



DEATHS IN CARE (DISABILITY)

Expert Review Panel Final Report

Coroners Court of Queensland

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OVERVIEW

This report provides a summary of discussions held by an Expert Review Panel (the Panel) of a review of eleven (apparent) natural causes deaths in care of people who were residents in supported residential accommodation¹, and in which potential concerns were identified about the adequacy of their health care management prior to the death.

The purpose of the Panel was to provide advice and make recommendations to the Coronial Registrar, and/or the investigating coroner, in relation to these deaths regarding:

- the health care management of the persons prior to the death, including whether the care provided was appropriate and whether any of these deaths could reasonably be considered to have been preventable
- the identification of any gaps, or potential opportunities for improvement, in the health care management of people with a disability with complex needs in care, including where there are multiple care providers (i.e. primary and specialist health care providers, community support agencies).

The Panel process also provided an opportunity to identify and consider a range of other issues with respect to the provision of care prior to these deaths, should those issues be considered by the Panel to have impacted on the provision of care. This included, but was not limited to:

- the involvement of government, non-government and private sector agencies with persons with a disability in care, who may have reduced or limited capacity to make health care decisions
- the coordination of clinical care for people with a disability with multiple

and complex needs including the involvement of health care professionals, care providers or other support workers

- the roles, responsibilities and capacity of residential service staff to recognise and respond to residents' health care needs including signs of clinical deterioration
- the role and responsibilities of general practitioners who provide services to the residents of these residential services
- the adequacy of current regulatory arrangements and oversight of supported accommodation services (specifically level 3 residential services and Disability Services Queensland (DSQ) funded accommodation).

BACKGROUND

The *Coroners Act 2003*, s. 8(3)(f) in conjunction with s. 9(1)(a) makes reportable the death of persons with a disability who lives in supported residential accommodation that is either a level 3 residential service under the *Residential Services (Accreditation) Act 2002*, or a government operated or funded residential service. These services provide varying degrees of personal support to residents ranging from the provision of meals and medication administration, to full support with the activities of daily living.

These deaths are reportable irrespective of the cause of death and whether the resident died somewhere other than the residential service, for example in hospital. This reflects the underlying policy objective of ensuring there is scrutiny of the care provided to residents of these services given their particular vulnerabilities. The focus of the coronial investigation of a death in care (disability) is whether the circumstances of the death raise issues about the deceased's care that may have

funded facility. The differences in governance and practice of these types of supported accommodation services are discussed below.

¹ Ten were residents in private level 3 residential services, one (Mr G) resided in a Disability Services Queensland (DSQ)

caused or contributed significantly to the death. The *Coroners Act 2003*, s. 27(1) (a) (ii) mandates an inquest if any such issues are identified.

In 2016, the Office of the Public Advocate (Qld) released a report, *Upholding the right to life and health: A review of the death in care of people with disability in Queensland*, which highlighted particular challenges associated with the health care management of people with disabilities in care. This report suggested that coroners could benefit from further expert advice regarding the provision of health and support services to people with intellectual disabilities and/or cognitive impairments to better inform the identification of potential care issues. The report further recommended that an appropriate agency be resourced and tasked to carry out regular systemic reviews of people with disability who have died in care in Queensland, with a requirement for the review outcomes to be reported publically at least biennially.

Having regard to these findings, the State Coroner agreed to trial an expert panel review process to examine the health care management of persons whose deaths have been reported to the coroner as a death in care (disability) in late 2016.

This trial recognises the capacity of the unit within the Coroners Court of Queensland currently responsible for systemic review of domestic and family violence, and child protection related, deaths to provide systemic review support to the investigation of deaths in care (disability).

CASE SYNOPSIS

A brief summary of the cases outlined below is provided for consideration and reference. Cases were selected to reflect the diversity and complexity of these types of deaths reported to coroners in Queensland.

Records obtained in regard to the deceased persons were extensive, covering any identifiable contact with health care providers or other community services, within reasonable proximity to the death.

Given the extensive nature of these files, they are not summarised in full within this report, although all records were provided to the experts for review. Salient service contact leading up to the death is however, referenced below, to provide context to the expert panel's comments.

An overview of the details of each case, including the treating practitioners, residential service providers, hospital presentations and medical conditions is also provided for further comparison in the Appendix.

Cases have been de-identified to protect the privacy of the deceased.

Mr A

At the time of his death, Mr A was 56 years old and a resident of [REDACTED], a level 3 residential service. He had been a resident since mid-December 2014.

Mr A's death was automatically reportable as a death in care and should have been reported to the Coroner's office, however this did not occur. Instead, Mr A's death was reported to the coroner by the Office of the Public Guardian one month later, his death having been brought to that agency's attention by a Community Visitor.

Mr A had a background history of liver cirrhosis; hepato-cellular carcinoma with liver failure and portal hypertension; hepatitis C; gastro-oesophageal reflux disease; previous alcohol

dependency and IV drug use; depression; and was a smoker.

Mr A was considered terminally ill and was being managed palliatively at the time of death.

SUMMARY OF EVENTS

On 18 January 2015, it was noted on the [REDACTED] transfer that Mr A was transferred to [REDACTED] Hospital due to being *very lethargic and confused the last 4 days. He has been falling asleep standing and at meal time he is confused and says he is in pain. 7 out of 10 in his stomach. Looking pale at times.*

On 27 January 2015, Mr A was seen by a palliative care physician who had written to Mr A's treating resident doctor, GP1 of [REDACTED] Medical Centre.

The palliative care physician noted in his correspondence dated 29 January 2015, that Mr A had been diagnosed 18 months prior with Hepato-cellular cancer and that he had not received treatment.

Mr A had previously attended [REDACTED] Hospital because he felt a *bit off* and was told then that he had six months to live. The palliative care physician further advised in his correspondence that Mr A is *eating okay, no nausea, no cough however, does get a bit short of breath on exertion. Mr A has poor sleep and was not sure why.* The palliative care physician planned to arrange a nursing service to start attending to Mr A to *keep an eye on him.*

On 31 January 2015, an entry in the [REDACTED] staff communication book stated that Mr A was *very swollen with fluid in his stomach and his legs, do we need to contact doctor or send to hospital, concerned.* It was also noted that *Mr A is refusing to go to hospital.* The service contacted the GP and consulted with 1300 HEALTH for advice. The advice provided was that Mr A could be at risk of developing fluid in the lungs. Staff were cautioned that Mr A could worsen quickly and they should closely monitor Mr A for shortness of breath and blood in bowel motions.

The Blue Care nurses were arranged to attend to Mr A by the palliative care physician on 4 February 2015. It was noted in the [REDACTED] communication book that the Blue Care Nurses

observed swelling on attendance however made no recommendations or requests for action.

On 5 February 2015, GP1 conducted a home visit to Mr A and observed the swelling and prescribed an extra dose of spiracvtin (50mg bd) to help with the swelling and noted that Mr A may take extra lasix (40mg bd).

On the evening of 6 February 2015, staff noted that Mr A's legs were swollen and leaking fluid.

On 7 February 2015, Mr A was taken to the [REDACTED] Hospital by the Queensland Ambulance Service (QAS) with increasing bilateral leg oedema and skin redness. He was diagnosed with sepsis due to bilateral lower limb cellulitis.

An Acute Resuscitation Plan was completed on 8 February 2015 confirming that Mr A was for comfort care only. An ascetic TAP (drainage of fluid that had accumulated in the abdomen) was performed on 9 February 2015 to ease his abdominal pain and shortness of breath. The fluid drained showed evidence of being infective (containing white cells and bacteria). Mr A quickly became hypotensive and deteriorated.

Mr A declined further treatment and was commenced on a syringe driver for comfort care measures. Mr A died on 9 February 2015.

CLINICAL FORENSIC MEDICINE UNIT REVIEW

An independent doctor from the Department of Health Clinical Forensic Medicine Unit reviewed the hospital and care facility records and made the following comments: *Mr A's health was failing due to his terminal hepatocellular cancer. The decision to manage him palliatively was informed and entirely appropriate.*

[REDACTED] [REDACTED] documented concerns regarding his leg swelling on the 31 January. They appropriately sought medical advice by phone and were advised to watch out for shortness of breath. Mr A does not appear to have been medically assessed following these concerns, nor am I aware if the nursing visits had commenced.

There is not much more documented until the 7 February when he is taken to hospital because of worsening swelling and redness of his legs. By this time he was becoming septic.

It would have been prudent to have Mr A reviewed by his GP prior to the 7 February. It would have also been beneficial if the nursing visits had commenced at this time. This may have resulted in earlier diagnosis of cellulitis and commencement of antibiotics. However, I accept that Mr A was reluctant to return to hospital, and given the end stage of his disease, this may not have altered the outcome.

Unfortunately, the ascetic TAP appears to have precipitated a septic shower which may have hastened his death; however, the benefit of this procedure needs to be weighed against this risk. Ultimately, comfort is of central concern in a palliative patient who is suffering. I do not have concerns with the decision to perform this procedure.

I am in agreement with the palliative care physician that Mr A was at the final stages of his terminal illness and that commencing oral antibiotics sooner would not have likely changed the outcome. Based upon this information, I have no other concerns with the care provided to Mr A.

Mr B

Mr B was a 55 year old male resident at [REDACTED]. He had been a resident since November 2013. Prior to this, Mr B resided at [REDACTED] supported accommodation house, also a level 3 residential service.

While Mr B resided at [REDACTED] GP2 was his treating doctor. Records have been obtained from GP2 for the period 2013-2014 which reflects that on a number of occasions, Mr B had been treated for chest pains. It is also noted that bloods were taken regularly and the Hb (haemoglobin level) was at its highest at 91 in February 2013 and 92 in March 2013 this then dropped over a period of three months to its lowest of 79 in June 2013.

While a resident at [REDACTED] [REDACTED], Mr B was seen by his treating doctor, GP3 of the [REDACTED] Clinic, [REDACTED]. Mr B had significant multiple medical comorbidities including ischaemic heart disease; associated cardiomyopathy; obstructive sleep apnoea; chronic kidney disease; a pacemaker (inserted in 2013); and Type II

diabetes requiring insulin to maintain normal blood sugar levels.

SUMMARY OF EVENTS

Mr B had been a long term patient of the [redacted] Hospital [redacted] Cardiology Department. In correspondence dated 27 February 2014, it's noted by the cardiologist that Mr B *has currently stable significant comorbidities and will review him in three months' time.*

On 2 March 2014, Mr B was taken to the [redacted] Hospital [redacted] Emergency Department for chest pain. The next day on 3 March 2014, Mr B was admitted to the [redacted] presenting with worsening shortness of breath and chest pain.

Recommendations were sent to Mr B's treating doctor, GP3, noting that Mr B's *Hb was noted to be 77 on admission which probably contributed to this presentation of shortness of breath. Haematology have seen Mr B regarding his thalassemia and recommended that Mr B may need investigation for bleeding if his Hb does not stabilise. Please review him within one week.* Mr B was discharged on 5 March 2014.

On 30 March 2014, Mr B was admitted to the [redacted] after feeling unwell presenting with shortness of breath and a cough productive of green sputum. Mr B was treated with Doxycycline antibiotics, STAT Frusemide and discharged home the following day with oral antibiotics for GP review.

A letter was sent from a [redacted] doctor to GP3, from the [redacted] Clinic, recommending he reassess Mr B for fluid overload and hydration management.

On 21 April 2014, Mr B was admitted to the [redacted] with central chest pain. It's noted on the discharge summary that the recommendations to the GP were to *review patient post discharge with NSTEMI, optimise the patient's blood pressure and pulse rate, titrate patient's medications accordingly, refer patient if develops chest pain similar to pain with NSTEMI and ensure patient continues on dual antiplatelets.* It is also noted that recommendations made to Mr B were to *follow up with his local GP next week, continue medications prescribed and chest pain, if shortness of breath continues to seek medical*

attention or return to hospital. Mr B was discharged on 27 April 2014.

On 15 May 2014, Mr B was admitted to the [redacted] after experiencing multiple episodes of chest pains that resolved with GTN and Hyperosmolar Hyperglycaemic Syndrome. Mr B was admitted for observation and stabilisation of glucose levels and IV fluids. He was given an insulin infusion which was later switched to SC insulin as per his normal regimen. He continued to improve and was discharged home on 19 May 2014.

On 3 June 2014, Mr B was found by staff members at the [redacted] unconscious, cyanosed and unresponsive. Mr B was fluid resuscitated by the QAS. The QAS notes state that Mr B had been feeling unwell and not eating normally for 2-3 days and that the nurses suspected hypoglycaemia. Mr B had advised QAS that he had been unwell with flu symptoms, diarrhoea and feeling hot and cold.

Mr B is said to have no recollection of events but was oriented to time/person/place. The [redacted] Hospital Emergency Department treated Mr B with the plan to continue 5% dextrose, oral carbohydrates, observe overnight and administer half dose of insulin. At this time, Mr B was unsure of his usual dose as he could not remember. The [redacted] was contacted and advised that Mr B self-administered his medication and they were unable to advise his dose.

On 4 June 2014, Mr B was admitted with Hypoglycaemia secondary to poor oral intake, cholecystitis, and troponin rise/angina in the setting of sepsis. The [redacted] Hospital Clinical Summary indicates that Mr B was treated by for Hypoglycaemia and LOC. It was further noted *worked up and diagnosed with acute cholecystitis – deranged LFTs with normal bilirubin. Treated with NBM and IV abx. Suffered NSTEMI during admission – monitored.*

The records note that Mr B *had been plagued with biliary colic for the 2-3 years, never seen a GP and that his pain would last for 30-45 minutes after a meal, however, over the past 2 months his biliary colic had worsened. Still hadn't seen a GP.*

It was also noted that Mr B would get constant pain if he ate and would have severe nausea

and vomiting. He had not eaten at all since last discharge and had not been taking insulin at all for fear of giving himself a hypoglycaemic event like his prior admission. Mr B stated that over the past few weeks he had been getting biliary colic with every meal.

Clinical Summary notes that *no other symptoms on systemic review, no chest pain*. Cholecystitis was Rx conservatively with triple Abx at the time. Mr B was noted as being a poor surgical candidate.

Mr B was discharged on 11 June and advised to see his GP for elective cholecystectomy.

On 16 June 2014, a doctor from the Diabetes & Endocrinology Ambulatory Clinic of the [REDACTED], wrote to the treating GP3 to notify him of Mr B's nonattendance for an appointment booked as per a referral made from the [REDACTED] in February. The [REDACTED] Doctor's letter details that Mr B *had several admissions, all with variable glycaemic control, in the recent admission in May did not seem to have most BSLs under 10*. They also sought to be notified if Mr B had problems that GP3 thought would be improved by specialist review with the opportunity made available to discuss this by phone.

On 18 June 2014, Mr B was transported to the [REDACTED] Hospital ED presenting with biliary colic and hyperglycaemia BSL 43 secondary to poor oral intake and decreased insulin intake. It is noted in the QAS notes that Mr B's chest pain was treated with aspirin. Mr B complained about his gall bladder pain. The [REDACTED] Hospital progress notes state that Mr B had not been able to tolerate food but was still drinking fluid, he was also vomiting three times each day. Mr B had advised the nurse that he was injecting insulin up until two days ago as he was told not to have insulin if he was not consuming food.

On 19 June 2014, Mr B was admitted after presentation to the ED with biliary colic hyperglycaemia BSL 43 secondary to poor oral intake and decreased insulin intake, for observation and IV cannula, inserted by QAS, be removed. IV therapy to commence and insulin infusion to continue. Mr B was on clear fluids, oxygen at 2l/min through nasal prongs and constant supervision until 20 June when Mr B had no nutritional risk and was eating independently.

Mr B was discharged home on day five of admission once BSL control was achieved and no further pain, with plan to follow up. It was noted that on discharge, Mr B was referred to the [REDACTED] Surgical POD for R/V and was advised to have Fe studies done.

On 7 July 2014, Mr B's death was reported to the Queensland Police Service (QPS) by the [REDACTED] [REDACTED] Director. Police attended the residence and observed Mr B to be lying on his left side naked on his bed with blankets partly down towards his waist and his head resting on his pillow. Police observed there to be tissues up Mr B's nose and some gel. An oxygen machine was observed to be next to Mr B's bed with no signs of disturbance.

The [REDACTED] [REDACTED] Director also emailed the Coroner's Office indicating that Mr B passed away overnight and that she had informed QPS and QAS of his death.

Police spoke to the overnight manager of the [REDACTED] [REDACTED] e and she advised the police that she had observed Mr B at approximately 8:00pm on 6 July 2014 and then again at 6.00am the following day.

She further advised the police that Mr B did not take his medications on 6 July 2014 and that she had taken them to him when he came out for lunch. Mr B had not taken his medication the previous day either and no records of Mr B's health, wellbeing, and medication intake was checked nor recorded to reflect this.

There are no records to indicate that Mr B had consumed any food from 5 July onwards.

CLINICAL FORENSIC MEDICINE UNIT REVIEW

An independent doctor and Director of the Department of Health Clinical Forensic Medicine Unit reviewed the hospital and care facility records and made the following comments: *The cardiac medications he was taking indicate he was on maximal medical therapy to prevent angina. A failure to take these medications is going to substantially increase his risk for a cardiac event. The 'seizure' events reported may have been seizures associated with blood sugar derangement: I can't really tell from the information here. The findings at autopsy identify metabolic derangement due to a diabetic crisis. A*

diabetic person who is not eating, not drinking and not taking their usual medication is always at risk of such a condition. I am not clear as to the responsibility of the carer in this facility, but I would have a minimum expectation that their role would include an appropriate reaction to a person who is unwell. A person with his condition appears very unwell indeed and needs urgent treatment in order to save their life. Monitoring and recording of blood sugars on a twice daily basis, ensuring medication is taken appropriately and an awareness of an unwell person would have prevented Mr B's death. The level of care here appears grossly inadequate on the information provided.

Mr C

Mr C was 53 years old and a resident at [REDACTED], [REDACTED], a level 3 residential service within the meaning of the *Coroners Act 2003*.

Mr C died at the [REDACTED] Hospital on 4 August 2016, which was reported to the coroner as a death in care (disability).

Mr C had a background medical history of Hepatitis B; Hepatitis C; Cirrhosis; SZD; Chronic thrombocytopenia; depression; and paranoid schizophrenia.

SUMMARY OF EVENTS

On 29 June 2016, Mr C presented to the emergency department via QAS to the [REDACTED].

Staff at [REDACTED] [REDACTED] were concerned that Mr C was not acting his normal self in the morning, he was feeling confused, with an unsteady gait, shivering and tremors. The [REDACTED] medical notes indicate that Mr C has *severe community acquired pneumonia*.

On the 5 July 2016, Mr C was transferred and admitted to the [REDACTED] Hospital Intensive Care Unit for further management. Numerous tests including CT and EEG brain, were done to ascertain the cause for failure to wake. It was noted in the letter to the coroner from the Intensive Care Unit *that the information revealed no structural reversible cause, only generalized low amplitude EEG trace in keeping with encephalopathy*.

Joint consensus for Mr C's condition with all of the ICU staff specialists who have looked after Mr C was that Mr C's hepatic encephalopathy has reached an irreversible stage and there is no further treatment that can be done to improve it. The decision was to change the level of care to comfort measure and extubate patient.

On 4 August 2016, Mr C died at the [REDACTED] Hospital. The discharge summary notes the principal diagnosis being influenza A; other active problems; respiratory failure; and hepatic encephalopathy.

No CFMU review was completed for this death.

Mr D

At the time of death, Mr D was 66 years old and was a resident at [REDACTED], a level 3 residential service within the meaning of the *Coroners Act 2003*.

Mr D was suffering from schizophrenia and had a number of chronic health conditions including; prostatomegaly; right humeral fracture; Urinary Tract Infection; previous cataract removal & IOL Implant; and hearing aid.

SUMMARY OF EVENTS

On 1 March 2016, Mr D was admitted to the [REDACTED] presenting with an extrinsic mechanical fall and low-grade fever. Hospital records indicate that Mr D fell over at the shops onto his right shoulder causing dislocation, mild swelling and moderate pain. The records indicate that Mr D had a decline in renal function secondary to dehydration. Mr D was subsequently treated and discharged on 4 March, with notes that Mr D's treating GP, GP4 of [REDACTED] Medical Centre follow-up and recheck renal function within two weeks.

On 4 March 2016, GP4's records indicate that pathology was requested for E/LFTs prerenal failure follow up.

On 7 March 2016, Mr D was found lying on the floor on his back by [REDACTED] staff. Mr D advised staff that he attempted to ring the phone but he fell on the floor and couldn't manage to get up complaining of back pain from lying on his back for a long period of time. QAS were contacted and arrived shortly after. Mr D refused to go to the hospital and indicated

to QAS officer's that he was not suffering any other pain, only back pain. The crew subsequently decided to transfer Mr D to his bed and asked [REDACTED] staff to contact them again if Mr D's pain continued.

On 9 March 2016, Mr D was seen by GP4 for check-up. The notes indicate that Mr D's "right humerus was in a sling not collar and cuff". The sling was repositioned and a plan to follow up on 17 March 2016. On review of the records, there doesn't appear to have been a follow up recorded on 17 March.

On 11 March 2016, Mr D was seen by GP4 post right humerus fracture. He was subsequently prescribed Panadeine Forte for pain relief.

On 17 March 2016, Mr D was seen by the [REDACTED] Orthopaedic Surgery. Mr D explained to the doctor that he wished to avoid surgery. His sling was replaced with a collar and cuff and a plan was made to review again in one week.

On the 24 March 2016, Mr D was seen by the [REDACTED] 3.5 weeks post fracture with notes stating that *Mr D does not wish for an operation*. Records indicate that although Mr D was encouraged at previous appointments to perform hand, finger and elbow movements, he had not been compliant due to his elbow being very stiff and unable to extend past 30 degrees.

Mr D was seen at the [REDACTED] by the Orthopaedic Surgery on 14 April 2016, for a check-up pertaining to his right humerus fracture. X-rays showed that the fracture was healing well and that Mr D could come out of the sling. Mr D was advised to stop smoking. A plan to see Mr D in six weeks' time was noted.

On 14 April 2016, Mr D was seen by the [REDACTED] for physiotherapy. Records indicate that Mr D complained of minimal pain in his shoulder and ceased wearing sling with nil issues. A plan for Mr D to be referred to the [REDACTED] for ongoing review.

On 20 April 2016, Mr D was seen at the [REDACTED] Urology and was subsequently discharged back to GP4 care with the plan to continue duodart

and to re-refer if needed. Mr D saw GP4 and received his Fluvax Immunisation.

On 9 May 2016, Mr D did not attend the scheduled physiotherapy appointment at the [REDACTED].

On 23 May 2016, the [REDACTED] performed an echocardiogram on Mr D. The records note that Mr D has *poor posture and positioning ... but functionally appears pleased with shoulder movement*. A plan to allow natural progression/healing through shoulder and time for improvements was made.

On 25 May 2016, Mr D did not attend the scheduled physiotherapy appointment at the [REDACTED]. Mr D did not call to reschedule or cancel appointment.

On 26 May 2016, Mr D was seen by the [REDACTED] at the Orthopaedic Surgery. Records indicate that Mr D's pain had improved with a plan to continue physio and review in 2 months' time.

On 8 June 2016, Mr D was seen by the [REDACTED] for physiotherapy.

On 29 June 2016, Mr D was seen by the [REDACTED] at the Orthopaedic Surgery for Physiotherapy Outpatient Review. A plan to allow natural progression/healing through shoulder and time for improvement.

The Form 1 – *Police report of death to Coroner* indicates that on 10 July 2016, a carer of the facility had provided Mr D with his pre-packaged medication consisting of three pills (1x Clozaril 100mg Tab and 2x Clozaril 25mg Tab) and had observed Mr D take these with water.

The worker had then attended to other duties when she was alerted by another resident that Mr D had collapsed, face down and his skin appeared blue and unresponsive. The worker then phoned triple zero from the kitchen before returning to Mr D in attempt to revive him through CPR².

No CFMU review was completed for this death.

Mr E

² Subsequent to the completion of the report pathology findings indicate the cause of death to be 1(a) Pulmonary

Thromboembolism (b) Deep Venous Thrombosis, Left Calf and 2. Coronary Atherosclerosis

Mr E was a 61 year old resident at [REDACTED], a level 3 residential service within the meaning of the *Coroners Act 2003*. Mr E died at the [REDACTED] on 11 May 2016. His death was reported to the coroner as a death in care (disability).

Mr E had a background medical history of epilepsy; schizophrenia; dyslipidaemia; cognitive impairment; Type 2 diabetes; chronic hyponatraemia; and hypertension. He had previous admissions to the [REDACTED] in July 2014 with community acquired pneumonia, and in July 2015 with 'behavioural issues'.

It is noted in files that Mr E was living in a low care [REDACTED] and was awaiting placement to a high care facility.

SUMMARY OF EVENTS

Mr E was seen by his treating doctor, GP5, [REDACTED] Medical Centre once a week for the month of January 2016.

On 16 February 2016, GP5 saw Mr E with progress notes indicating *came for depot injection, no complaining of issues, reviewed status and seems psychiatrically stable, due for regular shot, given injection of depot antipsychotic*.

On 8 March 2016 at around 8.16am, GP5 saw Mr E with progress notes indicating *came for depot injection, no complaining of any issues, reviewed status and seems psychiatrically stable, due for regular shot, given injection of depot antipsychotic abilitly maintena*.

That afternoon, at 1.44pm, the QAS were called regarding Mr E having multiple falls and according to nursing staff at [REDACTED], he had deteriorated in overall wellbeing with increased weakness, urinary and faecal incontinence, decreased mobility and worsening confusion.

In the QAS Report Form, it was noted that [REDACTED] staff were unable to provide adequate care as it was a low care supported accommodation facility, and that Mr E was refusing to eat and was rapidly deteriorating to the point where he was no longer able to self-care.

Mr E was transported to the [REDACTED] Emergency Department and was admitted due to functional

decline and reduced oral intake. Mr E was found to have urinary retention and required long-term catheterisation. Consolidation of the right lung was noted on x-ray and shown to be an abscess on CT scan. Mr E underwent bronchoscopy and was commenced on antibiotics for klebsiella pneumoniae. Mr E was also found to have adenovirus and treated for clostridium difficile.

On 10 April 2016, a MERT was triggered in response to a suspected seizure. An EEG was performed on 13 April 2016 which showed abnormal brain activity. Mr E was commenced on antiepileptic medication but further seizures occurred with eventual symptoms of L) sided weakness. It was noted that Mr E continued to have refractory seizures despite input from Neurology and treatment with sodium valproate and keppra.

Mr E was transitioned to comfort cares and passed away on 11 May 2016.

CLINICAL FORENSIC MEDICINE UNIT REVIEW

An independent doctor from the Department of Health Clinical Forensic Medicine Unit reviewed the hospital records and made the following comments;

The cause of death has been listed as: 1a) Status epilepticus (one month)

The GP notes indicate GP5 gave Mr E his monthly depot injection on 08/03/16 – the day he was admitted to the [REDACTED]. No comment was made re: any health issues. There were no notes provided from the care facility so I am unable to comment if there were any delays in transfer to hospital.

Nevertheless, it appears Mr E improved after treatment at the [REDACTED] and would have returned to his place of residence had he not developed seizures. From the discharge summary, it appears he was managed appropriately and despite maximal medical management, he developed refractory seizures with neurological impairment. I see no issues with the care provide whilst at the [REDACTED].

Mr F

Mr F was a 64 year old man who was a resident of [REDACTED] [REDACTED] at [REDACTED], a level 3 residential service within the meaning of the *Coroners Act 2003*.

Mr F had long term schizophrenia and had spent many years at Wolston Park. He had been a resident at [REDACTED] [REDACTED] since 2001. Mr F also had a medical history of anxiety disorder, hypercholesterolemia and dementia.

SUMMARY OF EVENTS

On 5 July 2016, the day prior to Mr F's death, his treating doctor, GP5 of [REDACTED] Medical Centre was contacted by [REDACTED] [REDACTED] to assess Mr F.

Mr F was treated with amoxil antibiotics as he appeared to have a chesty cough. In GP5's statement it is noted that when *examining Mr F he had his usual chronic obstructive airways disease which was a result of his lifelong smoking. Mr F's chest was crackly and a bit wheezy, but given that staff were concerned he was reviewed.*

The Form 1, *Police Report of Death to Coroner* details the summary of circumstances surrounding the death of Mr F.

It is noted that on 5 July 2016, Mr F entered his bedroom at [REDACTED] [REDACTED] to go to sleep for that evening. Another resident at the [REDACTED] told police that he heard a bang at approximately 7:00pm which he thought might have been Mr F banging his head on the floor; as such he did not think much of it and stayed in his bed and went to sleep.

The following day, on the morning of 6 July, a carer at the [REDACTED] was at the medication administration window waiting for Mr F to arrive. Mr F would usually collect his medication as early as 5:50am.

As he did not show up, the worker went to check on Mr F at 6.30am and observed Mr F to be in his bed, cold and stiff. The staff member attempted to feel a pulse and could not detect one. They subsequently phoned triple zero and informed the QAS to attend the scene. A life extinct certificate was issued by a QAS officer at 6.45am.

No CFMU review was completed for this death.

Mr G

Mr G was a 41 year old resident of [REDACTED] [REDACTED], a Disability Services Queensland funded facility. Mr G had a medical history of cerebral palsy, kyphoscoliosis and anxiety.

SUMMARY OF EVENTS

On 7 January 2016, the [REDACTED] [REDACTED] Hospital transferred Mr G to [REDACTED] Hospital due to functional decline and abdominal distension. Mr G was diagnosed as having a pseudo-obstruction in his sigmoid colon and treated with rectal tubes; enemas and rigid sigmoidoscopy to manage what seemed to be excessive constipation.

Initial dietetic involvement diagnosed severe malnutrition due to poor oral intake however it was noted that his mother told staff he *ate like a horse*. The food chart review found that he was eating 90-100% of his daily food requirements. Mr G slept on a mattress on the floor as he could not walk and tended to crawl on the floor.

On 23 January 2016, Mr G developed a fever and tachycardia. Blood cultures revealed staphylococcus aureus in the blood for which Mr G was treated with antibiotics. It was noted that the source of the infection was believed to be cellulitis in his right hand due to abrasions/lacerations from frictional injury with floor-crawling.

On 26 January 2016, a blood culture showed a gram negative bacillus. Mr G's condition continued to deteriorate despite hospital staff escalating antibiotic cover and intravenous fluids. Mr G passed away in hospital the next day on 27 January 2016.

CLINICAL FORENSIC MEDICINE UNIT REVIEW

An independent doctor from the Department of Health, Clinical Forensic Medicine Unit reviewed the hospital and residential service records and made the following comments; *this case is difficult. On first glance, the history of weight loss, functional decline, muscular wasting, abdominal distension and constipation in a 41 year old male would lead me to think of malignancy.*

I cannot form a view that this was not extensively excluded however whether curative treatment would be available is another matter.

I note a CT abdomen late in 2015 was inconclusive mainly because of anatomical difficulties due to Mr G's spinal issues (kyphosis). The pancreas was not adequately visualised. I am uncertain whether the elevated liver function tests were adequately explained by antibiotics. Shoulder pain can be caused by malignancy or other issues in the area of the pancreas and gallbladder. Huntington's disease is a possible explanation for his demise but would require the disease to have been present for a number of years (the co-existence of issues related to cerebral palsy would make diagnosis very difficult on a clinical basis). I am less concerned that this was a likely cause.

Thus there are a couple of matters that need to be addressed and may actually require coronial investigation/autopsy:

(1) Public health issue with respect to salmonella infection- if acute, then this could only have been acquired in hospital as Mr G had been there for nearly 3 weeks and this would be his only source of food unless family/carers had brought some in. There is a possibility that he was a 'carrier' after past disease- thus the organism may have been in his gut for some time. I note that he was admitted to [REDACTED] in December 2015 for a diarrhoeal illness but culture of faeces was negative for salmonella (and other organisms).

(2) Possible failure to diagnose underlying disease such as malignancy. This is possible as outlined above. It would be high on the agenda in normal circumstances however the issues of cerebral palsy, behavioural decline and functional decline may have led investigators to pursue a neurologic cause rather than follow a path that they may well have pursued in the absence of his pre-existing condition.

That being stated his decline may well have been a progression- natural or otherwise of his cerebral palsy. I can see no issues in his medical care that suggest that Mr G was not treated with dignity and respect. His medical care was very good and there was no suggestion that reasonable care was withheld. I am unsure whether the Cause of Death Certificate is correct in the circumstances.

Mr H

Mr H was a 42 year old resident at [REDACTED] [REDACTED] [REDACTED], a level 3 residential service.

Mr H died at the residential service on 29 July 2016. The death was reported to the coroner as a death in care (disability).

Mr H has a background medical history of schizophrenia, bipolar affective disorder and depression.

SUMMARY OF EVENTS

On 10 June 2016, Mr H was seen by his treating general practitioner, GP6. GP6 prescribed Bactrim DS, Brufen and Codalgin Forte. The records do not indicate the reason for these medications being prescribed.

On 5 July 2016, Mr H was seen by GP6 for prescription medication, Antenex, codalgin forte, Endone, Pristiq and Temaze.

On 26 July 2016, GP6 visited Mr H and noted the following in the records; *Resting when I visited. Staff claim he still smokes 10-15 smokes a day. No lethargy. No malaise. No fevers. No recent overseas travel. No nausea. No giddiness. No anorexia. No weight loss. Weight gain. BP: 122/98...Weight: 104.5kg...Hydration: not dehydrated. Not clinically anaemic. No jaundice*

GP6 also ceased Pristiq and Zydol medications and prescribed Codalgin Forte, Endone and Temaze.

On 29 July 2016, Mr H was observed to be stumbling near the entrance to his room at the [REDACTED]. Two [REDACTED] staff assisted Mr H to lie down. The QAS was subsequently called to attend. While waiting for them to arrive, staff at the [REDACTED] attended to Mr H by attaching a defibrillator and commenced procedure in an attempt to resuscitate Mr H.

The defibrillator was continued until QAS attended the scene. QAS arrived and were unable to resuscitate Mr H, issuing the life extinct at 7.04am.

GP6 had completed the death certificate which noted the cause of death being myocardial infarction, with antecedent causes being alcohol abuse.

No CFMU review was completed for this death.

Mr I

Mr I was 52 years old and a resident at [REDACTED], and a previous resident at [REDACTED], both level 3 residential services.

Mr I died at the [REDACTED] on 30 August 2016. The death was reported to the coroner as a death in care (disability). Mr I had a background medical history of schizophrenia, korsakoff's psychosis, poorly controlled epilepsy and alcohol dependency.

SUMMARY OF EVENTS

On 7 June 2016, Mr I was found lying unconscious by a bystander at [REDACTED]. The bystander stated that Mr I was sitting and having a cigarette when he started shaking for approximately 10 seconds, then slumped on the floor.

The bystander caught and lowered Mr I to the ground. QAS were called and transported Mr I to the [REDACTED] for assessment. The records indicate that Mr I had not had any drinks for an extended period of time and that Mr I thought that he had been taking antiepileptic medication (Keppra). Records further indicate that the plan for Mr I was to eat and drink, observe Mr I for a time in DEM and if well, he could be discharged home. It was noted Mr I was to be strict in taking medication and that if Mr I had another seizure then a need for change of medication and further review was to be conducted. Mr I was subsequently discharged on the same date and referred to his general practitioner.

On 21 June 2016, Mr I was found lying on the ground by staff at [REDACTED]. Staff at the residential facility state that Mr I was sitting on a chair when he started having a seizure causing him to fall sideways onto concrete. The seizure self-resolved after approximately *a few minutes*. Mr I was transported by the QAS to the [REDACTED] for assessment. A letter was sent to GP2 of [REDACTED] Medical Centre, who was believed to be Mr I's treating general practitioner.

The purpose of the letter was to advise GP2 that Mr I had presented to the hospital post-seizure of which no obvious trigger was found and that he was found to have no infective focus or

biochemical abnormalities. Furthermore, it noted that Mr I did not appear to sustain any injuries secondary to the seizure except for minor mouth lacerations that did not require any medical treatment.

On 5 July 2016, Mr I had a tonic clonic seizure while sitting in a chair outside the [REDACTED] residential care facility. The seizure was witnessed by bystanders. The bystanders assisted Mr I by preventing him from falling to the ground. QAS were called and transported Mr I to [REDACTED] for assessment. A letter was again sent to GP2 notifying him that Mr I had presented to the hospital with a short self-terminating generalised tonic clonic seizure and that he had been discharged home with advice to see his GP for further management of his seizure disorder. Upon review of the available records it does not appear that there was subsequent contact with Mr I's treating GP as a result of this communication.

On 17 August, Mr I was seen by GP2. GP2's records note the following; *Psych settled – sleeps well c current t dose. Reports settled sleep and good recent appetite. Nil wt loss. Chest – clear Check BP – 130.80. Nil dep oedema. Reprats medn as required. Prescription printed: Temaze tablet 10mg 1 nocte*

On 28 July 2016, Mr I was evicted from [REDACTED] subsequent to him assaulting another [REDACTED] resident. Mr I was subsequently transferred to [REDACTED] on 1 August 2016.

On 27 August 2016, Mr I was found slumped over on a bench unresponsive. QAS attended and performed CPR for 30 minutes. Mr I showed vital signs but nil brain activity. Mr I was transported to [REDACTED] where he was admitted to the Intensive Care Unit and the primary diagnosis was noted as being cardiac arrest.

On 30 August 2016, a decision was made to withdraw treatment in conjunction with the Adult Guardian.

Life support was subsequently withdrawn and Mr I declared deceased. The probable cause of death noted in the hospital records was a catastrophic hypoxic brain injury.

The Coroners Court has been advised that [REDACTED] do not hold records for Mr I, despite this being a legislative requirement to

do so, although an incident report was provided relating to the incident on 27 August 2016.

No CFMU review was completed for this death.

Mr J

Mr J was 52 years old and a resident at [REDACTED], [REDACTED], a level 3 residential service. Mr J died at the [REDACTED] on 26 April 2016. The death was reported to the coroner as a death in care (disability).

Mr J had a background medical history of metastatic melanoma to brain; bladder wall thickening; renal cysts; barretts oesophagus; intellectual impairment; declining cognitive function; and depression/anxiety.

SUMMARY OF EVENTS

On 11 March 2016, Mr J was admitted to the [REDACTED] Emergency Department with rapidly grown left CP angle brain tumour on a background of craniotomy 12 months prior for right parieto-occipital ICH. Mr J presented with a complaint of nausea and ongoing vertigo post craniotomy.

On 11 and 12 April 2016, Mr J underwent surgery for evacuation of a haematoma. He was transferred to the Intensive Care Unit (ICU) to be kept sedated overnight. The post operation management plan was noted to wean and wake Mr J after CT scan. The CT results were noted as follows; *EVD appropriately positioned. Minor progression of bilateral temporal SAH. No new ICH. No herniation or progressive hydrocephalus.*

It is noted on the ICU night ward round notes that *(1)Neurological decline post posterior fossa mass resection- Hydrocephalus & clot in surgical bed – EVD inserted & craniotomy for clot evacuation with subsequent improvement in neurology.* Mr J was to continue with cephazolin and 2.5mg PRN endone for pain.

On 14 April 2016, the records note that Mr J remained at high risk of aspiration and was not suitable to commence oral intake. Mr J reported experiencing chest pain upon initial review in the morning and stated the pain was 5/10. An ECG was conducted and a doctor attended to Mr J. The next day, on 15 April 2016, it was noted in the hospital's progress notes that *due to aspiration pneumonia precipitated by mucous*

plug, saturations have improved post nebs. The plan on record is to continue regular + PRN nebs, continue chest physio /triflow, continue antibiotics and continue to titrate oxygen down to target Sats > 94%.

On 16 April 2016, MET were called for tonic-clonic seizure after Mr J lost consciousness. Mr J was treated with Midazolam and Keppra. The seizure activity is noted as lasting under 2 minutes. The notes indicate that Mr J was not stable enough for radiotherapy as per the Medical Registrar and Oncology consult on 18 April. A family meeting was held, given poor prognosis with intracranial melanoma and multiple perioperative complications. The family consented to palliative care on 21 April 2016.

The next day, Mr J was transferred into a single room to facilitate comfort care measures. On 24 April 2016, the family requested for the EVD to be removed for comfort. The next day, the EVD still remained in-situ and was not removed due to an emergent procedure on another patient however, was removed on this date. On 26 April, Mr J died in the presence of family at 1731 after a respiratory arrest secondary to metastatic melanoma to the brain with multiple complications.

No CFMU review was completed for this death.

Mr K

Mr K was a 62 year old resident at [REDACTED] [REDACTED] a level 3 residential service within the meaning of the *Coroners Act 2003*. Mr K died at the [REDACTED] [REDACTED] residence on 9 July 2016. The death was reported to the coroner as a death in care (disability).

Mr K had long term treatment resistant schizophrenia with recurrent psychotically driven deliberate self-harm behaviours. He also had a depressive disorder and repeated previous suicide attempts and self-harm by swallowing unusual object (pebbles, batteries).

SUMMARY OF EVENTS

GP2, Mr K's treating doctor of [REDACTED] Medical Centre had seen Mr K at the [REDACTED] on the 7 July 2016. Prior to this, GP2 saw Mr K on 1 and 15 June 2016. GP2's medical progress notes indicate that Mr K was, *Still agitated, says*

sleeping OK, Carer staff say remains compliant, denies any drowsiness/falls. A prescription of Zyprexa Zydis Wafer 20mg was printed.

On 9 July 2016, Mr K was observed by [REDACTED] staff to be lying on the ground. Mr K was seen getting back up on his feet then suddenly collapsing to the ground. [REDACTED] staff immediately phoned triple zero. QAS commenced CPR upon arrival however, there was nil response to CPR.

No CFMU review was completed for this death.

DISCUSSION

In conducting their review of these deaths, it was decided the Panel would focus on clear themes and issues across cases, and as such did not conduct an in-depth analysis of all cases during discussions.

The Panel instead focused on those cases and points of intervention where there were significant issues identified in the provision of services prior to the death, a notable outcome changing event, or the case highlighted opportunities for improvements in services and systems.

While the provision of care prior to the death, quality of life, treatment provision and health care involvement varied significantly across cases, there were some common themes and trends identified throughout this review process.

Deceased persons had contact with a wide range of service providers, as a result of their complex health conditions, comorbidities and functional difficulties. As a result, records were extensive, reflecting a high level of engagement with the service system, including: general practitioners (GPs), specialist clinics, hospitals and mental health services.³

Despite this, there was limited indication of coordinated care, with the notable exception of Mr D, who the Panel identified as an example of an effective shared care arrangement. The positive impact of this in improving his quality of life was notable, compared to other deceased persons in this sample cohort.

A significant barrier to the provision of effective support was found in working with patients who were reluctant to engage or non-compliant with treatment regimes. In some cases it was likely non-compliance may have been because of an

underlying neurocognitive impairment or intellectual disability.⁴

The majority of the deceased had complex health and psychiatric conditions, and it was identified that persons with high care needs should not be in certain types of supported accommodation, as their care needs exceeded that which could reasonably be expected to be provided in these types of settings (i.e. level 3 residential services).

The case of Mr E was considered by the Panel to be indicative of the significant issues and challenges associated with the provision of support within these types of facilities for persons with high care needs. The Panel ascertained that Mr E received substandard care within the community setting, although there were attempts to move him into a higher care facility.

It was considered that the problematic behaviours exhibited by Mr E may have precluded the provision of appropriate support to him however, similar to other cases in this review, he was likely challenging to manage because he was unwell, and it appears this may not have been taken into adequate account by service providers. It is also important to consider Mr E's broader life circumstances with respect to his behaviour, as he was placed in this facility when his last support person had died. As such, he appeared to have limited social connections and few protective supports.

Needless to say, the presence of challenging behaviours in a patient should not preclude them from being able to access, or receive, appropriate clinical care. It was noted by the Panel that a lack of volition was a symptom of schizophrenia and this should have been taken into consideration in Mr E's care management.

While at point of entry to [REDACTED], Mr E's care needs could reasonably be considered to

³ In their review of these deaths the Panel identified a range of additional records that would be required, which have subsequently been gathered to inform the coronial investigations into these deaths where applicable. This material is not canvassed in this report as the Panel did not have the opportunity to review it as part of this review process.

⁴ For example Mr B regularly declined prepared meals and medication at the [REDACTED] and was responsible for self-administering his insulin. The Panel noted that he was non-compliant with this regime greatly affecting his clinical outcomes with some indicators that he may have had undiagnosed intellectual or cognitive impairment evident in the review of the files.

have been managed appropriately within the [REDACTED] more coordinated shared care arrangements would have been of significant benefit in the management of his health care needs. In the 12 months prior to his death, Mr E's clinical deterioration was notable and the Panel determined that he shouldn't have been in [REDACTED] at this time, as he was very unwell and would have received more appropriate support in a higher care facility.

Shortly prior to Mr E's death, ambulance records indicate that he had been refusing to eat and had been rapidly declining to the point where he was no longer able to self-care; leading to his admission to the [REDACTED] in March 2016 and subsequent death on 11 May 2016.

LEVEL 3 RESIDENTIAL SERVICE PROVIDERS

Ten deaths in this cluster occurred in accredited level 3 residential services.

As such the Panel considered the applicable regulatory frameworks and standards, as well as a range of other related issues including: eligibility screening and assessment for residents, staff training and capacity (particularly with respect to health care and medication management), and external stakeholder awareness of the support available within these settings.

REGULATORY FRAMEWORKS AND STANDARDS

Operators of a residential service in Queensland (e.g. a privately owned and operated boarding house, supported accommodation [REDACTED] or aged rental accommodation) need to comply with the *Residential Services (Accreditation Act) 2002*⁵ which ensures these types of services:

- protect the health, safety and basic freedoms of residents who reside in residential service accommodation
- are encouraged to continually improve their services

- support fair trading in the residential services industry.

This legislation sets requirements for registering a residential service, applying for accreditation, and following the correct procedure when there is a change in associated service providers.

The *Residential Services (Accreditation) Act 2002* regulates boarding house style accommodation where residents rent rooms and share facilities, such as the toilet, bathroom and kitchen. This Act also covers situations where residents occupy self-contained units and receive a food service and or personal care.

The Department of Housing and Public Works (DHPW) administers this Act with the Residential Services Unit (the Unit) registering and accrediting residential services, undertaking proactive compliance, and investigating complaints. The purpose of accreditation is to ensure services meet minimum benchmarks for service delivery

Levels of accreditation for accommodation facilities are based on a triaged system in which⁶:

- **Level 1 (Accommodation):** all services are required to be accredited at level 1. Accreditation requirements at this level relate to a resident's right to: privacy and independence; individual residential agreements; appropriate record keeping; protection from abuse and neglect; grievance mechanisms; adequate goods and equipment; access to external professional service providers; cleanliness and maintenance; appropriate security and emergency measures; appropriate business and workplace health and safety practices; human resource management and staff training.
- **Level 2 (Food Service):** services who regularly provide meals to a resident must obtain accreditation as a level 2 facility. Accreditation at this level relates to a resident's right to nutritious food;

⁵ Other relevant legislation also includes the Residential Services (Accreditation) Regulation 2002 and the Residential Tenancies and Rooming Accommodation Regulation 2009.

⁶ See more here: <https://www.business.qld.gov.au/industry/service-industries/operating-residential-service/accreditation>

While the intent of this standard is to ensure that support services from external entities are made available, facilities are not compelled to ensure they are accessed by residents. Specifically, they only need to ensure residents are aware of the services, which are made available and accessible as required.

For some cases under review, the Panel identified that there would have been substantial benefit to client outcomes had certain services, such as medication management reviews, been provided or accessed prior to the death.

Opportunities exist to further consider how this standard is operationalised to improve the proactive provision of services to residents of these facilities with complex health needs, or who have intellectual and cognitive impairments which may impact on their decision-making capacity in relation to personal self-care needs.

HYGIENE MANAGEMENT

Standard 3.6 requires that the personal hygiene needs of residents are met in a way that is consistent with individual needs and demonstrates respect for dignity and privacy. The service is required to have written permission to attend to the residents personal hygiene needs, and to ensure appropriate care is provided for their individual needs. The service *is required* to have:

- a clear, concise policy on hygiene management for residents and records maintained on their individual needs
- a policy encouraging residents to manage their own personal hygiene
- a list of external providers (e.g. BlueCare, Salvation Army) who are capable of meeting residents personal care needs as required

⁸Specific requests were as follows Mr B: 1. What arrangements, policies or procedures were in place at the facility at the time of Mr B's death to: (a) ensure that staff understood and endeavoured to comply with: his daily medication requirements; regular monitoring and recording of his blood sugar levels; his oral intake requirements; his supplemental oxygen requirements; directions given by his

- in the absence of external support for residents who require assistance, staff with the capacity to help residents with bathing, showering, cleaning teeth, shaving and other tasks related to their personal hygiene.

In practice this *must include* that the service demonstrates that the policy is implemented and personal hygiene needs of residents are addressed, and *may include* that:

- needs of residents are catered for and individuals are assisted as necessary
- service providers take appropriate action if a resident's personal hygiene diminishes
- appropriate assistive devices are available promoting continence and managing incontinence for residents
- information on residents requiring assistance with managing their personal hygiene is recorded and documented in their personal profile, and that resident's records are maintained and reviewed regularly for accuracy
- staff implement the procedures and encourage and remind residents, when necessary, to bathe, shower, clean teeth and maintain their personal hygiene
- where laundry is done for residents, separate storage for dirty and clean clothing is provided, and separate washing and disinfection of soiled clothing and linen is undertaken.

While the facilities identified in this review were required to maintain oversight of hygiene management in accordance with the standard above, it was debatable whether this was adequately met in nearly all cases subject to the Panel's consideration (or if these standards were being met, the information was not provided as part of the request for records to inform the coronial investigation into these deaths).⁸

general practitioner or on discharge from hospital (b) assist staff to identify when residents require medical attention 2. What information, if any, staff were given about these issues when Mr B was last discharged from hospital and/or seen by his general practitioner GP3. 3. Whether Mr B was receiving support for any non-government service providers and if so,

Applicable records that have been provided to date include:

- **Mr A:** Policies provided by [REDACTED] with no records relating to his personal hygiene management. Records indicate that Blue Care nurses were brought in for Mr A as the facility noted his care needs exceeded those they were able to provide. Blue Care nurses subsequently provided care and have provided five pages of records with a discharge form.
- **Mr B:** Policies provided. Records not provided (and they are believed to be destroyed). Hygiene management is mentioned in the [REDACTED] statement, *Centacare and other service providers attend regularly to assist residents with showering and other hygiene requirements beyond the scope of care that was required to be provided by a residential service. It cannot be recalled which, if any, of such services were availed by Mr B.*
- **Mr C:** Records relating to personal hygiene not provided.
- **Mr D:** Nil records or policies relating to hygiene provided by [REDACTED].
- **Mr E:** No records or policies relating to hygiene provided by the [REDACTED].
- **Mr F:** No records or policies relating to hygiene provided. In a letter from

which ones 4. Whether staff or any other resident alerted facility management to concerns about Mr B's condition over the week preceding his death and if so, what action if any was taken in response to those concerns and if no action was taken, the reason why? **Mr C:** Please provide information regarding deceased's health condition including quarterly medication summary, PRN medication sheets, 'notes for doctor' kept on a weekly basis, incident reports – and any information you have in relation to Mr C relating to community ITO. **Mr A:** A statement from you outlining: (a) what policies or procedures were in place at the facility over January-February 2015 to assist staff to identify when residents require medical attention; and (b) what information, if any, staff were provided in respect of the outcomes of Mr A's review by the palliative care physician on 29 January 2015 and how this information was communicated to staff. 2. a statement from each of the carers who made notes regarding Mr A in the carer communication book over the period 29 January – 7 February 2015 outlining: (a) his/her observations of Mr A's

[REDACTED] it states, *Staff always made a point of checking on Mr F at various times during the day and encouraging him to shower and/or to change his clothing. Mr F did not like showering, but would change his clothing when asked.*

- **Mr H:** Very limited information provided in [REDACTED] records.
- **Mr I:** No records provided by [REDACTED]. No records provided by [REDACTED] relating to personal hygiene.
- **Mr J:** No records provided by [REDACTED] relating to personal hygiene.
- **Mr K:** No records provided by [REDACTED]

One complaint was raised to the regulator regarding poor hygiene practices at the [REDACTED] where Mr H resided. No breach was identified when this matter was investigated.

MEDICATION MANAGEMENT

Standard 3.3 outlines that if residents ask for support to manage their medication, help is given in accordance with medical directions and all legislative obligations in relation to staff and carers helping with medications (for example the *Health (Drugs and Poisons) Regulation 1996*). Services are also required to minimise risks to residents which may include such practices as: ensuring they receive their medication at

condition on that day (b) his/her assessment of Mr A's condition and the extent to which it differed from his baseline condition (c) what efforts (if any) he/she made to seek medical attention for Mr A that day and if not, the reason why he/she did not seek medical attention for Mr A at that time. **Mr D:** Please provide an electronic copy of your complete records held in relation to Mr D. Please confirm if Mr D was receiving support from for any non-government service providers and if so, which ones. **Mr E:** Please provide the complete records you hold in relation to Mr E. Please provide information as to whether Mr E received community care services and if so, please provide a copy of these records. **Mr F:** Please advise whether Mr F received community care services and if so, please provide these records if possible. **Mr H, Mr I, Mr J & Mr K:** Please provide an electronic copy of your complete records you hold in relation to the deceased.

prescribed times, they do not receive other resident's medications, and they take their own medications.

This standard specifically acknowledges that residents may require help to take their medication however, staff in these types of facilities are unlikely to be medically trained, and it is therefore important that any help is provided in accordance with the instruction on the medication label. Residents are encouraged to self-administer their own medication if they have the capacity to do so.

In accordance with this standard, the service is required to have documentation pertaining to:

- written requests from the resident to the service provider seeking assistance with their medication management
- a consent form signed by the resident or their representative
- a list of all currently prescribed medication for each individual resident stored, updated and re-ordered as required.

Policies and procedures should cover:

- only helping residents where there is ongoing written consent which is stored in the residents personal records
- medication management, including PRN medication and complementary medication
- if PRN medication is prescribed by the resident's GP, it is given in accordance with medical directions
- each resident who is assisted by staff with medication, has a dose administration container such as a Webster pack, or other recognised medication scheme, filled and supplied by a pharmacist
- any changes to the resident's medication are to be made by the resident's GP and provided to the pharmacy for correct dosage amounts
- medication is only taken directly from a resident's own labelled containers and

provided to residents in accordance with the instructions on the label.

Where applicable, medication management sheets are to be used to record the medication administered, including PRN needs. Practices *must include* that the service maintains records, in accordance with the regulation, of all instances where medication is provided or refused. Appropriate secure or lockable storage also needs to be available for medication provided by both the service provider and for residents for self-medication, and processes should be in place to ensure any leftover medication is returned to the pharmacy.

Practices *may include*:

- staff helping residents with medication are trained, are aware of and apply the Service's policies and procedures in relation to storing, administering and safe disposal of a resident's medication
- residential medical records must be kept for 5 years
- appropriately trained staff should correctly identify the resident, and ensure that the correct medication is available at the correct time, in accordance with administration instructions
- proper legible records of help given with medication should be maintained in the medication register to avoid any gaps or absences in the medication regime
- staff helping residents with medication should record any gaps or absences in the medication regime and report these to the appropriate agency or health professional
- the service should ensure that any problems with helping residents with medication or side effects are brought to the immediate attention of the appropriate agency or health professional
- if PRN⁹ medication is prescribed it is only provided in line with the applicable directions

⁹ This refers to medication that should be taken as needed (i.e. Panadeine Forte).

- residents who administer their own medication are provided with a safe, lockable storage area which they can access as necessary
- the Service provider could maintain a recent photo of each resident and the contact details of the resident's substitute decision maker
- a syringe disposal process is in place for insulin dependent residents.

In their review of these cases, concerns were raised by Panel members regarding medication management prior to the deaths, as current standards were considered to be sufficiently broad to allow for substantial differences in practice across the facilities considered.

Clarity is also required regarding who is allowed to provide medications to a resident in these types of settings, as the Panel identified that this is not necessarily clear or reflected in current standards; although it is specified that the service is required to adhere to relevant legislative requirements in this area.

As specified by the *Health (Drugs and Poisons) Regulation) 1996* a person does not need an endorsement merely to deliver a controlled drug to a person for whom it has been dispensed or the person's agent (s. 74). A person (a carer) does not need an endorsement under this regulation to help another person (an assisted person) to take a controlled drug that has been supplied for the assisted person as a dispensed medicine if: (a) the assisted person asks for the carer's help to take the dispensed medicine; and (b) the carer helps the assisted person to take the dispensed medicine under the directions on the label attached to the dispensed medicine's container.

Although the Health (Drugs and Poisons) Regulation is very specific with respect to

dispensing controlled¹⁰ or restricted drugs¹¹, once the medication has been dispensed the important consideration within these types of facilities is predominantly appropriate storage, access and administration.

Panel members specified that they would not expect anyone without appropriate medical qualifications (i.e. a doctor or pharmacist) to identify the relevant scheduling provisions for different types of medication¹², with the management ideal to be rigorous with any medication (irrespective of whether it is controlled¹³, restricted or another schedule).

The optimal example within these types of residential services would be to have a medication room, with a medication basket for each patient, labelled and administered in accordance with the doctor's instructions. This accords with best practice approaches to medication management and would ensure that the facility was compliant with relevant legislation.

Notably, community visitor and regulator concerns regarding these facilities, while not pertaining directly to the provision of care to any of the deceased persons, predominantly related to issues associated with this standard (Standard 3.3) and those pertaining to Health Care Standard 3.4 (which is interrelated and discussed in the next section), specifically:

- Community visitor concerns were raised regarding the documentation of medication administration at [REDACTED] [REDACTED]¹⁴ as well as regulator concerns with unsatisfactory medication management practices.
- Community visitor concerns were raised about mental health case management, intravenous drug use, and medication

¹⁰ As per schedule 8 of the Standard for Uniform Scheduling of Medicines and Poisons

¹¹ As per schedule 4 of the Standard for Uniform Scheduling of Medicines and Poisons

¹² The storage and administration requirements for different medications differ according to the respective scheduling provision.

¹³ While strict provisions exist for Controlled Drugs (schedule 8) unless it is used for the purposes of opioid substitution

therapy it does not need to be locked away within a community setting or facility, dosing in this regard is usually done in a pharmacy. The introduction of medicinal cannabis may also be treated in this way, but this is yet to be determined at the time of this report being written.

¹⁴ in which Mr B resided, though none relate directly to him

administration management at [REDACTED].¹⁵

- Regulator concerns were raised with respect to a *medication administration documentation issue* which was subject to quality improvement recommendations at the [REDACTED].¹⁶
- Community visitor concerns were identified about the inaccuracy of the depot injection register maintained by [REDACTED].¹⁷ Regulator concerns regarding this facility included residents being administered medication by non-qualified staff (unable to be substantiated) and a current complaint involving multiple issues (including unqualified staff concerns) which were subject to ongoing investigation at the time of writing this report.
- Regulator concerns were identified about the need to provide more comprehensive procedures in relation to medication management practices in July 2014 at [REDACTED].¹⁸ The DHPW Accreditation Report for this facility indicates that the recommendation was for the [REDACTED] service to be accredited at level 1, 2 and 3 for three years without conditions. Issues identified were (1) Distribution not being signed as required in the medication register and (2) Coding system not being correctly utilised in the medication register to indicate whether residents had received medication. Medication management was subsequently re-assessed and the overall level was assessed as 'matter rectified'¹⁹ indicating the concerns had been addressed to the satisfaction of the DHPW.

Taking into account these issues, and available records, the Panel identified a need for the

¹⁵ Nil concerns pertaining specifically to Mr C or Mr F who resided here – the documentation of medication issues was raised with the service provider

¹⁶ Where Mr H resided though none relate directly to him

¹⁷ Where Mr K resided though none relate directly to him

¹⁸ In which Mr E resided. Community visitor concerns were raised directly about Mr E in late January 2016 which are discussed later in the report

greater standardisation of practices, and the establishment of clear minimum standards for medication dispensing in these facilities, developed in consultation with persons of appropriate clinical expertise.

The Panel further noted that there were elements of optimal practice in this area with certain facilities managing it very well.

For example [REDACTED] [REDACTED]²⁰ had a dispensing room, with the medication having to be obtained at certain times. This was considered of significant benefit because if the person didn't receive their medication then staff were required to locate the resident, improving the likelihood of adherence to medication regimes for residents. Other facilities required photos to be attached to the packaging to minimise the possibility of mistakes in the administration of medication.

At a minimum, all relevant staff should be trained in the storage, administration and safe disposal of a resident's medication, with regular reviews of training and processes to ensure compliance with any applicable policies and procedures.

Additionally, in accordance with current standards, practices *must include* that the service maintains records where medication is provided or refused. In some instances, records pertaining to the care provided prior to the death where there were issues with medication non-compliance, do not indicate that this was reported to the relevant health practitioner. This may be reflective of poor record keeping practices or indicative of a lack of communication between care providers in accordance with the required standards.

Significantly, with respect to the death of Mr B, no records have been produced by the residential facility pertaining to Mr B.²¹ This is

¹⁹ The service provider had a coding system detailed on a notice on the wall at the time of the site audit. This system was immediately reintroduced during the visit and the service provider has been completing the lunchtime medication register since the date of the site audit.

²⁰ Where Mr F resided

²¹ The facility has advised that they have been unable to be located and may be in archive or destroyed.

particularly salient given that the Form 1 notes that the overnight manager mentioned that Mr B had not taken his medication on 5 July (Mr B died on 7 July) and that no records of Mr B's health, wellbeing and medication intake were checked or recorded.

In the coronial statement provided by [REDACTED] regarding this death, it notes that on a number of occasions the Manager of the service [REDACTED] [REDACTED] Director] phoned the GP, GP3, regarding Mr B's refusal to take medication including that on occasion he had been sighted disposing of the medication in the garden outside his room. The extent to which any intervention regarding Mr B's noncompliance was addressed by his treating GP is unclear from the available records, although records indicate that GP3 proposed a review of treatment plans for his diabetes with him (which was declined by Mr B).

HEALTH CARE

Health care provision as defined by the applicable standards requires that facilities have the capacity to provide health care where necessary.²² This was considered by the Panel to be an ambiguous statement, with little clarification about who is responsible for making the determination about a resident's health care needs. They further considered that it was focused on the maintenance of a resident's physical, dental and mental health needs, whereas it should be focused on the improvement in the health of residents as a more aspirational aim.

Standard 3.4 outlines that residents have their choice of care providers, and where necessary, residents are encouraged and helped to maintain their physical, dental and mental health. This means that the facility has a positive duty of care to encourage and assist residents to access health care providers as required and where necessary; including prompting or assisting residents to maintain their health.²³

²² Specifically that the residential service provider has a positive duty of care to encourage and assist residents to access health care providers as required and where necessary.

If the health of the resident deteriorates, the service provider or staff must also take reasonable steps to rectify this, and the resident's health must not be left to deteriorate until it reaches a critical point.

Based on a review of these cases, circumstances in which staff at facilities adhered to these standards included:

- **Mr A:** staff at the facility noted swelling around his stomach and legs. He advised staff at the [REDACTED] that he was ok and not in pain and refused to go to hospital when asked. [REDACTED] contacted 1300HEALTH and were advised to monitor closely.
- **Mr C:** between 2011 and 2014, Mr C refused medication offered to him on a number of occasions from [Mr C's former GP7], [Mr C's former GP8], and [Mr C's former GP9] of the [REDACTED] Clinic. Calls were made by these GPs to the [REDACTED] Mental Health Case Worker to advise of this noncompliance. Since seeing GP5 in late 2015, the records indicate Mr C only refused to have an operation and go to hospital. No other complaints were noted.
- **Mr I:** a seizure occurred and Mr I refused to go to hospital so [REDACTED] [REDACTED] contacted QAS for treatment.

Under the relevant standards, facilities must also retain documentation that includes records of each resident's daily living and medical or health supports, as well as the name and contact details of each resident's doctor. Documentation may also include:

- written policies and procedures on access to external service providers and for encouraging residents to maintain their personal health and well-being
- professional caseworkers and other health care support providers have full and complete access to residents they are supporting

²³ This may include encouraging activities, making dental appointments, assisting with transportation to appointments and ensuring that residents are not spending all day in bed.

- the service's staff inform relevant health care professionals of any significant matter related to residents they are supporting
- residents have a choice of health care services and health care professionals they, or staff at the service, can contact for health care assistance.

Practices within these facilities *must include* details of each resident's medical and other requirements in their medical records in accordance with s. 10(3) of the Residential Services (Accreditation) Regulation 2002 with a regular pattern of residents accessing relevant health professionals being visible when viewing personal records for health or medical needs. Practices *may* include that:

- the service communicates the procedures to residents
- residents have on-site access to information on healthy lifestyles, preventative health measures and other health service/treatment options
- details of the care providers of individual residents are included in the register of personal information, including any prescription medication or instructions by their health care provider
- staff encourage and support residents to maintain their physical, dental and mental health, including matters pertaining to personal appearance and well-being
- a first aid cabinet for the use of residents, staff and visitors is available and is monitored to ensure the contents are complete, relevant and first aid supplies are obtained
- the service provider ensures that residents do not share razors, toothpaste and toothbrushes.

While accreditation for a level 3 service includes the provision of support for health care and medication management, regulatory assessment is conducted by persons employed under the *Residential Services (Accreditation) Act 2002* with no apparent requirement for that person to have a medical background. The Panel specified that a requirement for a regulator to have

medical qualifications would be unnecessary if the criteria for compliance was stricter and more clearly defined.

In the short term, a clear and standardised checklist for regulators to use would likely lead to a substantial improvement in enforcement and compliance activities within the current standards. Over the longer term, consideration could be given to a review of current standards, with the potential for legislative reform which would be likely to lead to sustained change and improvement in the quality of care to this cohort.

The Panel identified that it does not appear that there was medical input into the development of standards for level 3 residential service providers despite them being in relation to personal care needs pertaining to a resident's medical or psychiatric care. The standards were considered by the Panel to be so vague and open to interpretation that anyone *could or could not* meet them. This is problematic given the complex health conditions of some of the deceased, which required a high level of care that exceeded that able to be provided by the service.

For example, Mr A, who had a terminal illness, was a short term resident within [REDACTED] [REDACTED] [REDACTED] as his family was desperate for an alternative accommodation as he was unable to look after himself. He received assistance from Blue Care nurses which was arranged by a palliative care specialist and while staff sought assistance when they noted a change in his condition, it is likely he would have been more appropriately managed within a specialist palliative care facility.

The Panel noted further that, as indicated in this case, there is sometimes a reluctance to seek palliative care support, even though these services are designed to ensure a person's comfort care needs are appropriately met at end of life.

APPROPRIATE RECORD KEEPING

Under the *Residential Services (Accreditation) Regulation 2002* services are required to ensure that a register of residents is maintained

containing, for each resident, relevant information reflecting the type of residential service and the resident's needs. Where food services are provided this includes a record of each resident's special dietary requirements.

Level 3 service providers must make and keep a record of the following:

- the daily living and medical or health supports required by each resident
- the name and contact details of each resident's doctor
- the name and contact details of each entity that referred a resident to the service (if known)
- the details of any direction or instruction given by each resident to the service provider, an associate to the service provider, an associate of the service provider or a staff member of the residential service about the personal care service required by the resident.

These records must be kept for at least three years after the day a resident to whom the record relates leaves the residential service or the day a resident dies.

Records pertaining to all deceased persons within this cluster of deaths were requested from their residential service providers. The quality of record keeping varied significantly dependent on the facility. Of concern was that a number of these facilities were unable to provide records to inform the coronial investigation²⁴ even though the death occurred within the requisite three year timeframe for retention, as the records had been disposed of or destroyed.²⁵

For the death of Mr I, [REDACTED] advised that they had no records pertaining to his

²⁴ Specifically for: Mr I ([REDACTED]), Mr B. ([REDACTED])

²⁵ At the time of writing this report, for the matter of Mr B records were yet to be provided to the Coroner's office by [REDACTED] as they had already been archived.

²⁶ The incident report outlined the following events: [REDACTED] Worker1] came into the office and said that Mr I is sitting in an uncomfortable position on the chair in the backyard. He further said that he is not alert. I went to the back yard. Mr I was sitting in the chair with his head on his

residency at this facility however, they have provided a brief incident report relating to the circumstances of the death.²⁶ For the death of Mr B, [REDACTED] provided a statement and submissions which included operational policies and procedures, procedure manuals, Residential Services Accreditation Branch Audit information, and statements of attainment by [REDACTED] employees.

The Coroners Court of Queensland was formally advised by [REDACTED] that all medication records are maintained for a period of 12 months after a resident has left the facility or had died. As such the Manager of [REDACTED] had disposed of all Mr B's medical records as was the orthodox practice because the period of 12 months had expired since his death. This disposal was in direct contravention of the legislative requirement to retain them for a minimum three years²⁷ and the regulatory standards which require medical records be retained for a minimum five years.

Needless to say, this made it difficult for Panel members to effectively assess the facilities compliance with relevant legislation and regulatory requirements, or identify additional areas for improving service system responsiveness to a resident's health care needs.

The Panel further determined that the three year timeframe for retention of records was too short and insufficient comparative to other equivalent standards for documentation retention, such as for those within a health care environment that need to be retained for a minimum seven year period.

STAFF TRAINING AND EXPERIENCE

In the case of Mr K, the Residential Services Unit received two complaints in 2016 which were

knees. He wasn't conscious. I called the ambulance. [REDACTED] Worker2] helped me put him down on the ground. I then did resuscitation until the ambulance arrived. The sections for 'Senior Management Response' and 'Any strategy or training required that may prevent future incidents' was not completed.

²⁷ s.10 of the Residential Services Accreditation (Regulation) 2002 outlines that records pertaining to a resident must be kept for at least 3 years after a resident leaves or dies.

noted to be relevant to the standard of care provided by [REDACTED] [REDACTED]. One of the complaints was that residents were being administered medication by unqualified staff, which was unable to be substantiated.

The other complaint involved multiple issues (including unqualified staff concerns) which was subject to ongoing investigation at the time this report was written.

Standards for the management of persons with complex disabilities or health needs in these type of settings should specify that staff have appropriate training, as well as the capacity to manage a resident's personal care needs. While staff training is required even to obtain level 1 accreditation, the type and nature of this training or staff qualifications, as they relate to personal care needs, are unclear. Further information is required to consider current approaches to staff training and skills development within these facilities, noting the aforementioned regulator concerns and the need for standardisation in practice across facilities.

Most services have not provided any substantive records regarding staff training however, records identified as relating to staff training for medication management and health care for [REDACTED] [REDACTED] included:

- a reference to staff training being delivered at [REDACTED] [REDACTED] with 'no issues' identified, as well as details regarding their induction program (which include training programs with the requirement for a first aid certificate and training in inoculations to be completed)
- relevant certifications (completed in 2013) were also provided for three staff which included: Manage Asthma emergencies; Provide first aid management of severe allergic reactions and anaphylaxis; Develop risk minimisation and management

strategies for allergic reaction of anaphylaxis; and Perform CPR.

A workforce unqualified or inexperienced in working with people with a disability, results in poorer outcomes for people in care, may contribute to delayed diagnosis of diseases and other clinical conditions, and may manifest in challenging behaviours among clients.²⁸ In addition to training with respect to medication and health care management, there are a number of areas in which residential service staff, at a minimum, require training and support including hygiene management, and working with residents with challenging behaviour.

While some of the deceased in this cluster exhibited challenging behaviours in the residential services, to the extent it led to their exclusion from the facility, it is apparent that some of them were coping with quite severe health conditions or associated comorbidities. For example:

- **Mr F:** was asked to leave the [REDACTED] [REDACTED], [REDACTED] (now known as [REDACTED]) as he was bringing garbage into the [REDACTED], pestering patrons at a local café and became 'untenable'. The [REDACTED] manager asked him to leave and he was moved to [REDACTED] [REDACTED].
- **Mr C:** is noted to have been either evicted or asked to leave [REDACTED] [REDACTED] due to substance and alcohol abuse (the notes indicate he was evicted for using marijuana on the premises).
- **Mr B:** left on his own volition following conflict with residents who reportedly threatened to 'knife him'; and because it was too loud and he wanted to move elsewhere ([REDACTED] [REDACTED]).

In any interaction, staff responses and reactions to a client's behaviour can exacerbate a client's distress and anger²⁹, potentially contributing to

²⁸ Community Affairs References Committee (2015) *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities* in Australia, Commonwealth of Australia.

²⁹ Farrel, G.A., Shafiei, T. & Salmon, P. (2010) Facing up to 'challenging behaviour': a model for training in staff-client interaction. *Journal of Advanced Nursing*, 66(7), 1644-1655.

a deterioration in the relationship and impacting on the optimal provision of care to a client.

The Panel considered that upskilling of staff in this area would be beneficial and was not considered an unreasonable requirement within these facilities, with the potential for staff to be able to access free online courses, meaning that there would be limited impact on resources in ensuring staff were appropriately trained.

For example, the Queensland Centre for Intellectual and Developmental Disability (QCIDD), in collaboration with other partner agencies, have developed free courses that would be of utility for staff, specifically: *Intellectual disability healthcare around the world; Improving the physical health of people with intellectual disability and mental health and people with intellectual disability.*

ELIGIBILITY SCREENING AND ASSESSMENT

The deaths of Mr E and Mr B were considered by the Panel in detail as both deceased had high care needs which the Panel identified would have been better addressed in a different setting.³⁰ Community visitor concerns were raised in relation to Mr E's health in late January 2016.³¹ Specifically, it was noted that Mr E's appetite was poor and he had lost five kilos in one month with his current weight at the time being 55.9 kilos. He had also been hospitalised for six months during the previous year.

The manager of [REDACTED] raised these concerns with the community visitor on the 28 January 2016 as she identified that Mr E's personal care needs were beyond those that they would normally deliver.

A number of months later, on 12 April 2016 the community visitor made enquiries about what action had been undertaken to date around supporting Mr E's current and future needs and was advised that his caseworker at [REDACTED] Mental

Health had made an application to DSQ for an Aged Care Assessment Team (ACAT) assessment. The manager of the service was under the impression that this assessment was awaiting the approval of Mr E's guardian.

The community visitor sought advice from her regional visiting manager who contacted Mr E's guardian. The guardian advised that there were varying stakeholder opinions about whether Mr E was too young for an ACAT assessment as opposed to whether this was what he required. The guardian advised that they would make contact with the service to ensure there were *clear communication lines*.

The community visitor subsequently understood that an ACAT assessment had been made and that Mr E had been transferred to Woodlands Aged Care however, he was seen as not ready for this level of care and transferred back.³² The status of this concern was then marked as 'clarified' with no indication of whether any further action was taken with respect to the original concerns.

Corresponding agency records indicate the following timeline of events:

- **26 February 2016:** The Office of the Public Guardian gave consent for Mr E to undergo an ACAT assessment.
- **2 March 2016:** The [REDACTED] ACAT called the Mental Health Service to make arrangements for the assessment. Multiple attempts were made to return this call.
- **3 March 2016:** The manager from [REDACTED] called the Mental Health Service and informed them that Mr E was continuing to deteriorate and was very difficult to manage. The GP advised that there was a vacancy at the [REDACTED] Nursing Home and was wondering whether Mr E's ACAT had been completed.

³⁰ Mr A and Mr G also would have been more appropriately managed within an aged care or palliative care facility

³¹ No corresponding regulator concerns were raised regarding Mr E within this facility.

³² It is unclear whether this actually occurred with some discrepancies in different agency's records

- **4 March 2016:** an ACAT assessment was completed for Mr E.
- **7 March 2016:** Plans were made to move Mr E to the [REDACTED] Care facility ASAP.
- **8 March 2016:** Mr E was admitted to [REDACTED] (confusion and hypotension – noted as refusing meals) and he was given IV thiamine.
- **9 March 2016:** an ITO hearing was set for 22 March. Mental Health Service notes indicate that [REDACTED] *state that as he has now had his ACAT completed that he would be best transferred to an aged care facility upon discharge rather than returning to [REDACTED] where they do not have sufficient staff to look after him.*

Arrangements for this transfer were in progress when Mr E deteriorated and he subsequently died at the [REDACTED] on 11 May 2016.

While no community visitor or regulator concerns were raised in relation to Mr B, the Panel considered that his care needs also exceeded those able to be provided by a level 3 service.³³ The CFMU report completed after this death, identified that the level of care provided to Mr B was grossly inadequate (on the information provided) and that a person with his condition would have appeared very unwell and would have needed urgent treatment to save his life. Monitoring and recording of blood sugars on a twice daily basis, ensuring medication was taken appropriately and an awareness of signs of clinical deterioration would likely have prevented Mr B's premature death.

Of concern with respect to this death was that the [REDACTED] director provided a statement to inform the coronial investigation saying that she didn't know that Mr B was an insulin dependent diabetic, and that he had lied about his condition on admission to the facility. Her statement alleged: *At the time of his admission neither Mr B nor Mr B's daughter*

*advised myself nor any other staff member that Mr B had diabetes and required insulin injections on a regular basis and that he used supplemental oxygen. If either Mr B or Mr B's daughter had advised of those requirements at the time, he would have been refused admission as a resident as [REDACTED] [REDACTED] is a residential care facility and not a nursing home.*³⁴

She stated further that she told his family that it was inappropriate for Mr B to reside within the facility as his care needs were too high. However, there were limited indicators in available records that any attempt was formally made to transfer him to a more appropriate facility or to discharge him from the residence. Several days after Mr B's admission, Mr B had a refrigerator delivered to his room for the storage of his insulin along with oxygen bottles and other equipment. The [REDACTED] director asked Mr B's daughter for an explanation and suggested Mr B be removed and put into a nursing home.

Mr B's daughter reportedly declined at that time (and on several subsequent occasions) to remove Mr B to an aged care facility. It is also mentioned that Mr B's daughter had no viable alternative substitute placement for Mr B and therefore the [REDACTED] director felt *forced* to allow Mr B to stay. Mr B insisted that he could manage his own blood sugar monitoring and insulin injection requirements without assistance.

He resided in the facility for eight months prior to the death.

The Panel questioned the extent to which there was any specified selection or eligibility criteria for entering a level 3 residential service, and no documentation was available reflecting any legislative, policy or practice requirement that care needs must be at a certain level to either include, or exclude, potential residents.

It was apparent to the Panel that level 3 accreditation is subject to interpretation and *may mean a lot of things to different persons*

³³ Mr B had significant multiple medical comorbidities including ischaemic heart disease, associated cardiomyopathy, obstructive sleep apnoea, chronic kidney

disease, pacemaker inserted (2013) and type II diabetes requiring insulin to maintain normal blood sugar levels.

³⁴ Para 48 of [REDACTED] Submission.

given the diversity in practice among the nine facilities reviewed as part of this cluster. There were significant inconsistencies in the provision of services and support in the facilities. In some, residents seemed to receive the bare minimum of support (i.e. [REDACTED]) where as others provided more appropriate levels of care.

Further, in a statement provided to the Coroners Court in relation to the death of Mr B his treating GP, GP3, states that *it is my understanding that the [REDACTED] [REDACTED] is a level 3 accredited residential service. There are no trained staff at the [REDACTED] and the residents are independent of care. In my experience, it is not usual for full assistance to be provided to residents. However, from time to time I do speak with (the manager) and attend the [REDACTED] to see residents, on other occasions the residents come to see me at my rooms.*

The GP's understanding was that [REDACTED] kept Webster packs for the residents and provided these to them at the appropriate time but did not supervise medication administration. He states further that *I never had any concerns regarding the care that was being provided to Mr B by the [REDACTED], having regard to the level of care and assistance that is, in my experience provided in such facilities.* Records also indicate that GP3 was aware that Mr B was non-compliant with his medications, refused to have his blood sugar checked or obtain pathology tests.

On one occasion, GP3 reports he asked Mr B to have non-fasting blood tests taken, and that Mr B told him that these had already been taken at the hospital. GP3 provided the pathology request form to Mr B anyway but it was ultimately not performed. Records indicate that GP3 also asked Mr B whether he would like a treatment plan for his diabetes which was further declined on the basis that Mr B told him the hospital was already looking after this.

Mr B had a complex history and there was a reference in the files to him having a suspected intellectual impairment which may have impacted on his decision making ability however, he was assessed as not requiring

assistance in decision making on at least one occasion.³⁵ The Panel identified that his health issues would have been better managed by specialist services and a GP in a coordinated care arrangement. Mr B also did not appear to have a level of personal responsibility around his health care needs, despite assurances made to residential care staff that he was capable of managing his own medication.

Ultimately, the Panel identified that Mr B's level of disability was not well understood and his diabetes not well managed in the environment he was residing in which contributed to his premature death. The Panel further identified that, generally speaking, there are two types of insulin dependent diabetics; there is a cohort who is high functioning and able to manage the treatment regime and can reside in the community, and others who can't and need assistance with regular monitoring and treatment adherence. Mr B was the latter and he clearly required more intensive support for his condition. The Panel found that such support, which accords with the specified standards for level 3 residential services (health and medicine management), would likely have prevented this death.

They also determined that a specified criteria for assessing a (prospective) resident's medical and psychiatric conditions and associated complexity, to determine entry into these facilities may have led to Mr B being excluded from the facility, and a corresponding identification that he required a higher care needs facility (i.e. an aged care facility). In this setting, his condition would have been better managed and his substantial clinical deterioration in the days prior to his death most likely identified and responded to at an earlier point.

His treating GP, GP3 saw Mr B on 3 July 2014, a few days prior to his death. Patient notes indicate that he checked Mr B's blood pressure (161/72 - high), pulse (74) and weight. A change to his dose of Frusemide was noted (from 1 x 40 mg tablet in the morning to 3 in the morning

³⁵ [REDACTED] Hospital determined that Mr B didn't need assistance in decision making.

and 2 at midday). Atorvasin (80mg) and Arntodipine (5mg) were also ceased and his dose of Coversyl was changed from a 5mg table to a 20mg one. Various other repeat prescriptions were printed and he also gave Mr B his vaccination (vaxigrip).

A statement provided by GP3 after this death indicates that this was the third time GP3 had seen Mr B. GP3 recalls that Mr B looked unwell and had recently been discharged from hospital where he was given medication for heart failure.³⁶ He had been discharged with insulin for his diabetes, and he was carrying an oxygen container with him on that occasion.³⁷

GP3 notes that Mr B declined to allow him to take his blood sugar measurement that day. The aforementioned adjustments to his medications were based on information that was received from the [REDACTED] Hospital pharmacy as well as those that Mr B normally required. In his statement, GP3 outlines that he had not received any additional information about the recent hospital admission (outside of what was provided by the pharmacy) and as it was apparent that Mr B was not well, GP3 advised him that he would call the hospital to request the discharge summary. A follow up appointment was made for 10 July 2016.

In this case, the Panel considered there were opportunities for GP3 to provide advice about the appropriateness of this accommodation for Mr B, as he should have had a better idea of the personal care support provided by the facility and what they were reasonably able to provide. GP3 had attended the facilities previously for medical appointments and provided care to Mr B on 3 July 2014, just four days before the death. He also indicates in his statement that he was aware that there were no trained staff at the [REDACTED] and that residents were (meant to be) independent of care.

The Panel determined that for Mr B the outcome changing event prior to his death was entry into [REDACTED] [REDACTED]. Had eligibility screening been conducted at this time it would have indicated that he needed more intensive support than the [REDACTED] could provide, leading to his transition to a higher care facility able to provide more intensive health care support for his multiple health conditions.

The use of assessment practices by GPs such as those existing to assist in the determination of whether a person is medically fit to hold a driver's license was considered an example of an applicable equivalent process for such eligibility screening.³⁸ The *Assessing Fitness to Drive* guidelines by AUSTROADS contain standards for medical professionals to use to provide advice to patients who drive, which are used by all drivers licensing authorities in making decisions across jurisdictions.

An alternative proposed by the Panel, and relevant to the circumstances of Mr E's death was an ACAT assessment³⁹, a comprehensive assessment process of primary use for older people who have complex care needs that cannot be met by Home and Community Care services. The intent of this assessment process is to let the individual know what their options are, and to choose the help that best meets their needs.

Using the *Aged Care Assessment Program (ACAP)*, the assessment considers the capacity of the whole persons, including their current functioning⁴⁰, areas where assistance is required, as well as their health care and social needs. It is applicable to persons over the age of 65, Aboriginal and Torres Strait Islander persons who are over the age of 50 and persons who are no longer able to manage at home without assistance. In certain circumstances, it is also

³⁶ Following his discharge on 23 June 2016

³⁷ [REDACTED] [REDACTED]'s submission indicates that he had oxygen cylinders upon his admission to the facility

³⁸ See more here: <http://www.austroads.com.au/drivers-vehicles/assessing-fitness-to-drive/for-health-professionals>

³⁹ See more here:

<https://agedcare.govcms.gov.au/programs-services/guidelines/aged-care-assessment-and-approval-guidelines>

⁴⁰ Specifically medical condition, physical capability, cognitive and behavioural factors, social factors, physical environmental factors and personal choice

considered applicable to younger people with a disability.

The program is considered of benefit in determining low and high care needs, and associated pathways to care. While it is effective in determining which facilities a person should or shouldn't be in, the means through which an ACAP assessment can be obtained for this cohort was questionable as they are difficult to obtain with potentially long waiting periods after a referral for assessment is made. This was evident in the case of Mr E where there was debate as to the appropriateness of a referral for an ACAP assessment, and an incorrect belief that a referral to DSQ needed to be made prior to an ACAP assessment being conducted which led to unnecessary delays in the assessment process.

While referrals or requests for an ACAP assessment can be received from any source, there is no mandated requirement to accept a referral. Screening is undertaken as part of the intake process⁴¹ to ensure that only persons requiring a comprehensive assessment receive one. Priority category ratings apply in ensuring those persons with urgent needs are seen in a timely manner.

Ultimately there is a need to see these types of misconceptions dismissed as it was identified by the Panel as a significant barrier in getting an ACAP assessment completed to ascertain the appropriateness of a person with high care needs residing within these facilities. Referral to an ACAT for a person who is not an aged person can occur where the person meets the eligibility criteria for aged care services and where it can be demonstrated that *'there are no other care facilities or care services more appropriate to meet the person's needs'*.⁴²

For residents in these types of settings it is imperative to identify those persons with high

care needs and get them the care they require. To achieve this systematically it would be necessary to develop and implement a screening process to ascertain when a referral for further assessment may be required. If eligibility screening excluded a person for entry into a level 3 residential service then an ACAP assessment should also be completed, with the person subsequently transitioned to a higher care facility.

There may however be a reluctance or refusal by practitioners to conduct this type of screening and assessment, in part due to limited resources and competing demands, and as such the potential for multiple assessments was considered.

The Panel considered whether it would be appropriate for a medical or hospital assessment to be conducted to ascertain eligibility for admission, and/or whether a screening check list should be completed by the community care provider.

Both were seen to have certain benefits and limitations, and as such a role was identified for multiple concurrent, but intersecting, processes to ensure a comprehensive assessment of capacity and functionality. For example, for assessments in hospitals while the staff may have the relevant clinical expertise, they may not have an awareness of the services provided within different types of supported accommodation, which may impact on their capacity to conduct a robust assessment appropriate to the respective facility. If the person at the hospital conducting such an assessment wasn't aware of the type of personal care support provided by these facilities they could provide approval even in circumstances in which there were complex care issues. As such, there is a corresponding need to ensure a level of familiarity with people at hospitals regarding relevant standards and legislation in level 3

⁴¹ An appropriate intake process seeks to establish whether the person: has a condition of frailty or disability which indicates they may need the type and intensity of aged care services under the Act; is incapable of living in the community without support; is a person with special needs (refer to section 11.3 of the Act), and has any culturally specific assessment requirements (e.g. the assessment would be assisted by an interpreter and/or Aboriginal

Liaison Officer). It is important to note that the Act does not define the age of an older person. Department of Social Services (2015) *Aged Care Assessment Programme Guidelines*, Queensland Government

⁴² Although ACAT may redirect a referral to disability, mental health or other services where they consider it appropriate to do so. Department of Social Services (2015) *Aged Care Assessment Programme Guidelines*, Queensland Government

residential services to improve discharge and care planning.

In this regard, GPs play a critical role in the coordination of care for this cohort, and they were seen to be the most appropriate person to conduct initial screening and assessment, particularly as most persons will have access to a GP in a community. In circumstances where concerns are identified, GPs are also in the position to refer to ACAT where it is considered appropriate to do so. Funding is available from Medicare for these types of assessments for GPs and therefore it was not seen by the Panel as representing any financial impost or something which would be considered an extension of a GPs current roles and responsibilities.

The development of admission criteria based on medical needs, no matter how strict, would need to be implemented concurrent to the required improvements with accreditation guidelines outlined above, particularly around health care issues. There is also a need to be very strict in defining the provision and criteria for admission as while there are existing standards, it appears they are subject to interpretation.

Based on the diversity of practice evident from a review of the cases, the Panel felt it would be unable to reliably say that people with complex medical needs entering in to these types of facilities would be appropriately or consistently supported.

With stricter provisions it would also be the case that people may be selected out of certain residential accommodation as their support needs would be too high. The Panel determined that this was not necessarily a bad outcome, as long as prospective residents are not selected 'out into the street' and as such, the identification of pathways to alternative accommodation should be considered concurrently to the introduction of tighter restrictions.

It is important to acknowledge that with the introduction of any assessment process comes the need for reassessment when red flags are identified with a client, or there is a noted increase in care needs. For example, entry into

supported care accommodation or a change in accommodation. The panel considered it highly relevant that people should have an assessment during these transition periods as they may be indicative of underlying issues, and it is also a time of increased vulnerability as new staff may not have an awareness of a resident's underlying conditions or behavioural patterns.

Consequently, both entry and change assessment would be critical in being able to successfully screen and assess a client's eligibility for admission to a level 3 residential service.

There is also the potential to incorporate support plans into this process. For example, upon entry to a residential care facility there should be a requirement that if certain 'red flags' are identified than it may indicate the need for a treatment plan, which would differ dependent upon an individual's medical and/or psychiatric condition/s.

In addition, a salient factor in the case of Mr E was that although it was determined at the hospital that his support needs exceeded those able to be provided by a level 3 residential service, he was still discharged on 31 July 2015 back to this accommodation due to Mr E's age being *less than 65 years* and that the *process* (an ACAT assessment) *will likely take months, (Mr E) should not remain in hospital for that process to be conducted.*

Records from the [REDACTED] indicate that at this time Mr E was assessed as medically well with no medical cause identified for his increased care needs and that they were *behavioural only*. He was subsequently assessed by a psychiatrist with a recommendation that he be transferred to a high care nursing facility on the 31 July 2015 although this did not occur and he was discharged back to the [REDACTED].

Further consideration needs to be given to identify how to improve system responsiveness in circumstances like this, in which it is determined that a person is ineligible for one level of supported accommodation and there is a gap in being able to enter another service, to ensure that their care needs are still addressed sufficiently.

HIGHER CARE FACILITIES

The need to ensure the availability and accessibility of appropriate supportive accommodation for this cohort is one that raises systemic concerns.

Currently with ACAT assessments those persons found to be low care would be transitioned to a low care facility while they wait for accommodation however, the importance of preventative health measures and early intervention in reducing adverse health outcomes should not be discounted, even for those persons screened as 'low care'.

If a person is residing in a facility which is unable to meet their care needs they may deteriorate and will end up needing to move to a higher care facility if their community support systems are unable to meet their requirements, or preventative measures are not implemented for chronic health conditions (such as diabetes).

It is important to note that the management and treatment of a person with complex medical and psychiatric issues is currently very difficult outside of an aged care facility, although short term places are available in hospitals (which was considered by the Panel to be less than ideal).

As level 3 residential services are private enterprises, they are likely to operate on a business demand model and it was unclear to the Panel whether there are waiting lists for entry into this level of accommodation.

With the implementation of any proposed process there needs to be a corresponding identification of any *unintended consequences*. For example, although there needs to be tighter criteria about what services are delivered in level 3 residential services, this may be associated with an increased financial impost for these services, and if this process is not managed properly may result in persons becoming homeless.

The Panel recommended that consultations with other relevant agencies (i.e. YoungCare, Micah Projects or the Institute of Social Science Research) will likely identify whether there are existing barriers to entry into level 3 services because of availability, and whether this has a corresponding association with homelessness or residency in a lower care facility (i.e. a level 1 or 2 service).

Nationally, the accessibility and availability of places in higher care facilities for those persons under the age of 65 is a limiting factor in the smooth transition between different types of supported accommodation.

As highlighted in the federal Senate Inquiry into the *Adequacy of existing residential care arrangements available for young people*⁴³ with severe physical, mental or intellectual disabilities in Australia (2015)⁴⁴ there is a notable proportion of young Australians under the age of 65 with disabilities who currently occupy residential aged care facility beds.

This is predominantly because the current system cannot provide the appropriate supports and services for this cohort and while aged care facilities can provide suitable health care support, they are designed to meet the needs of older persons nearing the end of their life. As such, these facilities are not adequately equipped to be able to meet the education, employment, social and recreational needs of younger people.

Further, access to, and availability of, suitable support services can also be problematic in these settings, as they are not designed to meet the rehabilitative needs of younger persons, or the facility's resources to support such initiatives are likely to be limited.

Ultimately, the demand for specialist disability accommodation facilities exceeds supply. For a person who is assessed as unsuitable for a level 3 residential service, the only place currently available would be a hospital or an aged care

⁴³ 'Young people' are considered within this report to be under the age of 65. The report found that nearly 90% of young people living in aged care facilities were aged 50-64 years.

⁴⁴ Community Affairs References Committee (2015) *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*, Commonwealth of Australia.

facility, without substantial investment in alternative accommodation options by government.

Practitioner awareness of level 3 residential services

From a review of available records, the Panel identified that there appeared to be a lack of understanding among clinicians and other hospital staff in relation to the roles and responsibilities of level 3 residential services. This has significant implications for discharge planning, and in ascertaining a patient's longer term care requirements.

The Panel determined that while this may potentially be associated with a lack of understanding among hospital staff or other specialists, it could also be attributed to the seemingly wide variability in the support these types of facilities provide and the substantial differences in the services they deliver.

Such misunderstanding is problematic as it means that clinicians may develop discharge plans that exceed the capability of the service resulting in critical, and potentially fatal, outcomes for patients. For the death of Mr B, for example, hospital records refer to him being in a nursing home, indicative of a disconnect in understanding as to where he was being discharged to.

As evident in this case there are substantial implications for a resident's care and support needs when clinicians are discharging patients with complex health care needs and comorbidities to facilities which are not able to meet the patient's support needs necessary to achieve optimal patient outcomes.

While full records have not been supplied from this facility, staff were ill-equipped to ensure Mr B's treatment plan was monitored or adhered to, however they did identify that they knew he was non-compliant with his medication and do not appear to have identified his clinical

deterioration prior to his death, in which earlier intervention may have saved his life.

At a broader level, there is a requirement for increased awareness of working with people with a disability in health care services including their eligibility for certain services and appropriate pathways to specialist care. There appears to be a common myth among health care practitioners within hospital facilities that disability services have their own system for health care and as such people who have a disability may be denied health care, or they do not receive proactive referrals to appropriate supports.⁴⁵

An additional misconception is that the patient may be at risk of losing their pension if they are provided certain services from mainstream providers, which is also false but may impact on clinical decision-making or service provision.

The development of an education package for hospitals designed to improve awareness in this area may be of benefit and should take into consideration the varying roles and responsibilities of clinical staff, tailored to meet their area of focus. For example, there has been a shift in some hospital settings to having specialists in discharge care.

The Panel considered there is a paucity of knowledge among these clinicians as to what discharge into a level 3 service may mean for patient care. Informed and robust discharge planning can substantially improve treatment outcomes. In a number of cases considered in this cluster, records indicated that staff was under the impression ongoing support was being received within the community setting when clearly it wasn't.

Part of this discrepancy in understanding is also likely attributable to the differences in legislation, regulatory frameworks and standards between level 3 residential services and DSQ funded facilities; indicative of a need for standardised care in all supported accommodation services irrespective of whether

⁴⁵ This has been identified by multiple reviews including in the Public Advocate report and considered in depth as part of the transition to the NDIS

they are government funded or privately owned.

DISABILITY SERVICES QUEENSLAND (DSQ) FUNDED FACILITIES

The death of Mr G occurred within a DSQ funded facility which is governed by different legislation and regulatory frameworks than those applicable to level 3 accredited residential facilities.

As this was one death in the cluster of eleven, the Panel did not explore issues regarding the provision of care and support in these settings in substantial detail however, the differences are discussed below to inform the coroner's investigation of the death.

The Panel determined that given there was only one death which occurred within a DSQ funded facility, it would be unable to consider whether there were any opportunities for systemic reform with respect to the supported accommodation services funded by DSQ, outside of highlighting the importance of consistent standards with respect to a resident's personal care support needs.

Departmental funded services are required to deliver services in accordance with the *Disability Services Act 2006*, which aims to protect and promote the rights of people with a disability, and the Human Services Quality Framework (HSQF).⁴⁶ The HSQF is a system for assessing and improving the quality of human services and applies to organisations delivering services under a service agreement with the Department of Communities, Child Safety and Disability Services (DCCSDS) or other specified arrangements. It incorporates:

- a set of quality standards, known as the Human Services Quality Standards, which cover the core elements of human service delivery

- an assessment process to review the performance of service providers against the standards
- a continuous improvement framework, which supports the participation of customers in quality improvement.

The HSQF aims to increase consistency in service quality and ensure public confidence in service delivery. It is designed to increase administrative efficiency and enable service providers to focus their resources on service provision and continued quality improvements. Applicable to the provision of services in disability, child safety, and community care services, the framework contains six Human Services Quality Standards:

1. **Governance and management:** sound governance and management systems maximise outcomes for stakeholders.
2. **Service access:** sound eligibility, entry and exit processes facilitate access to services on the basis of relative needs and available resources.
3. **Responding to individual need:** the assessed needs of the individual are being appropriately addressed and responded to within resource capacity.
4. **Safety, wellbeing and rights:** the safety, well-being and human and legal rights of people using services are protected and promoted.
5. **Feedback, complaints and appeals:** effective feedback, complaints and appeals processes that lead to improvements in service delivery.
6. **Human resources:** effective human resource management systems, including recruitment, induction and supervisory processes result in quality service provision.

The HSQF is the approved certification framework for disability service providers but does not contain specific reference to any

⁴⁶ Found here: <https://www.communities.qld.gov.au/gateway/funding-and->

[grants/human-services-quality-framework/tools-and-resources](https://www.communities.qld.gov.au/gateway/funding-and-grants/human-services-quality-framework/tools-and-resources)

health care, medication management or other personal care needs.⁴⁷

As part of the implementation of the National Disability Insurance Scheme (NDIS), a new national quality and safeguards framework is being developed so that there are consistent standards and safeguards across Australia.⁴⁸

Accommodation support delivered by the Department is through an Accommodation Support and Respite Service (AS&RS). The AS&RS provide accommodation support to adults with a disability in their own homes through public housing, DCCSDS funded services, or the private rental market.

Typically two to four people sharing a home are supported by Residential Care Officers (RSO) who provide day-to-day assistance and support to people with an intellectual disability focusing on a person-centred approach. Support systems reflect individual needs and may include occupational or speech therapy, physiotherapy, social workers, psychologists or other community services.⁴⁹

The Panel identified that specific information would need to be obtained from DSQ regarding how policies and procedures in relation to personal care needs (medication management, health care and hygiene management) are articulated through the HSQF, in order to consider whether there were opportunities for improvement in this area. It is important to note that in the transition from the DSQ to NDIS,

compliance and auditing of NDIS standards will remain a state responsibility, although it will not cover complaints with respect to health care as that is seen to be exclusive of the NDIS.

Records clearly indicate that there was a noted deterioration in Mr G's health and functioning in the 18 months prior to his death. By the time of his death, Mr G⁵⁰ was sleeping on a mattress on the floor as he no longer had full mobility so he tended to crawl.

In early January 2016, he was transferred from the [redacted] Hospital to the [redacted] Hospital due to functional decline and abdominal distension. On 23 January 2016, while still in hospital he developed a fever and tachycardia. It was noted on records that the source of the infection was believed to be cellulitis in his right hand due to abrasions/lacerations from frictional injury with floor-crawling. His condition continued to deteriorate despite medical intervention and he passed away four days later.

The CFMU review conducted into the death of Mr G identified two possible issues with this death that needed to be addressed (1) a possible public health issue with a salmonella infection and (2) a possible failure to diagnose an underlying disease such as malignancy.

For the latter, the CFMU review doctor noted that such a diagnosis would be high on the agenda in normal circumstances however, the issues associated with behavioural and

⁴⁷ Policies and procedures on the Department of Communities records for this death include those pertaining to the appropriate use of electronic monitoring equipment; advocacy policy; conflict of interest policy; duty of care policy; code of conduct policy; privacy, dignity and confidentiality policy; privacy statement; whistleblower's protection policy; abuse, neglect and exploitation (response and prevention policy) presumably provided in relation to the request for information associated with the complaint in 2012 (discussed below). A PRN protocol was also provided which is intended to act as a guide for the type of information that should be included (i.e. history/medication/reasons for PRN medication/ warning and accountabilities. This should not be considered to indicate that specific agencies don't have requisite policies and practices in place as records for Mr G, while seemingly incomplete, do indicate that staff had a high level of training and focus on his health care needs. Copies of these

however, have not been provided to the Coroners Court but were requested subsequent to the writing of this report.

⁴⁸ Until this time Queensland's existing quality and safeguard system applies to all NDIS providers registered to deliver specialist disability services in Queensland during the transition to NDIS or until a national quality and safeguards system is implemented

⁴⁹ Policies have been provided to date for this death in relation to the Duty of Care Policy, Conflict of Interest, Code of Conduct, Privacy, Dignity and Confidentiality, Abuse, Neglect and Exploitation (Response and Prevention)

⁵⁰ In communication to the Coroners Court, Mr G's mother has raised significant concerns in relation to the care and treatment provided to him by hospital staff in the 16 months prior to this death. These are discussed in more detail later in this report.

functional decline in persons with cerebral palsy may have led investigators to *pursue a neurologic cause rather than follow a path that they may well have pursued in the absence of his pre-existing condition.*

According to statements, and other supporting evidence, Mr G had full mobility and could originally walk while in the facility.

A family member's statement indicates that: *Disability Services reported in May 2014 that Mr G needed more assistance, equipment and support at home however, did not action this at any time. No case manager was assigned until the [REDACTED] Hospital enforced this 1-2 weeks ago. Having no case manager until the week before his death meant there was no consistency in his treatment, deterioration was ignored, carers were distressed and the obvious pain Mr G had was disregarded as 'behavioural'. We felt that because Mr G could not speak, the medical teams over the past year or so had no urgency except to send him home to Centacare to deal with.*⁵¹ It is clear from records that Centacare staff were supportive and attempted to advocate for Mr G and his family within the hospital setting.

Unlike some of the other cases considered within this review, records were available to

indicate that Mr G was provided with hygiene management and health care support (although they predominantly refer to wound care).

Records were obtained from DCCSDS relating to the care and support pertaining to Mr G. Four critical incident reports were provided as part of this documentation for the following matters:

- **12 September 2012:** Mr G resided in a co-tenancy arrangement⁵² with another resident, and a staff member reported that he struck his flatmate with a closed fist a number of times. Mr G also reportedly kicked a staff member in the face. Centacare was noted to have conducted an assessment and review of the arrangement, and strategies were subsequently successfully implemented to the satisfaction of all parties.⁵³
- **17 September 2012:** Mr G was observed to be sitting beside his bed in the morning by a support worker. He was noted to have blood over his face and hand from a small cut over his left eye. Mr G had been in bed and the cause of the injury was unidentified. Background notes indicate that: *his behaviour regarding his personal hygiene and his requirement for high rapport with staff*

⁵¹ Records from both Centacare and Department of Communities with respect to the care provided to Mr G prior to his death appear incomplete. The earliest records we have from Centacare services are from 1 June 2015 and from DCCSDS is 2012 however, it appears he had contact with both agencies prior to this point. There are also corresponding statements made by Mr G's family to the Coroners Court that they were aware of his clinical deterioration and did not take any additional action shortly prior to his death. This is yet to be verified based on the records provided from this agency to date.

⁵² Both parties had resided in the arrangement for approximately ten years. Centacare was the third agency to provide support under this arrangement and had done so since 2009.

⁵³ On 9 October 2012, a Centacare Employee contacted the [REDACTED] Region Disability Services seeking a response to his request to dissolve a co-tenancy. It is noted that Centacare had acknowledged the support and strategies provided by Departmental staff to address behavioural issues in the house however, it is further stated that there was systemic abuse between a co-tenant and Mr G residing at the residence and that this could not continue. The comprehensive report was to be provided by Centacare by a

compliance date of 2 January 2013⁵³. On 21 January 2013, Centacare provided their comprehensive response responding to each of the allegations as follows; Allegation 1: Centacare employee claims there is systematic abuse of Co-Tenant by Mr G. Centacare response: *"to date strategies implemented have not effectively eliminated the occurrences of the assaults. We have also been unsuccessful in sourcing additional funding", "Centacare has raised concerns with the department and proposed dissolving this co-tenancy"*. Allegation 2: Centacare's lack of response to implementation support strategies to resolve behaviours of concerns within the co-tenancy arrangement. Centacare response: *"IBST did not conduct a functional assessment or write a Positive Behaviour Support Plan for Mr G, after numerous referrals"* Centacare also advised they had raised concerns of the funding hours allocated to this arrangement to ensure clients safety. Based on the information received by Centacare and the complaints officer's analysis of the information, the Disability Services, [REDACTED] Region formed an opinion that systematic abuse allegations have not been substantiated. It was acknowledged that Mr G had on occasions assaulted his co-tenant, but Centacare have made an attempt to implement support and to address the behaviours. The other allegations pertaining to the staff member were substantiated.

adds an increased level of complexity to meeting his support needs...he has displayed increased aggressive physical behaviour over the past three years...he has resided in current setting for the past five years with support from Centacare commencing in 2009. The vast change in his support environment coincides with his increase in behavioural incidents. Appropriate medical assistance was provided to Mr G, although his behaviours were noted as hampering the provision of assistance. A family member was contacted and subsequently transported him to hospital the following morning.

- **27 November 2013:** Mr G was observed as continuing to present as unwell after receiving medical treatment on 23 and the 25 November 2013 Staff contacted QAS reporting that he was refusing personal care assistance, was not eating and appeared unwell. He was subsequently transported to [REDACTED] Public Hospital with a large faecal mass being noted. He was transferred to [REDACTED] Hospital and was discharged the following morning. Background notes indicate that Mr G *requires pervasive support to manage his complex behaviour and meet his daily living requirements.*
- **26 January 2016:** a critical incident report was completed relating to the death, and it noted that Mr G had been admitted to the [REDACTED] Hospital on 6 January 2016 for investigation and treatment of health concerns. Planning was underway for Mr G's discharge between hospital staff, Centacare and Disability Services who had met on Thursday 21 January however, his condition deteriorated at this point as a result of a Staphylococcus infection.

It is evident from a review of the care needs of Mr G that issues were identified as early as 2012 specifically, that his support needs were increasing and he required more intensive assistance from staff, although this was attributed mostly to his (difficult) behaviours.

Records from the complaint in 2012 highlight the extent of staff training and provide an example of the intensive support provided to Mr G by the DSQ funded service including that:

- Staff were rostered 24/7, with the majority of shifts being one staff member for two clients.
- While difficulties with retention of staff was acknowledged, in addition to mandatory training, staff also undertook a range of courses and workshops (including Bowel Management, Behavioural Support, Sensory Modulation and Active Support and Key Word Signing, Professional Boundaries, Non-Violence Crisis Intervention and learning about continuous improvement).
- Clients had a lifestyle folder and a health folder which contained vital information regarding the client's health and well-being, including consultation records and an appointment register⁵⁴.
- The presence of recording at the time was noted as excellent with respect to the use of various Centacare templates (inclusive of Bowel Management Charts, Behaviour Forms, Health and Well-being Consultation Records and Health and Wellbeing Appointment Register). The importance of this monitoring to inform the identification of evidence based reasons for the challenging behaviours, was also identified at the time (including the potential for them to be associated with an underlying health issue).

⁵⁴ These are currently not available as part of the coronial investigation into this death. Efforts should be made to ascertain whether the use of these folders were in place in the 12 months prior to the death as they should allow for a more comprehensive review of the clinical care and support provided to the deceased during this time period;

particularly given the significant and noted clinical deterioration in the last 18 months. The only records currently held by the office are PBSP Records; Individual Support Needs; PRN Protocol; Understanding of Mr G and Consultation Records.

- A Comprehensive Health Assessment Program (CHAPS) was being completed for both clients annually and that professional hygiene practices were of a good standard⁵⁵.

The standard of care provided to Mr G appeared to be higher than for the other cases in this review, which is particularly relevant given that only eight (11%) of the cases within the cluster reviewed by the Public Advocate in their report were in level 3 residential services with the majority residing in DSQ funded services (specifically 65 individuals). Of these persons, 26 were in government supported AS&RS and 39 were in supported accommodation provided by a non-government organisation.

According to Mr G's Occupational Therapist report completed on 4 August 2014, Mr G's mobility had deteriorated over the past twelve months and it was noted that he required an increased amount of effort to walk, negotiate stairs and transfer in and out of the bath when assisted to shower. Walking or standing for sustained periods, was difficult and Mr G had a preference for squatting. Several recommendations were made as an outcome of this assessment.

Mr G experienced a significant decline in overall health and wellbeing after this point. Mr G would crawl on his knees and elbows which would cause tearing to his skin. References were identified in the medical files and in the DSQ consultation notes that Mr G had cuts and bruises on knees, (as well as other injuries from falls, a swollen forearm, etc.) and that this was being treated with medication, being moisturised and cleaned. It was also noted that Mr G was supervised and monitored closely.

Centacare also requested support from the Department of Housing for modifications to the

home environment to occur to ensure Mr G was able to access his bathroom more appropriately and for other modifications to occur if and where necessary to promote Mr G's mobility and overall health and wellbeing.⁵⁶ It is noted that Centacare had been proactive in engaging various health professionals for further examination, however *the cause of this deterioration has yet to be identified*.

In the DSQ Centacare facility Positive Behaviour Support Plan (PBSP) dated June 2015 it states that *Mr G is able to sit still and appears comfortable when his podiatrist is attending to his feet and clipping his toe nails. Mr G is able to independently sit, stand and walk around his home environment and for short distances in the community, although he has an unsteady gait and substantial issues with posture. His preferred position appears to be squatting, kneeling or lying on the ground. Mr G can stand with support for changing duties and will lift each leg with tapping from staff as a prompt along with verbal reassurance*.

The Panel questioned why the relevant regulatory authorities didn't seem to notice, or respond to, Mr G's deterioration in function to the point that he was crawling along the floor. These records, unfortunately, had not been provided to the Coroners Court at the time of this review⁵⁷ and there is nothing to indicate that a complaint was made in this regard.

His family report that they had complained about Mr G not being in the right facility (with respect to his care needs, including requesting his transition to a palliative care facility) but nothing happened, and they consider that this request should have been escalated. The Panel were unable to identify the obstruction to this occurring from the available records, as they appeared to be incomplete.

⁵⁵The use of the CHAPS is mentioned in the DSQ Facility Centacare consultations records and in Dr Yates Medical Records as *CHAPS report completed; CHAPS review today and Annual CHAPS Apt*. But the results of this assessment have not been provided to date to this office.

⁵⁶ DSQ CentaCare records refer to 'Facility Individual Support Needs' document (dated 2/10/2009 and last reviewed 07/01/2015)Re: bathroom safety that when *getting*

self up and out of bath/ shower – Mr G uses rails to get himself out of the bathtub, - full assistance and supervision – Rails have been installed/non slip mats in place.

⁵⁷ They have subsequently been obtained to inform the broader coronial investigation into this death, but were unavailable to Members at the time of the report being compiled.

It was evident however, that Mr G should have been moved out of the disability facility a lot earlier, or screened out with revised criteria.

Given there are similarities in support needs for those residing in both level 3 residential services and DSQ funded services, the Panel found that greater standardisation in practice is required for the management of personal care needs and eligibility requirements for entry into these facilities, with prompt transition to a higher care facility if required. Any such processes need to be developed and reviewed with input from appropriately qualified medical personnel.

PUBLIC GUARDIAN INVOLVEMENT

The Office of the Public Guardian⁵⁸ (OPG) is an independent body who work to protect the rights and interests of adults who have an impaired capacity to make their own decisions. Their charter is to:

- make personal and health decisions for adults with impaired capacity if the OPG is their guardian or attorney
- investigate allegations of abuse, neglect or exploitation of adults with impaired capacity, as well as
- advocate and mediate for people with impaired capacity and educate the public on the guardianship system.

For clients of the service, the OPG may also consider a residential aged care placement for a person if all community-based options for their proper care and support have been exhausted, and if that person would be placed at unacceptable risk of harm or neglect if they were to remain in their current accommodation arrangements.⁵⁹

⁵⁸ The legislative functions of the Office of the Public Guardian are set out in the *Public Guardian Act 2014* <https://www.legislation.qld.gov.au/LEGISLTN/CURRENT/P/PublicGuardianA14.pdf>

⁵⁹ See more here: <http://www.publicguardian.qld.gov.au/adult-guardian/our-decisions/residential-aged-care-decisions>

⁶⁰ Departmental funded services are required to deliver services in accordance with the *Disability Services Act 2006*, which is an Act to protect and promote the rights of people

They also support the administration of the Community Visitor Program in Queensland, which is responsible for the independent monitoring of three different types of accommodation or *visible sites* in which vulnerable adults live, specifically:

1. disability accommodation provided or funded by the Department of Communities⁶⁰
2. authorised mental health services
3. private [REDACTED] (level 3 accredited residential services)

Community visitors make enquiries and [REDACTED] complaints for, or on behalf of, residents of these visible sites, and have the power to refer complaints to an external agency where appropriate (the DCCSDS, Queensland Health or the Residential Services Unit).

Community visitors help protect the rights and interests of adults with intellectual, psychiatric or cognitive disability and provide rights protection and abuse prevention services to those adults in Queensland who may be subject to abuse, neglect or exploitation due to their impaired decision making capacity resulting from a disability.⁶¹ During visits, the community visitor will seek information about whether:

- Adequate services are provided for assessment, treatment and support.
- The standards of accommodation, health and wellbeing are appropriate.
- Services are provided in a least restrictive manner.
- Adequate information is available to consumers about their rights.
- There is an accessible and effective complaints process in place.

with a disability, and the Human Services Quality Framework (HSQF) found here: <https://www.communities.qld.gov.au/gateway/funding-and-grants/human-services-quality-framework/tools-and-resources>. The HSQF is a system for assessing and improving the quality of human services and applies to organisations delivering services under a service agreement with the Department of Communities, Child Safety and Disability Services or other specified arrangements.

⁶¹ Office of the Public Guardian, the Community Visitor Program (Adult) Fact Sheet.

Excluding site visits associated with the community visitor programs, records indicate that the OPG had contact with, and advocated for, Mr K, Mr E and Mr I.

Mr K

The OPG provided consent as Statutory Health Attorney and not as an appointed guardian on 12 Sept 2000, for Mr K to undergo surgical treatment, being a laparotomy and removal of foreign body (dessert spoon, four batteries and a cigarette lighter) from his bowel.

Mr I

The OPG was appointed by QCAT on 4 Nov 2010 for health care matters for five years. This was revoked on 29 October 2015, approximately ten months prior to his death. (At the time of Mr I's death the OPG was not appointed as guardian).

At the time the order was revoked, the OPG ascertained that *there is no longer a need for a decision maker in relation to Accommodation, Service Provision, Health Care or Legal matters pursuant to s. 12 of the Guardianship and Administration Act 2000*. While noting that Mr I had a history of homelessness and transiency this determination was made on the basis that:

- Mr I had been stable since residing in [REDACTED] with their supported services. He appeared well settled and staff and community services were involved with his access to social and community supports.
- Mr I was seen by the visiting GP as required and staff had a risk management plan in place to contact QAS to transport him to hospital when he was experiencing an epileptic episode.
- His health was stable and the OPG could still act as a statutory health authority of last resort if no one else was available for decision regarding his health care.
- He had no current legal matters and no formal legal decisions were required during the appointment of the OPG except to support him with legal representation through the Aboriginal

and Torres Strait Islander Legal Service for his court matters.

Mr E

The OPG was appointed by QCAT on 16 September 2015 as Mr E's guardian for accommodation, health care and provision services, approximately eight months prior to his death, the circumstances of which were described above.

The Panel commented that in their experience over recent years, there appears to have been a shift in focus by the OPG from a proactive model of care to one which appears much more restricted with respect to strict adherence to its legislative obligations. This was seen to be reflected in their involvement in the cases considered as part of this review process; which was predominantly at a crisis point where statutory decision making was required (for example with transition to palliative care).

While this is a perception that remains untested and is likely to be in part due to the circumstances of each case where a vulnerable person may be identified, the Panel saw it as a missed opportunity for the agency to become involved earlier; even in circumstances where a person with a cognitive impairment or intellectual disability is identified as currently having decision-making capacity.

It was also considered that where care providers identify issues associated with a person's capacity to provide consent then it is important to ensure the OPG are aware of, and involved with, this person even if a decision-maker is not required at that point in time.

With respect to recommendations considered as part of this review, referral to the OPG could perhaps be triggered when a screening and assessment is conducted (as described above) and a vulnerability identified, as proactive and earlier intervention may improve client outcomes, or at the very least, ensure that the

agency is aware of the person, given their identified vulnerability within the community.

The extent to which systemic issues were identified, and responded to, across facilities by the Community Visitor program was also discussed, as a substantial proportion of cases in which issues were raised by Visitors were in respect to health care and medication management across multiple level 3 residential services. If issues are identified across multiple services with respect to adherence to relevant quality standards then it would seem indicative that there may be a need for a broader review of the applicable standards, or the need for improvement, education or intervention across all services to ensure compliance.

The extent to which the Community Visitor program undertakes this type of systemic surveillance function was not clear to the Panel however, their role is critical in protecting the rights of vulnerable persons, and ensuring adequate and appropriate service delivery to this cohort.

The Panel also identified that there is the potential for improvements with respect to compliance documentation provided to Community Visitors to ensure it was prescriptive and promoted consistency in the interpretation of the relevant standards (inclusive of a glossary of terms to ensure that terminology was standardised and promoted correct interpretation of relevant provisions).

Of significant concern is that it took nearly four months for a response when issues with respect to Mr E needing to be relocated to a higher care facility, were reported to the Community Visitor.

During this period of time, Mr E's condition continued to deteriorate and given the concerns were raised by the manager of the supported accommodation, in that they were unable to meet his care needs, the significance of such a concern would seem to require a more intensive

and timely response. Further clarification is required as to what is an appropriate response time in these circumstances, and if one does not currently exist, then consideration should also be given to whether timeframes should be implemented to ensure that such issues are promptly addressed.

CLINICAL MANAGEMENT AND CARE

QUALITY OF CLINICAL RECORDS AND DECISION MAKING

A review of clinical records for some cases demonstrated limited discourse regarding the clinical decision making associated with the initial prescribing of medication. It is important to note, however, that the absence of records may not necessarily reflect the quality of care but instead may simply reflect poor note-taking.

In busy clinical settings, where time and resources are limited, there is no easy solution for this, outside of enforcing a need to write notes. Unfortunately, where an adverse event occurs, and there is no record of decision-making then there is generally a presumption of bad practice.

In these instances, a clinician may refer back to their usual practice or treatment plans regarding what action they may have taken with the patient or what they would usually do in particular circumstances, which is not generally considered appropriate for evidentiary purposes.

This is particularly problematic when family or friends raise concerns that a certain action wasn't taken or was inappropriate. While record keeping is important from a medico-legal perspective it is also the case that clinical records are used to inform future decision-making if practitioners are changed or take leave. As such, there should be a sustained focus on improvements in this area.

As an example, Mr G had cerebral palsy, anxiety, severe kyphoscoliosis, epilepsy, atonic bowel, insomnia and a progressive neurological and functional decline over 18 months prior to the death with weight loss, increasing agitation, decreasing mobility, chronic abdominal pain and constipation being noted in files.

As outlined above, Mr G's family has raised significant concerns to the coroner regarding the clinical care provided to him over this time period, specifically that:

- Mr G was non-verbal meaning that his family and support carer's would have to advocate for him.
- He had been losing weight for over 16 months even though he ate *more and more* and the low weight made him vulnerable to infection.
- They had requested multiple tests to try and work out what was wrong with him.
- Clinical staff refused to provide appropriate pain management for him up until his death and denied that he was in pain, attributing it to behavioural problems.
- Clinical staff refusing to discuss palliative care as it was *just for cancer patients*.

His family further allege that hospital staff were not proactive and discharged Mr G on many occasions without effective pain relief and without conducting tests they felt were obvious and necessary for his diagnosis. They felt that the hospital staff consistently *passed the buck* to Centacare staff to care for Mr G as they wanted him out of hospital quickly. They considered that he was discharged at inappropriate times and without the tests/pain management they felt he required.

DSQ reported in May 2014, that Mr G needed more assistance, equipment and support at home. However, available records do not reflect what actions were taken to manage this. According to his mother, no case manager was assigned to Mr G until the [REDACTED] Hospital enforced this requirement one to two weeks prior to his death. Having no case manager until this time, in their opinion, meant there was no consistency in Mr G's treatment, his deterioration was minimised or not detected, his carers and family were distressed and the obvious pain Mr G had was disregarded as 'behavioural'.

His family state further that *this is a situation that we never want another family or human being to go through. We also believe it is happening every day in hospitals across Australia and we want to ensure that something changes in the minds of doctors, nurses and also Disability Services. To change the way clients without a voice are diagnosed and how the admission*

process is undertaken for anyone without a voice or is too ill to speak. Not only was his voice not heard but his wonderful carers in his house and his family spoke out but also were ignored. This is double disregard for his welfare and his valuable life.

Consensus was unable to be reached by the Panel as to the quality of the treatment provided to Mr G prior to the death with Professor Lennox identifying that he didn't agree with other members that there was a substandard level of care by some providers. For example, it was evident from a review of the files that the GP was trying different strategies on a number of occasions to try and address Mr G's recurring constipation, including referrals to appropriate specialists⁶².

As Professor Lennox further clarified Mr G's decline may well have been a progression-natural or otherwise of his cerebral palsy. I can see no issues in his primary medical care⁶³ that suggest that Mr G was not treated with dignity and respect. His medical care was very good and there was no suggestion that reasonable care was withheld. I am unsure whether the Cause of Death Certificate is correct in these circumstances.

Based on currently available records, key issues identified by some Panel members in this case included a loss of interaction with appropriate specialist teams (such as a gastroenterologist and palliative care support), with it being suggested that this lack of engagement may have been a contributory factor for his prolonged poor care.

Videos provided by family members of Mr G taken approximately 12 months apart do show a progressive decline in a person who was independently mobile. From the latter video footage, Panel members suggested that Mr G appeared to be carrying a malignancy and his

abdomen had become distended. Autopsy results however found no evidence of a malignancy.

The pathologist found that the cause of death was 1. (cerebral) hypoxia and bronchopneumonia and 2. Toxic megacolon, cerebral palsy and salmonella typhimurium infection. Given that Mr G was being treated for constipation the Panel could not identify why the Toxic megacolon wasn't detected earlier. Indeed, constipation had factored heavily in Mr G's health care management for years prior to this death.

As is evident in the case of Mr G, there is a critical need for constipation to be appropriately managed by specialists (i.e. gastroenterologists) and while there may be a lack of responsiveness to what can be seen as a relatively minor issue, constipation may have serious and (at times) fatal outcomes.

In 2012, available records indicate that Mr G was having one Movical sachet daily with support workers continuing to monitor his bowel motions, with a plan in place for escalation as required.⁶⁴ There were also records of medical appointments throughout 2012 in relation to this issue. Changes to Mr G's diet were also recommended at this time, with a dietician being consulted and advising dietary restrictions.

The critical incident in 2013 described above related to staff contacting the QAS as Mr G was refusing personal care assistance, was not eating and appeared unwell. He was transported to the ██████████ Hospital where x-rays revealed he had a large faecal mass. He was subsequently transferred to ██████████ Hospital and admitted for medical treatment. It was noted at this time that Mr G had a medical history of faecal impaction, had dietary

considered with respect to the coronial investigation of this death.

⁶⁴ Specifically to call the Support Coordinator or Manager if concerned, To call a doctor if Mr G was experiencing bloating and difficulty in passing bowel motions, and to have two sachets a day. Report mainly due to having atonic colon and bowels need to be kept loose to continue appropriate motions and bypass blockages.

⁶² These records have subsequently been obtained as part of the coronial investigation, subsequent to the completion of this report.

⁶³ At the time of writing this report, the Panel members only had access to Mr G's primary medical care records, as such they wish it to be specified that any reference to medical care for Mr G refers to this only. Records for his specialist care have subsequently been obtained and should also be

restrictions and required medical supplements to assist in managing his condition.

The Panel identified that Mr G's Cerebral Palsy put him at risk of constipation due to his lack of mobility. This issue rarely just spontaneously emerges; it was present previously for Mr G and referred to in multiple records.

As noted above by the Panel it appears that many services do not take constipation seriously even though it can be a clinical symptom indicative of a range of different (and serious) conditions.

This was also identified in the Public Advocate report which noted that people with a disability may be prone to constipation due to sedentary behaviours, poor diet and medications however, they also may not be able to articulate their symptoms to health practitioners, carers or their supportive others.⁶⁵ Recommendations outlined in the Public Advocate report include that carers and support staff should be more aware of the signs, symptoms and risks associated with chronic constipation, and actively seek medical advice and intervention as required.⁶⁶ Where chronic constipation is a concern, appropriate monitoring of daily bowel motions needs to occur.

A further recommendation was made that health practitioners should be alert to the possibility of chronic constipation in patients with intellectual and cognitive disabilities who may not be able to describe the typical symptoms but experience behavioural changes, changes to sleeping patterns, refusal to eat, weight loss, nausea and vomiting.

While constipation may be trivialised in the general population, there is an overrepresentation in people with a disability.

The Panel identified that because of this increased vulnerability, persons with a disability with multiple and complex needs should be prioritised during any triaging process within a health care setting, as there is an

overrepresentation of gastrointestinal issues in this population associated with restricted mobility and the regular prescribing of pharmaceuticals known to increase constipation. For example, metabolic and gastrointestinal processes can be affected by the prescription of antipsychotic medication for persons with mobility issues increasing the risk of constipation.

The Panel further identified that a health care reassessment may have resulted in Mr G's degeneration in the 18 months prior to the death being identified earlier and his care being prioritised. However, this may not have changed the clinical course of his condition/s.

Best practice approaches to clinical care are founded on regular engagement with services and a referral to a specialist if there is no improvement in the condition. It is notable that Mr G's GP did make such referrals and expressed concern in his patient notes at not being able to alleviate the deterioration.

While increased engagement with available specialist services is critical this is not always a clear care pathway. At an operational level, the Panel identified that sometimes hospitals may 'push back' as they may not recognise the severity of a person's condition based on the referral or they may have limited resources to be able to assist. As such there is no clear-cut culpability with respect to this case in terms of the apparent lack of engagement with specialists.

Due to a need to prioritise referrals by hospitals, some specialist outpatient departments will assign a triaging process and not automatically make an appointment for referred patients. The person will subsequently be assigned to a waiting list, sent a letter and the GP accordingly notified. It is salient to note with respect to persons with a cognitive impairment or intellectual disability, that they may not always have the capacity to follow up with these letters

⁶⁵ Office of the Public Advocate (2016) *Upholding the right to life and health: a review of the deaths in care of people with a disability in Queensland*, Queensland Government

⁶⁶ Office of the Public Advocate (2016) *Upholding the right to life and health: a review of the deaths in care of people with a disability in Queensland*, Queensland Government

and attend an appointment without additional support.

In terms of other specialist supports missing in the provision of care prior to this death, records indicate that Mr G was experiencing malnutrition, and as such dieticians should have also been involved in his care to try and address this issue. Records do not indicate this occurred in the immediate time leading up to the death (although they had previously been involved).

As outlined above, there was also a suggestion to refer Mr G to palliative care a year before he died because of his deterioration and increased care needs. There is a discrepancy in available records as to whether a referral had occurred but it is clear he was not transitioned to such a facility. If this had occurred, even if the service was unable to address his clinical condition, it could have dealt with his comfort care needs and ensured that appropriate pain management strategies were implemented.

ANNUAL HEALTH ASSESSMENTS

The Public Advocate acknowledged in their report that due to deficiencies in available records, it was unable to confirm whether the people considered in the report were having regular health checks or annual health reviews, using the Comprehensive Health Assessment Program.^{67,68}

⁶⁷ Office of the Public Advocate (2016) *Upholding the right to life and health: a review of the deaths in care of people with a disability in Queensland*, Queensland Government

⁶⁸ As this tool was developed by the QCIDD, Professor Lennox wished to declare a conflict of interest because of his role in the design of the development of this tool; which should however not detract from the substantial benefit of using the tool among this cohort. Since 2007 the CHAP has been included as a Medicare Benefits Schedule Item, meaning that there is specific funding available for GPs to conduct an assessment using this tool. Professor Lennox would like it noted that he receives royalties that are paid to license the tool from Uniquist, who are the corporate arm of the University of Queensland.

⁶⁹ They further recommended that a CHAP review should be conducted prior to transition to the NDIS for all people with disability; people with disability should have access to appropriate specialist medical care and reviews relevant and appropriate to the management and monitoring of any conditions that may have such as epilepsy, chronic

The Public Advocate report did however reiterate the critical importance of regular GP check-ups for people with a disability who live in a residential care environment as many of them have multiple and serious health conditions. To this end, a number of recommendations were made in relation to access to health care including that people with a disability should have access to regular check-ups by their GP and dentist, including annual CHAP reviews.⁶⁹

As records were obtained for the deceased within this cohort from all health practitioners where known contact could be identified, more information was available with respect to the provision of primary health care prior to the death. There were limited indications that any annual health reviews were conducted by GPs as recommended although there was noted intervention when symptoms prompted a review.⁷⁰

Annual health assessments for people with an intellectual disability have been identified as important.⁷¹ It encourages GPs to look beyond just the acute presentation and, with the patient's approval, can be provided as a treatment or *action plan* to the support workers

respiratory disease and heart disease; Queensland Health should lead the development of a Framework to improve the Health of People with Intellectual or Cognitive Impairment that aims to: promote better understanding of the health needs of people with intellectual or cognitive impairment; improve the quality, accessibility and integration of services needed to meet the health care needs of people with intellectual or cognitive impairment; and improve coordination between disability and health care services.

⁷⁰ i.e. with Mr F when his symptoms of OCD became more pronounced in May 2015 and he received a specialist review by the [REDACTED] Hospital, Mental Health Services. Notably there are references to CHAP assessments being conducted for Mr G however records remain incomplete for this case, and it is unclear whether they were conducted in the more recent years prior to his death.

⁷¹ State Government of Victoria (2011) *Health Assessments for People with an Intellectual Disability*

in residential services to ensure recommendations are carried out.⁷²

The Panel identified that there was a definitive need to embed a routine medication review in the system for people residing in supported accommodation by a GP every six – 12 months. Medication reviews do not cost the consumer or service as they are Medicare funded and therefore this could be built into existing processes. There should also be criteria for specifying communication between specialists that are supported within coordinated care guidelines.

In Victoria the Residential Service Practice Manual⁷³ (RSPM) outlines the roles and responsibilities of disability services support staff working in residential services managed by the Department. The manual describes best practice approaches to supporting people who live in residential services and applies to department managed group homes, facility based respite, and residential institutions.

While the manual was designed for departmental staff, it is accessible to funded community service organisations that provide residential services for people with disabilities. The manual provides guidance for supporting the health and wellbeing of residents, including the management of deteriorating health, specific health management for certain conditions (epilepsy, Prader-Willi syndrome and dementia) and instructions for medication management (including authorisation, administration and storage).

It also outlines requirements for an annual health review to be completed by the resident's usual doctor and new residents are required to

have a health review completed within a month of entering the residential service. As a part of this annual health review the doctor is required to:

- monitor the residents health
- coordinate management advice from medical specialists and other health professionals
- review their medications and ensure routine immunisations, and vaccinations are up to date
- identify their risk of disease at an early stage through health screening, (i.e. pap smear tests, vision and hearing tests)
- identify health promotion strategies to reduce the risk of disease
- provide information for up-dating the residents health plan including a health support needs summary and specific health management requirements.

This manual also provides guidance for residential care staff to assist residents to prepare for an annual review⁷⁴ including making arrangements for family, friends or supportive others to attend.

Such instructions clearly delineate the roles and responsibilities of facility staff, GPs and supportive others in ensuring regular reviews of a vulnerable person's health care needs and are applicable to level 3 residential services in Queensland; although provisions for supported residential services in Victoria are similar to those currently in place in Queensland.⁷⁵

⁷² State Government of Victoria (2011) Health Assessments for People with an Intellectual Disability

⁷³ More information can be identified here: <http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/reports-publications/residential-services-practice-manual> .

⁷⁴ The manual also recommends the use of the CHAP to conduct an annual health review for residents. The Comprehensive Health Assessment Program (CHAP) is an annual health assessment format developed specifically to monitor the health needs of people with an intellectual disability. CHAP is the preferred annual health assessment

format for residents of the department managed in long-term residential services. People with an intellectual disability are often unable to adequately recognise, or report health concerns and CHAP provides an opportunity to ensure health issues are not overlooked.

⁷⁵ Discussed in this report which can be found here: <https://www2.health.vic.gov.au/Api/downloadmedia/%7BDD5B3161-C6A9-4462-B49C-92F91A5709FA%7D> . In Victoria, Supported residential services (SRS) are privately operated businesses that provide accommodation and support services for Victorians who need help with everyday activities. Each SRS determines the services it offers and its fee structure.

ASSESSING CAPACITY

In addition to a screening and assessment process for determining eligibility for admission (and exit) from level 3 residential services, it was apparent there may have been undiagnosed intellectual disabilities or cognitive impairments that impacted on the provision of care to some of the deceased (for example Mr B).

The Panel considered that earlier identification of these issues may have improved patient outcomes.

Research indicates that health conditions in people with an intellectual disability are more likely to be undiagnosed and under-treated and that they:

- have more multiple, chronic and complex health conditions than the general population
- have a higher prevalence of particular medical conditions as well as more lifestyle related health risks, such as obesity and poor physical fitness
- are less likely to be offered preventative health measures and experience greater barriers in accessing health care.⁷⁶

Factors identified as contributing to this under-diagnosis and under-treatment include communication or cognitive difficulties that make it hard for a person with an intellectual disability to recognise and communicate pain, and an associated reliance by clinicians on family or support staff to be able to articulate this for them; even though they may not be aware of symptoms and an accurate history may be difficult to obtain from staff (due to turnover and high workloads, etc.).

It may also be hard for clinical staff to physically examine a person with an intellectual disability due to anxiety or challenging behaviours; the person's symptoms may be attributed to their

intellectual disability with limited exploration of other physical or mental health disorders (as is alleged to be the case with Mr G); and a comprehensive assessment is likely to take longer than for other persons which may not always be considered practical in busy practices or hospitals.⁷⁷

Where intellectual disabilities or cognitive impairments are suspected then an appropriate assessment may lead to a different clinical care pathway and improve health outcomes.

The Panel identified a number of tools applicable to this cohort which would be appropriate to assist practitioners to better identify whether a person had an underlying intellectual disability or cognitive impairment as opposed to relying on clinical judgement.

These include the Mini Mental State Exam (MMSE), the Montreal Cognitive Assessment (MoCA) and the GUDDI.⁷⁸ Unlike the MMSE the MoCA is not copyrighted and is therefore freely available and accessible for use in primary care settings.

ROLES AND RESPONSIBILITIES OF GENERAL PRACTITIONERS

The role of GPs in the provision of support to residents in these facilities was noted by the Panel as integral in facilitating shared care arrangements, with an identifiable improvement in patient outcomes and quality of life comparative to other cases where this level of coordinated care was less apparent.

In a number of cases, available records indicate that the GPs seemed to be prescribing medications on the advice of a pharmacist, with limited assessment of the patient (i.e. Mr F). This was seen as not aligned with accepted practice by the Panel, but may be reflective of poor

⁷⁶ Centre for Developmental Disability Studies (2006) Health care in people with an intellectual disability – Guidelines for General Practitioners, NSW Department of Health

⁷⁷ Centre for Developmental Disability Studies (2006) Health care in people with an intellectual disability – Guidelines for General Practitioners, NSW Department of Health

⁷⁸ This is a tool designed to measure disability among people of Aboriginal and/or Torres Strait Islander descent; suitable to be administered by health, social and/or disability support professionals.

record keeping as opposed to inadequacies in clinical decision-making.

Needless to say, the complexities of working with patients who have multisystem disease or comorbidities should not be underestimated.

There are challenges for GPs in managing this cohort and it is highly unlikely that any of the patients had a choice of their specialist or treating practitioner as they were being managed by the public health system. The extent to which a treating GP can successfully manage someone with high care and complex needs is limited. In these types of cases the onus should be placed on hospitals to identify and connect the issues, particularly where there have been multiple previous admissions.

Although the particular circumstances may be too complex for a GP to be the primary case manager, this type of patient is best managed when specialist services intersect and are arranged by a GP within the community.

As was demonstrated in Mr B's case, it is also important to consider a person's engagement with services and their own behaviours (including persistent medication non-compliance) on treatment outcomes. In this case Mr B appeared to be frustrated at the system and there was a real disconnect in therapeutic alliance. This includes with his GP who attempted to put a treatment plan in place for his diabetes but Mr B refused stating that it was being managed by the hospital.

Of all chronic illnesses, diabetes has good outcomes with appropriate management and is a medical condition for which treatment and coordinated care is relatively well resourced compared to other conditions.

The absence of a diabetic nurse educator in the treatment provided to Mr B was noted by the Panel as they considered that he would have benefited from a case manager of this type.

Dedicated nurse educators are able to work with all services to ensure coordinated patient management in these types of cases.

Effective service coordination for a person with high and complex needs requires a single point of contact, acting as a *central linkage point* who can operate across sectors and is suitably qualified to work effectively with relevant services and systems to negotiate and advocate for the necessary supports to meet the person's needs.⁷⁹ It also requires high-level cross-sectoral commitment and agreement, extending beyond the disability sector as well as the development of key linkage points in relevant sectors (such as health, disability and housing).

Coordinated care arrangements should be extended to working with staff in supported accommodation as they are likely to hold valuable collateral information about a patient's current state of health and compliance with a treatment plan, as well as being responsible for the provision of daily support.

CLINICAL MANAGEMENT GUIDELINES FOR SCHIZOPHRENIA

Seven persons within this cluster had a diagnosis of schizophrenia (along with other associated comorbidities). This included:

1. **Mr C:** Paranoid Schizophrenia (diagnosed at age 31)
2. **Mr D:** Schizophrenia (age of diagnosis unknown)
3. **Mr E:** Schizophrenia (diagnosed at age 19)
4. **Mr F:** Schizophrenia (diagnosed at 17)
5. **Mr H:** Schizophrenia (age of diagnosis unknown)
6. **Mr I:** Schizophrenia (age of diagnosis unknown) + Korasakoff's psychosis
7. **Mr K:** Long term treatment resistant schizophrenia with recurrent psychotically driven deliberate self-

⁷⁹ Madden, R.H., Fortune, N., Collings, N. & Madden, R.C. (2014) Cross-sector Service Coordination for people with high and complex needs, *Policy Bulletin*, 2

harm behaviours (age of diagnosis unknown).

The Royal Australian and New Zealand College of Psychiatry have existing guidelines for the management of people with Schizophrenia which outline recommendations for the provision of optimal care through different phases (i.e. pre-psychotic or prodromal phase/first-episode psychosis) as well as a range of other treatment considerations applicable to different cohorts.

There are many sections of direct applicability to the persons reviewed in this cluster of deaths including those that relate to: the management of acute relapse; the management of severe persistent or remitted illness; the management of comorbid substance use (including alcohol use disorder); the management of service provision; illness self-management, family support and psychoeducation; the management of physical health of people with psychosis; services for older people with schizophrenia; managing comorbid conditions; and psychological considerations.

The extent to which the treatment provided to the deceased in this cluster accorded with these guidelines was considered by the Panel to be variable, for example, there was limited evidence to indicate that any psychological interventions were provided to Mr F.^{80,81}

⁸⁰ Relevant recommendation: (b) A recovery plan should be negotiated and agreed upon with the individual and review regularly. (c) Psychological interventions should be provided. Available records do not indicate the presence of any psychological interventions delivered to Mr G outside of a (poly)pharmacological intervention.

⁸¹ In 26 May 2015 he was referred to the [REDACTED] ACT by the GP and [REDACTED] manager due to a deterioration in mental state and behaviours over the prior month. A comprehensive review was undertaken by the [REDACTED] ACT, with a range of recommendations to be implemented regarding his medication, including a re-introduction of Sertraline as it was considered efficacious in the treatment of OCD and a very gradual taper off Diazepam over a couple of months as it was noted this may contribute to confusion and was unlikely to be having any positive effects.

⁸² Recommendations on management of service provision: (a) Assertive community treatment should be offered after initial contact, during crises and after discharge from hospital. (b) Service models should include clearly established pathways for transition of patients between

The Panel further identified the care provided to Mr D as being almost optimal (which was reflected in his quality of life prior to the death) in comparison to that provided to Mr E which was considered substandard. The differences in the management of Mr D and Mr E were salient, with the biggest difference being the absence of shared care arrangements between the GP and specialist services for Mr E.⁸²

A review of the case file for Mr D indicated the presence of a very good partnership arrangement between the GP and the Clozapine Clinic which included regular metabolic assessment, and communication between the respective care providers.⁸³ Further, there was regular follow up regarding his smoking with a concentrated focus on reducing his use across multiple stakeholders resulting in a sustained (self-reported) reduction in use over time.⁸⁴

While they are important for ensuring standardised practice among clinicians, and optimal patient outcomes, one of the major problems with treatment guidelines is that people don't always use them, so a concurrent focus on improving awareness and uptake of current applicable guidelines, as well as any future guidelines is critical in this area.

For the death of Mr E the Panel found that there was limited quality of care provided to the deceased prior to the death. Of significant

services, especially between mental health services (e.g. child and youth services to adult services) and external partners (mental health services to GPs, private psychiatrist, non-governmental organisations). (c) People with schizophrenia should be strongly encouraged to see a GP for preventative health care and treatment of physical conditions. (d) Mental health services and private psychiatrists must have the ability to monitor physical health and arrange appropriate treatments, particularly for people who refuse to see GPs. (e) Mental health services should develop clear guidelines for clinical communication and shared responsibility between GPs, private psychiatrists and non-governmental organisations

⁸³ Relevant recommendation: Encourage people with schizophrenia to see their GP regularly. Mental health service clinicians should communicate with each patient's GP at least once every 6 months.

⁸⁴ Relevant recommendation: All mental health services should provide evidence based programmes to help smokers quit

concern with the treatment of Mr E was that he received a depot injection from GP5 shortly before his death on 8 March. The Panel found it difficult to consider that he was properly assessed on this occasion by the GP, as Mr E would have been very sick and this should have been very obvious to the GP based on an observation of his physical state.

GP5's notes state: *Management: came for depot injection, no complaining of any issues, reviewed status and seems psychiatrically stable, due for regular shot, given injection of depot antipsychotic ability maintained.* There is nothing to indicate that any other symptoms were identified (or treatment provided) during this time, with his clinical notes the same as those made on previous appointments.⁸⁵

The Panel further identified that Mr E was also prescribed Clozapine relatively late with respect to his diagnosis and he only appeared to have been taking it in the year prior to the death.⁸⁶ There was no indication when this prescribing was initiated or by whom in available records.

Clozapine requires close monitoring and this does not seem to have occurred for Mr E as there does not appear to have been any cardiology assessments undertaken, although there is reference to some monitoring occurring.⁸⁷

For Mr D, a CT was recommended in 2012⁸⁸ but it wasn't clear that this occurred, although there was communication between the hospital and the GP regarding the requirement for this test. The Panel considered that this was something

that was outside the scope of the GP to organise and that overall this potential oversight was an anomaly in the provision of care to Mr D. It was mentioned as a concern as the cause of death for Mr D was related to his heart (preliminary cause of death findings were: pulmonary embolus with left calf DVT, focally significant DVT, awaiting toxicology to assess possible Clozapine impact).

It was noted by the Panel with respect to the management of Clozapine that the requirement to ensure regular cardiology monitoring is conducted isn't necessarily always adhered to and that the CIMHA system used by Queensland Health doesn't encourage clinicians to conduct them.

In terms of coordinated care arrangements, a team approach is optimal in the management of people on Clozapine, and if psychiatrists do not look at cardiology results, or can't interpret them, then they should obtain advice from a suitably qualified person, such as the GP. While the psychiatrist may lead the treating team, they should have access to cardiologists to seek advice, particularly in circumstances such as this where treatment is being provided in a public hospital.

It was noted by the Panel that in the United Kingdom the pharmacy are the 'safety net' for Clozapine management and they ensure that the appropriate steps are occurring.

The Panel further identified that it seems to be harder to coordinate metabolic monitoring⁸⁹ in community settings and it is really dependent

⁸⁵ For example on 3 November 2015 and 13 October 2015

⁸⁶ (g) Clozapine is the treatment of choice for people with treatment resistance schizophrenia. When treatment resistance has been clearly demonstrated, clozapine should be offered within 6-12 months. (h) Optimal, comprehensive evidence-based biopsychosocial care should be made available to all people with severe, unremitted psychotic illness.

⁸⁷ Recommendations relating to the management of physical health of people with psychosis: (a) Engage the individual and carers in strategies to ensure healthy living (b) If the person is gaining weight or has other metabolic complications of treatment, switch to a weight-neutral antipsychotic agent. (c) Consider the use of agents such as metformin to reduce weight gain and insulin sensitivity in

people taking antipsychotic agents associated with obesity. (d) Liaise with the GP to ensure optimal treatment for hypertension, elevated cholesterol and other cardiometabolic conditions. (e) For people who do not attend a GP, consider undertaking investigations, monitoring and prescribing as needed to treat physical health problems within the mental health service. (f) Liaise with an endocrinology specialist or other specialist colleagues as appropriate

⁸⁸ Specifically on 20 November 2012 with a note to F/U with cardiology on the 22 January 2013, and a referral for a Cardiology Screening Echo on the 6 May 2016

⁸⁹ More information on metabolic monitoring can be found here: http://www0.health.nsw.gov.au/policies/ib/2012/pdf/IB2012_024.pdf

on the calibre and experience of the treating GP. The impact of metabolic conditions in the community is significant, including costs associated with obesity, so there is a need for building capacity in this area among relevant practitioners.

ADVANCED HEALTH CARE DIRECTIVES

The importance in ensuring strategies were put in place regarding end of life decision making for this cohort was discussed by the Panel, for example, prior completion of advanced health care directives (AHCD). It was considered by the Panel to be of significant benefit for GPs to sit down with residents in level 3 residential services to assist with the development of an AHCD as the process requires an assessment of decision making capacity which has broader applications for the overall treatment and support provided to the person.

AHCDs were also identified as an opportunity to get multiple specialists involved with a patient with high care needs and of substantial benefit for hospitals and health care facilities in clinical decision-making for people with an intellectual disability or cognitive impairment.

Such directives are critical in enabling a patient to plan for their future medical treatment and care, while preserving their autonomy and dignity. AHCDs ensure that a patient can communicate their decisions at a time they are competent to do so, before their capacity to direct treatment and care is compromised.

The process of establishing an AHCD requires significant reflection, discussion and communication between a patient, their family and specialist. An AHCD is also focused on living situations so can be used in other circumstances and for other uses within health care facilities, as opposed to just end of life decision making.

The implementation of an AHCD for use in ongoing management in a health care setting, in addition to end of life planning, is based on the fundamental principles of self-determination, dignity and avoidance of suffering. An AHCD is intended to apply to periods of impaired decision making, and

although it is not a clinical care or treatment plan, it can act to inform the scope of this care.

Clinicians must complete a section in the AHCD form, and thus they have responsibility to discuss with their patient the prognosis of their condition, outlining the significance of decisions surrounding options of ongoing care and treatment. Further, physicians need to raise with their patient the importance of discussing their AHCD with family and support people to ensure their dignity and autonomy are preserved.

An AHCD can be changed or revoked at any time while a person is competent to do so. It is recommended that clinicians discuss and review with their patients any established directives every two years or as their health condition changes significantly. Any amendments made to AHCDs must be in writing and witnessed by an eligible person, as per the original document.

A significant limitation identified by the Panel with comprehensive medical assessments and AHCDs is the time required to complete them. It can be a lengthy process spanning multiple appointments. However GPs would be eligible for reimbursement through payment associated with long consultations and the development and review of an AHCD could accord with an annual health assessment to prompt a comprehensive review of the patient's current and future care needs.

While the Public Advocate's report emphasised the importance of such a document in end of life decision-making, it did not recognise it as a potentially effective tool for the provision of ongoing care within a health setting for people with complex health and psychiatric needs, who may have an intellectual disability or cognitive impairment.

NATIONAL INITIATIVES

There are a number of significant reforms currently being undertaken nationally relevant to this cohort, specifically the National Disability Insurance Scheme (NDIS)⁹⁰, the roll out of Personal Health Care Records, and Primary Health Care Networks.

These are briefly discussed to provide an understanding in relation to significant systemic reforms being undertaken nationally that aim to improve outcomes for people with complex mental and physical care needs.

NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

Established by the *National Disability Insurance Scheme Act 2013*, the NDIS is designed to support the independence and social and economic participation of people with disability through the funding of reasonable and necessary supports, and has been progressively introduced into trial sites since 1 July 2013 around Australia. As a needs based entitlement system, the transition provides for a significant opportunity to use an evidence informed approach to identify opportunities to minimise the risk of people *falling through the cracks*.⁹¹

Cross-sector service coordination is a key element of NDIS design involving:

1. high level inter-sectoral collaborative agreements, along with related infrastructure, so that system barriers do not undermine the aims and objectives of the NDIS
2. active negotiation of coordinators between sectors and services to ensure that people obtain the necessary supports, in addition to a range of local and cross-sectoral mechanisms to enable coordination activities
3. agreed goals, including those pertaining to social and economic participation that are focused on outcomes for people.⁹²

The NDIS for people like Mr E was considered by the Panel to be of potential benefit where there is an appropriate investment of effort. There is some indication from trial sites in Western Australia⁹³ that the NDIS is improving outcomes for people with a diagnosis of schizophrenia.⁹⁴

For people with a psychosocial disability, early findings demonstrate that the number, length and duration of admissions are reduced under this scheme as there is an increased investment of funding, however there may be problems with the sustainability of this funding over the longer term.

The Public Advocate report identified a number of risks associated with the implementation of the NDIS, which are also applicable to the cases subject to review. These included the potential

⁹⁰ Queensland Government departments (excluding the Department of Communities, Child Safety and Disability Services (DCCSDS) delivering specialist disability services under the NDIS will not be required to comply with the safeguards contained in the *Disability Services Act 2006* (DSA) or provide evidence of compliance with the HSQF when registering with the NDIS. These government providers will remain subject to and regulated by their own specific set of quality and safeguard measures. DCCSDS delivered specialist disability services registered with the NDIS will be subject to the safeguards contained in the DSA and be required to provide evidence of compliance with the HSQF. While relevant standards under the NDIS may be set nationally, regulation and compliance will be the responsibility of individual states.

⁹¹ Madden, R.H., Fortune, N., Collings, N. & Madden, R.C. (2014) Cross-sector Service Coordination for people with high and complex needs, *Policy Bulletin*, 2.

⁹² Madden, R.H., Fortune, N., Collings, N. & Madden, R.C. (2014) Cross-sector Service Coordination for people with high and complex needs, *Policy Bulletin*, 2

⁹³ An independent evaluation of the NDIS trials in Western Australia is being conducted by Stantons international. The Terms of reference for this evaluation is here

<http://www.disability.wa.gov.au/Global/Publications/WA-NDIS-My-Way/WA-Comparative-Evaluation-Terms-of-Reference-February-2014.pdf>

⁹⁴ In the Western Australian trial sites the most common primary disability for new individuals entering the trial during the last quarter is psychosocial disability with initial findings continuing to deliver positive outcomes for people with a disability in Western Australia.

[http://www.disability.wa.gov.au/Global/Publications/WA-NDIS-My-Way/Quarterly%20reports/Q8 NDIS Report to the Commo wealth.pdf](http://www.disability.wa.gov.au/Global/Publications/WA-NDIS-My-Way/Quarterly%20reports/Q8%20NDIS%20Report%20to%20the%20Commo%20wealth.pdf)

for a widening divide between health and disability services, which ultimately requires structural changes to health policy, programs and practices in order to recognise and respond to the health rights of people with a disability.

This divide was also noted by Panel members and seen as a significant barrier in the provision of effective supports across the service system.

PERSONAL HEALTH RECORDS

The Panel identified that mandating the use of Personal Health Care Records in people with complex health needs will ensure everyone is aware of what is happening, and clinicians should have enhanced capacity to detect deterioration in a person's condition to improve the quality of care across services.

Further with the transition to an 'opt out' approach of personal health care records, it is likely that there will be an improvement in information available to inform review by multiple care providers and improved coordinated case management. This is particularly salient as it is difficult to access records from other departments regarding a patient.

There are still challenges with this system however in terms of the information available for review by clinicians.

My Health Record is a secure health summary facilitated by the Australian Government to operate as an online platform for the purpose of information sharing between an individual, doctors, specialists, health services, and residential care facilities. The online clinical record strives to enable more efficient and effective treatment of patients by health practitioners, assisted by a consumer's ability to access and manage their own record in

cooperation with health providers to improve care.⁹⁵

Previously, My Health Record was known as the Personally Controlled Electronic Health Record (PCEHR) and operated on an 'opt in' basis⁹⁶ meaning that people would need to choose to be part of the scheme. Since the transition to the reformed My Health Record, the system has shifted to an 'opt out' system, requiring persons to specifically request to be excluded from the program.

My Health Records may contain copies of a patient's prescriptions, Medicare claims history, organ donor status, immunisation records, clinical summaries, discharge information, diagnostic imaging and pathology reports, and specialist letters.⁹⁷ Users are able to add information such as allergies, emergency contacts, personal health notes, advance care planning information and current medications. Further, My Health Record users are also able to customise and set access controls to restrict who is able to see the information and cancel their record indiscriminately.

The capacity for users to edit their file and restrict who can view the file has significant implications for the clinical management of a patient as the clinician cannot be assured that they have access to the patient's full medical file or that it is accurate. While patient privacy is critical there is a requirement to balance this with a comprehensive shared electronic medical record to increase the safety, efficiency and effectiveness of clinical care.⁹⁸

The Australian Medical Association has suggested that while an important tool, My Health Record does not include every aspect of a patient's medical record and thus cannot

⁹⁵ Department of Health (2016). *Final Review of PCEHR December 2013*. Retrieved from [http://www.health.gov.au/internet/main/publishing.nsf/content/17BF043A41D470A9CA257E13000C9322/\\$File/FINAL-Review-of-PCEHR-December-2013.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/17BF043A41D470A9CA257E13000C9322/$File/FINAL-Review-of-PCEHR-December-2013.pdf)

⁹⁶ Ibid

⁹⁷ Department of Digital Health Agency (2016). *My Health Record Summary*. Retrieved from

<https://myhealthrecord.gov.au/internet/mhr/publishing.nsf/Content/consumer-my-health-record>

⁹⁸ More information on this issue can be found here: Australian Medical Association (2016). *AMA Position Statement on Shared Electronic Medical Records – Revised 2016*. Retrieved from <https://ama.com.au/position-statement/shared-electronic-medical-records-revised-2016>

replace their medical record.⁹⁹ They further suggest that in its current form My Health Record cannot be realistically relied upon by health care providers to make clinical care decisions, as it is not necessarily complete or accurate. Rather, the information contained in My Health Record should be viewed as bonus clinical information accessible at the time of care, and regarded with the same form of 'clinical suspicion' as other forms of documentation such as paper records or verbal information.¹⁰⁰

PRIMARY HEALTH CARE NETWORKS

Another issue identified by the Panel that impacts on service provision is the delineation between state and national funding as hospitals are state funded and disability services are now nationally funded.

The challenge in determining who is responsible for the provision of services by different government departments is well documented in this area particularly between mainstream services (health, housing and aged care) and the disability sector. Unfortunately, this has a significant impact on the provision of support and services at an individual level and this siloed approach impacts on the capacity to work across agencies to provide coordinated care.

Service availability and accessibility remains a challenge for people with complex comorbidities or high care needs, including the identification of appropriate care pathways, as there may be a wide range of services that could be accessed that aren't.

Panel members identified that the national roll out of the Primary Health Networks (PHN) has

the potential to improve health pathways and outcomes for patients with complex clinical care needs, (noting that Medicare Locals and Divisions of GP Practice were predecessors of this initiative). They are considered to be a vehicle through which to achieve better integration of care between hospitals, care facilities and GPs.

PHN have been implemented to enhance the efficiency and effectiveness of medical services for patients, specifically those at risk of poor health outcomes, and in improving the coordination of care to ensure patients receive appropriate services.¹⁰¹ They are a vehicle for better integration of care between hospitals, care facilities and GPs, although it varies across regions as to whether all GPs are part of the PHN.

The national roll out of PHN has the potential to improve health pathways at a local, regional and state level; and serves to institute higher performance in the standard of patient care, and benchmark best practice principles, by supporting general practice and the management of stakeholder relationships and engagement.¹⁰² Strengthening a patient's access to early identification and intervention in response to a moderate to high risk diagnosis, is essential for better outcomes in clinical care and reduces the strain on community service providers.¹⁰³

A focus on allied care at the local, state and national level also aims to ensure that patients most at risk of poor health outcomes receive clinical intervention streamlined across their interactions with multiple service providers. Inter-disciplinary information sharing and cooperation in a range of health care settings,

⁹⁹ Australian Medical Association (2016). *AMA Position Statement on Shared Electronic Medical Records – Revised 2016*. Retrieved from <https://ama.com.au/position-statement/shared-electronic-medical-records-revised-2016>

¹⁰⁰ Ibid

¹⁰¹ Australian Government Department of Health. (2015). *Primary Health Networks (PHNs)*. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/primary_Health_Networks

¹⁰² Australian Government Department of Health. (2016). *Primary Health Networks – Grant Programme Guidelines*. Retrieved from Department of Health website [http://www.health.gov.au/internet/main/publishing.nsf/Content/F4F85B97E22A94CACA257F86007C7D1F/\\$File/Primary%20Health%20Network%20Grant%20Programme%20Guidelines%20-%20V1.2%20February%202016.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/F4F85B97E22A94CACA257F86007C7D1F/$File/Primary%20Health%20Network%20Grant%20Programme%20Guidelines%20-%20V1.2%20February%202016.pdf)

¹⁰³ Primary Health Care Research and Information Service. (2016). *The Divisions of the General Practice Program*. Retrieved from http://www.phcris.org.au/guides/about_divs.php

promotes more effective management of chronic disease and positively influences outcomes.¹⁰⁴ Additionally, a focus on correcting a fragmented system is critical for improved population health and sustainability of services in being able to adjust to a continued increase in demand.

Professor Lennox identified an initiative currently being implemented called 'Health Pathways' as part of this transition process, which is a platform used to assist GPs and other frontline practitioners to have greater awareness of pathways to care for certain clinical conditions (i.e. Autism). While not containing clinical notes, the system will include directives for clinical care to ensure a standardised approach and promote consistency across practitioners. There is the potential for this system to be shared across all divisions (i.e. North and South Brisbane) and to be used for the management of a range of medical conditions.

WORKING WITH ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

Two people included in this cluster identified as Aboriginal and as such the Panel gave consideration of the specific needs of this population within these types of settings. The Panel discussed whether there was anything that could be improved with respect to the care provided prior to the death of these persons, which is a salient issue given the prevalence of disability amongst Aboriginal and Torres Strait Islander persons is higher than non-Indigenous Australians.¹⁰⁵

Working with Aboriginal and Torres Strait Islander patients is impeded by a number of issues including a lack of accessible, culturally appropriate services and poor engagement with, or acknowledgement of, the broader

cultural context of commonly co-occurring issues such as mental illness or addiction.

It is also the case that specialist cultural support services, such as Indigenous Liaison Officers, are under-resourced and this impedes the timeliness and accessibility of tailored support for Aboriginal and Torres Strait Islander people in many cases.

Isolation from country and kin is also a significant issue, as often people requiring high-level care and support are forced to move to a regional centre because these acute services are not available in rural or remote communities. This is further influenced by the fact that many persons residing in non-metropolitan areas have limited access to services, and transport options, and there are higher rates of disability among those residing in rural and remote communities.¹⁰⁶

Panel members acknowledged the cultural sensitivities associated with working with people who identify as Aboriginal and Torres Strait Islander in relation to matters pertaining to the coronial jurisdiction. The Panel saw significant value in consulting with community elders regarding systemic reviews of these types of deaths, as they would be able to provide significant insight into the unique experiences of Aboriginal and Torres Strait Islanders in this regard. However, in recognising the diversity of Aboriginal and Torres Strait Islander cultures and tribes, and the cultural beliefs that elders or other community members have regarding death, this would be a complex process, and one which would likely require a personal introduction of someone trusted by the community. It is of critical importance to be culturally informed and not prescriptive in any approach that is adopted relevant to the needs of Aboriginal and Torres Strait Islander people.

¹⁰⁴ Primary Health Care Research and Information Service. (2016). The Divisions of the General Practice Program. Retrieved from http://www.phcris.org.au/guides/about_divs.php

¹⁰⁵ Community Affairs References Committee (2015) *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities* in Australia, Commonwealth of Australia.

¹⁰⁶ Estimated to be 22% (Regional), 20% (Outer Regional) and 17% (Remote) than in metropolitan areas. Community Affairs References Committee (2015) *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities* in Australia, Commonwealth of Australia.

RECOMMENDATIONS

The Public Advocate report *Upholding the right to life and health: a review of the deaths in care of people with disability in Queensland* (2016) highlighted that people with intellectual or cognitive disability have more complex health needs and a higher mortality rate than the general population, while also correspondingly facing significant barriers in accessing appropriate health care, and experiencing the health impacts associated with poverty and social exclusion.

This was attributed to a lack of appropriate supports including to access health care and appropriate health care providers, as well as ineffective coordination between disability and health services.

Unsurprisingly, many of the recommendations for improvement identified by the Panel also accord with those outlined in the Public Advocate report, including:

- that support staff and carers need to be aware of the signs of serious illness, and be appropriately equipped with the necessary education and training to be able to carry out basic observations of a person (i.e. temperature, pulse and heart rate)
- the need to ensure professionals working in the area are aware of, and comply with, their obligations to report deaths in care to a coroner to ensure a better understanding of the prevalence and circumstances of these types of deaths
- people with a disability who reside in residential care should have a designated person/role to take responsibility for coordinating and reviewing their health care (in consultation with the person and/or their substitute decision maker)

- the critical importance of annual health reviews for people with a disability, including that service organisations should prioritise and allocate resources to ensure people with a disability in residential care are supported to access regular medical check-ups (including dental) and annual comprehensive health reviews
- that disability residential services have a designated person/role that takes responsibility for coordinating the health care for each resident with a disability. The role should be responsible for ensuring health care strategies are being carried out, health appointments are booked and attended, annual health checks are conducted, hand held records are maintained and behavioural support is coordinated to attend health appointments if necessary.

Such findings are consistent with mortality reviews conducted in other jurisdictions¹⁰⁷ and are highlighted again in this Expert Panel Report.

The Panel further found that there were substantial areas for improvement with respect to the death of Mr E and Mr B, and that aspects of the care provided to Mr G were substandard. With enhanced assessment processes, improved clinical management, coordinated care and improved shared care arrangements it is likely there would have been improvements in the health and well-being of these persons, and as such these deaths were potentially preventable.

Mr E was considered by the Panel as an example in which there were clear opportunities for improvement with respect to the management of his mental health care. Mr B was an example of a situation where complex and chronic medical conditions were not adequately managed by existing guidelines and

¹⁰⁷ Both nationally and internationally. For example the Disability Rights Commission report *Equal Treatment: Closing the Gap, a formal investigation into the physical health inequities experienced by people with learning disability and/or mental problems* (2006); *Deaths by*

Indifference (2007) by Mencap of 6 people with learning disability who died while in the care of the national Health System and the *Confidential Inquiry into the Premature Deaths of People with Learning Disabilities Final Report* (2013).

approaches. Mr D was an excellent example of shared care working well.

Opportunities exist to recommend a review of current standards for level 3 residential services with input provided from persons with appropriate medical qualifications and experience in working with this vulnerable cohort.

The Panel also identified a significant need for improved standardisation of processes for level 3 residential services, particularly with respect to a resident's personal care needs (including health care, medication management and hygiene management). These should include the development of eligibility criteria and a process for triaging residents into higher care facilities where there needs exceed those reasonably able to be met by a level 3 residential service.

Staff training should also be considered to ensure that all employees who come in to contact with residents, have the capacity to identify, and respond to, any signs of clinical deterioration.

While more information is required with respect to the management of health care needs within Disability Services Queensland funded facilities, as a general principle the Panel considered that there should be a clearly specified, minimum standard of care across all types of residential support services.

The Panel identified opportunities to enhance the role of the OPG in terms of ensuring earlier involvement with people who may have an impaired capacity, even if the circumstances are such that they don't immediately require the assistance of a statutory decision-maker. This includes encouraging health care professionals to proactively make referrals to the OPG when

someone is identified as having an impaired capacity.

The Panel also raised the potential for the Community Visitor program to be more involved in responding to systemic issues associated with the application of relevant standards within supported accommodation; where such issues have been identified through the program at multiple sites. Further consideration is also required as to whether there are requisite timeframes for responding to issues identified through the Community Visitor program where the circumstances are such that they may reasonably be considered to impact on a person's clinical care needs (as occurred with respect to the case of Mr E).

The Panel further recommends the appropriate prioritisation of persons with a disability, who have a co-occurring intellectual impairment or cognitive disability, in specialist outpatient settings to ensure they are responded to in a timely manner, noting their increased vulnerability and high care needs.

While not a recommendation relevant to the coronial consideration of whether there were failures in the provision of care prior to the deaths reviewed within this cluster, or opportunities to prevent future deaths, the Panel also considered it appropriate to recommend the continuation of this initiative within the Coroners Court of Queensland, highlighting the volume of information and files available for consideration and review that would otherwise not be available outside this jurisdiction and the need for a continued systemic focus on these types of deaths.

Although the Panel determined it was outside their Terms of Reference, a potential conflict of interest was identified with a number of the matters under consideration.¹⁰⁸ This issue has

¹⁰⁸ Specifically that four of the [REDACTED] are owned by a Trust whose Directors include GP5 and GP2 who were also treating GPs within these facilities. GP5 is also training as a psychiatric registrar and the Royal Australian and New Zealand College of Psychiatrists guidelines discourage a registrar from continuing to practice as a GP during training. The college's guidelines on Financial Conflicts of Interest are summarised below. 'Financial interest' is defined as the contribution of capital, the receipt of dividends or director's

fees, the receipt of any benefit whether in cash or kind other than fees charged to a patient. There has been general interest in and criticism of doctors who have a financial interest in a facility to which they refer patients or in which they treat patients. Such facilities may be a hospital, day surgery facility, nursing/rest home or even a specialised boarding or lodging house. Unless the relationship with the facility is absolutely clear and ethical, criticism is bound to

particular implications should an eligibility and screening process be implemented within level 3 residential services, as there would be a conflict of interest if a person responsible for considering admission into the facility, is also the GP or registrar responsible for conducting the admission assessment for their own service (and they have a financial interest in that facility).

While the Panel identified that it is not unusual for GPs or other practitioners to have a financial interest in private practices, it is important that there is transparency in this process and that any potential conflict of interest is declared to the patient and/or their supportive other.

It is important to acknowledge that there are perceived issues surrounding the 'informed' nature and quality of this consent particularly when working with a person with a cognitive impairment or intellectual disability. Further, when services are being delivered in a certain setting (i.e. a supported accommodation service owned by a treating GP) then opportunities need to be available to see another GP if the resident wishes to.

The underlying principle remains that patients must be able to actively choose their health care provider in the facilities owned by these providers.

occur. This may include allegations of over servicing, relative neglect, inappropriate treatment and even fraud. All of these accusations have been made and occasionally sustained. The College believes that it is important for psychiatrists to be absolutely clear and transparent to their patients, patients' families and carers about psychiatrists having financial interests in a facility to which they refer patients or in which they treat patients. It is hoped that the following guidelines will assist psychiatrists in the above. (1) It is mandatory that psychiatrists who have a financial interest in a facility to which they propose to refer a patient whether they personally treat the patient or not should declare that interest to the patient and if necessary the responsible relatives/ carer. (2) The same applies if the psychiatrist's

financial interest is indirect, for example through a family member or family trust. (3) Having made the declaration it should be noted in the psychiatrist's clinical notes. (4) Any psychiatrist having a direct or indirect financial interest in a private facility should notify those funding agencies which would contribute to or provide rebates to the fees charged for example Health Insurance Commission, Private Insurance Funds, and others, if requested