Blignault et al, 2014).

The Nelson Mandela Rules also indicate that prison staff must be able to provide adequate treatment and care. Recent publications highlight the qualities, skills, training and supports Aboriginal and Torres Strait Islander people have which enables them to provide culturally safe care in Aboriginal and Torres Strait Islander community-controlled health service settings (Bailey, 2020); evaluation of NSW Health workforce training show a lack of full completion of cultural awareness training among government workforce (Jaques & Kemp, 2015) with no evaluation of its impact on health service delivery. Instead racism is frequently reported as an issue in mainstreamgovernment workplaces by Aboriginal and Torres Strait Islander people (Bargallie, 2020) and patients (Kelaher, Ferdinand, & Paradies, 2014).

Effective and timely access to support and palliative care

Mr Goolagong's diagnosis and prognosis is made clear in clinical notes and referral forms. There is a clear expectation that Mr Goolagong would not recover but would pass and in a relatively short period of time.

Very few times was palliative care planning mentioned, nor was referral to support services for aged care, palliative care or cultural support mentioned or actioned.

Material in Brief of Evidence volumes indicates that health professionals were engaging with Mr Goolagong in March and April, only a very short period of time before July when he passed away, but a reasonable amount of time for palliative andcultural care planning and support.

Provision of timely care is based on effective assessment, which relies on skills of health care providers to choose relevant tools, and engage cross-culturally (Bennett et al, 2013; Dudgeon, Milroy, & Walker, 2014; Eckermann, 2010; Heffernan, Andersen, & Kinner, 2009). Relationships of mainstream health care providers to Aboriginal and Torres Strait Islander organisations are required (Haswell et al, 2013; Haswell et al, 2014; Jackson Pulver et al, 2019), including to gain support of others experienced in engaging with Aboriginal and Torres Strait Islander people and in this case of Mr Goolagong's life stage, gender and Aboriginal cultural background.

Access to information

The Nelson Mandela Rules assert that prisoners have right to be spoken to in a language they understand (UN, 2015), which refers to level of local language literacy,the need to use plain language, and using local colloquialisms as appropriate. These can all occur about palliative care for Aboriginal and Torres Strait Islander people in prisons, and their families, and about the range of issues to do with palliative care including multi-morbidities.

The Nelson Mandela Rules also assert that clear information is to be kept on prisoner family members, in part to be contactable should the need arise (UN, 2015). Aboriginal and Torres Strait Islander families are more diverse and extended than mainstream Australian families (Ulrik, Foster, & Davis, 2011); staff training may be required so that they can identify family appropriately, to then identify how they are best contactable.

Death and dying

In Wiradjuri culture, an individual is to understand their life and actions and plans across seven generations (Sheehan, 2009). Since time immemorial Aboriginal people have constructed, followed and conveyed physical, spiritual and educational pathwaysand Songlines across Australia. There was not one part of Country, society or person unaccounted for, without meaning or purpose, without a Songline (Gay'wu Group of Women, 2019; Minmia, 2007).

A person is thought not to die and disappear but enter into another cycle of being in the world. Their spirit is to be set free from this world as it is understood (Ulrik, Foster,& Davis, 2011). This is reflected in the Aboriginal definition of health: the cyclical nature of life-death-life (NACCHO, 2011). This is broader and thus very different to dominant views that shape health professionals' education in Australia (Fitzpatrick et al, 2019; Jackson Pulver et al, 2019).

The reifying, misconstruing and altering of Aboriginal and Torres Strait Islander people's knowledges is common (Nakata, 2007; Pascoe, 2014) and in my experience extends to death and dying.

One view perpetuated is that an Aboriginal person's name must not be mentioned after they have passed away, and/or a cultural name is applied (Ulrik, Foster, & Davis, 2011). However, the family of Yorta Yorta woman Ms Tanya Day, who died in police custody, have asserted 'Remember her name' (Hooper, 2020). The important actions are:

- not project one local nation's information onto other Aboriginal and Torres Strait Islander people and nations
- seek local and other appropriate guidance
- have an Aboriginal and Torres Strait Islander professional and/or Elder involved in care planning and provision.

A range of Aboriginal and Torres Strait Islander people's protocols about death and dying are outlined in Question 2 below.

Intergenerational responsibilities and family care

Aboriginal and Torres Strait Islander people have written about their deep capacity for love and other principles including forgiveness and hope (Langford, 1988), healing

and overcoming trauma (Laliberte, Haswell-Elkins, & Riley, 2009) and asking all Australians to 'work together with us' (First Nations Constitutional Convention, 2017).

It is well recognised that most, if not all, Aboriginal and Torres Strait Islander families are affected inter-generationally through transfer of oppression, grief, loss, trauma, poor parenting and poor social capital (Atkinson, 2002). The effect of colonisation, loss of language, land and cultural systems, poverty and incarceration on whole family systems and communities of Aboriginal and Torres Strait Islander people is regonisablein poor outcomes among individuals (Atkinson, 2009; Steels, 2008).

'Stolen Generations' have been over-represented in the criminal justice system (Human Rights and Equal Opportunities Commission, 1997), and have up to four generations of descendants (Blignault et al, 2014).

Families are well-recognised in a range of literature as fundamental in the experience of social support (Christian, Mellow, & Thomas, 2006; Gideon, 2007) and Aboriginal and Torres Strait Islander family members are often intermediary support people between formal services and the individual in need (Williams, 2015).

Evidence-based Aboriginal Family Wellbeing Program (FWB) has long recognised the value of strengthening the capacity of family members to provide support, including through individual personal growth and collective healing strategies (Onnis et al, 2018).

Long-term Aboriginal health promotion charity Mibbinbah use a range of strategies for spiritual healing with groups, families and individuals, including to strengthen and heal relationships, reconcile people with Country, identity and family, process forgiveness and set boundaries for self-care (Bulman & Hayes, 2011). A range of international literature identifies these themes as essential for end-of-life care, grief and loss for individuals who are terminally ill and their families and communities (Santrock, 2004).

End-of-life care is also identified as an opportunity for passing on family and financial information, affirmations and material items (Santrock, 2004). In my experience, for Aboriginal and Torres Strait Islander people this time is important for passing on cultural knowledge including for Country, cultural heritage preservation, identity matters and hope for future generations.

Connection to support people including Elders during end-of-life stage and for bereavement and grief is essential to reduce pressure and risks from multiple, compounding traumas (Glaskin et al, 2008; Ulrik, Foster, & Davis, 2011; Wanganeen, 2014).

2. Outline whether there is a recognised system of best practice in relation to addressing the needs of Aboriginal patients with terminal illnesses more generally, and any barriers that incarceration poses to those best practices.

Because Aboriginal and Torres Strait Islander cultures are diverse, there is no one system of best practice.

The key protocol is respect for end-of-life needs and protocols from the Aboriginal nationhood, culture and community that the individual identifies with (Ulrik, Foster, &

Davis, 2011) such as Wiradjuri, rather than 'Aboriginal' broadly. Thus, cultural identity must be clearly understood from the individual's perspective and care providers mut be skilled at asking about and responding to this.

Aboriginal and Torres Strait Islander professionals operate with sets of principles and core modes of caregiving (Eckermann et al, 2010; Haswell et al, 2013; Haswell et al, 2013). These are usually developed by peak organisations of e.g. in the health sector the National Aboriginal and Torres Strait Islander Community Controlled Health Organisation and for Stolen Generations the Healing Foundation.

Aboriginal and Torres Strait Islander people's recommended models of care have a varied evidence base that can be drawn on (Onnis, Klieve, & Tsey, 2018), with critical success factors clearly identified that can be used to inform local solutions to local Aboriginal and Torres Strait Islander community issues, always under guidance of Aboriginal and Torres Strait Islander Elders (Haswell et al, 2013; Williams, 2018).

Features of Aboriginal and Torres Strait Islander people's caregiving are outlined below, and barriers identified that incarceration poses:

- Cultural support and Country
- Aboriginal holistic health, trauma-informed care and social and emotional wellbeing programs
- Strengthening cultural identity
- Peer support and collective healing
- Optimal care pathway: Cancer Australia
- In-reach of community organisations
- Cultural safety plans
- Eldership and journeys of healing
- Traditional healing
- Family care
- Supporting and Palliative Care Indicators Tool.

Cultural support and Country

Some strategies related to end-of-life care respected and used by Aboriginal and Torres Strait Islander people include:

- Acknowledgement that most families have experienced multiple losses
- Family members being together, including extended family members across generations
- Use of healers, bush medicines, smoke and ceremonies
- Asking questions, seeking answers
- Reconciling in relationships
- Use of interpreters among multi-lingual family members
- Use of cultural brokers to ensure the right people are involved in planning the funeral, memorials and preparation of the site of burial
- Preparation of the body before burial
- Ensuring the spirit of the deceased is considered free
- Gatherings on Country including to return the body to country, and for camps for families to mourn together
- Communal as well as individual expressions of sorry business

- Language use such as 'finishing up' about acknowledging death, 'sorry business' and 'feeling sorry' rather than grief and death (Ulrik, Foster, & Davis, 2011).

Without these and other actions outlined below, "it is the long-term effects of sadness and worry that creates even more stress" (Ulrik, Foster, & Davis, 2011, p. 196).

Aboriginal holistic health, trauma-informed care and social and emotional wellbeing programs

As discussed earlier, NSW and Australian governments assert that the holistic definition of Aboriginal and Torres Strait Islander health is to be used, meaning that the following dimensions of health are relevant to address among terminally in Aboriginal patients:

- Social including finances, relationships and housing
- Emotional including anxiety and grief
- Mental including worry about the future
- Physical including multiple health issues to address
- Spiritual including perseverance and feeling cared about.

In my understanding, Mr Goolagong showed needs in all these areas across time since his diagnosis.

Australian and NSW governments have clearly indicated they are committed to trauma-informed care and care that improves social and emotional wellbeing of Aboriginal and Torres Strait Islander people (Department of Health, 2017; Department of Prime Minister and Cabinet, 2018; NSW Government Department of Aboriginal Affairs. (2013); NSW Ministry of Health. (2012. Again, access to care based on culture is a right of Indigenous people (UN, 2007) and prisoners (UN, 2015).

That is, government policy should enable such care; such care should be possible.

For people with life-limiting conditions in prisons, trauma-informed and social and emotional wellbeing programs can be part of treatment, obviously without the expectation that a person will recover from the illness. That a person will die rather than recover should not be a reason to exclude care for other dimensions of wellbeing.

Strengthening cultural identity

Aboriginal and Torres Strait Islander culture is a protective factor that promotes wellbeing (Thurber et al, 2020). Strengthening can occur at any point in a person's life,

> acknowledging that stronger connections to culture and Country buildstronger individual and collective identities, a sense of self-esteem, resilience and improved outcomes across the other determinants of health including education, economic stability and community safety (Brown, cited in Department of Health 2017, p. 7).

Strengthening cultural identity and wellbeing of one person is understood to improve wellbeing across multiple generations (Blignault et al. 2014, p. 14) and hence is relevant to the care of Aboriginal and Torres Strait Islander people with a terminal illness.

Peer support and collective healing

There is a large literature about the role of peer support among Indigenous peoples and programs to improve access to perceived, instrumental, and practical support. Engaging community members as support people is empowering for all involved, creates a sense of community where government forces may have removed that, and stimulates individual, family and community-level healing (Sheehan 2012). This type of dynamic has some likenesses to the sizable field of peer support that has been proven effective in the care of other health conditions including HIV/AIDS (for example Rufurwadzo, Inarukundo, Noviyanti, & Subero, 2020) and drug-related harms (for example Bardwell, Thomas, Boyd, & McNiel, 2018).

In Aboriginal and Torres Strait Islander ways of knowing, being and doing, the 'unit of intervention' is rarely at first the individual – it is a collective because of the collectivist identity Aboriginal and Torres Strait Islander people have (Blignault et al, 2014) rather than the individualist concept of western science (Walter & Andersen, 2013).

This is relevant to caring for Aboriginal and Torres Strait Islander people with terminal illnesses because the healing is in the mind, emotions, spirit and family system, not (only) the physical body. That is, a person who is terminally ill can experience healing in these aspects of themselves, even if not in their physical body.

Optimal care pathway: Cancer Australia

The *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* by Cancer Australia (2018) guide Aboriginal and Torres Strait Islander people and their caregivers through a seven-step process of diagnosis, treatment and support.

It highlights that systems and workforces need to be culturally safe, providing holistic care. They also need to address reasons Aboriginal and Torres Strait Islander people experience inequities, being over-represented among people with cancer yet under-represented in the workforce, program design or leadership of decision making.

Key considerations outlined are:

- The health care provider must understand the patient including their cultural identity
- Care coordination is required for each person, informed by their culture, gender, socio-economic status and family connections
- An expert in Aboriginal and Torres Strait Islander health care must be included in provision of services and support such as an Aboriginal Hospital Liaison Officer or Aboriginal and Torres Strait Islander health worker
- Plain English must be used with guidance on using Aboriginal cultural languages and expressions
- Take time to build rapport
- Involve family in care planning and appointments
- Appropriate engagement including touching.

Cancer Australia include what they call 'evidence-based' principles related to tumour-specific pathways but do not detail what evidence they have drawn on from an Aboriginal and/or Torres Strait Islander perspective. Their principles are:

- patient-centred care
- safe and quality care

- multidisciplinary care
- supportive care
- care coordination
- communication
- research and clinical trials (Cancer Australia, 2018, p. 8).

Prevention and early detection are also identified as necessary and relevant to end-of-life care, as is screening, immunisation, risk reduction for other illnesses and investigation of co-morbidities.

Step seven of the Optimal Care Pathway relates to end-of-life care. This recommends:

- A return to Country
- Multidisciplinary palliative care
- Pain management
- Cultural practices for death and dying discussed with local Aboriginal and Torres Strait Islander personnel and communities.

No aftercare is included in the seven-step plan, nor a specific step for supporting family.

In-reach of community organsations

In-reach by community organisations to prisons has been found effective in a number of prisons around the world to address health issues among prisoners and provide continuity of care post-prison release (Conroy & Williams, 2017). Aboriginal and Torres Strait Islander organisations are well placed to provide such care because they are accessed at higher rates by Aboriginal and Torres Strait Islander people, provide culturally-safe care according to local protocols and have a skilled and large Aboriginal and Torres Strait Islander workforce (Bailey et al, 2020). Aboriginal and Torres Strait Islander community organisations also have capacity, willingness and experience working with people in the criminal justice system (Pettit et al, 2019).

Cultural safety plans

Cultural safety plans are commonly in place and used by Aboriginal and Torres Strait Islander organisations and are growing in use by mainstream organisations. Clear guidelines are available for many professions, as are resources and training (AHPRA, 2020)

Eldership and journeys of healing

The importance of Aboriginal Elders, counsellors and other pastoral care providers is described throughout the edited book *Working together* by Dudgeon, Milroy and Walker (2014). In part this is because Aboriginal people require "authentic Aboriginal input, not 'mainstream' interpretations of what it is to be Aboriginal' (Peeters, Hamann,& Kelly, 2014, p. 503)

The *Working together* chapter about Stolen Generations is particularly relevant to Mr Goolagong, who was identified as being impacted.

A journey of healing is recommended, such as through the *Murumali* program, with Murumali meaning to be 'put back together' in Kamilaroi language (Peeters, Hamann,

& Kelly, 2014, p. 498). A journey of healing is recommended for all Aboriginal people who have been removed from their communities (Peeters, Hamann, & Kelly, 2014, p. 498).

Murumali is led by experienced Aboriginal counsellors and Elders, and 'offers a comprehensive, coordinated and risk-managed approach which cuts through the pain and confusion and allows survivors to find a safe path home to themselves, their families and their communities' (Peeters, Hamann, & Kelly, 2014, p. 498).

Traditional healing

The Anangu Ngangkari Tjutaku Aboriginal Corporation (ANTAC) (2019) make hands-on, traditional healing available to all community members. Ngangkari are accredited through a strict process in accordance with *Ngangkariku Tjukurpa* (Law). They have successfully operated one-on-one clinics in NSW government health facilities, and can also run workshops, coaching, counseling and home visits. Their work is potentially suitable to those terminally ill in prisons because it provides non-invasive, culturally-informed health care that does not require equipment or other onerous arrangements for treatments to occur.

Family care

Responsibility for the care of an Aboriginal and Torres Strait Islander person dying in prison must, by virtue of Aboriginal and Torres Strait Islander people's holistic sense of wellbeing, include family members. One relevant framework to guide this, particularly post-death, is the *Seven Phases to Integrating Grief and Loss* outlined by the Australian Institute for Loss and Grief (n.d.) and CEO Kaurna Aboriginal woman Rosemary Wanganeen. Their recommended framework focusses on:

- 'Aboriginal prosperity' and focusing on cultural strengths and strengthening
- Honouring lived experience
- Working in partnership with local Aboriginal and Torres Strait Islander organisations
- Designing programs specifically for releasing unexpressed intergenerational grief and loss that Aboriginal and Torres Strait Islander people often experience.

The seven phases Wanganeen (2014) outlines are related to the past, the present, and the future, and are especially valiable for the care of families bereaved by a death in custody.

Supportive and Palliative Care Indicators Tool (SPICT)

The Supportive and Palliative Care Indicators Tool (SPICT, 2021) is used in parts of NSW Health, and in the *National Palliative Care in Prisons Project*. SPICT is used to identify people with deteriorating health, with advancing conditions, and at risk of dying in the next 12 months. It prompts assessment and future care planning.

To the best of my reading of the Brief of Evidence volumes, I did not see SPICT used ina way that informed care planning for Mr Goolagong.

While SPICT has not been designed for Aboriginal and Torres Strait Islander people, it does identify that palliative care is to be holistic. SPICT uses non-medical language and is relevant for use in correctional settings and non-medical staff.

Barriers that incarceration poses include:

- Lack of staff in prisons positioned to address multiple dimensions of holistic health
- Lack of funding for justice health services to provide more comprehensive holistic health care
- Lack of skills and experience of prison and justice health staff to engage in culturally safe and culturally responsive ways with Aboriginal and Torres Strait Islander people (Banga-ma-la-nha Project, 2020)
- Program and system bias, discrimination and racism which excludes or fails to act on Aboriginal and Torres Strait Islander people's rights, policy frameworks or needs
- 'Cultures of complacency' in justice and health system staff (English, 2020; Fogliani, 2016)
- Aboriginal and Torres Strait Islander staff shortages and government services not able to meet Aboriginal and Torres Strait Islander staff targets (NSW Public Service Commission, 2019)
- Lack of community based organisations in-reaching to prisons to provide services (Haswell et al, 2014)
- Difficulties for family to visit prisons; separation from culture, kin, community, identity and Country which are essential to Aboriginal and Torres Strait Islander people's wellbeing (Williams, 2017)
- Prisoners not having access to Medicare, which Aboriginal and Torres Strait Islander community-controlled health organisations use to help provide services

○ Aboriginal and Torres Strait Islander community-controlled health organisations being funded by the Australian Government and rarelyby state governments, the jurisdictions that fund criminal justice and justice health services (Pettit et al, 2019)

- Deficit discourse about Aboriginal and Torres Strait Islander people as defective, ineffective, less deserving, incapable and recalcitrant, which compounds with overwhelmingly negative perceptions of prisoners, perpetuated by the mainstream media and cited by parliamentarians as impacting on resource allocation for rehabilitation of prisoners (McCallum & Holland, 2010; Williams, Sweet, Finlay, & Mclnerney, 2017)
- Gaps in data (AIHW, 2020) on which to base holistic healthcare, aged care, advanced care planning, end-of-life care and palliative care service delivery decisions
- Little evaluation, accountability or recourse to Aboriginal and Torres Strait Islander people's rights, policy frameworks and needs not being met
- The focus on physical health and wellbeing, and on security and containment of prisoners rather than effective assessment and care planning, particularly for those who are terminally ill.

3. Section 160 of the Crimes (Administration of Sentences) Act 1999 ("CAS Act") allows (subject to conditions not arising on the present facts) the Parole Authority to make an order for early release from custody where an inmate is dying or where the Parole Authority is satisfied that exceptional extenuating circumstances exist. If the Parole Authority exercises their discretion under s. 160 of the CAS Act, and considers an application for early release under that section, are there particular considerations that ought to be taken into account for Aboriginal people in custody with a terminal illness?

This section outlines a range of considerations for Aboriginal and Torres Strait Islander people in custody with a terminal illness:

- Connection to Country
- The need for effective, culturally-informed assessment
- Systemic bias and racism
- Timeliness of assessment for decision making
- Patient chart accuracy
- Access to quality, culturally informed health information
- Access to Aboriginal and Torres Strait Islander community-controlled health services
- Family connections and obligations
- Barriers to visits
- Planning for a system effective at supporting early release
- Family and community-based support.

Connection to Country

An ongoing connection to Country, a return to Country for death and post-death processes are vital elements of culture for Aboriginal and Torres Strait Islander people. Aboriginal people from central Australia, for example, have said about people who cannot die on Country that they "hope that they will return when they die, 'proper way"– that connection to country is the expectation and right thing to do (Ulrik,Foster, & Davis, 2011, p. 196). Many Aboriginal and Torres Strait Islander nations have advocated for remains of their community members to be repatriated and returned to Country post-death, such is the meaning of a connection to Country (Danalis, 2009).

The need for effective, culturally informed assessment

The timely and effective assessment of Aboriginal and Torres Strait Islander people's needs is an important consideration in early release. This is currently lacking, and improvements are urgently required.

Many of the forms I reviewed in the Brief of Evidence volumes inadequately assess for or record considerations from Aboriginal and Torres Strait Islander people's perspectives. This puts the onus on the practitioner to be highly skilled at engaging with depth with Aboriginal and Torres Strait Islander people – to interpret questions and answers to capture information in a relevant way that is an honest, non-culturally biased perspective.

Again, assessment that identifies social, emotional, mental, physical, spiritual and environmental dimensions of need and from an Aboriginal perspective is required – and then care planning in relation to those dimensions.

Care planning based on culturally-relevant assessment should include an Aboriginal and Torres Strait Islander expert, and family. This appears lacking in the mainstream settings responsible for Mr Goolagong's care.

Systemic bias and racism

Bias is evident in current NSW prison and justice health settings to a general, mainstream prisoner population, with western and biomedical approaches to offendingand rehabilitation. This is despite Aboriginal and Torres Strait Islander people being 29% of Australia's prison population (Australian Bureau of Statistics, 2020).

This type of bias, that affects a large proportion of people, is a representation of systemic discrimination and racism (Bargallie, 2020; Jackson Pulver et al, 2019).

Training about culturally-informed assessment is lacking in much health curriculum; current generations of mainstream health care providers are not prepared sufficiently well to provide care from an Aboriginal and Torres Strait Islander perspective. This risks perpetuating systemic bias, discrimination and racism (Jackson Pulver et al, 2020; Manton & Williams, in press).

Timeliness of assessment for decision making is required

In addition to quality, culturally-relevant assessment of needs, assessment for early release should be conducted and reported in a timely way, to then influence an application and subsequent actions in a timely way.

Timeliness must respect the realities of Aboriginal and Torres Strait Islander community life, in which people have multiple roles, competing demands, disparate locations, large families, and multiple needs for support (Williams, 2015).

Additional time must be made to act in relation to these realities.

Skilled health care and legal professionals will understand this reality, and will have experience navigating community realities and professional care providers.

Patient chart accuracy

In addition to quality, culturally-relevant and timely assessment, Aboriginal and Torres Strait Islander patient charts must record information accurately. That is, information relevant from an Aboriginal and/or Torres Strait Islander person's perspective – to then accurately inform care planning. Instead, it is a reality that information about Aboriginal and Torres Strait Islander people is interpreted by non-Indigenous people, conveyed on forms to other non-Indigenous people, and risks missing needs, timeframes, caregivers and cultural information (Eckermann et al, 201

Cultural bias and a 'blind spot' can occur in well-intentioned people (Banaji & Greenwald, 2013) including professionals who are successful in other areas of their practice. Patient chart contents influence future care provision and risk perpetuating inequities for Aboriginal and Torres Strait Islander people.

Access to quality, culturally informed information

To guide decision making including timeframes in relation to care of Aboriginal and Torres Strait Islander people, professionals require knowledge of and access to information about Aboriginal and Torres Strait Islander cultures.

Because current tertiary education and professional training is lacking about this (Universities Australia, 2017) professionals require access to Aboriginal and Torres Strait Islander Elders and care providers to provide expert guidance. The Public Health Association of Australia's Aboriginal and Torres Strait Islander Special Interest Group and its colleagues in the World Federation of Public Health Associations state simply 'nothing about us without us' (Finlay & Kakoschke-Moore, 2017). This represents Aboriginal and Torres Strait Islander people's right to self-determine delivery of services, their processes and standards (UN, 2007).

Following on from this, Aboriginal and Torres Strait Islander care providers must be involved in such a way as to be able to influence care – with power, in a timely way and with resources to undertake tasks required for quality, culturally-informed care.

Access to Aboriginal and Torres Strait Islander community-controlled services

Aboriginal and Torres Strait Islander people are known to access Aboriginal and Torres Strait Islander community-controlled health services at higher rates, with more adherence to appointments and treatment and with greater follow up than they do to mainstream health organisations (for example, Mazel, 2016). Aboriginal and Torres Strait Islander people's access to Aboriginal and Torres Strait Islander community-controlled health organisations in prisons is at present limited and Aboriginal and Torres Strait Islander people are unable to experience equivalence of care in prison as in the community (Pettit et al, 2019); to which they have the right (UN, 2015). Because of their extremely limited availability for Aboriginal and Torres Strait Islander people in prisons and few public strategies to improve on this (Banga-ma-la-nha Project, 2020), Aboriginal and Torres Strait Islander people may have better access to Aboriginal and Torres Strait Islander community-controlled health organisations, informal Aboriginal and Torres Strait Islander community-based cultural care and safe spaces in the community than in prison, which will be facilitated by early release.

Family and cultural connections and obligations

As identified earlier, Aboriginal and Torres Strait Islander people's individual health is inextricably linked to that of family, community and Country, and with this comes cultural connections and obligations to respect. These are difficult for mainstream Australian health service providers to understand and interpret, particularly without meaningful relationships with Aboriginal and Torres Strait Islander people (Fitzpatrick et al, 2019) and are easily minimised and overlooked. Early release may facilitate terminally ill prisoners time with family and community to fulfil cultural obligations, which can include including intergeneration transfer of knowledge, reconciliation in relationships, addressing legal matters and attending to governance of Aboriginal andTorres Strait Islander community organisations (Bulman, 2021; Bulman & Hayes, 2011).

Barriers to visits

Aboriginal and Torres Strait Islander people are from large extended family and community networks, who expect to be involved in processes of death and dying (Ulrik, Foster, & Davis, 2011). The many identified barriers for Aboriginal and Torres Strait

Islander family and community members, and community-controlled services and informal caregivers accessing prisons (Williams, 2017; Alexander, Martin, & Williams, 2011) will be avoided by early release of terminally ill Aboriginal and Torres Strait Islander prisoners.

Planning for a system effective at supporting early release

While the focus of 'cultural considerations' for Aboriginal and Torres Strait Islander people is often the individual Aboriginal and Torres Strait Islander person, much of the above information explains the need for cultures of the current mainstream criminal justice and health systems to improve in their responsivity to Aboriginal and Torres Strait Islander cultures. This includes use of Aboriginal and Torres Strait Islander cultures in planning of programs and other considerations for all prisoners, given holistic care is likely to be relevant for people of most, if not all, cultures (Jackson Pulver et al, 2019).

The s. 160 of the CAS Act appeared effective in a legal sense, and had health professionals' support in Mr Goolagong's case. However, other parts of the system were not effective.

Any consideration of early release must take into account the capacity of the system and staff to support it into being a reality. It is likely any lack of capacity of systems and staff to support early release to a reality could be considered a contravention of Indigenous peoples' and prisoner rights.

Consideration must therefore be given to development of effective systems to enable early release to occur, in practical terms. This includes access to care coordination, and skills in the workforce to engage respectfully with Aboriginal and Torres Strait Islander people.

Family and community-based support

Aboriginal and Torres Strait Islander people are frequently described as a resilient people, having survived the major calamity of colonisation and ensuing loss of land rights, languages and power in society, as well the overwhelmingly negative impacts of Stolen Generations. As described earlier, Aboriginal and Torres Strait Islander people have written about their enormous capacity for inclusion, as well as understanding, forgiveness, and thinking about needs of future generations (Langford,1988; First Nations National Constitutional Convention, 2017).

Family and community support should be understood and accurately reported on in consideration of early release. This should include details about support for access to health and holistic care, support with mobility, extent to which the people will be present in daily life, quality of relationships, wishes of family members, and recommendations of local Elders.

Such information, of support for early release, may provide a compelling rationale for non-Indigenous service providers to generate action plans that see early release cometo reality.

This information may be required in the unfortunate event of 'cultures of complacency' found by Coroner English (2020) among non-Indigenous criminal justice and health system care providers, and Coroner Fogliani (2016) who of overwhelmingly negative

stereotypes of Aboriginal and Torres Strait Islander people as un-deserving of culturally-informed, timely care.

4. Ms Priscilla Goolagong first raised the Goolagong family's desire to explore early release for Mr Goolagong at the end of February 2017. However a formal application regarding same was not received by the State Parole Authority (through Legal Aid on behalf of Mr Goolagong) until 28 June 2017. In your view should CSNSW have made greater efforts to assist Mr Goolagong to make such an application. In any event, are you of the view that the process for seeking early release in such circumstances could be improved upon for Aboriginal inmates and if so how?

I am of the view that the process for seeking early release for terminally ill prisons could be improved upon. There are a number of ways CSNSW can make greater effort, including through the following, which are briefly outlined further below:

- Partnerships and networks
- Care coordination
- Timeliness of assessment and care planning
- Quality of assessment
- Increase support
- Inclusion of family
- Increase staff numbers
- Legal generalist services
- Access for families to prisons
- Workforce development.

Material in response to questions above is also relevant including adherence to Aboriginal and Torres Strait Islander definition of health, enacting human rights and government commitments to Aboriginal and Torres Strait Islander health and cultures, and cultural safety planning.

Partnerships and networks

These are required with community-based government services and staff as well as Aboriginal and Torres Strait Islander community-controlled organisations and informal caregivers. Criminal justice system leadership can make and resource these partnerships and networks, as can individual staff within their roles to ensure coordination of care and culturally-informed care.

Care coordination

The relationship between the SAPO and RAPO is instrumental and should be well-resourced, including with additional staff to ensure continuity of care, enacting of holistic health care planning, and management of workload.

The Brief of Evidence volume 7 in particular included information that indicated some staff were not contactable in a timely way, were on leave, were experiencing changesin employment, experienced some lack of clarity and understanding of roles by others,and lack of community-based networks required for referrals.

While a cancer care nurse was mentioned in the Brief of Evidence volume 7 p. 126 and issues about funding of Palliative Care Consultant Physician were documented, additional consideration of care coordination roles by social workers, welfare workers and Aboriginal health workers is required.

An increase in Aboriginal and Torres Strait Islander staff workforce to better reflect the over-representation of Aboriginal and Torres Strait Islander prisoners is required. This will be instrumental in delivering culturally-responsive, timely care with networks to Aboriginal and Torres Strait Islander services and people in the community for early release support.

Care coordination roles are important intermediary roles, who could navigate and negotiate in a timely and skilled way between family, legal, accommodation and social and cultural supports as well as mainstream health services, local health districts,aged care, cancer care, palliative care, funerals and bereavement.

Timeliness of assessment and care planning

As outlined above, timeliness of assessment and care planning is essential to take into account the realities of Aboriginal and Torres Strait Islander people's lives as well as system biases and disconnects. Further, the Nelson Mandela Rules are clear that prisoners be provided with adequate time to make arrangements they require for legal support (Rule 61).

All staff with responsibilities for care and security of terminally ill prisoners must receive training that better orients them to Aboriginal and Torres Strait Islander family and community life, with implications for service delivery and care planning. This shouldbe delivered by skilled Aboriginal and Torres Strait Islander practitioners and evaluated.

Quality of assessment

The expert report item 7.15 P. 292 indicated Mr Goolagong was looking "frail and gaunt" even though said he was "good". As discussed above, accurate assessment from Aboriginal cultural perspective is essential, to not take this type of discrepant communication at face value. Skilled practitioners will understand and respond to this in a way that brings to light underlying meanings and implications including using tools or measures for and by Aboriginal practitioners. Using skills of Aboriginal and Torres Strait Islanderpractitioners to attain a more accurate assessment to then plan types and timing of care and early release application process is essential.

Increase support

Mr Goolagong's case notes indicated the need for improve support a number of times. However, there is little evidence of this occurring, except for physical-level interventions. As discussed above, assessment and care planning, with skilled staffing and resourcing is required.

Inclusion of family

As also indicated above, prisoners have the right to involvement of families, as do Aboriginal and Torres Strait Islander people generally in relation to health. The Aboriginal definition of health clearly identifies families have a role, and Australian

and NSW government agencies have indicated their commitment to this holistic definition of support. The needs and wishes of Mr Goolagong's family are only minimally visible in the Briefs of Evidence; it appears feasible for their inclusion to be improved, and for additional support to also be provided to family members.

Increase staff numbers

As discussed earlier, Aboriginal and Torres Strait Islander staff offer much for mainstream organisations in their meeting cultural safety plans, policy framework objectives and locally-informed care. While an Aboriginal Health Worker – Palliative Care role is reported as being in place from March 2020 in Justice Health and Forensic Mental Health Network, evaluation of this role must occur including whether the level of staffing meets need, and the extent to which other staff roles and parts of the system support this role to achieve their tasks. It is a common experience of Aboriginal and Torres Strait Islander people that racism occurs in government organisations, which plays out as obstructions, misinformation, delays and other microaggressions (Bargallie, 2020). It is never the recommendation of Aboriginal and Torres Strait Islander workforce planning to only appoint one Aboriginal and Torres Strait Islander person; teams are required for peer support, a broader base of powerand to influence system-level change, including through leadership positions (Williams, Ragg, & Manton, 2020).

Legal generalist services

The Brief of Evidence volumes highlight legal needs, and confusion about legal information and processes for Mr Goolagong. It appears Mr Goolagong had a number of types of legal needs identified, and there was a lack of coordination to address these e.g. for family law, estate planning, natural resources on Aboriginal Country, early release. Generalist legal services have been considered in other contexts for Aboriginal and Torres Strait Islander people, to improve their access to legal support (Williams & Ragg, 2019). Consideration of generalist legal services for terminally ill prisoners and those applying for early release, and those approved for early release may ensure release becomes a reality.

Access for families to prisons

As discussed in earlier sections of this report, there are many barriers for Aboriginal and Torres Strait Islander families to access prisons. However, strategies are required to reduce these barriers and improve access. Improving access is important to enable families to provide practical assistance, financial assistance, information, emotional support, cultural support and other resources including connection to local volunteers and Elders. Family support is well-acknowledged in international criminal justice literature as having an important role in resourcing prisons to meet their objectives (Alexander, Martin, & Williams, 2011; Williams, 2015; Conroy & Williams, 2017). However, programs for family support, and their resourcing and evaluations are minimal in Australia and in relation to Aboriginal and Torres Strait Islander people.

Workforce development

As discussed above, great concerns about cultural bias, discrimination, interpersonal racism and institutional racism have found in criminal justice and health practices. As Universities Australia (2017) well recognises, training about Aboriginal and Torres Strait Islander culrures and cultural safety has long been inadequate, with the ensuing effects of cultural incompetence and service delivery risks by mainstream staff, lack of

safety for Aboriginal and Torres Strait Islander staff and difficulties recruiting and retaiing Aboriginal and Torres Strait Islander staff.

Workforce development is essential to understand bias, discrimination and racism, develop anti-racism strategies and develop human resource systems which evaluate and report on extent of Aboriginal and Torres Strait Islander cultural respect and responsivity staff are able to demonstrate. Repercussions must be clear, swift and effective including termination of employment of those unable to enact Aboriginal and Torres Strait Islander people's rights.

5. Do you have any suggested recommendations for improvements that could be made to better provide for the end of life and palliative care needs of an Aboriginal person in Mr Goolagong's circumstances?

Earlier action

Interpretations I have made of Brief of Evidence volumes is that relevant staff ran outof time to achieve early release arrangements for Mr Goolagong, and that palliativecare was late, not holistic and not inclusive of Aboriginal cultural needs or rights.

An understanding was clear since 2016 that Mr Goolagong's health was deteriorating, with multiple issues identified and a terminal diagnosis also being made.

A focus on quality care and holistic care could have included an application for early release, as well as engagement with family, Aboriginal and Torres Strait Islander cultural care providers.

With palliative care being thought of as holistic, engagement earlier may have triggered actions that were respectful of Aboriginal and Torres Strait Islander people's worldviews, family, needs and rights.

Elders' involvement, employment

The Nelson Mandela Rules (UN, 2015) are clear that 'If a prison contains a sufficient number of prisoners of the same religion, a qualified representative of that religion shall be appointed' and on a full time basis (Rule 65). In some traditions religion is interpreted as a set of spiritual beliefs. Aboriginal and Torres Strait Islander people have clearly identified spiritual beliefs, and despite much diversity, some are core to all cultures including beliefs about Country, relationships and creation stories.

A program of engaging and resourcing Aboriginal and Torres Strait Islander Elders and other cultural supports and authorities is relevant to palliative care, and costings and planning should occur based on current and projected need.

Family relationships

The Nelson Mandela Rules (Rule 106) and legislation and policy in the Australian context support that prisoners maintained and improve relationships with family and community members (Williams, 2015).

It is essential this right is highlighted and included in prison palliative care. Efforts are required improve options for such care including using digital technologies.

This is especially important in light of complex trauma experienced in families, preparation for bereavement, and passing of cultural and family information to next generations – issues highlighted earlier in this document.

Aboriginal and Torres Strait Islander staff

Economic modelling and planning is required to understand what Aboriginal and Torres Strait Islander staff targets should be – parity with the community population of3% (ABS, 2018) or of the prison population (29%; ABS, 2020).

The Nelson Mandela Rules indicate there should be a "sufficient number" of specialists (UN, 2015); Aboriginal and Torres Strait Islander health workers could be considered such a specialist.

Additional economic modelling, resourcing and evaluation is required to ensure that Aboriginal and Torres Strait Islander recruitment and retention targets are met, and across all levels of employment, including leadership.

Accurate recording of cultural identity prompted for

Two questions are relevant to this:

- How meaningful is that information to influence corrections and care planning?
- Do CSNSW, JH&FMHN and other organisations do anything with that information

– respond in any particular way?

If Aboriginal and Torres Strait Islander cultural identity is asked about, and noted, organisations such as CSNSW and JH&FMHN have the responsibility to respect Aboriginal and Torres Strait Islander people's rights.

Charts and recognition of Aboriginal and Torres Strait Islander cultures Consider revision of all charts, case reports, referral and handover forms used torecord information about Aboriginal and Torres Strait Islander people, including cultural identity and needs. Ensure re-development is by and trialed among Aboriginal and Torres Strait Islander people with cultural authority and expertise in service delivery.

Aboriginal and Torres Strait Islander cultures should not be considered 'other' on forms, or excluded from forms, out of cultural respect, and in light of Aboriginal and Torres Strait Islander people being over-represented in prison and a majority not minority population.

Greater detail on the death in custody protocol is required so that it outlines specifics relevant to Aboriginal and Torres Strait Islander people and cultures, including local protocols and protocols of the nation/s of deceased people and their families.

Staff must be trained and evaluation conducted about adherence by staff to accurate recording of Aboriginal and Torres Strait Islander cultural information.

Holistic health

As discussed earlier in this report, ensure commitments made in the NSW context to Aboriginal and Torres Strait Islander people experiencing holistic health and culture in health are achieved. Given holistic health is likely to have benefits for all people, whole-of-system approaches can be made, and are also supported by current government policy frameworks.

For an individual practitioner such as a medical doctor and nursing staff to put an holistic understanding into their own practice, the following are just some of many critical success factors:

- boundary mapping with other professionals and care providers
- willingness to work in new ways and with others of varied professional and informal support backgrounds
- developing referral networks
- care coordinator roles
- coordination among multi-disciplinary teams
- updated referral, case note and handover forms
- advocacy for resourcing
- evaluation to improve evidence-based decision making (Haswell et al, 2013; Haswell et al, 2014).

Cultural safety framework and staff training

The Nelson Mandela Rules assert staff should have adequate standard of education (Rule 75).

Implementation of cultural safety frameworks, training and evaluation should occur.

Currently there are regonisable gaps in NSW justice workforce opportunities to engage in cultural safety training (Banga-ma-la-nha Project, 2020) and the types of transformative learning required to engage effectively with Aboriginal and Torres Strait Islander people (Fitzpatrick et al, 2019). There are also grave concerns in tertiary sector capacity to prepare staff for culturally safe practice (Manton & Williams, in press).

As already identified above AHPRA released its cultural safety framework in 2020, which provides resources and guidance for workforce development.

Universities Australia (2017) must continue its leadership to influence curriculum that prison and health system staff are influenced by, that achieves Aboriginal and Torres Strait Islander cultural respect.

Care coordination

Social casework is asserted in Nelson Mandela Rules (Rule 91) (UN, 2015). Care coordination has been discussed in response to questions above, and has been found effective in post-prison release contexts (Conroy & Williams, 2017; Haswell et al, 2014), despite assertions that 'nothing works' being made for decades and recently in the NSW context (Banga-ma-la-nha Project, 2020). Evidence of care coordination and post-release program evaluation from Aboriginal and Torres Strait Islander people's perspectives and using Aboriginal and Torres Strait Islander people's data collection tools is required.

The Nelson Mandela Rules also assert that prisoners have the right to coordinated contact with and access to services that meet their needs (Rule 108).

It is essential, as discussed earlier, that justice and health agencies involved in palliative care of prisoners have positive working relationships with community and Aboriginal and Torres Strait Islander organisations. These should be formalised into partnerships so that they do not rely on individual Aboriginal and/or Torres Strait Islander staff. Aboriginal and Torres Strait Islander organsations and people should beremunerated for their time; they will be providing services that justice health and prison staff are not able to, including to meet right to equivalent care in the community.

Care coordination is also required to address the likelihood that Aboriginal and Torres Strait Islander people experience multiple health and wellbeing issues. Partnerships and Aboriginal and Torres Strait Islander expertise is required to address complex trauma, grief, loss and spiritual issues, particularly so that mental health problems are not exacerbated or incurred (Nelson Mandela Rules; UN, 2015; Rule 109).

In accordance with the Nelson Mandela Rules, prisoners have the right to access to specialised facilities, which for Aboriginal and Torres Strait Islander people means Elders, traditional healers such as the Ngangkari and healing journey programs such as Murumali, outlined earlier.

Modelling of need – future projections

Like international trends, Australian correctional and justice health services increasingly need to provide palliative and end-of-life care to people in prisons. Between 2000- 10 in Australia, there was an 84 percent increase in people aged over 65 years in prison, with a 286 percent increase among Aboriginal and Torres Strait Islander malesin prison aged between 60-64 and a 200 percent increase among Aboriginal and Torres Strait Islander women in prison aged 60-64 (Baidawi et al, 2011).

Aboriginal and Torres Strait Islander people are at greater risk than others of dying in prison. Of the 89 deaths in Australian prisons during 2018-19 (Doherty & Bricknell, 2020), 16 were Aboriginal and/or Torres Strait Islander people, being almost 18 percent of all deaths despite being 3.3 percent of Australia's community population (ABS, 2018).

Clear projections and economic modelling is required for justice and health systems to act in accordance with future trends and to meet human rights, policy framework and local Aboriginal and Torres Strait Islander cultural obligations.

A response to such modelling and realistic resourcing from governments is required; Aboriginal and Torres Strait Islander people have the right and the expertise to influence advocacy for evidence-based system reform.

The compelling point is about evidence being accurate and given over-representation of Aboriginal and Torres Strait Islander people in prison, Aboriginal and Torres Strait Islander people's expertise is required to gather, interpret and convey such evidence.

Annexure 1

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[redacted]

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28 May 2021

Dear [redacted]

Recommendations with respect to Mr Goolagong death in custody

Thank you for the opportunity to provide recommendations with respect to the death in custody of Mr Ivan Goolagong.

These recommendations are based on my professional health service, research and Wiradjuri family experience about the wellbeing of Aboriginal and Torres Strait Islander people in the criminal justice system.

To demonstrate cultural responsivity
Develop an Aboriginal and Torres Strait Islander cultural safety plan for Justice Health and Forensic Mental Health Network (JH&FMHN), guided by Aboriginal and Torres Strait Islander experts, with resources allocated for its development, staff training, implementation and evaluation.

Ensure JH&FMHN and Corrective Services NSW (CSNSW) provide Aboriginal and Torres Strait Islander people with holistic, cultural, trauma-informed social and emotional wellbeing care

- reflecting the type of care accessible at Aboriginal and Torres Strait Islander community-controlled organisations in the community
- respecting the right of people in prison to equivalent health care as in the community
- taking into account the over-representation of Aboriginal and Torres Strait Islander people in custody.

Ensure JH&FMHN include an Aboriginal and Torres Strait Islander health care expert in provision of services and support to terminally ill Aboriginal and Torres Strait Islander people in custody, in accordance with the right to specialist facilities and care.

Ensure that health care by JH&FMHN for terminally ill Aboriginal and Torres Strait Islander people in custody is age-, language- and gender-appropriate, according to assessment by skilled practitioners.

JH&FMHN and CSNSW to coordinate, engage and remunerate local Aboriginal and Torres Strait Islander people to provide Eldership, cultural and peer support for Aboriginal and Torres Strait Islander people diagnosed or living with a terminal illness in custody.

Release from prison

Increase the capacity of CSNSW and JH&FMHN staff to use Section 160 of the Crimes (Administration of Sentences) Act 1999 in a timely, effective way to release terminally ill Aboriginal and Torres Strait Islander people from custody.

NSW Government make available generalist legal services for Aboriginal and Torres Strait Islander people with a terminal illness in prison, and their family, to improve S160 and post-release administration, death and burial arrangements.

Ensure JH&FMHN and CSNSW have staff roles responsibile for administration and health care arrangements to support the release of Aboriginal and Torres Strait Islander people with a terminal illness from custody

- including facilitating continuity of health care with Local Health Districts, community-based organisations and cultural supports.

Palliative care

Expand capacity of JH&FMHN to provide timely palliative care for Aboriginal and Torres Strait Islander people with a terminal illness in custody

- for longer periods
- in ways that are inclusive of family members and cultural needs.

Ensure palliative care practitioners engaging with Aboriginal and Torres Strait Islander people with a terminal illness in custody are trained and skilled in anti-racism and culturally safe care with Aboriginal and Torres Strait Islander people, families and organisations.

Increase funding for Palliative Care Consultant Physicians in JH&FMHN settings, and ensure they have training and experience working with Aboriginal and Torres Strait Islander people, families and organisations.

Evaluate the role of the JH&FMHN Aboriginal Health Worker – Palliative Care to ensure it meets level of need and can achieve holistic Aboriginal and Torres Strait Islander health care requirements and partnerships with Aboriginal and Torres Strait Islander community organisations and cultural supports.

Cancer care
Evaluate JH&FMHN cancer care nurse roles and allocated funding to ensure they meet need and cultural responsivity for Aboriginal and Torres Strait Islander people in custody with cancer.

Ensure JH&FMHN staff have training and capacity to effectively use the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* by Cancer Australia (2018).

Coordinated care
Fund, implement and evaluate JH&FMHN care coordination roles to better support Aboriginal and Torres Strait Islander people with a terminal illness in custody.

Record keeping
Improve comprehensiveness and accuracy of JH&FMHN and CSNSW records about Aboriginal and Torres Strait Islander people in custody with a terminal illness.

Ensure timely transfer of records of Aboriginal and Torres Strait Islander people in custody with a terminal illness between correctional centres, health care and other supports, and family where appropriate.

JH&FMHN and CSNSW to revise record keeping to more accurately record cultural identity of Aboriginal and Torres Strait Islander people

- ensure re-development is by and trailed among Aboriginal and Torres Strait Islander people with cultural authority and expertise in service delivery
- train all staff in accurate recording of and responsivity to Aboriginal and Torres Strait Islander cultural identity.

End-of-life care
Ensure JH&FMHN is resourced to provide earlier and comprehensive end-of-life care to Aboriginal and Torres Strait Islander people in custody with a terminal illness including engagement with cultural supports and family members.

Ensure JH&FMHN includes family of Aboriginal and Torres Strait Islander people dying in custody in end-of-life care planning and support.

Ensure family of Aboriginal and Torres Strait Islander people dying in custody are communicated with openly and routinely, and that correctional facilities and hospitals are made accessible for extended family visits at the end-of-life stage.

JH&FMHN to develop protocols to ensure that no Aboriginal and Torres Strait Islander person with a terminal illness dies alone in its facilities.

Death in custody protocol
Update and add greater detail to JH&FMHN and CSNSW death in custody protocols, to include information about achieving cultural protocols of Aboriginal and Torres Strait Islander people.

Family
Gather, retain, and communicate clear information to family members about the prognosis, progression, care plan and movements between centres of Aboriginal and Torres Strait Islander people in custody with a terminal illness.

Use digital technologies to maintain and improve relationships that Aboriginal and Torres Strait Islander people in custody with a terminal illness have with family and cultural supports.

Autopsy and coronial inquest processes
Develop an Aboriginal and Torres Strait Islander cultural safety plan for the NSW Coroners Court, guided by Aboriginal and Torres Strait Islander experts, with resources allocated for its development, staff training, implementation and evaluation.

Ensure all staff of the NSW Coroners Court complete cultural competence training, Aboriginal and Torres Strait Islander cultural awareness training and Aboriginal and Torres Strait Islander cultural safety training.

NSW Coroners Court identify and meet needs of family members in relation to autopsy processes and reporting including remuneration for travel and related expenses.

NSW Coroners Court ensure accuracy of autopsy information that is recorded, retained and reported, with a quality assurance process developed.

NSW Coroners Court develop an accessible, culturally-informed support service for Aboriginal and Torres Strait Islander people before, during and after the autopsy process and coronial inquest.

NSW Coroners Court to provide plain language statements about the autopsy and coronial inquest purposes and processes for Aboriginal and Torres Strait Islander people, easily accessible online and in print

- routinely provided by NSW Coroner and JH&FMHN staff
- developed by Aboriginal and Torres Strait Islander experts.

NSW Coroners Court return all remains of Aboriginal and/or Torres Strait Islander people who have died in custody according to requirements of family, with expenses met by NSW Government.

Partnerships
JH&FMHN develop and resource partnerships with Aboriginal and Torres Strait Islander community-controlled organisations, Elders and informal caregivers, to provide cultural, holistic support Aboriginal and Torres Strait Islander people in custody with a terminal illness

- establish in-reach services to correctional centres and prison hospitals
- extend to supporting Aboriginal and Torres Strait Islander family members through the coronial inquest.

Aboriginal and Torres Strait Islander workforce
JH&FMHN increase Aboriginal and Torres Strait Islander workforce numberswho provide health care for Aboriginal and Torres Strait Islander people in custody with a terminal illness, and their family

- achieve parity with numbers of Aboriginal and Torres Strait Islander people in custody and in light of over-representation of Aboriginal andTorres Strait Islander people in custody
- increase Aboriginal and Torres Strait Islander staff numbers at all levelsof the workforce.

Evidence-based decision making
JH&FMHN and CSNSW form a collaboration of Aboriginal and Torres Strait Islander researchers, policy makers and service providers to improve the evidence base on which care for health and wellbeing of Aboriginal and Torres Strait Islander people in custody are planned and evaluated.

Please feel free to contact me directly for any clarifications to these recommendations.

Yours sincerely

Megan Williams