SHERIFFDOM OF GRAMPIAN, HIGHLAND AND ISLANDS AT INVERNESS

[2024] FAI 1

INV-B259-22

DETERMINATION

BY

SHERIFF EILIDH MACDONALD

UNDER THE INQUIRIES INTO FATAL ACCIDENTS AND SUDDEN DEATHS ETC (SCOTLAND) ACT 2016

into the death of

JESSI-JEAN MACLENNAN

Inverness, 21 December 2023

FINDINGS

The sheriff, having considered the information presented at the inquiry, determines in terms of section26 of the Inquiries into Fatal Accidents and Sudden Deaths etc. (Scotland) Act 2016 (hereinafter referred to as "the Act") that:-

1] In terms of section 26(2)(a) of the Act, Jessi-Jean MacLennan (hereinafter referred to as "Jessi"), born 26 March 2018, and resident in Inverness, died at the Royal Hospital for Children, Glasgow at or about 01:50 hours on 25 November 2019.

2] In terms of section 26(2)(b) of the Act, Jessi MacLennan's death was not caused by an accident.

3] In terms of section 26(2)(c) of the Act, the cause of Jessi's death was complications of left nephroblastoma, otherwise known as Wilms' tumour, and associated therapy.

4] In terms of section 26(2)(d) , there are no findings as Jessi's death was not caused by an accident

5] In terms of section 26(2)(e) of the Act,

(i) the following precautions could reasonably have been taken; and

(ii) had they been taken, might realistically have resulted in Jessi's death being avoided.

These precautions were:

a) On 3 October 2019, at Culloden Surgery Inverness, Dr Toby Gilbertson the attending GP could have made a referral for an urgent paediatric opinion.

b) On 20 October 2019, Dr Bhutto the attending paediatrician at the Paediatric Assessment Unit, Raigmore Hospital, Inverness (PAU) could have made further investigation into the cause of Jessi's symptoms by way of abdominal ultrasound.

c) On 20 October 2019, Dr Bhutto the attending paediatrician at the PAU could have made arrangements for a complete set of observations, including urine tests and blood tests to be carried out on Jessi.

d) In respect of Jessi's attendance on 20 October 2019 at the PAU there could have been a discussion between Dr Abdul Jabber Bhutto the attending paediatrician and a consultant either during her attendance or post- discharge, to review Jessi's attendance there on that date,

e) On 1 November 2019, at Culloden Surgery Inverness, Dr Karen Duncan the consulting GP could have referred Jessi to the PAU for further assessment.

f) On 6 November 2019 at PAU, Dr Bhutto the attending paediatrician could have made arrangements for Jessi's urine to be tested.

g) On 6 November 2019 at PAU, Dr Bhutto the attending paediatrician could have made further investigations into the cause of Jessi's high blood pressure readings recorded at the consultation.

h) In respect of Jessi's attendance on 6 November 2019 at PAU there could have been a discussion between Dr Abdul Jabber Bhutto the attending paediatrician and a consultant, either during her attendance or post-discharge, to review her attendance there at PAU for a second time with the same symptoms.

6] In terms of section 26(2)(f) of the Act, there were two defects in the relevant system of working at Raigmore Hospital, Inverness at that time which contributed to Jessi's death. These were:

a) No requirement for a consultant discussion or review of the patient's first admission to PAU.

b) No requirement for a consultant discussion or review of the patient's re-admission to PAU with similar symptoms.

7] In terms of section 26(2)(g) of the Act, the following facts are relevant to the circumstances of Jessi's death:

a) A missed opportunity by Dr Gilbertson on 3 October 2019 to request an urgent paediatric referral in light of a significantly abnormal blood clot present in Jessi's nappy.

b) A missed opportunity by Dr Bhutto on 20 October 2019 to refer Jessi for either an abdominal x-ray or abdominal ultrasound examination which could have alerted the treating team to the presence of an abdominal mass consistent with the left sided renal tumour.

c) A missed opportunity by Dr Karen Duncan GP on Friday 1 November to complete an examination of Jessi's abdomen and thereafter to refer Jessi to the Paediatric Registrar for an urgent review.

d) A missed opportunity by Dr Bhutto on 6 November 2019 to carry out further investigations by way of urine test and a failure to investigate Jessi's elevated blood pressure reading recorded at that consultation, either of which might have led to correct diagnosis.

RECOMMENDATIONS

The Sheriff, having considered the information presented at the inquiry, makes no recommendations in terms of 26(1)(b) of the Act.

NOTE

Introduction and Contents

[1] This is a discretionary inquiry in terms of section 4 of the Inquiries into Fatal Accidents and Sudden Deaths etc. (Scotland) Act 2016, as the Lord Advocate considers that the death of Jessi-Jean MacLennan occurred in circumstances giving rise to serious public concern and decided that it was in the public interest for an inquiry to be held

into the circumstances of her death. The purpose of the inquiry was to establish the circumstances of the death and to consider whether the death was a result of systemic failure and if so, whether appropriate remedial action should be put into place to address the issues identified and whether any other action should be taken for the purpose of protecting the public from the risk of these particular circumstances being repeated in the future.

The participants and their representatives at the inquiry

[2] The Procurator Fiscal issued notice of the inquiry on 16 November 2022, almost three years after Jessi's death. That is a significant delay and is regrettable and must have been, without doubt, difficult for the family to endure. The Covid-19 pandemic did have a part to play in that delay. Preliminary hearings took place at Inverness Sheriff Court on several dates before the inquiry started on 6 June 2023. There was a delay in concluding the Inquiry whilst the parties waited for the outcome of the pending referral to the Royal College of Paediatrics and Child Health. Mrs Laura Arthur, Procurator Fiscal Depute, appeared for the Crown; Ms Toner, counsel, appeared on behalf of Highland Health Board; Jill Harris, solicitor, appeared for Dr Abdul Jabber Bhutto, Paediatrician; and Helen Watts K.C. appeared for Dr Toby Gilbertson and Dr Karen Duncan, both GPs at Culloden Surgery, Inverness.

The witnesses

[3] The parties co-operated and worked closely together to agree a substantial amount of evidence in two joint minutes of agreement. Most of the witnesses' evidence-in-chief was by way of their witness statements, thereby significantly reducing the need for oral evidence at the inquiry. The witnesses were cross examined orally by the parties. The Inquiry took place at Inverness Sheriff Court on 6 June 2023, 14 and 15 August 2023 and 14 November 2023. Police witness statements of Dr Ellen Heathcote, Dr Abdelraman Mahmoud, Dr Mark Davidson and Dr Dermot Murphy were agreed by Joint Minute and accepted as the evidence of those witnesses for the purpose of the Inquiry. The Inquiry heard testimony from Jessi's mother, Mrs Sara MacLennan; Dr Toby Gilbertson, GP; Dr Karen Duncan, GP; Dr Norman Wallace expert witness; Dr Abdul Bhutto, paediatrician; Dr David Goudie Consultant paediatrician; and Professor Hamish Wallace, expert witness. Mrs Sara MacLennan gave evidence in person: the remainder of the proof was conducted by WebEx. Written submission were lodged by all parties and supplemented with oral submissions on 14 November 2023.

The legal framework

[4] The Inquiry is held under section 1 of the Fatal Accidents and Sudden Deaths etc. (Scotland) Act 2016 (the 2016 Act) and is governed by the Act of Sederunt (Fatal Accident Inquiry Rules) 2017 ("the 2017 rules"). The purpose of such an Inquiry is set out in section 1(3) of the 2016 Act and is to:

(a) establish the circumstances of the death, and;

(b) consider what steps (if any) might be taken to prevent other deaths in similar circumstances.

Section 26 of the 2016 Act states, among other things, that:

"(1) As soon as possible after the conclusion of the evidence and submissions in an Inquiry, the sheriff must make a determination setting out –

(a) in relation to the death to which the Inquiry relates, the sheriff's findings as to the circumstances mentioned in subsection,
and

(b) such recommendations (if any) as to any of the matters mentioned in subsection (4) as the sheriff considers as appropriate.

(2) The circumstances referred to in subsection 1(a) are –

(a) when and where the death occurred;

(b) when and where any accident resulting on the death occurred;

(c) the cause or causes of the death;

(d) the cause or causes of any accident resulting in the death;

(e) any precautions which –

(i) could reasonably have been taken, and

(ii) had they been taken might realistically have resulted in the death or any accident resulting in the death, being avoided;

(f) any defects in any system of working which contributed to the death or any accident resulting in the death;

(g) any other facts, which are relevant to the circumstances of the death.

(3) For the purposes of subsection 2(e) and (f) it does not matter whether it was foreseeable before the death or accident that the death or accident might occur –

(a) if the precautions were not taken, or;

(b) as the case may be, as a result of the defects.

(4) The matters referred to in subsection 1(b) are –

(a) the taking of reasonable precautions;

(b) the making of improvements to any system of working;

(c) the introduction of a system of working

(d) the taking of any other steps which might realistically prevent other deaths in similar circumstances.

The procurator fiscal represents the public interest. An Inquiry is an inquisitorial process and it is not the purpose of an Inquiry to establish civil or criminal liability. The standard of proof at any Inquiry under the Act is the civil standard of proof on the balance of probabilities."

Summary

[5] Jessi Jean MacLennan, herein referred to as Jessi, was born on 26 March 2018 and died on 25 November 2019 at Royal Hospital for Children, Glasgow. She was 20 months old at the time of her death.

[6] Jessi's parents are Sara and Paul MacLennan. Mr and Mrs MacLennan have been in a relationship for thirteen years and have been married for six years. When she was born Jessi had two older siblings Aiden and Lacey. They all lived together as a family in the Inverness area. Jessi was born at 36 weeks by planned Caesarean section at Raigmore hospital in Inverness. She was small at birth but did not require special care after birth. She was a healthy and happy baby. She was bottle fed and began eating solids around six months of age. In July 2019 her appetite decreased and Mrs MacLennan took her to the local GPs surgery, which was the Culloden Surgery in Culloden, Inverness with concerns about her appetite and a high temperature. She was given antibiotics for an ear infection.

[7] On 27 August 2019 Mrs MacLennan telephoned Health Visitor Linda MacLennan with her ongoing concerns about Jessi's weight and eating habits. The Health Visitor visited the family that day at 15.00 hours. Jessi's weight was recorded as being 9.62kg. As Mrs MacLennan had raised concerns, the Health Visitor sought input from the dietician. The dietician's advice was for food to be left out for Jessi for 30 minutes and her weight was to be taken again in one month. The Health Visitor passed this advice to Mrs MacLennan on 3 September 2019. The Health Visitor attended a scheduled appointment to the family on 26 September 2019. Jessi's weight was recorded as

being 9.6kg. As there was weight loss, the Health Visitor referred Jessi to the dietician. The referral was made on 10 October 2019.

[8] At the beginning of October 2019 Mrs MacLennan noticed a "lump" protruding from the left side of Jessi's stomach. Jessi's tummy was bloated. Around that time. Jessi was frequently crying with what Mrs MacLennan believed to be pain.

[9] On 2 October 2019 Jessi attended an appointment with Dr Toby Gilbertson, GP, at Culloden Surgery in relation to her concerns about Jessi's weight loss and continued high temperature. No abdominal examination was carried out at this appointment.

[10] On 3 October Jessi passed a large blood clot in her nappy which was approximately 2 inches long. Mrs MacLennan took a photo of it. On that same day Mrs MacLennan took her to the GP. They attended an appointment with Dr Gilbertson. Mrs MacLennan showed the photograph of the bloody clot to Dr Gilbertson. Dr Gilbertson did consider the blood clot to be unusual at that time. A limited abdominal examination was carried out by Dr Gilbertson. The examination was limited because of Jessi's presentation: she became distressed when asked to lie down and was too active for a deep palpation to be carried out. He believed Jessi "appeared well" when he saw her at that consultation. He noted the possibility of intussusception but decided to take no further action, concluding that no further review was necessary.

[11] On Sunday 20 October 2019 at 1604 hours, Mrs MacLennan contacted NHS 24 and reported that Jessi had had a lump in her stomach for 2 days which seemed painful when touched and that she was presenting with an unusual cry, described as either

high-pitched or weak or moaning. An appointment was given for Jessi to be seen by a practitioner in the Out Of Hours service at Raigmore Hospital, Inverness.

[12] At 1737 hours on Sunday 20 October 2019, Jessi was seen by Nurse Practitioner Diane MacLeod at the out of hour's facility at Raigmore hospital, Inverness. Nurse MacLeod was advised by Mrs MacLennan that Jessi had had a lump on the left side of her abdomen for 2 days and was in pain. Mrs MacLennan advised that Jessi had passed a blood clot in her stool following recent antibiotics and that her GP had been made aware. Mrs MacLennan showed Nurse MacLeod the photograph of Jessi's nappy containing the blood clot in her stool. Mrs MacLennan told Nurse MacLeod that she had concerns about Jessi's weight loss and her reduced intake of food. Nurse MacLeod was informed that there was no history of constipation or vomiting and that Jessi had passed a loose stool about midday that day. Nurse MacLeod noted that Jessi was clearly distressed, that her abdomen appeared distended, that Jessi became more distressed when touched, bowel sounds could not be heard and Jessi's temperature was 37.7 degrees. It was not possible to obtain a heart rate or oxygen level as Jessi was so distressed. Nurse MacLeod attempted a physical examination of Jessi which she was unable to complete due to Jessi's distress. As the examination was incomplete, Nurse MacLeod felt that it was unsafe to send Jessi home without further examination, observation and, if needed treatment. Nurse MacLeod advised that Jessi would be referred for an assessment in paediatrics as no cause could be identified for her severe abdominal pain. Details of Jessi's presentation and history were passed by Nurse MacLeod to on-call paediatrician Dr Bhutto who agreed that Jessi required

further examination, treatment and observation in the paediatric ward. Jessi was then admitted to the paediatric ward at Raigmore Hospital as an emergency attendance and assessed by Dr Bhutto at approximately 1830 that day. Dr Bhutto was a locum doctor.

[13] Dr Bhutto conducted the assessment with his junior colleague Dr Ellen Heathcote. He took a history from Jessi's mother and was advised that she had not eaten for 3 days; had abdominal pain; was crying constantly; had passed a large blood clot in her stool two weeks ago; and that her bowels were opening every day. Jessi was very distressed during the consultation. Dr Bhutto carried out a basic ENT examination, listened to her heart sounds and chest and visually examined her. He conducted an abdominal examination and felt a mass or lump on the left side which he incorrectly concluded was a faecal mass. His diagnosis was constipation. He ruled out the need for an abdominal x-ray. He prescribed a glycerine suppository, known as "relaxit" as a laxative. The 'relaxit was administered by Nurses at 1900 hours. He also prescribed Ibuprofen. He thereafter discussed with Jessi's mother that she be discharged with Movicol, which another laxative. He discharged Jessi that evening with "open access" to the children's unit for 48 hours which allowed Jessi's parents to contact the children's ward at any point during that time for advice. It was explained to Jessi's mother that if there was any deterioration in her condition Jessi should be brought back to hospital for review.

[14] On 28 October 2019, Jessi attended an appointment with Dr Calum Urquhart, GP, at Culloden Surgery. He was aware from the notes that Jessi had previously attended with his colleague Dr Gilbertson and he noted that she previously "had blood

in her nappy". He was aware that she had subsequently been diagnosed with constipation by the PAU and prescribed treatment. Mrs MacLennan described ongoing symptoms and concerns of the same nature. He prescribed more constipation treatment by way of Movicol as requested by Jessi's mother, Mrs MacLennan.

[15] On 1 November 2019, Jessi attended an appointment with Dr Karen Duncan, GP, at Culloden Surgery. This was an emergency appointment booked by Mrs MacLennan. Mrs MacLennan described on-going anxiety for Jessi because of continuing symptoms of the same nature as previously complained about. Mrs MacLennan advised Dr Duncan that she could feel a mass on the left side of Jessi's tummy. Dr Duncan was unable to carry out a full examination of Jessi's abdomen because of her presentation. She did not believe that Jessi's tummy was distended. She was unable to find any lumps or masses. Her examination was not as extensive as she would have liked. She did not think her findings were reliable as a result. Nevertheless, she assumed that the mass reported by Jessi's mum was perhaps related to the paediatric diagnosis of constipation and offered this explanation to Mrs MacLennan. She was asked by Mrs MacLennan about the possibility of the family arranging a private scan of Jessi's tummy. Dr Duncan dismissed this suggestion. Dr Duncan did not enquire what current treatment Jessi was receiving for the diagnosis of constipation. She was advised by Mrs MacLennan that Jessi was moving her bowels regularly. Dr Duncan did not issue any further prescription nor did she refer Jessi for any further investigation or treatment. She did not consider that there was any information gained at that appointment to merit any further referral or investigation.

[16] On 6 November 2019, Jessi attended an appointment with Dr Toby Gilbertson, GP, at Culloden Surgery. At this consultation Jessi was clearly unwell: feverish and distressed. Dr Gilbertson was unable to carry out any physical examination of her abdomen because of her presentation. He did not carry out any other tests. He concluded that Jessi needed to be admitted to hospital for specialist assessment. He spoke to the on-call paediatric doctor and shared Mrs MacLennan's concerns that there may be some serious underlying condition present; confirmed that he had been unable to do an abdominal examination and asked for Jessi to be seen that day. The referral was accepted and Jessi and her mum Mrs MacLennan attended the Paediatric Assessment Unit at Raigmore Hospital later that same day.

[17] On 6 November 2019 at approximately 19.00 hours, Jessi was admitted to the paediatric assessment unit at Raigmore Hospital as an emergency attendance. She was assessed by Dr Bhutto. Jessi was unsettled during examination: crying and irritable. Her blood pressure was recorded and was elevated. No further investigations into this were considered. No dipstick urine test or blood tests were carried out. Dr Bhutto carried out an ENT examination and recorded no abnormal findings. He examined and listened to her chest. He carried out an abdominal examination. Jessi was "tender" on her left side. He felt a mass on her left side again and again recorded it as faecal loading. He checked for bowel sounds which were present. He did not request any imaging in respect of the mass which was detected on her left side. He concluded that Jessi was still suffering from constipation. Jessi was discharged with increased levels of constipation

treatments at approximately 21.05 hours. Mrs MacLennan was asked to contact the children's ward on 8 November as a follow up.

[18] Jessi's mother contacted the ward on 8 November 2019 to report that Jessi was managing 8 sachets of Movicol, was drinking well but had poor appetite, was playing and energetic and was passing stools 4 times per day.

[19] On 15 November 2019, Jessi collapsed at home after vomiting. An ambulance was called at 10.15am and arrived at 10.24am. On arrival, paramedics found Jessi to blue, cold, unresponsive and exhibiting agonal breathing. She was taken to the Accident and Emergency department of Raigmore Hospital. On arrival, she was seen by Dr David Valentine, locum paediatric consultant. Jessi was intubated and ventilated and fluid resuscitation was undertaken. Jessi was treated with antibiotics and glucose for low blood sugar. An x-ray was taken of her heart, lungs and abdomen to look for serious lung problems or obvious abdominal pathology and none were identified. On examination, Dr Valentine felt what appeared to be an abnormal mass on the left side of Jessi's abdomen. An ultrasound examination revealed a tumour on Jessi's left kidney. Jessi was then taken by air ambulance to the Royal Hospital for Children in Glasgow for treatment.

[20] Jessi was then diagnosed as suffering from a Wilms' tumour on her left kidney, otherwise known as nephroblastoma. She commenced emergency chemotherapy treatment with vincristine the following day, on 16 November. A management plan was agreed in order to best support Jessi's organs. Despite Jessi receiving maximum organ support, her liver was failing. Jessi continued to require to be ventilated. Over the

course of the next 7 days, Jessi improved on the ventilator. She received a further dose of chemotherapy with vincristine on 23 November. At approximately 0100 on 25 November 2019, Jessi suffered cardiac arrest. Despite extensive efforts to resuscitate her, Jessi died a short time later, with her time of death recorded as at 01.50 hours.

[21] On 29 November 2019, Jessi's remains were examined by Doctor Dawn Penman, Consultant Forensic Paediatric Pathologist. A report of her findings was prepared. The medical cause of death, as stated in Post Mortem Examination Report, is "Complications of left nephroblastoma and associated therapy".

[22] Wilms' tumour or nephroblastoma is a very rare childhood cancer. There are fewer than 50 cases per year in the UK. It is a kidney tumour and usually affects children between 1 and 3 years old. Current research shows that even advanced stage Wilms' tumour has a cure rate of 85%.

Investigations subsequent to Jessi's passing

[23] On 27 November 2019 an internal paediatric department mortality review took place at Raigmore hospital in Inverness.

[24] On 26 February 2020 a Significant Adverse Event Review (SAER) took place at Raigmore Hospital, Inverness. An amended report of the SAER was circulated on 2 June 2020.

[25] The headline recommendations of the SAER were as follows:

i. Paediatric Assessment Unit (PAU) discharge forms must be completed in real time prior to patient discharge and by the assessing doctor.

ii. Treatment and Medicine (TAM) guidance on constipation in children should be reviewed and updated accordingly.

iii. Structured consultation led review of all patients that attend PAU prior to discharge.

iv. Child with second presentation to PAU with abdominal pain must have urinalysis checked prior to discharge.

v. Paediatric Department to develop written education on collecting a urine sample at home for parents/next of kin.

vi. Short life working group to review the current arrangements in place for monitoring locum doctors' practice with aim of identifying improvements and standardising procedures across NHS Highland.

vii. Develop a patient safety alert for dissemination to all clinical staff across NHS Highland to highlight key learning points on the clinical signs and symptoms of Wilms' tumour in a child.

viii. To share patient safety alert with NHS Education for Scotland to upload to the Knowledge network page.

[26] During 2020 Dr David Goudie, Consultant Paediatrician in NHS Highland was the Acting Clinical Lead for Acute Paediatrics at Raigmore Hospital, Inverness and he had the responsibility for initiating the implementation of the recommendations of the SAER into Jessi's death.

[27] Not all of the recommendations of the SAER were implemented in full. The NHS Highland response to the numbered recommendations of the SAER amounted to the following:

i. The introduction of the software system known as "Formstream" to replace the Immediate Discharge Letter system which has improved the compliance of timely communication to GPs following discharge, with the expectation that these are completed prior to discharge.

ii. This guidance is now linked to the guidance from the National Institute of Clinical Evidence (NICE).

iii. A Standard Operating Procedure for Supervision of PAU has been introduced which promotes appropriate Consultant assessment and decision making. Additionally a second presentation to PAU now triggers automatic consultant review before discharge and a new requirement has been introduced which is that all children who go home from PAU without having seen a consultant must subsequently be discussed with the consultant on-call afterwards and that discussion recorded.

iv. This recommendation has been implemented in full.

v. This recommendation has been implemented in full.

vi. This has been reviewed and there has been a decrease in reliance on locum doctors.

vii. This has been implemented.

viii. This has been implemented.

[28] In addition there have been several other changes within Paediatrics in NHS Highland following on Jessi's death. These are:

a) A PAU working group was established in April 2022, comprised of members from the Nursing profession, paediatric doctors, educators and clerks and is chaired by Paediatric consultants. They meet to address any working issues and review and improve the working of PAU.

b) A weekly "Risk Huddle" for Highland Children's Unit including PAU to ensure timely communication between teams of important matters, including quality and safety issues.

c) All Tier 1 &Tier 2 Doctors and Advanced Nurse Practitioners are recommended to request ultrasound investigation for all patients presenting with an abdominal mass, even if constipation is suspected.

d) The Common Admission Document has been expanded to include additional information to be included at the time of discharge, which improves communication with GPs.

[29] As indicated above, there is now a revised Standard Operating Procedure on the Paediatric Assessment Unit Supervision in place. This document is dated June 2023 and is the standard operating for the PAU as of today. The Standard Operating Procedure is directed towards ensuring adequate consultant supervision at the PAU. The procedures now in place ensure that the Consultant of the Week (COW) will discuss and review, if necessary, admissions of all children with acute medical problems attending the PAU. In addition any patients returning to the PAU for a second time must be seen by a

consultant before being discharged or admitted, with certain exceptions only at the discretion of a consultant. During "Out-of Hours" (5pm-9am) provision is made for a discussion to be had with the on-call consultant in relation to all PAU attendances and discharged patients who have not already been discussed with a consultant. A discussion with a consultant has to be documented.

[30] On 16 February 2023 NHS Highland submitted a request to the Royal College of Paediatrics and Child Health (RCPCH) for them to undertake an independent expert external invited review of the Paediatric Assessment Unit (PAU) at Raigmore Hospital, Inverness. This "self-referral" to RCPCH was prompted by the circumstances surrounding Jessi's death and NHS Highland were seeking, amongst other things, assurances of quality of care and/or ways to improve their service, even after the implementation of their own changes following the SAER. The RCPCH agreed to the request and notified this decision to NHS Highland on 3 March 2023. Terms of reference for the review were agreed between RCPCH, NHS Highland and the Invited Review Team on 9May 2023. The detailed terms of reference are set out in section 3 of the final report. The review team were tasked with considering the safety and quality of care provided by the PAU. The initial review took place at Raigmore Hospital on 26 and 27 July 2023. The final report was produced on 23 October 2023.

[31] The RCPCH review makes significant findings in two matters of relevance to the circumstances surrounding Jessi's death: the need for a "structured consultant review" of all patients prior to discharge from PAU; and the reduction in clinical locum cover since Jessi's death. The review report opines that a "structured consultant review" of all

patients prior to discharge was unnecessary because tier-two Doctors are sufficiently skilled in terms of the RCPCH standards to be able to review and discharge patients appropriately. However it was noted by the RCPCH that a clearly defined Standard Operating Procedure has now been established to ensure a consistent procedure for patient review. Consultant review of cases is now part of the standard procedure at PAU. The RCPCH report stated that the reduction in the PAU's reliance on locum doctors was noteworthy and welcome. The RCPCH report was positive about the procedures now in place for the PAU.

Submissions

The Crown

[32] The Crown submitted that in respect of S26(2)(e) I should make a significant number of findings in relation to the precautions which could reasonably have been taken. These largely followed the criticisms made by the experts Dr Wallace and Professor Wallace in their evidence. The precautions proposed were all said to meet the test: namely that, had they been taken they might realistically have resulted in the death being avoided. In relation to causation the Crown rely on Professor Hamish Wallace's evidence about the cure rate of diagnosed Wilms' tumour and his opinions about prospects for Jessi if the tumour had been identified during consultations up to and including 6 November 2019.

[33] In respect of section 26(2)(f) the submissions were that there was a defect in the system of working in the PAU at Raigmore Hospital in a number of areas and I was

asked to make findings in accordance with this analysis. The defects suggested by the Crown included the absence of consultant oversight of cases as standard.

[34] No submissions were made in respect of section 26(2)(g).

[35] In respect of possible recommendations, the Crown did not make any submission relating to possible recommendations, submitting that the court might be satisfied that relevant and sufficiently robust mitigatory steps have been taken by NHS Highland and that these can be reviewed and developed without oversight by the court. In respect of the GPs it was submitted that there were no outstanding concerns that could be addressed by formal recommendations.

NHS Highland

[36] NHS Highland submitted that there were no reasonable precautions which could reasonably have been taken by NHS Highland as an organisation and which had they been taken, might realistically have resulted in Jessi's death being avoided.

[37] It was also submitted that there were no defects in the system of work within NHS Highland as an organisation which could be considered causative of or contributory to Jessi's death. It was accepted that had Jessi's case been reviewed by a consultant it was likely that further inquiry into her symptoms would been prompted. The submission was that the lack of consultant input at the time of Jessi's assessments on 20 October and 6 November were not defects in the system of work within NHS Highland for the purposes of section 26(2)(f). This was mainly because the opportunity

existed at the time for Dr Bhutto to have consultant input into his decision making and diagnosis but he chose not to do so.

[38] In terms of section 26(2)(g) I was asked not to make any finding that the use of locum doctors, as Dr Bhutto was at that time, to be a fact relevant to the circumstances of Jessi's death. There was no evidence that because Dr Bhutto was engaged as a clinical locum that was causative of, or contributory to, Jessi's death.

[39] In relation to NHS Highland it was submitted that, on the evidence, there were no matters that would be usefully addressed by a recommendation under the Sheriff's discretion to do so. A "very thorough approach" had been taken by NHS Highland following Jessi's death to improve the service within PAU at Raigmore Hospital. The review by RCPCH was concluded and reported on in October 2023, was positive and confirmed that the improvements already made addressed the issues in the service provision which the Inquiry might consider to have contributed to Jessi's death.

Dr Bhutto

[40] The submissions made on Dr Bhutto's behalf repeated Dr Bhutto's acceptance of his failings at the consultations with Jessi on 20 October and 6 November 2019. With the benefit of hindsight he recognised mistakes were made and it was acknowledged that the court might find that reasonable precautions could have been taken by Dr Bhutto in these circumstances as long as causation was found to be established.

[41] No substantial submissions were made on behalf of Dr Bhutto in respect of any findings that the court might make in respect of sections 26(2)(f) or 26(2)(g).

Drs Gilbertson and Duncan

[42] The submissions centred on whether the court should make findings under section 26(2)(e) relating to Drs Gilbertson and Duncan. The focus was on their respective consultations of 3 October and 1 November. Some criticism was made of the Crown in adducing the relevant evidence to enable the court to consider the question of what may be a "reasonable precaution". I was generally directed to be cautious about making any finding that these two doctors could have taken reasonable precautions as it was submitted that the evidence was insufficient.

[43] It was accepted that the court was entitled to make a finding that Dr Gilbertson could have taken a relevant reasonable precaution by referring Jessi to the PAU on 3 October 2019. I was, however, asked to consider that the evidence led by the Crown was less than precise on this point. I was also asked to take into consideration that the GMC had made no finding against Dr Gilbertson following on a complaint made to them about his management of Jessi on 3 October 2019. In the submission it was stated that there was insufficient evidence led by the crown to establish how the adopting of the reasonable precaution by Dr Gilbertson, as suggested by them, would have led to Jessi's death being avoided. The submission appeared to be that even if Dr Gilbertson had referred Jessi to PAU on that date the outcome would have been the same. The conclusion was that the court should find that causation had not been established. I was therefore asked to make no finding in terms of section 26(2)(e) as far as Dr Gilbertson was concerned.

[44] In respect of Dr Duncan it was submitted that the court would not be entitled to conclude that Dr Duncan could have taken any reasonable precautions at her consultation with Jessi on 1 November 2019. It was submitted that there was "no evidence" from which the court could make such a finding. This was firstly because Dr Duncan did not, herself, accept that she did not take a precaution which she should have taken; and secondly Dr Wallace in cross-examination conceded that Dr Duncan's inaction might also be seen as being reasonable in the circumstances. I was asked to make no finding in terms of section 26(2)(e) as far as Dr Duncan was concerned.

Discussion and Conclusion

[45] The issues for the Inquiry as identified by the Crown were as follows:

i. was Jessi's death a result of systemic failure,

ii. if so, has appropriate remedial action has been put in place to address the issues identified,

iii. whether any other action should be taken for the purpose of protecting the public from the risk of these particular circumstances being repeated

[46] Findings 1-4 in this judgment were not controversial.

Precautions

Evidence of the Doctors

[47] In making these findings firstly I gave consideration to the evidence of the doctors who attended on Jessi from 3 October to 6 November and considered the events of each consultation.

[48] Dr Toby Gilbertson in evidence indicated that on 3 October, whilst he recognised the bloody stool in Jessi's nappy, as seen in the photograph, as being "unusual" he considered that it might be a result of some constipation. He stated that one can regularly see blood in a baby's nappy caused by straining from constipation. Therefore at that time he did not think it to be sufficiently concerning to warrant further investigation. In evidence at the Inquiry Dr Gilbertson conceded, with the benefit of hindsight, that it would have been reasonable for him to arrange a PAU clinic review for Jessi at that time given the unusual appearance of the blood clot.

[49] Dr Bhutto in evidence conceded that he made mistakes by not arranging further investigations for her on both 20 October and 6 November. In particular he conceded that he should have made further investigation on 6 November, when Jessi presented with a detectable mass for a second time.

[50] Dr Karen Duncan in evidence stated that at the consultation on the 1 November she carried out an abdominal examination of Jessi. She conceded that the abdominal examination was limited because of Jessi's presentation and confirmed that her examination was not as thorough as she would have liked. She did not consider therefore that her findings following that examination were reliable. She did not record

Jessi's stomach as being distended. She was unable to find any lumps or masses during the abdominal examination, but she stated that given the limitations of her examination she could not dismiss Mrs MacLennan's reported finding of a lump. She offered an explanation to Mrs MacLennan that her report of a left sided mass was potentially consistent with the previous diagnosis of constipation. She does not recall Mrs MacLennan asking her advice about having a private scan carried out on Jessi. She noted that in Jessi's case there were repeated attendances, significant parental concern and that she had been unable to carry out a "proper examination". In those circumstances "in most cases" this would have led her to at least call the paediatric registrar to ask if they would be willing to review. She did not do so in this case. She conceded that her conclusions at the consultation on 1 November 2019 were heavily influenced by the paediatric assessment on 20 October 2019. In evidence she concluded that she would now have a much lower threshold for seeking further specialist input to reconsider diagnosis and investigate further.

Expert evidence

[51] I then looked at the expert evidence. As part of the investigations made by the Crown in the preparation for the Inquiry, they instructed two experts: Dr Norman Wallace an expert in General Practice; and Professor Hamish Wallace an expert in paediatric oncology. Dr Norman Wallace produced a report on the circumstances of Jessi's death dated 16 March 2023 and which was relied on during the Inquiry hearing as his Evidence-in Chief. Professor Hamish Wallace produced a report on the

circumstances surrounding Jessi's death dated 19 November 2021 which was also relied on at the Inquiry as the basis of his Examination-in Chief.

Dr Norman Wallace

[52] Dr Norman Wallace is a medico-legal adviser who was a principal in General Practice for 31 years and has experience in providing independent expert opinions in relation to General Practice.

[53] In his analysis, Dr Wallace made reference to the Oxford handbook of General Practice which represents the knowledge he would expect an ordinary GP to have. With reference to "Diagnosis of childhood malignancy", the handbook explains that:

> "Always have a high index of suspicion and if in doubt refer for a specialist opinion….If a mass is found refer immediately. If the child is uncooperative and abdominal examination is not possible or if examination is difficult consider referral for urgent abdominal ultrasound….Referral to be seen on the same day or within two weeks – any child with…abdominal mass".

[54] In the remit Dr Norman Wallace was asked what the earliest date that a referral to specialist care by the GP service ought to have been made. His response was: 3 October 2019 when Jessi presented as being very unsettled to Dr Gilbertson having passed a "redcurrant jelly type stool in the form of a clot of blood".

[55] He was critical of the consultation with Dr Gilbertson on the 3 October 2019. On reviewing the notes it was clear that at that appointment "Jessi was clearly very unsettled and passed quite a dramatic clot of blood in her nappy". He continued by stating that he was "startled" that Dr Gilbertson did not consider urgent paediatric referral, having seen this. He opined that "normal practice would certainly be to obtain

an urgent paediatric opinion on this significant sign". The significant sign was the "significantly abnormal clot" as seen in the photograph produced by Mrs MacLennan, Jessi's mother. He further explained that on occasion one can see smears of blood in a child's nappy but this was not simply that. He further criticised the findings of the review carried out by Culloden Surgery which was summarised in a letter produced by them. The letter refers to "presence of blood in a child's stool". Dr Wallace's response to that was he did feel that "such a large clot from an unsettled child, as evidence in the photograph, comes into this category". He indicated that the presence of this clot, as seen, did merit paediatric review, and together with Jessi's general presentation, Dr Gilbertson's inability to properly examine Jessi's abdomen, and his concerns noted in the records about "possible intusseption" a referral should have been made. This was a missed opportunity.

[56] Dr Wallace was again critical of the consultation with Dr Karen Duncan GP at Culloden Surgery on 1 November 2019. This was an emergency appointment booked by Mrs MacLennan because Jessi was continuing to display the same symptoms despite treatment. His opinion was that there was yet another missed opportunity to correctly diagnose the patient at that meeting. Dr Duncan remarked in the medical notes "Mum thinks she can feel a mass on the left side of her (Jessi's) tummy". According to Dr Wallace this history alone from a concerned parent should have mandated an urgent referral to Paediatrics. It would have been reasonable to refer to PAU at that time. No referral was made by Dr Duncan. Dr Duncan did consider that abdominal examination

of Jessi was indicated and attempted to do so. She was unable to complete the examination and she was therefore unable to satisfy herself that there was no mass.

[57] Dr Wallace did say in evidence he had some sympathy with Dr Duncan and could understand why she was reassured by the previous paediatric opinion. He described her assessment on that day as "substandard" but mitigated by the false reassurance given by the previous paediatric opinion. In cross-examination he agreed with the proposition put to him that, given the recent paediatric opinion, it was also reasonable for Dr Duncan not to re-refer to PAU.

Professor Hamish Wallace

[58] Professor Hamish Wallace is a consultant paediatric oncologist at The Royal Hospital for Children and Young People and Honorary Professor in Paediatric Oncology at the University of Edinburgh. He was specifically asked to comment in respect of the care and treatment of Jessi MacLennan in Inverness by NHS Highland.

[59] Professor Hamish Wallace was clearly of the opinion that the first missed opportunity for assessment that would have revealed an abdominal mass requiring further investigation and onward referral to a specialist was on 3 October 2019 in primary care.

[60] Thereafter he stated that there was a missed opportunity to diagnose on 20 October 2019. He stated:

> "the presentation of Jessi at the age of 19 months on 20.10.2019 with significant abdominal pain, an abdominal mass and a blood clot in the stool, in my opinion warrants further investigation."

He noted that a diagnosis of constipation was made, despite the recording of there being bowel movements that day. He highlighted that no explanation was given for the recorded clot in the nappy and:

> "either an abdominal x-ray or abdominal ultrasound examination would have alerted the treating team to the presence of an abdominal mass consistent with the left-sided renal tumour and appropriate further investigations and referral arranged."

In his opinion at that consultation there was an "inappropriate management strategy and further investigations should have been arranged and could have been carried out the next day in normal hours".

[61] In respect of the next consultation at the PAU on 6 November 2019, Professor Hamish Wallace noted Jessi's blood pressure was significantly elevated. He stated: "significantly elevated BP in a child always requires further investigation to rule out a renal cause and is a common finding in a Wilms' tumour." Professor Wallace criticised the management plan was again as it was not in keeping with guidance, specifically in relation to the lack of consultant overview. He observed that a urine test taken on this date might have revealed blood in the urine which would have alerted the treating team to a problem. Professor Hamish Wallace was critical that there was no consultant oversight of the attendance and no consultant review of re-attendance at PAU with the same complaint. In evidence he stated that consultant review of the case may have led to further investigations being carried out and a recognition of Dr Bhutto's inappropriate treatment of a detected abdominal mass. It is likely that a consultant review would have detected "the red flag warnings" that Jessi's treatment was

inappropriate and may have led to a correct diagnosis. His opinion was that a structured consultant review of all patients that attend PAU should occur before the patient is discharged.

[62] Professor Hamish Wallace advised that "even advanced stage Wilms' tumour has a cure rate of around 85%" and that in his opinion "if further investigations had been arranged the abdominal mass would have been discovered and onward referral to a children's Cancer unit made."

[63] Commenting only on the consultations in secondary care Professor Hamish Wallace's opinion was if Jessi had been appropriately investigated on 20 October 2019 or 6 November 2019, "cure was not just possible but probable."

[64] In summary his evidence was clear that any diagnosis in the period up to and including 6 November, in his opinion, would have resulted in the likelihood of cure. He was clear that delays in Jessi's diagnosis significantly contributed to her death.

Conclusions in relation to precautions

[65] The precautions found in terms of section 26(2)(e) are all the precautions which could reasonably have been taken from 3 October until 6 November. During this period Mrs MacLennan consulted health care professionals 5 times. The complaints made by Mrs MacLennan were consistent over that time. Jessi's symptoms were consistent and persistent.

[66] The opinions of Dr Wallace and Professor Wallace were consistent with each other: there were missed opportunities on at least 3 occasions to correctly diagnose Jessi during the period from 3 October to 6 November.

[67] Both Dr .Wallace and Professor Wallace were clear that there was a missed opportunity to refer Jessi to PAU on 3 October. Her presentation merited it. Dr Gilbertson accepted in evidence, with the benefit of hindsight, that he did not take appropriate action on 3 October to investigate Jessi's condition further. Referring Jessi to PAU on that that date would have been a reasonable precaution to take.

[68] Professor Wallace was critical of the assessment of and treatment provided to Jessi on 20 October 2019. Dr Bhutto accepted that on 20 October he did not take appropriate action to investigate Jessi's condition properly. A more thorough investigation of the mass in Jessi's tummy by way of further tests and ultrasound were reasonable precautions to take. If that had been undertaken the abdominal mass would have been discovered, and onward referral to a children's cancer unit made, where it was likely Wilms' tumour would have been confirmed and treatment commenced.

[69] Dr Wallace gave an opinion that Dr Duncan should have made an urgent referral to PAU 1 November 2019. In his opinion the fact that mum had reported a mass on the left side of Jessi's tummy was enough to mandate such a referral, and therefore this was a reasonable approach, instead Dr Duncan assumed that the reported mass was due to a loaded bowel. Dr Wallace describes Dr Duncan's assessment of Jessi on that date as "substandard" but conceded in cross-examination that on one view it was "reasonable for her not to refer" given the false reassurance of the paediatric opinion obtained some

days prior to that consultation. Dr Duncan in her evidence did not accept that she could have taken any other reasonable measure at the consultation on the 1 November. She did concede that now, in similar circumstances, she would act differently and have a "lower threshold" for onward referral. Dr Wallace described the consultation with Dr Duncan on 1 November as a further missed opportunity to correctly diagnose Jessi. A summary of Dr Wallace's opinion on Dr Duncan's consultation on 1 November is that it would have been reasonable to refer Jessi back to PAU given the reported abdominal mass, but it was also reasonable not to refer back given the recent paediatric diagnosis.

[70] On the basis of Dr Norman Wallace's opinion, a referral to PAU was one reasonable course of action which could have been taken by Dr Duncan.

[71] Was a referral to PAU by Dr Duncan at that stage a reasonable precaution which, had it been taken, might realistically have resulted in the death being avoided? In accordance with the evidence of Professor Wallace any full and proper investigation of Jessi's symptoms was likely to have led to diagnosis which in turn would have led to immediate treatment. Any opportunity for such investigations to have taken place is a relevant consideration for the court. If treatment had commenced during the period up to and including 6 November, according to Professor Wallace, survival and cure was not just possible, but probable. A further referral to PAU on 1 November 2019 would have resulted in further investigations at PAU. This was another opportunity for a correct diagnosis to have been made. If further investigations at PAU had been completed properly that would have resulted in a correct diagnosis. If a correct diagnosis had been made treatment would have commenced and survival was likely. Therefore if a referral

had been made at this stage by Dr Duncan it might realistically have resulted in the death being avoided. Further referral to PAU by Dr Duncan on 1 November 2019 was a reasonable precaution to take in all the circumstances.

[72] Professor Wallace was again critical of the assessment of and treatment given to Jessi at the PAU on 6 November 2019. Dr Bhutto again accepted that he made mistakes and did not take appropriate measures to investigate Jessi's condition on that date. More thorough examination and testing was reasonable in the circumstances of Jessi's second admission to PAU with the same issues and the same palpable mass. If further investigations had been carried out the abdominal mass would have been discovered and diagnosis and treatment commenced.

[73] In relation to the issue of causation relating to the precautions I have found, Professor Wallace's evidence was clear: Wilms' was a perfectly treatable disease once diagnosed; it was curable; and in Professor Wallace's opinion if diagnosis had been made at any of the "missed opportunities" from 3 October 2019 until 6 November, it was his view that cure was not just possible, it was probable. According to him this was the window of opportunity within which, if a diagnosis had been made, Jessi's death would probably have been avoided.

[74] All of the precautions found in terms of section 26(2)(e) relate to maximising the opportunity for full and exhaustive investigations into Jessi's symptoms to have taken place. If proper investigations had taken place at any point during the period from 3 October to 6 November 2019 it is likely Jessi's condition would have been correctly diagnosed and treatment could have commenced immediately, making her chances of

survival and cure probable. These precautions, if taken, might realistically have resulted in the death being avoided.

Defects in the relevant system of working

[75] The defects in working identified by Professor Hamish Wallace in his report were largely uncontroversial. Although in submissions NHS Highland did not accept that there were defect in the system of working, they had taken immediate steps after Jessi's death to investigate, review their service, propose changes and made a self-referral to RCPCH for further analysis of their improved services. There is sufficient evidence before the Inquiry, which I accept, that had there been a system of work which mandated any kind of consultant review of PAU cases, as there is now, that would have made the correct diagnosis of Jessi's condition more likely. In the opinion of Professor Wallace the absence of consultant review was a defect in the system of working which contributed to the failure to diagnose Jessi's condition and therefore contributed to Jessi's death. I made findings in terms of section 26(2)(f) accordingly.

[76] I have not concluded that the significant reliance at that time on locum doctors by NHS Highland was a defect in the system as such, as there has been no persuasive evidence placed before the Inquiry to show that the fact Dr Bhutto was a locum clinician contributed in any way to his misdiagnosis and Jessi's subsequent death.

Facts relevant to the circumstances of Jessi's death

[77] These set out the "missed opportunities" for Jessi's condition to have been correctly diagnosed by the doctors.

Recommendations

[78] None of the parties sought for the court to make recommendations, despite Professor Wallace's view that this was "vital". I made no formal recommendations, however, for the reasons set out below.

[79] Some of the reasonable precautions which should have been taken and which I have identified above were not taken because of individual human error, for which I cannot make formal recommendations.

[80] Some of the reasonable precautions which should have been taken for Jessi are now mandated by changes in formal procedure implemented by NHS Highland in the operation of PAU and therefore I do not need to make formal recommendations for those.

[81] Improvements and additions to the formerly defective system of working as identified above have already been made. Mandated consultant overview of admissions to PAU are now part of the Standard Operating Procedure and therefore I do not require to make formal recommendations in this process in that regard.

[82] All of the steps necessary to realistically prevent other deaths in similar circumstances have already been made. NHS Highland worked hard to ensure that relevant investigations took place after Jessi's death; procedures at PAU were

improved; and those improvements were reviewed and audited by the appropriate expert authority, namely the Royal College of Paediatrics and Child Health resulting in positive feedback.

[83] I accept that relevant steps have been taken by NHS Highland to improve their Paediatric service as a direct result of, Jessi's death. I am persuaded these improvements can be carried out, reviewed and developed without oversight from the court.

[84] In all of these circumstances I am persuaded that no formal recommendations are required. No other action requires to be taken for the purpose of protecting the public from the risk of these particular circumstances being repeated in the future.

Summary

[85] The evidence clearly shows that Mrs MacLennan did absolutely everything she could to try and get the help her daughter needed from the doctors. Mrs MacLennan could have done no more than she did for Jessi. All participants in the Inquiry recognised the enormity of the family's loss and I extend my deepest condolences to Mr and Mrs MacLennan and the family.