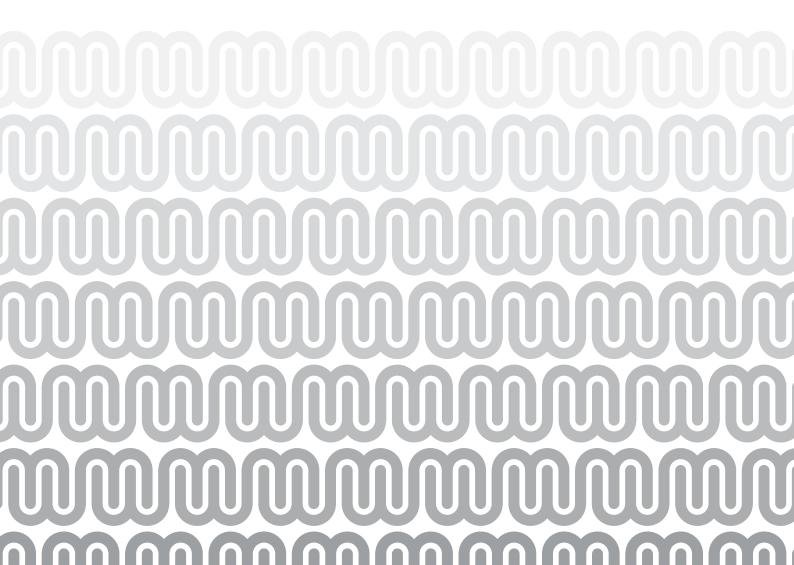


An investigation into the care and treatment of Mr D prior to his death

Investigations

September 2023



Our mission and purpose

Our Mission

To be a leading and independent voice in promoting a society where people with mental illness, learning disabilities, dementia and related conditions are treated fairly, have their rights respected, and have appropriate support to live the life of their choice.

Our Purpose

We protect and promote the human rights of people with mental illness, learning disabilities, dementia and related conditions.

Our Priorities

To achieve our mission and purpose over the next three years we have identified four strategic priorities.

- To challenge and to promote change
- Focus on the most vulnerable
- Increase our impact (in the work that we do)
- Improve our efficiency and effectiveness

Our Activity

- Influencing and empowering
- Visiting individuals
- Monitoring the law
- Investigations and casework
- Information and advice

An investigation into the care and treatment of Mr D prior to his death: a death that occurred whilst a person was subject to mental health detention in Scotland; carried out by The Mental Welfare Commission for Scotland.

We acknowledge and appreciate the cooperation of all the individuals, organisations and staff who assisted us with this investigation. The subjects of this report have been anonymised as is our practice in our published investigation reports.

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Executive summary

Mr D was an 18-year-old man who died in December 2018 from the consequences of water intoxication as a result of ingesting an excessive quantity of water. This occurred while he was an inpatient in an acute adult mental health services (AMHS) ward where he had been admitted on an urgent basis under a short-term detention certificate (STDC) of the Mental Health (Care and Treatment) (Scotland) Act 2003 (the 2003 Act).

Mr D's previous contact with psychiatric services was with child and adolescent mental health services (CAMHS), initially in his early to mid-teens due to behavioural difficulties associated with cannabis use until the age of 16 when, following the emergence of psychotic symptoms, he was admitted to an acute hospital intensive care unit following a seizure due to water intoxication. This first admission to intensive care, some two years before Mr D's death, had also resulted from him having ingested an excessive quantity of water. It was quickly realised Mr D had symptoms of an early onset psychotic illness and he was transferred to the regional CAMHS inpatient unit for psychiatric treatment under the 2003 Act. There followed two years of treatment under the care of the local community based CAMHS service with particular responsibility for early onset psychosis (CAMHS-PS) during which time Mr D had a further inpatient spell while detained under the 2003 Act in 2017 before his final admission under the 2003 Act on 4 December 2018.

Mr D was treated for a psychotic disorder, which at times resembled bipolar disorder but also featured symptoms more suggestive of schizophrenia. He was treated with three different antipsychotic medications with variable levels of success in achieving a therapeutic dose and treating his underlying symptoms. Throughout Mr D's treatment there were times when doubt existed as to whether he was taking the prescribed medication and he also experienced troublesome side-effects, most notably weight gain and disturbance of his metabolic monitoring blood tests. For periods of as long as eight months, he was known to refuse treatment with antipsychotic medication in spite of advice from the treating CAMHS-PS team that he should be taking it.

Mr D's treatment plan included psychological support in the form of one to one sessions with clinical psychology and around 12 sessions of behaviour family therapy with his parents and sibling. Community psychiatric nurses, occupational, and music therapists provided support and input. His treatment plan took into consideration his personal likes and wishes in addition to his views of future educational and occupational opportunities.

Mr D turned 18 while still under the care of the CAMHS specialist psychosis service. The service was moving away from a treatment model that supported young people with first onset psychosis for at least three years from the point of diagnosis towards one in which transition to adult mental health services¹ occurred around the age of 18 years.

In the year before Mr D's death, his parents raised concerns about the extent of his ongoing psychotic symptoms and the behaviours he displayed in association with his illness. They

¹ The transition of a young person from CAMHS to adult mental health services should be undertaken with reference to; <u>Principles of Transition (www.gov.scot)</u> See recommendations page 9 and findings page 36.

thought their son's treatment with medication was not optimised and were concerned about it being delivered voluntarily, when he was so clearly affected by psychotic illness and was not showing sustained symptomatic improvement or progress towards reasonable social integration or educational goals. Mr D's parents thought a change in the approach to their son's treatment was needed. During those times when Mr D was most acutely unwell he engaged in behaviour which brought considerable risk of physical harm to himself and concern existed he would die by his own hand as a result of such behaviours.

At a point of crisis in early December 2018, Mr D was admitted out of hours to an adult mental health service (AMHS) inpatient unit in a neighbouring health board, as there were no local beds available. During the 70 hours of this admission Mr D's case records from his years of contact with the CAMHS-PS team were unavailable. Relevant clinical information was passed to members of the new treating team in a combination of letters, emails, telephone calls and the 2003 Act detention papers. In addition, there was telephone and face-to-face contact between Mr D's parents and the receiving general adult consultant psychiatrist and ward staff. Not all of this valuable clinical information made it into the care plan in use during Mr D's admission.

On the evening of 7 December 2018, nursing staff noticed Mr D's bedroom floor was wet and he had vomited clear mucus-like fluid. He stated that he had drank water, before suffering a seizure and rapidly deteriorating. Paramedics swiftly transferred Mr D to the acute hospital intensive care unit but he did not recover and died on 10 December 2018. Mr D's death was notified to the Commission and Procurator Fiscal and a jointly commissioned significant adverse event review (SAER)² undertaken by the two health boards in which he was treated.

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² Significant adverse event reviews are conducted to national standards but are not usually made public. <u>Learning from adverse events through reporting and review - A national framework for Scotland: December 2019 (healthcareimprovementscotland.org)</u>

Key findings

1. Lack of assertiveness in treatment of psychosis in a young person

- Had Mr D's care-plan with the CAMHS psychosis service been more specific to his
 clinical presentation and therapy goals, it could have facilitated a more responsive
 approach to changes in his mental state and shortened the time periods during which
 he was not in receipt of effective treatment.
- Had the array of symptoms of psychosis experienced by Mr D and the impact of his lack of insight on his ability to meaningfully engage in a treatment plan been consistently recognised as core features of his illness then a more assertive approach towards his treatment might have followed.
- While it proved difficult to establish Mr D on an effective dose of antipsychotic medication of therapeutic benefit to him due to side effects and tolerability, his ongoing illness warranted the outlining of a clearer rationale for continuing, changing or stopping medication and the effects of such changes. This could have assisted in decision-making about switching to treatment with the antipsychotic Clozapine³.
- Different views existed about whether an application to extend Mr D's compulsory treatment order (CTO) should have been lodged with the mental health tribunal in July 2018. As the lapsing of his detention was so strongly opposed by his family, and surprised some members of the multidisciplinary team (MDT), further discussion should have been considered.

2. Risks associated with psychotic illness not coherently managed

 The worrying behaviours Mr D exhibited when unwell were described contemporaneously and summarised in social circumstances reports (SCR), but were not consistently seen as a likely feature of his psychotic illness and coherently linked in later risk assessment and management planning.

3. Problems in transition from child and adolescent mental health services to locality adult mental health services

Although clinicians acknowledged that transition to AMHS needed to be done at a
pace Mr D could engage with, after eight months this was overtaken by his need for
urgent inpatient care, by which stage only preliminary steps towards transition had
been made. This contributed to a confused service response when, in crisis, his family
sought help.

4. Team dynamics and effect on patient care and safety

The Significant Adverse Event Review (SAER) identified that team dynamics at NHS A
negatively affected the delivery of care to Mr D by impeding communication and
clinical decision-making within the CAMHS-PS team, and recommended NHS A
address this. (In the process of this investigation, the Commission established that in
response to the SAER's findings senior management made significant changes to the

³ Clozapine is recommended for young people with schizophrenia whose illness has not responded adequately to two trials of antipsychotic treatment at optimal dose for 6-8 weeks (NICE CG 155 para 1.8.9. See also <u>Clozapine | Drugs | BNF | NICE</u>

service structure and model of care, and there was considerable individual reflection and management oversight).

5. Problems in the inter-board transfer of an acutely ill young person

- Although the service had no other viable option, the transfer of an unwell young person
 with a complex clinical history to another board area during the night was a high-risk
 action. The manner of Mr D's transfer contributed to the failure to impart and properly
 document key clinical information promptly and for that information to be understood
 and acted upon from the outset.
- The failure to transfer Mr D's original CAMHS casefile and problems with the standard
 of contemporaneous note-keeping and risk assessment documentation led to missed
 opportunities for safer risk management in the delivery of Mr D's care and treatment
 in the AMHS inpatient unit in NHS B.

6. The significant adverse event review (SAER) process and Duty of Candour⁴ (DoC) actions

 The SAER was well conducted. Had this been followed by a robust response from both boards to Mr D's family under organisational DoC responsibilities subsequent to the unexpected death of Mr D, his family would have had more confidence in the boards' commitment to learn from the findings of the SAER and reduce the likelihood of something similar happening to future patients.

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⁴ <u>Duty of Candour - Healthcare standards - gov.scot (www.gov.scot)</u>

Conclusion

The investigation concluded there were aspects of the care and treatment delivered by each board which had it been conducted differently might have prevented Mr D's death. A more assertive approach to the treatment of Mr D's psychotic illness in the two years before his death was warranted.

The failure to impart key clinical details to the treating ward staff during his final admission, both in the provision of all relevant casefiles and the creation of an informed and updated risk assessment and care plan, meant Mr D was able to engage in risky and ultimately fatal psychosis-driven behaviour without mitigations having been put in place.

The subsequent learning points and recommendations are relevant not just to the two boards involved but to NHS and social work more widely which is why we are publishing this investigation. Acknowledgement must be given to the difficulties staff face when service delivery arrangements undergo change, where service structural arrangements introduce barriers to the timely and effective delivery of care, and where difficulties exist in accessing inpatient beds when urgently needed.

Recommendations

Recommendations will be subject to formal follow up and review by the Commission with the relevant agencies.

Recommendations for NHS A

NHS A must complete their responsibilities under organisational duty of candour to offer an explanation for Mr D's unexpected death and an apology where indicated, and ensure local policies fully reflect Scottish Government's non-statutory guidance⁵.

NHS A should audit their compliance with the now established Principles of Transition in Scotland⁶ in the care of child and adolescent patients with a diagnosis of psychosis who require ongoing treatment and transition to adult mental health services and demonstrate that robust and clear processes are in place.

NHS A to ensure staff are fully aware of and supported during the process of an SAER involving their care area or the treatment of patients under their care.

Recommendations for NHS/HSCP B

NHS B must complete their responsibilities under organisational duty of candour to offer an explanation for Mr D's unexpected death and an apology where indicated, and ensure local policies fully reflect Scottish Government's non-statutory guidance⁷.

Recommendations for all NHS/HSCPs

Mental health service managers should ensure they have robust local procedures in place for the acute or planned transfer of patients between services and between health boards, staff are aware of the local requirements and safeguards required, and audit their implementation.

Uncommon acute physical health scenarios can occur in patients in mental health inpatient services. To reduce the risk of harm, mental health service managers should ensure staff have information on recognising and responding to uncommon acute physical health scenarios including polydipsia⁸ and water intoxication. This may take the form of alerting staff to CPD opportunities to build and maintain competence and should be auditable.

All health boards must raise awareness among staff of the organisation's obligations under duty of candour and related local policies. This should include a focus on organisational duty of candour when training staff to undertake SAERs and especially the requirement for a full apology (which is not the same as an admission of liability or blame).

Recommendation for NHS Education Scotland (NES)

In partnership with stakeholders, NES should support educational and workforce developments on the recognition of uncommon acute physical health scenarios which can

⁵ Organisational duty of candour: guidance - gov.scot (www.gov.scot)

⁶ Principles of Transition (www.gov.scot)

⁷ Organisational duty of candour: quidance - gov.scot (www.gov.scot)

⁸ 'Polydipsia' is the term used to describe the drinking of excessive quantities of water

occur in psychiatric inpatients including polydipsia and water intoxication and make this available nationally.

Recommendation for Royal College of Psychiatrists CAMHS Faculty

The Royal College of Psychiatrists CAMHS faculty should explore with its members whether barriers exist to the use of clozapine in young people who meet established clinical criteria for its use.

Recommendation for Scottish Government

Considering the different digital record systems across mental health services in NHS Scotland, the Scotlish Government should set standards within the next six months for the safe transfer to, or management of patients who present from other health boards, including minimum standards for information sharing and use of a standardised form.

Learning Points

Learning points are not formal recommendations but points of best practice for consideration by all mental health care providers.

- Mental health services for young people should ensure a variety of educational materials about psychosis and treatments are available and shared with the affected young person and their family. NICE guidelines⁹ inform best practice in health care and treatment in the UK. SIGN guidance provides the same function in Scotland¹⁰. Clinicians should be aware of NICE guidance on treatment of psychosis in children and young people (updated 2016)¹¹ and SIGN guidance on management of schizophrenia 2013¹² (endorsed as current 2016, but not specific to children and young people) and any local guidance when delivering interventions to children and young people with psychosis.
- To ensure psychotic symptoms in young people are adequately assessed and treated, findings on mental state examination should be clearly recorded and incorporated into care and treatment plans. Where access to the mental state of a young person with psychosis is limited and they appear 'guarded' in what they share when interviewed by professionals it becomes even more important to draw on collateral information from family or carers, particularly their observations of the young person's preoccupations, behaviour and functioning.
- Clinicians are advised to be aware of NICE guidance¹³ on initiating clozapine therapy for the treatment of psychosis in children and young people, any local protocols for clozapine use, and to use local and national specialist advice where indicated.
- Balancing respect for individual autonomy in the face of deteriorating mental health and risky behaviours is complex. Clear goals for treatment, consistency in the systematic assessment and recording of progress, and credence given to family concerns, especially when a young person with a psychotic illness lacks insight or presents as guarded can help manage this balance.
- Mental health service managers should ensure when providing training in risk management or revising risk management tools, they include the importance of recognising the presence of active symptoms of psychosis and psychosis-driven unpredictable behaviours that could cause the individual physical harm. The presence of such symptoms warrants focus and mitigation, as is the case with identified risk of suicide or a history of previous suicide attempts for which there is evidence of greater risk of completed suicide, especially in people with schizophrenia or bipolar disorder¹⁴.
- Managers should be aware of the importance of staff psychological safety and wellbeing in relation to team dynamics. If staff do not feel comfortable sharing their views they can become burned out and stop expressing their views. In mental health,

⁹ Find guidance | NICE

¹⁰ Home (sign.ac.uk)

¹¹ Overview | Psychosis and schizophrenia in children and young people: recognition and management | Guidance | NICE

¹² Management of schizophrenia (sign.ac.uk)

¹³ Overview | Psychosis and schizophrenia in children and young people: recognition and management | Guidance | NICE p33, paras 1.8.9-10

¹⁴ Suicide risk after a suicide attempt | The BMJ

where decisions made can be complex and ambiguous, staff must feel empowered and comfortable expressing opposing views. Managers should consider making use of Scottish Patient Safety Programme (SPSP) and NHS Education for Scotland (NES) resources.

- Family and carers, who often deliver informal care, should have opportunities and space to express their opinions, have candid discussions and have input into mutually agreed care plans.
- Concerns raised by relatives should be responded to in a timely and courteous manner.
 Staff may not agree with, or be able to action requests from relatives, but concerns should be responded to and the information used to inform care and treatment.
- Clinicians and managers should ensure concerns raised by relatives and others are managed in accordance with the local complaints procedure. Complaints should not be viewed as an unnecessary burden but an opportunity for improvement.
- When MDT members are not in agreement with the view of the responsible medical officer (RMO) on detention under the 2003 Act, or where there is a difference of opinion about care planning between senior medical staff or within an MDT, there should be an escalation policy. A policy which includes a mechanism to seek a second opinion and resolution is particularly important when there is recognised to be high risk of harm to the patient or others if compulsion is removed.
- Clinicians are reminded of the importance of keeping up to date, accessible, contemporaneous notes and risk assessment and management plans which make clear when new information is added, including in electronic format.

Introduction

This investigation into the care and treatment of Mr D was conducted under Section 11 of the Mental Health (Care and Treatment) Act 2003 (the 2003 Act) by the Mental Welfare Commission for Scotland. Section 11 gives the Commission the authority to carry out investigations and make recommendations as it considers appropriate in many circumstances, including where an individual with mental illness, learning disability or related condition may be, or may have been, 'subject to ill treatment, neglect or some other deficiency in care and treatment'¹⁵.

In addition, Mr D's case was identified as one that would contribute learning to the Deaths in Detention Review (DIDR) due to it involving transitions between services and between health boards. Recommendations for a new system of review of deaths in detention were submitted to Scottish Government in 2022¹⁶ in response to the first recommendation from the section 37 review of the 2003 Act, which reported in December 2018¹⁷.

Mr D was an adolescent who had a diagnosis of first episode psychosis treated by a specialist early psychosis team for young people. He had three hospital admissions for detention and treatment under the 2003 Act. The first followed an admission to intensive care in a general hospital due to water intoxication, an acute physical illness which had been caused by his high risk behaviour – excessive drinking of water - secondary to delusional beliefs about his physical wellbeing. Two years later, around 70 hours after Mr D's final admission under the 2003 Act, having engaged in the same risky behaviour he again required intensive care input for significant metabolic disturbance due to water intoxication from which he failed to recover.

The initial approach undertaken by the commission was to consider the Significant Adverse Event Review (SAER). The two health boards, NHS A and NHS B, that provided Mr D's care and treatment, undertook this jointly. The Commission considered whether the terms of reference were appropriate and addressed in the SAER report and in the subsequent action plans produced by each board. A key initial step was to speak with Mr D's family to hear their views of how the investigation had addressed the issues that they believed to be important.

Key points of concern included:

- Aspects of the clinical management of Mr D's illness in the two years before his final admission which were brought to the fore in the SAER but, in the opinion of the Commission, were not clearly enough carried through into subsequent action plans and the related learning not widely enough disseminated.
- The importance of careful management of transitions and transfers needed to be emphasised with standardisation of inter-service and inter-board processes followed through.

¹⁵ Mental Health (Care and Treatment) (Scotland) Act 2003 (legislation.gov.uk) Section 11(2)(d)

¹⁶ Full details can be found at; <u>Deaths in detention reviews | Mental Welfare Commission for Scotland (mwcscot.org.uk)</u>

¹⁷ Review of the arrangements for investigating the deaths of patients being treated for mental disorder (www.gov.scot)

• The Commission also had concerns about the extent to which the two boards met organisational duty of candour¹⁸ responsibilities.

Background

At the age of 16 in January 2017, Mr D was admitted as an emergency to an acute general hospital for five days following a seizure induced by drinking large quantities of water, which he believed would remove toxins from his system. This affected his sodium metabolism (blood salts) with near fatal consequences. Mr D was treated in the intensive care unit (ICU), where concerns about his mental health ensued.

Mr D presented as likely to be experiencing an early onset psychotic episode with mood-related symptoms. He did not wish to be admitted to the specialist Child and Adolescent Mental Health Service (CAMHS) inpatient unit for assessment or to take medication. Mr D's decision-making about the need for assessment and treatment was significantly impaired. He thought others could read or control his thoughts and he needed to leave hospital immediately to undertake life-changing work. Mr D had little or no insight into the thinking processes that led to him drinking so much water that he became critically ill. He was then detained on a short-term detention certificate (STDC) and admitted to the CAMHS unit for assessment and treatment.

Mr D lived at home with his parents and younger sibling. Mr D had a good relationship with his parents, one of whom was a retired mental health professional. Mr D used cannabis in his early teens (age 13-15 years) to help him relax and experimented with other substances. There were concerns about Mr D's aggressive behaviour at home from February 2015 (age 15 years). He engaged in low level offending and aggression toward others for which Court action followed through to 2017. Mr D's parents became more worried about his mental health in the autumn of 2016 (age 16 years) as he was increasingly aggressive towards them and had suspicious thoughts about them poisoning his food. In October 2016, police at the airport intercepted Mr D after his parents had contacted them as he had impulsively set off to rough camp abroad with inadequate preparation or provisions.

Hospital admission to CAMHS inpatient unit, 20 January 2017 – 29 March 2017 Mr D was admitted to the regional CAMHS inpatient unit after acute water intoxication warranted his admission to medical intensive care. He was commenced on antipsychotic medication following psychiatric assessment when in ICU.

Weekly multi-disciplinary team (MDT) meetings reported evidence of disturbed mental state and poor insight with a gradual initial response to the antipsychotic treatment. During Mr D's admission, there were doubts about his compliance with medication and visits home were characterised by behaviours driven by active illness. Mr D's parents regularly advised the treating team of their anxieties around untreated psychotic symptoms and behaviours of concern towards them when he was home on pass. Across this inpatient admission, there were several examples of Mr D's ability to present a good façade, which was at odds with very unusual and socially unacceptable behaviours and appearing to respond to auditory hallucinations. The diagnosis considered most likely was bipolar disorder, unlikely to be a

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^{18 &}lt;u>Duty of Candour - Healthcare standards - gov.scot (www.gov.scot)</u>

single episode of illness, and it was suggested Mr D had presented with some schizophrenialike symptoms. Mr D was discharged to the care of the child and adolescent mental health services' psychosis service (CAMHS-PS) on regular antipsychotic medication.

Community treatment from 29 March 2017 – 23 November 2017

Upon Mr D's discharge, the CAMHS-PS team noted they were potentially not gleaning the full clinical picture from their interactions with Mr D. Within the first month, Mr D had stopped taking his medication and at home, he was brittle, irritable towards his parents, and there were concerns regarding his water intake. There appeared to be an overall decline in Mr D's level of functioning and the clinical team observed a deterioration in his mental state.

Mr D, his parents and younger sibling participated in behaviour family therapy (BFT)¹⁹, which followed a set programme. Twelve sessions took place over a four-month period, of which Mr D attended eleven sessions.

In May 2017 Mr D's parents shared with the team their son's concerning behaviour around food and that Mr D was not taking any medication, which was against medical advice. The CAMHS-PS team were of the opinion Mr D seemed stable, however notes indicated they were concerned about the significant risk of relapse given he was not taking antipsychotic medication.

Mr D's parents requested a medical review on 20 June 2017 due to their son appearing irritable destructive, high, laughing to himself, making odd noises, wanting to spend money excessively and expressing odd ideas about lucid dreaming and visualisations. Mr D's parents believed their son was hearing voices. As Mr D did not want to take any medication, it was agreed to continue with a psychological approach to the management of his psychotic illness.

On 30 June 2017 Mr D's GP informed the CAMHS-PS team of a concerning consultation with Mr D in which he wanted his voice box removed. Mr D was reviewed by a duty doctor and a member of staff from CAMHS-PS who established Mr D had a highly distressing and bizarre delusion that his voice box was speaking out his thoughts to others, a symptom most usually associated with a diagnosis of schizophrenia. All were of the opinion Mr D's mental state and risk of harm to himself needed to be monitored closely and appropriate action taken if the level of risk increased. Mr D's parents told the CAMHS-PS team he had been researching ways to get his voice box removed in order to cure this and they thought treatment under the Mental Health Act was needed. The team offered Mr D a supply of the antipsychotic medication he previously took, to use 'if required' and his treatment continued informally.

Throughout this period of outpatient care Mr D's mental health continued to deteriorate. He displayed disinhibited behaviours, stopped eating well due to a belief pesticides would kill him, and was so concerned about air pollution he wore a mask outside. Mr D's family felt their son was too unwell to change his behaviour and reported he had become increasingly delusional,

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¹⁹ Behaviour family therapy is a psychological intervention for young people and their families which should have a specific supportive, educational or treatment function and include negotiated problem solving or crisis management work(Recommendations | Psychosis and schizophrenia in children and young people: recognition and management | Guidance | NICE section 1.3.28

angry and overbearing, whilst being preoccupied with health threats in food and the environment.

The CAMHS-PS consultant saw Mr D on 2 and 9 August 2017. They noted Mr D continued to refuse antipsychotic medication and his presentation remained concerning but concluded he did not meet criteria for detention under the 2003 Act. Mr D agreed to psychology sessions but did not regularly attend and did not greatly engage in any therapeutic intervention. He continued to refuse medication.

In November 2017 a legal report prepared at the request of Mr D's solicitor stated Mr D was suffering from a first episode psychosis which was not fully in remission and he was not fit to plead in the subsequent court proceedings. The report stated Mr D had limited insight into his illness and posed a risk to himself through neglect because of his partially treated mental disorder. Mr D was noted to be stressed about the potential court action.

On 23 November 2017, Mr D was seen by the CAMHS-PS consultant urgently and was admitted to hospital voluntarily due to being very psychotic. By this point Mr D had not taken prescribed antipsychotic medication or fully engaged with psychological therapy for eight months. There was an increase in bizarre behaviour and he was expressing delusions about the earth and nature. Mr D had tried to break his teeth with a dumbbell in response to a delusional belief that doing so would return calcium to the earth as a sacrifice for his wrongdoings.

Hospital admission from 23 November 2017 – 2 March 2018

On admission, Mr D displayed disinhibited behaviours and was commenced on another antipsychotic medication. After a few days, he was detained under the 2003 Act; an STDC initiated on 27 November 2017 was followed by an interim CTO, and then a CTO from 25 January 2018. Mr D discussed bizarre ideas and refused antipsychotic medication. There was no clear improvement noted from the latest medication trial and the treating team found it difficult to establish Mr D on suitable medication due to his experience of side effects on two previous antipsychotics. He was also suspected of pretending to take his medication. Mr D did not want his parents invited to weekly CAMHS inpatient service meetings.

In January 2018, Mr D's parents observed odd behaviour when he was at home and questioned his compliance with medication. He was pacing, meditating and doing what he called lucid dreaming for lengthy periods. They had concerns about their son's increasing social isolation. Mr D was on his third antipsychotic medication as it had been difficult to establish him on one he could tolerate and was effective in reducing troubling symptoms. Mr D found talking about personal issues difficult; he didn't want to take medication as it had a dampening effect on him, he felt talking therapies were the least bad option available to him, and was described as appearing very stuck.

In February 2018, Mr D spent increasing time on pass to his family home and returned to the ward in the evenings for medication, an arrangement which generally worked well for him. He graduated to extended periods on pass and control of his medication at home. A first discussion was held with Mr D regarding a future transition to adult mental health services.

Upon discharge on 2 March 2018, with the approval of the MDT and his parents, Mr D was to have ongoing access to the CAMHS-PS team, occupational therapy (OT) and music therapy. He was to continue with antipsychotic medication and his CTO was suspended.

Community treatment from 2 March 2018 – 4 December 2018

At his first out-patient (OP) attendance on 8 March the reviewing consultant, who covered the CAMHS-PS team at that point²⁰, felt there was substantial improvement, but Mr D still had unusual thought content, albeit much less intensely held or behaviourally relevant. It was acknowledged Mr D only wanted to continue with music therapy and outpatient review and was ambivalent about psychology; however, his psychologist reported he was more talkative and able to engage.

Mr D's parents were concerned about the prospect of his detention coming to an end, and wanted to pursue a conversation around the use of Clozapine²¹ (a form of antipsychotic medication which is used when first-line treatments aren't effective or can't be tolerated, and can be used for treatment of polydipsia in people with psychosis²²). On 29 March Mr D's parents requested a medical review, they recalled the consultant from their son's inpatient spell had been keen to make a decision about Clozapine before he turned 18. Mr D's parents thought he had not gained enough benefit from the prescribed antipsychotic as he was still spending most of his day pacing which he said helped him be creative. The psychologist reported Mr D felt awkward at home and was spending most of the day upstairs meditating.

On 16 April Mr D's parents requested a case review. Mr D was now 18 years old and was on a suspended compulsory treatment order (CTO) which required review. A multidisciplinary team (MDT) professional meeting on 4 May was immediately followed by a meeting with Mr D's parents, where they expressed concern about his ongoing psychotic symptoms and poor quality of life. They wanted the CTO to remain, as they were not confident Mr D would continue with medication without compulsion.

At an MDT meeting on 30 May, Mr D and his parents reported little change and their relationship was becoming more strained. Mr D was putting on weight (a medication side effect) which he said was an attempt to become more Buddhist. The psychologist observed Mr D had begun to reflect on and recognise his own thoughts. The suspended CTO, due to end 24 July, was discussed. Mr D said he would take medication and attend appointments.

A reformulation of Mr D's care plan took place on 5 July. The care plan continued with music therapy, individual psychological therapy, support for Mr D with his mental health and support for Mr D's parents to manage his behaviour. Mr D told his psychologist he found it annoying to be in contact with mental health services and take medication, however he acknowledged the latest antipsychotic medication (olanzapine) helped keep him calm.

²⁰ Different consultants provided responsibility for CAMHS-PS in the first half of 2018 due to staffing changes.

²¹ Clozapine is recommended for young people with schizophrenia whose illness has not responded adequately to two trials of antipsychotic treatment at optimal dose for 6-8 weeks (NICE CG 155 para 1.8.9. See also <u>Clozapine | Drugs | BNF | NICE</u>

²² Relationship between polydipsia and antipsychotics: A systematic review of clinical studies and case reports - Science Direct

At a meeting with Mr D and his parents on 12 July discussion centred around the CTO, current and future medication and treatment, including the possibility of treatment with Clozapine, as well as his parents' wider concerns. Mr D's parents suggested he might not take medication if the CTO ended - they believed their son was only compliant because of the compulsion (and potential for recall to hospital). The MDT decision was to continue treatment with the antipsychotic medication he was prescribed, psychology and music therapy, and despite the view of Mr D's parents, the CTO was left to lapse on 25 July, as he had been attending appointments and said he would take the antipsychotic medication. Mr D's parents felt the onus was on them to ensure he took his medication, a situation they weren't fully comfortable with as it seemed like a de facto detention.

Mr D continued to struggle with aspects of his mental health and motivation. He spent most of the time in his room and was not interested in social interaction. Mr D described spending more time visualising colours and shapes and trying to learn about lucid dreaming. Mr D's parents asked again about Clozapine on 23 August, but were told the indications for clozapine treatment were not met, based on Mr D's current mental health and engagement with psychology and music therapy. Mr D's parents told the community psychiatric nurse (CPN) on 13 September their son's level of functioning was at its worst and they intended to put their concerns in writing.

Mr D received a letter from the CAMHS Head of Service on 24 September regarding his transition to AMHS, which mentioned difficulties providing psychiatric cover within parts of the CAMHS service.

Mr D's CAMHS-PS consultant received by email a letter from Mr D's parents on 1 October outlining their concerns about his level of functioning and stating they felt listened to but not heard. They felt staff were failing to recognise how ill their son was and included a further request to consider treating him with Clozapine. No formal response was made to this letter. Later in October 2018 the consultant discussed transition to AMHS by December 2018 with Mr D. Mr D stated he would not complete transition paperwork unless he decided he wanted to transition to adult services. Mr D was advised they would work on a care plan together. A risk assessment was completed and the main risks identified included; water intoxication, mental health deterioration due to non-compliance with medication, self-neglect, and risk of accidental death. Mr D completed a number of self-report and observer-rated psychometric assessments, which did not highlight any difficulties. The administrator of these tests noted Mr D appeared to experience more symptoms and distress than he felt able to report. Mr D's parents had seen a slight improvement and were observing him carefully. This followed a reduction in Mr D's medication in response to blood-test abnormalities.

Mr D's GP wrote to his consultant on 31 October 2018 describing how Mr D had sought their advice having inserted an item into his body for which he gave a bizarre explanation. The GP compared this behaviour to the incident when he had smashed his teeth. The MDT discussed this letter; there were differing views as to the clinical significance of the information. No action followed as the team concluded they had no authority to discuss it with Mr D.

On 31 October Mr D's parents contacted the CPN stating Mr D had moved his agreed medication time from 9pm until after midnight to allow himself more time for visualisation, his personal hygiene was poor and he was again engaging in lucid dreaming.

In November 2018 Mr D's consultant met with Mr D and his parents and recommended he increase his level of exercise (to assist in weight reduction) and his antipsychotic was reduced again at Mr D's request. The consultant stated Mr D reported feeling fine in his mood, was aware of relapse indicators, and would seek help if required. Mr D was continuing to meet with his psychologist for routine appointments. By mid-November the psychologist noted Mr D looked tired and unkempt. Mr D and his parents were invited to a meeting planned for 13 December to discuss his transition to adult mental health services (AMHS).

At a review on 22 November, the consultant agreed with Mr D's request to reduce his antipsychotic medication further to olanzapine 10mg daily though Mr D pressed for and was given the even lower dose of 5mg. His parents were asked to observe him closely and to make contact with the team for assessment if required. Mr D's consultant recorded they contacted AMHS to get details of the team ahead of Mr D's transition and started the referral process by email.

Mr D's parents told the CPN on 27 November they did not know if their son was taking his medication. They contacted the CPN again on 3 December to advise they were very concerned about their son. Mr D had gone missing from home the previous evening for several hours and on return told his parents he had gone to a local bridge over an expanse of water. The CPN tried to arrange a medical review to assess if Mr D was detainable, however there were no doctors from the team available and a duty doctor agreed to see Mr D if his parents brought him into the team base for an already scheduled appointment with the dietitian. Mr D refused to attend the dietitian appointment or visit the doctor. The duty doctor liaised with the duty consultant who advised further assessment at home that day was not appropriate as they thought he was unlikely to be detainable and his level of risk was well known. Concern was offered that the introduction of new faces could be detrimental and escalate behaviours that might prove difficult to handle without containment in place. The duty doctor was advised to wait and see Mr D at the appointment scheduled for the following day with the music therapist.

A referral to the area crisis team made by the CPN on 3 December was not accepted as Mr D was not yet under the care of the adult mental health service (AMHS) and hadn't been assessed face to face in the 24 hours before referral. Mr D's parents were contacted, informed of the decision to postpone medical assessment to the next day – 4 December - and were advised that if Mr D left the house to notify the police and make them aware he would need a mental health assessment. Mr D's parents stressed how unwell their son was and in their opinion, he was displaying relapse indicators. On 4 December Mr D's parents contacted the CPN to advise they had observed their son overnight and he would not be attending music therapy. The CPN agreed to visit Mr D at home.

Hospital admission from 4 December 2018 - 8 December 2018 under MHA

On the afternoon of 4 December Mr D was assessed at home by a community psychiatric nurse (CPN), a mental health officer (MHO), and a locum doctor from the child and adolescent mental health service and was detained under the 2003 Act. Mr D was taken to the adult

mental health service (AMHS) admissions unit in NHS A whilst awaiting transfer to an AMHS unit in NHS B due to lack of available beds in NHS A. NHS B were advised Mr D was in transition from CAMHS-PS to adult mental health services.

Mr D transferred by ambulance accompanied by two registered mental health nurses and was admitted to an AMHS acute ward at NHS B in the early hours of 5 December. On admission it was established Mr D had not taken medication for a few weeks and was a significant risk to himself given previous behaviours. Only the detention paperwork and referral letter mentioned the history of previous water intoxication. Mr D was re-started on oral antipsychotic medication (olanzapine) with a view to being switched to medication in the form of a long-acting injection once back in his usual service locality.

A comprehensive list of risks was emailed to the admitting AMHS staff at NHS B by the CAMHS locum doctor from NHS A who had detained Mr D and it was noted Mr D's parents were concerned their son may be suicidal. The speciality doctor from CAMHS at NHS A, contacted the admitting AMHS consultant at NHS B, highlighting Mr D could appear more well than he actually was and stressed the high level of concern from the treating team and Mr D's family. Mr D's community psychiatric nurse (CPN) from NHS A recalls contacting the acute ward in NHS B by telephone to reinforce her concerns about Mr D's high level of risk due to his previous history.

A clinical risk screening and management tool was completed which highlighted some relevant risk factors such as: Mr D's previous history of self-harm from breaking his teeth, and the potential for suicide when he absconded from home and went to a bridge. The history of excessive water consumption remained as a historical fact in the detention paperwork and the referral letter. On mental state examination, it was noted Mr D had no suicidal ideation, intent or plan superficially, but there was no real access to his inner world and he presented with acute psychosis. Mr D was guarded and suspicious around staff. He disclosed he did not feel safe in hospital. The admitting AMHS consultant at NHS B undertook a medical review and obtained detailed background information from Mr D's parents. The consultant acknowledged receipt by email of information from the CAMHS speciality doctor at NHS A and summarised their plans for Mr D.

Mr D slept late on 6 December and was visited by his parents. Later that day Mr D flooded his bedroom with the shower and sent a text to his parents expressing concern he had water in his lungs from jumping into water (on 3 December) and was attending Accident and Emergency. When alerted to the text by a phone call from Mr D's parents, staff checked on Mr D, who was on general observations²³ on the ward, and found him to be sleeping.

On 7 December during a medical review, Mr D reported things were good and medication had helped, but he was worried about his lungs as he had previously fallen in water, choked, and subsequently found breathing difficult. Vital signs were within normal parameters and Mr D declined further assessment by the ward doctor. The consultant advised Mr D was to be transferred back to NHS A that afternoon. Later in the afternoon Mr D told a nurse he had

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²³ General observations are the lowest level of observations on inpatient wards. Assessment on admission concluded this level of observations was appropriate for Mr D's clinical presentation.

drank too much water – then retracted this. No record was made of this conversation or action taken. The transfer back to NHS A did not take place, as the bed identified in an AMHS acute ward was no longer available.

Mr D's casefile from NHS A was not transferred with him to the AMHS acute ward at NHS B and did not follow during his near three-day admission. Much of the clinical information subsequently received by telephone, email and from his parents was not transcribed contemporaneously into the working care-plan, or the risk documentation updated to include the new information obtained.

At 10.35pm on 7 December, nursing staff noticed Mr D's floor was wet with water and he had vomited mucus like fluid. Mr D told nursing staff he had drank water. He suffered a seizure for around five minutes and the duty doctor attended. Mr D's physical state rapidly deteriorated, paramedics attended and transferred him to the intensive care unit (ICU) in Acute Hospital, NHS B.

ICU, Acute Hospital NHS B, admission from 8 December 2018 – 10 December 2018 (died 10 December 2018)

On admission to the ICU Mr D received relevant medical tests and treatments. Brain stem death was confirmed on 10 December 2018. His family were with him throughout his stay.

Focus and lines of enquiry

The purpose of this investigation was to examine:

- The care, treatment and support given to Mr D by NHS A from January 2017 until 10 December 2018.
- The care, treatment and support given to Mr D by NHS B from 4 December 2018 until 10 December 2018.

The terms of reference for the investigation were to:

- Examine in detail the care, treatment and support Mr D received in the two-year period prior to his final admission to hospital.
- Pay particular attention to Mr D's transfer to acute inpatient care at NHS B for emergency admission, while in transition from child and adolescent to adult mental health services at NHS A.
- Bring added oversight to the pre-existing Significant Adverse Event Review conducted at board level and shared with the Commission in keeping with boards' statutory responsibility to notify the Commission of all deaths of patients while subject to detention under the 2003 Act.
- Identify any lessons learned both locally and nationally in addition to those already proposed by the SAER process.
- Establish the existence of an effective response to the recommendations from the SAER process.
- Make further recommendations as appropriate to the investigation of this case.

Investigation process

The investigation team had access to health records, (medical, nursing and allied professional) from September 2015 until 10 December 2018, but focused on the period from January 2017. The jointly commissioned SAER report completed following Mr D's death and the subsequent Action plans for NHS A and NHS B (including updates) were viewed and the following policy documents and guidance consulted:

NHS A

- Draft NHS Model Complaints Handling Procedure (NHS B, last accessed 4 January 2023)
- CAMHS Procedure for Accessing Urgent Psychiatry Assessment
- Principles of Transition Document (Scottish Government 2018)
- Responsibilities of services to ensure good transition (Scottish Government 2018)

NHS B

- Admission Pathway
- Clinical Risk Screening and Management Policy Pilot 2021
- CRAFT (Clinical Risk Assessment Framework for Teams) Support Document
- Standards of Ward Management (Revised September 2013)
- Mental Health Services: Nurse Line Management Supervision Guidance (June 2018)
- Mental Health Services: Nurse Clinical Supervision Policy and Framework (June 2018)
- Safe and Supportive Observation: Policy Practice Guidance (December 2016)

In addition to considering these records, the investigation team conducted interviews with key individuals who were part of the process of care or the significant adverse event review during the period identified:

- 1. Mr D's parents
- 2. Clinical director A, CAMHS, NHS A
- 3. Associate medical director A, NHS A
- 4. Clinical director B, AMHS, NHS B
- 5. CPN, CAMHS-PS, NHS A
- 6. SAER independent chair, NHS B (consultant psychiatrist and SAER lead clinician)
- 7. SAER review team member, NHS A (general medical background and SAER lead clinician)
- 8. SAER review team member, NHS A (nursing background)

The Commission's investigation team comprised:

- Mental Welfare Commission head of Deaths in Detention and Homicide review team
- A Deaths in Detention project consultant psychiatrist
- A Deaths in Detention project nurse advisor

We obtained expert opinions from the following:

- A CAMHS specialist consultant psychiatrist
- A consultant psychiatrist with expertise in treatment of first episode psychosis

The investigation team decided against meeting with staff interviewed during the SAER process as sufficient information was available and to avoid creating unnecessary anxiety among staff, unless as the investigation progressed their input was necessary. It was on this basis the investigation team met with a CPN from NHS A for a longer-term overview of Mr D's presentation and progress when in the care of CAMHS-PS in NHS A.

Mr D's family acknowledged the findings made by the SAER and asked the Commission to bring added focus to; their son's treatment plan, the response from NHS A to their requests for a reconsideration of his treatment plan, and the process by which he was transferred between health boards and the communications which followed.

Once the interviews concluded, the information was analysed using a content analysis model, using the following thematic headings:

- Treatment of psychosis in a young person
- Psychosis and associated risks
- Transition from child and adolescent to adult mental health services
- Team dynamics and effect on patient care and safety
- Inter-board transfer of patients and clinical communication
- Significant adverse review process across two health boards
- Response to duty of candour obligations.

Findings

1. Treatment of psychosis in young person

Good practice - treatment of psychosis in a young person

We saw good practice in establishing therapeutic relationships with Mr D and his family, and his views respected on how he wanted his parents involved in his care. Relationship building in which trust and non-judgemental support was central and contact and communication was maintained flexibly with personal choice given to appointment times and venues. Mr D was involved in treatment decisions including dealing with the side effects of his medication and his self-management was encouraged. There was regular input from specialists within the multidisciplinary team. We saw good examples of mental state assessment and recording at key points such as on admission, when in crisis and in reports to the court. There was much focus on the psychosocial treatments Mr D received. Mr D had access to a range of therapists such as psychologists, music therapist, occupational therapist, and nurse therapists who delivered eleven sessions of BFT. Consideration was given to Mr D's recreational, educational, and employment goals and aspirations, for example, contact was made with third sector and further education and skills organisations to explore with Mr D areas of interest with which he could engage. The activities explored and connections made were appropriate for a young person, with recognisable elements of a 'recovery'24 focus and were chosen or pursued with his personal likes and interests at the centre.

Observations by the Commission

Care planning 'siloed' and lacking in responsivity

The care planning documentation varied very little in the two years of his care with the CAMHS-PS at NHS A. Generic areas of care management were updated regularly however the care plan contained only minimal detail about medication as a treatment or compliance with a medication treatment plan as a core treatment goal.

There was little cross reference to inter-disciplinary work, although all members of the team contributed to multi-disciplinary discussions at clinical meetings at which Mr D and his parents were present and had the aim of their input outlined in the care plan. We saw no mention or evidence of educational materials given to him on psychosis as an illness and factors known to influence outcome or relapse.

Psychology formulation and therapy goals

Psychology was active with much emphasis on formulation and many contacts over a twoyear period although not in manualised cognitive behavioural therapy (CBT) for psychosis format and his engagement with psychology wavered with his mental state. We saw one detailed letter from the clinical psychologist to the consultant psychiatrist and GP which summarised this work some eight months into his care with the CAMHS-PS team and two detailed diagrammatic formulations which were stored under 'third party notes' with no accompanying narrative.

²⁴ Recovery | Mental Health Foundation

NICE guidance on psychological interventions is very specific²⁵,

"If the child or young person and their parents or carers wish to try psychological interventions (family intervention with individual (CBT) alone without antipsychotic medication) advise that psychological interventions are more effective when delivered in conjunction with antipsychotic medication. If the child or young person and their parents or carers still wish to try psychological interventions alone, then offer family intervention with individual CBT. Agree a time limit (1 month or less) for reviewing treatment options, including introducing antipsychotic medication. Continue to monitor symptoms, level of distress, impairment and level of functioning, including educational engagement and achievement, regularly."

NICE guidance also recommends monitoring progress across a range of outcomes including the young person's satisfaction. We noted Mr D viewed psychology as 'the least worst' treatment option for him and the notes suggest he struggled to work within a CBT framework in the treatment of his psychotic illness. In the final months of his treatment, he attended music therapy and made a particularly strong therapeutic link with the music therapist.

The Commission's view is the 'formulation' of a case in early onset psychosis should provide a basis and reference point from which a care plan²⁶ or CBT-informed case management approach can be constructed, reviewed, and revised²⁷, or from which a CBT approach to the treatment of psychotic symptoms can be delivered²⁸.

Recording of mental state examination, questionnaires, and assessment against goals

The assessment of Mr D's mental state in a systematic way was seldom recorded following regular outpatient reviews. Psychologists assessed Mr D with symptom scales on two occasions, February 2017 and October 2018. They administered a Positive and Negative Syndrome Scale (PANSS²⁹), Beck Depression Inventory Version 2 (self-report) and the Inventory of Personal Problems short version (self-report) questionnaires. The PANSS is clinician-administered, widely used in treatment trials and is seen as the 'gold standard' against which how well antipsychotic medication is working is measured.

The first of the PANSS assessments produced scores in the moderately severe range. The 2018 assessment produced a lower (severity) score. Mr D returned the simultaneously administered self-report inventories with the minimum score against all questions. A letter to his consultant and GP stated he appeared to experience more symptoms than he felt able to report but beyond this letter (which included a useful and clinically relevant observation), there was limited evidence of systematic assessments of his mental state being used as a benchmark or a measure of progress in treatment.

²⁵ NICE Overview | Psychosis and schizophrenia in children and young people: recognition and management | Guidance | NICE

²⁶ Formulation young people.pdf (changingmindsuk.com)

²⁷ Understanding Psychosis and Schizophrenia (Revised) | BPS - British Psychological Society

²⁸ Case formulation-A vehicle for change? Exploring the impact of cognitive behavioural therapy formulation in first episode psychosis: A reflexive thematic analysis - PubMed (nih.gov)

²⁹ Positive and Negative Syndrome Scale - Wikipedia

The Commission's view is that where systematic mental state examinations or validated symptom questionnaires are used, the findings should be incorporated more readily into care plans to assist with ongoing assessment and treatment planning.

Non-engagement vs failure to engage

We thought at times what was taken as a choice not to engage was actually evidence of the treating team's failure to successfully engage Mr D, and behind this still, was the issue of his deteriorating mental state. We saw this most clearly in those periods when Mr D was not taking medications (e.g. between April and November 2017) and when his treatment with medication was sub-optimal (between September and December 2018). This pattern continued over time and as Mr D replaced each educational or work-related desired outcome with a new desired goal, there was no explicit revisiting of what he did not attain, and the factors behind this non-attainment such as under-treated psychosis. When we asked about this we were told only the smallest of goals were possible.

Symptoms taken at face value

Symptoms of psychosis were not always addressed as such by the treating team. Mr D reported 'visualising' and 'detoxing' with these behaviours taken at face value by some members of the team and seen as problematic and illness-related behaviour by others. Mr D's family also described his very restricted eating and drinking habits and other activities in which they saw the measure of his preoccupation with his beliefs and behaviours as a good indicator of how bad things were or conversely, where there was improvement.

The clinical notes record these symptoms very much at face value, without evidence of exploration of the existence of any delusional underpinnings and without comment on the impact <u>and risk</u> of extreme behaviours, some of which were seen as Mr D's choice to make. An exception to this was documentation by CPNs that he was at high risk of death by misadventure based on details of a concerning consultation with his GP.

The Commission's view is that where access to the mental state of a young person with psychosis is limited and they appear 'guarded' in what they share when interviewed by professionals it becomes even more important to draw on collateral information from family or carers, including their observations of the young person's preoccupations, behaviour and functioning.

Role of medication in treatment of psychosis in young people

Guidance for the pharmacological treatment of psychosis in children and young people is outlined in NICE clinical guideline 155³⁰ sections 1.3.18-1.3.19. Of relevance to this investigation is that "Treatment with antipsychotic medication should be considered an explicit individual therapeutic trial" and include attention to "side-effects tolerance, the indications and expected benefits and risks of oral antipsychotic medication, the expected time for a change in symptoms and appearance of side-effects, and a record made of the rationale for continuing, changing or stopping medication, and the effects of such changes."

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³⁰ Overview | Psychosis and schizophrenia in children and young people: recognition and management | Guidance | NICE

The British Association for Psychopharmacology (BAP) advocates a 'start slow, go slow' approach to initiate treatment with antipsychotics in young people and that if therapeutic levels cannot be reached with one type of antipsychotic then an alternative should be tried until two adequate trials of antipsychotic medication have been used³¹.

We saw evidence of good practice in the monitoring of physical side effects of medication and action taken in response to significant weight gain and metabolic side effects. Both Mr D and his family's views were taken into account and a dose reduction made which reduced the side effects of concern. Less prominence was given to the effects of dose reductions on his mental state. Mr D continued to request reductions in his medication up to and including his last outpatient review on 22 November 2018.

The SAER established the team was concerned about Mr D being on the low dose of antipsychotic medication, while his engagement with psychological therapies had fallen away (by then he managed around 20 minutes of one to one input). Mr D's family recalled on leaving the outpatient review of 22 November a member of the MDT told them they could call the team, as they had before, if things were to get worse.

Mr D was noted to have met the criteria for Clozapine treatment during his second admission under the 2003 Act after a year of illness, however, consideration of its use at the time did not progress to an initiation plan. Mr D's leave from hospital on suspension of the CTO on 2 March 2018 was undertaken without further planning for treatment with Clozapine as some benefit had been gained from the antipsychotic Olanzapine. In late March 2018, a few weeks before his 18th birthday, it was recorded in third party notes the treating consultant during his months as an inpatient was keen for a decision to be taken about treatment with Clozapine before he reached 18 years.

Over the months following Mr D's discharge from hospital, initially on a suspended CTO, his mental health deteriorated, and his parents, whose understanding was he had previously met the criteria for Clozapine treatment, repeatedly raised it for discussion between March and October 2018, including putting a request for this by email on 1 October 2018.

Our view is the response Mr D's parents received to this written request was insufficient. No reference was made in the notes to what the usual criteria for commencing Clozapine were or on what basis Mr D didn't meet these criteria other than to note he was engaged with therapies. Nothing was documented as to whether the decision would be reviewed or in what time frame a review would be appropriate. Given Mr D didn't always take the medication recommended to him both when an inpatient in hospital and when back at home and supervision of him taking medication wasn't always possible, it is understandable there was a degree of caution about starting him on Clozapine. However, there was limited documented discussion of what the alternative treatment options were, and how to progress with these, should his clinical presentation worsen. There was no specialist pharmacy input or second opinion obtained.

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³¹ Common practical questions – and answers – at the British Association for Psychopharmacology child and adolescent psychopharmacology course (bap.org.uk)

NICE clinical guideline 155 sets out steps to take when a young person with psychosis has not responded adequately to treatment:

- Review the diagnosis
- Establish that there has been adherence to medication
- Review engagement with and use of psychological interventions
- Consider other causes (substance misuse, concurrent medicines, physical illness).

The Commission's view is, as Mr D's adherence to medication treatment varied, more assertive approaches to gain better adherence, including the use of medication in injectable format, could have been considered. A more assertive approach in consultation with specialist pharmacy support and with appropriate safeguards in place may have improved Mr D's response to treatment.

NICE clinical guideline 155 sets out the following indication for Clozapine use:

"Offer Clozapine to children and young people with schizophrenia whose illness has not responded adequately to pharmacological treatment despite the sequential use of adequate doses of at least two different antipsychotic drugs each used for 6 to 8 weeks."

This requires careful consideration of the risk/benefit ratio of Clozapine initiation and a proactive approach to assessment and intervention from psychiatrists³². The NICE clinical guideline acknowledges Clozapine treatment in children and young people is an area for further research. However, there is some support from international research for the timely use of clozapine in young people with early onset psychosis (before the age of 18 years).³³

Given that between August and October 2018 the treating consultant did not support commencing Clozapine we think the offer of a second opinion to Mr D on his treatment at this point would have been justified. It is reasonable practise to offer young people and their family the option of discussion with a consultant psychiatrist colleague or a management-sourced independent clinician for further consideration of diagnostic and treatment issues about which there is disagreement or contention.

We appreciate it may be difficult to obtain a local second opinion in a small specialty such as CAMHS but as Mr D was already eighteen and was to transition to AMHS then the offer of a second opinion or advice from a consultant in general adult psychiatry would have been appropriate. The involvement of specialist pharmacists with expertise in treatment with Clozapine can be helpful when practical issues and the management of side effects and treatment compliance needs exploration with patients and families.

<u>adolescent psychopharmacology course (bap.org.uk)</u>
33 <u>Clozapine use in childhood and adolescent schizophrenia: A nationwide population-based study - PubMed</u>

(nih.gov) 2015

³² Common practical questions – and answers – at the British Association for Psychopharmacology child and adolescent psychopharmacology course (bap.org.uk)

Recommendation

The Royal College of Psychiatrists CAMHS faculty should explore with its members whether barriers exist to the use of Clozapine in young people who meet established clinical criteria for its use.

Potential of Mental Health Act powers not optimised

When Mr D's first STDC was revoked, treatment continued voluntarily as an inpatient before discharge home after successful periods on pass from the ward. In November 2017 following voluntary admission to hospital and then detention under a second STDC Mr D was placed on a compulsory treatment order (CTO) following a tribunal hearing. The 2003 Act paperwork, including the social circumstances report (SCR), made clear the severity of Mr D's illness and his limited and varying compliance with treatment, most particularly medication.

Mr D's CTO was reviewed in July 2018 at a regular MDT meeting at which Mr D, MHO A, Consultant D, Psychologist A, CPN B and subsequently his parents had input at various points. Mr D's family did not support the decision made, not to extend the CTO. When interviewed for the SAER and for this investigation some members of the MDT recalled they were surprised at this decision and offered to revisit it if requested. Mr D's family made clear their disappointment with and concerns about the decision not to extend the CTO and, when interviewed for the SAER and this investigation, were critical of the MDT for initially not having extended an invitation to the MHO to the meeting at which the CTO was reviewed.

When assessing whether a patient still meets criteria for compulsory powers, the presumption is always in favour of revoking the CTO unless the consultant, as RMO, is satisfied the criteria for continued detention are met. When assessing a patient against these criteria the RMO must be fully supported by and draw on the members of the MDT engaged in providing support and treatment and consult with the MHO and other persons the RMO deems appropriate such as carers. The RMO must consider if the active care plan represents the least restrictive environment in which the patient can safely be treated and evaluate the risks to the patient of the elements of compulsion being removed. When undertaking a mandatory review of a CTO subsequent options for the RMO include revoking the CTO, or making an application to the tribunal to extend or extend and vary the CTO.

A learning point for MDT members is if they are not in agreement with the RMO's view on detention or where there is a difference of opinion about care planning between senior medical staff or between professional disciplines within an MDT, particularly where there is recognised to be high risk of harm to the patient or others if compulsion is removed, there should be a clear mechanism to seek a second opinion and resolution.

Over-reliance on supervision by family versus inadequately responding to concerns

We saw evidence of a lot of involvement of Mr D's family in his treatment. Members of the MDT contacted his parents directly to arrange appointments with Mr D. Mr D's parents facilitated his attendance at routine clinic appointments when needed and, with his agreement, contributed feedback to MDT meetings on how he was progressing.

Mr D's family supervised medication when he would allow it including during his more acute periods of illness. When crises occurred, they acted decisively in seeking help. We noted there was an expectation Mr D's family would continue to raise the alarm in times of crisis but this was not matched with a robust crisis plan. On 3 December 2018 their request for an urgent assessment of Mr D was not fully met. This appeared to have occurred initially because of lack of availability of or clarity about medical staff cover arrangements and the requested assessment was then scheduled for the following day on the advice of duty medical staff.

We noted the parents' request for a change in Mr D's treatment, when progress appeared to have stalled, was turned down. In a conversation with the CPN Mr D's family expressed their dissatisfaction with the treatment plan and were encouraged to put their concerns in writing. They did so in a letter sent by email on 1 October 2018. The family's concerns included Mr D's ongoing illness symptoms, a request to consider clozapine treatment and they felt they were not being listened to.

Mr D's family met with members of the MDT on 4 October 2018. They believed the MDT discussed the content of their letter but were deeply disheartened when their suggestion about Clozapine treatment was not taken up. The absence of a written response to their letter compounded their sense that their concerns were not given due weight. Mr D's family were not offered support or advocacy in their own right, which they should have received as outlined in the Carers (Scotland) Act 2016³⁴ (the 2016 Act).

Service response to expression of dissatisfaction from family of a young person in receipt of treatment

The letter of 1 October 2018 from Mr D's family constitutes a complaint when compared with the SPSO's NHS Model Complaints Handling Procedure³⁵ definition, adopted by NHS A as follows:

A complaint is: "An expression of dissatisfaction by one or more members of the public about the board's action or lack of action, or about the standard of service provided by or on behalf of the board. A complaint may relate to: care and/or treatment."

The letter from Mr D's family was not framed as a complaint but it clearly outlined their dissatisfaction and should have been formally responded to as a complaint within five working days – 20 if complex - in keeping with the board's procedure. The jointly commissioned SAER made the same finding that "a written response should have been given".

The Commission's good practice guide on *Carers and confidentiality* ³⁶ gives advice for services on how to respond to concerns from carers about the care and treatment of their family members including young people and those whose capacity to make complex treatment decisions might be impaired.

35 The Model Complaints Handling Procedures | SPSO

³⁴ Carers (Scotland) Act 2016 (legislation.gov.uk)

^{36 2018} update_carers confidentiality_final_draft_16_oct_2018.pdf (mwcscot.org.uk)

Communication with primary care - response to concerns raised by GP

Mr D's GP was proactive in alerting the CAMHS-PS team by letter to their concerns about contacts made by Mr D which signified his mental state was leading to behaviours which could cause him physical harm.

How services communicate with primary care and respond to concerns raised by GPs is an important aspect of ensuring safety and reducing risk in the delivery of community based mental health care. One such GP letter about Mr D resulted in urgent contact with his CPN and a duty doctor, but no effective change to his treatment. A second letter, which described worrying behaviours, was not discussed with Mr D as the team had come to the view they did not have the authority to do so and the opportunity to explore what this meant and associated risks was missed.

Observations by the Commission

Overall, the Commission's view is the team met established key principles in the management of first episode psychosis in a young person³⁷ of flexibility, striving for autonomy and engagement, and the involvement of Mr D and Mr D's family in his treatment. This would have been greatly strengthened by: a more focused treatment model and plan with clearer treatment, social and educational goals; consistency in the systematic assessment of progress against these goals; and a clear crisis response plan. Better communication with Mr D's GP could have assisted the MDT respond to the new clinical information received while balancing patient confidentiality.³⁸ Greater credence could have been given to the family's concerns and their right to support and advocacy as outlined in the 2016 Act.

2. Risks associated with psychotic illness not coherently managed Good practice – psychosis is a condition with risks

The use of tools to assist in the identification and mitigation of risk for individual patients occurred across the mental health services sites accessed by Mr D. The response by NHS B's ward staff to Mr D's sudden physical deterioration was swift and the SAER found the emergency treatment provided ahead of his transfer to ICU was appropriate.

Observations by the Commission

Behavioural risks associated with psychosis were not coherently catalogued

The worrying behaviours Mr D exhibited when unwell were described contemporaneously in the case record across admissions and community treatment, and were summarised in two SCR reports produced by MHOs when treated under the 2003 Act. However, these behaviours were not consistently recognised as a feature of his psychotic illness by the CAMHS-PS team, or coherently linked in the assessment and management of risk at NHS B.

³⁷ Overview | Psychosis and schizophrenia in children and young people: recognition and management | Guidance | NICF

³⁸ Ethical and legal duties of confidentiality - professional standards - GMC (gmc-uk.org)

The more extreme actions evoked concern and sometimes assessment, but risk assessments focused on the moment(s) in question rather than the accumulation of a set of behaviours which could be predicted to recur or worsen when Mr D was unwell but which were also unpredictable in their level of impulsivity and dangerousness. It was Mr D's history of various actions driven by psychotic illness, along with lack of insight, that put him at risk of harm to himself, which was the greatest risk he posed (see section on response to concerns raised by GP). Routine risk assessment and management plans did not sufficiently capture that.

Mental health service managers should ensure that when providing training in risk management or revising risk management tools they include the importance of recognising the presence of active symptoms of psychosis and psychosis-driven unpredictable behaviours which could cause the individual physical harm. The presence of such symptoms warrants focus and mitigation, as is the case with identified risk of suicide or a history of previous suicide attempts for which there is evidence of greater risk of completed suicide in people with schizophrenia or bipolar disorder³⁹.

Staff awareness of uncommon medical emergencies associated with psychiatric inpatients such as water intoxication

In our discussion with a representative from NHS B we were told the initial concern about risk of physical harm to Mr D centred on the risk of delayed effects of possible water immersion when he had been missing from his home on the evening of 3 December 2018, some 48 hours before his admission, and his comments about having drank too much water were believed to be with reference to that.

From the NHS A notes it is clear Mr D returned from having gone to a local bridge on 3 December 2018 without his parents' knowledge and without having given an explanation of why he had gone there, but stating he had been in a body of water. Mr D arrived home dry, so doubt existed as to whether he had been immersed in water. Even so, this behaviour by Mr D was seen as concerning and possibly indicating suicidal intent. Two days later he again referred to this event, of having been in the water, in a text to his parents when already admitted to NHS B.

The risk assessment on admission to the adult psychiatry unit at NHS B included risk of self-harm and of absconding, and Mr D's history of seizures, but the potential for excessive drinking of water (which caused his previous seizures) was not brought forward into the risk assessment. It remained as a historical condition, listed in the admission letter, the detention papers, and in the information passed on by Mr D's parents.

Water intoxication, or the excessive intake of water pushing electrolytes outside safe limits, can occur in endurance sports, from MDMA use (the drug 'ecstasy'), or – as in Mr D's case – from 'psychogenic polydipsia'. The term psychogenic polydipsia applies where an underlying mental disorder leads to water-seeking and excessive drinking⁴⁰. Water intoxication with

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³⁹ Suicide risk after a suicide attempt | The BMJ

⁴⁰ Psychogenic polydipsia - Symptoms, diagnosis and treatment | BMJ Best Practice

resultant seizures due to the effects of dangerously low electrolytes preceded Mr D's first hospital admission under the 2003 Act in January 2017 following assessment in intensive care by the liaison psychiatry service and subsequent transfer to the CAMHS inpatient unit.

The SAER into Mr D's death was unable to answer the question posed by the Procurator Fiscal's Office and included in the terms of reference, of how much the treating staff at NHS B knew about water intoxication. In the BMJ Best Practice paper⁴¹ it is described as "commonly seen in people with psychiatric disorders particularly in those with schizophrenia". The references given to case reports go back decades and confirm the association between psychogenic polydipsia and severe mental illness and some treatments for mental illness.

Observations by the Commission

The Commission's view is the swift onset of physical deterioration and cardiovascular collapse and death could have happened in any inpatient site into which Mr D was received in the compromised circumstances in which his admission took place. Our conclusion therefore is learning on the topic of water intoxication and psychogenic polydipsia is relevant to all mental health services' staff.

In response to the SAER NHS B fulfilled an action point to disseminate relevant teaching locally on polydipsia and water intoxication. Information on this condition was included as one of a bundle of acute physical health scenarios that can present in psychiatric inpatients and pose an acute risk to individuals' physical health.

Our view is learning on the topic of polydipsia and water intoxication should be made available to all medical and nursing staff who care for people in psychiatric inpatient services.

The Commission added a summary 'Question and answer' scenario on water intoxication and the management of polydipsia in psychiatric settings to its own bank of materials from which Commission staff can draw when contacted by clinicians for advice.

Recommendations

Uncommon acute physical health scenarios can occur in patients in mental health inpatient services. To reduce the risk of harm, mental health service managers should ensure staff have information on recognising and responding to uncommon acute physical health scenarios including polydipsia⁴² and water intoxication. This may take the form of alerting staff to CPD opportunities to build and maintain competence and should be auditable.

In partnership with stakeholders, NES should support educational and workforce developments on the recognition of uncommon acute physical health scenarios which can occur in psychiatric inpatients including polydipsia and water intoxication and make this available nationally.

⁴¹ Psychogenic polydipsia - Symptoms, diagnosis and treatment | BMJ Best Practice

⁴² 'Polydipsia' is the term used to describe the drinking of excessive quantities of water

3. Problems in transition from child and adolescent to adult mental health services

Service design/redesign created gaps with unintended consequences

The positive relationship building referred to under clinical findings area 1 was subsequently undermined by service changes. Although services all strive to maintain continuity of individual therapeutic relationships wherever possible, several changes in the consultant or senior doctor directly responsible for Mr D's treatment (out-with the inpatient/outpatient consultant pairing) reduced continuity of care.

In addition, there was uncertainty around future arrangements for Mr D's treatment. The service model moved away from its adherence to NICE recommendation of 'three years with an early psychosis team irrespective of age at entry' to a cut-off in this arrangement at aged 18. Mr D was informed of this in a letter from the CAMHS service manager but a follow-up letter outlining what this change meant for him personally did not follow.

Mr D was given transition paperwork to complete and told a care plan would be drafted to help him transition to AMHS. Opportunities to discuss Mr D's transition to AMHS were taken up at contacts with individual practitioners and at MDT meetings with his parents present, but there was little detail in his case records and no formal referral made to the receiving AMHS community team. Mr D was urgently admitted to a neighbouring health board two weeks before the planned transition meeting with AMHS, and died just a few days beforehand, at which stage no transition documentation personal to him had been completed or shared.

Once it was clear Mr D would transition across to the care of adult mental health services (AMHS) the process of linking with his new team should have commenced. Although his parents recall expecting to see someone from AMHS at some of his MDT meetings we learned formal contact had not been made until late November 2018.

Observations by the Commission

Guidance on transitions between children's and adult services for young people using either health or social care in the UK published by NICE in 2016⁴³ highlight support for transition should be developmentally appropriate, strengths based and person centred, holistic, and fully involve each young person in the transition process, taking full account of their views. The point of transition should take place at a time of relative stability for the young person and a named worker should co-ordinate their transition support. Involved organisations should have overarching structures to support transition processes with oversight from both senior executive and senior management level, of transition policies for the organisation and the implementation of these on the ground.

Mr D's transition to AMHS should have been carried out in keeping with the national Principles of Transition for young people moving from CAMHS to AMHS services in Scotland⁴⁴ issued in August 2018, at the time when transition for Mr D was being discussed. The national

⁴³ https://www.nice.org.uk/guidance/ng43

⁴⁴ Principles of Transition (www.gov.scot)

Principles of Transition in Scotland draw on the 2016 NICE guidance and reflect the NICE Clinical guideline for treatment of Psychosis in Young People⁴⁵ in which it states:

"Anticipate that withdrawal and ending of treatments or services, and transition from one service to another, may evoke strong emotions and reactions in children and young people with psychosis or schizophrenia and their parents or carers. Ensure that such changes, especially discharge and transfer from CAMHS to adult services, or to primary care, are discussed and planned carefully beforehand with the child or young person and their parents or carers, and are structured and phased."

The national Principles of Transition in Scotland are supported by a Transition Care Plan and Guidance, and a Care Plan Evaluation Form⁴⁶. They include an emphasis on the broad range of support needed by young people, the importance of maintaining important relationships and of considering housing, educational and employment needs when coordinating a holistic approach to transition. The Principles of Transition also outline that if a decision is made to delay transition from CAMHS then there should be an explicit agreement about how the young person can access unscheduled care so they are not disadvantaged by remaining under the care of CAMHS⁴⁷.

From our discussions with staff and Mr D's family we believe he had mixed feelings about transferring to AMHS services and would have preferred to be independent of mental health services altogether. Even so, our conclusion is preparation for Mr D's transition to AMHS was not well enacted over the eight months it was discussed with him by members of the MDT and contributed to a confused service response when assistance was sought in a crisis.

We see this as a systems failure most likely due to the specific set-up and rapid service reorganisation, which was underway at the time, however we will ask NHS A for an assurance that barriers to effective transition between CAMHS and AMHS for young people with a diagnosis of psychosis have been eliminated.

Recommendation

NHS A should audit their compliance with the now established Principles of Transition in Scotland⁴⁸ in the care of child and adolescent patients with a diagnosis of psychosis who require ongoing treatment and transition to adult mental health services and demonstrate that robust and clear processes are in place.

⁴⁵ Overview | Psychosis and schizophrenia in children and young people: recognition and management | Guidance | NICE (p11 para 1.1.24)

⁴⁶ Transition Care Plans | NHS inform

⁴⁷ Principles of Transition (www.gov.scot) p2 para1.

⁴⁸ Principles of Transition (www.gov.scot)

4. Team dynamics and effect on patient care and safety

The SAER identified that team dynamics at NHS A negatively impacted the delivery of care to Mr D by impeding communication and clinical decision-making within the CAMHS-PS team, and recommended NHS A address this.

In the process of this investigation the Commission established that in response to the SAER's findings significant changes were made by senior management to the service structure and model of care, and there was much individual reflection and management oversight. The Commission noted there had been concern among staff about working relationships within the team and as it is an area of importance for patient safety and staff wellbeing, some commentary and follow up is appropriate.

Observations by the Commission

The Commission's view is poor team dynamics not only affects the quality of care and treatment experienced by patients and their representatives, it also impacts on safety and steps to address poor team dynamics should be robustly implemented and monitored.

Psychologically safe working for staff is particularly important in mental health care where recovery-oriented approaches rely on the collaborative efforts of multidisciplinary teams to make complex decisions.

Research underpins the importance of local leadership behaviours to enhance psychological safety; these behaviours include transformational leadership, leadership inclusiveness, managerial openness, trustworthiness and behavioural integrity⁴⁹. Teams must also be supported at operational level in their decision-making including having clear routes to obtain second opinions when clinical decisions are not mutually agreed upon.

The Commission will ask NHS A for a further update on how they identify and respond to the needs of teams where issues such as individual communication styles, or difficult relationships are impacting on team dynamics, particularly in CAMHS services.

5. Problems in the inter-board transfer of an acutely ill young person Sharing of key clinical information when patients transferred out of area

Among the issues raised by the SAER review team and in the Commission's investigation was the question – 'Why was this acutely ill (young) patient transferred to another health board for admission?'

The SAER explored the availability of admission beds at NHS A and confirmed the service was under immense pressure at the time of Mr D's emergency admission, and on the evening of his admission there were patients admitted to units out of the board area. Mr D's family raised

⁴⁹ Enhancing psychological safety in mental health services. Hunt et al. International Journal of Mental Health Systems, 2021, 15:33

their concerns with the Commission about the lack of available beds. We are aware of work done by NHS A around this time, which subsequently improved bed availability.

The National Confidential Inquiry into Suicide⁵⁰ lists among its 10 key elements for safer care for patients the importance of avoiding out of sector admissions where possible:

"Very ill patients should be accommodated in a local in-patient unit. Being admitted locally means that patients stay close to home and the support of their friends and family, and are less likely to feel isolated or to experience delayed recovery. Local admission should also result in simpler discharge care planning."

Observations by the Commission

To transfer an unwell young man with a complex clinical history to another board area during the night was a high-risk action. The service had no other viable option available to them on the night in question. However, the absence of a consultant to consultant discussion about Mr D's transfer, out of hours, from Board A CAMHS psychosis service to Board B AMHS inpatient service also contributed to the failure to impart and properly document key clinical information in a timely manner which, had it been available to treating staff from the outset, may have contributed to a different outcome.

We note that following their joint review of this incident both boards took decisive action to revise and firm up the implementation of their out of hours admissions and boarding patients policies and protocols. We also note the SAER recommended that at NHS Scotland level, agreement is reached on principles to be applied when transferring patients between health board areas. The Commission's view is this recommendation should now be taken forward by Scottish Government.

Recommendations

Mental health service managers should ensure they have robust local procedures in place for the acute or planned transfer of patients between services and between health boards, staff are aware of the local requirements and safeguards required, and audit their implementation.

Considering the different digital record systems across mental health services in NHS Scotland, the Scotlish Government should set standards within the next six months for the safe transfer to, or management of patients who present from other health boards, including minimum standards for information sharing and use of a standardised form.

Clinical record keeping post-admission

Not all of the clinical and historical information received from the transferring board and Mr D's family was conveyed to the receiving board's ward-level working casefile. Mr D's original casefile did not accompany him to NHS B and remained 'lost' over the 70 hours of his admission to the neighbouring board. The absence of Mr D's NHS A casefile containing available pertinent information on his illness and treatment meant the initial admitting staff

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⁵⁰ NCISH | The University of Manchester

had to work from transfer documents and did not have the opportunity to review, digest, and draw from the original casefile when carrying out their initial assessments of Mr D.

In the absence of Mr D's NHS A casefile, there were several points at which key information was relayed to NHS B about Mr D's clinical history. The joint SAER explored this in detail. We revisited this in our review of the casefiles and in discussions with NHS B. We were told of the assessments which were made of Mr D by the receiving consultant psychiatrist – who themselves did not ordinarily work from the ward into which Mr D was placed – accompanied by a higher trainee (doctor) in psychiatry and nursing staff. Mr D's admission occurred the day after the usual weekday on which the ward's formal MDT meeting was held, which further reduced the opportunity for formalised MDT discussion and communication, but face to face consultant-led assessment of Mr D alongside nursing staff occurred twice.

Detailed background information was passed to the consultant psychiatrist in person and by phone by Mr D's family. An email was sent to the consultant psychiatrist from a doctor in the CAMHS Team at NHS A containing relevant clinical detail, and a phone-call made to the ward by the CPN from NHS A, each emphasising concern for Mr D's mental state.

The Commission's view is that whilst there was active seeking and imparting of information this fell short on three aspects. Crucially, it did not make up for the absence of Mr D's original clinical casefile from NHS A, but also fell short as the information conveyed was not recorded into the NHS B ward-level accessible case file, either as detailed and clear contemporaneous notes, or as a comprehensive update of the risk assessment made on Mr D's admission.

Risk assessment and management

The joint SAER concluded that risk assessment documentation from both health boards was not of a good standard. It was noted there was no clinical risk assessment completed in NHS A at the time Mr D's transfer was initiated on 4 December 2018. We agree the risk assessment documentation completed on admission to NHS B did not adequately detail Mr D's historical risk of psychosis-driven behaviours. Additionally, there was a lack of clear communication of past and present risks within the multidisciplinary teams, both in CAMHS – PS at NHS A and in the AMHS inpatient ward at NHS B.

Following the SAER both health boards were tasked with improving the 'reliability and regularity of risk assessment updates as new information becomes available in order to optimise the multidisciplinary team's shared understanding of risk' and NHS A was required to 'develop risk assessment prior to transfer' as this had not been a routine element of the existing transfer protocol and to improve the reliability of transfer of patient information.

Observations by the Commission

The Commission's view is failure to transfer the clinical casefile and problems with the standard of contemporaneous note-keeping and risk assessment documentation led to missed opportunities for safer risk management in the delivery of Mr D's care and treatment at NHS B and potentially a safer outcome.

Had the historical risks been more consistently outlined and there been a clearer understanding of the link between Mr D being acutely unwell and engaging in psychosis-driven

harmful behaviour such as excessively drinking water, then mitigations might have followed. The significance of him flooding his room on two occasions and referring to having drank too much water might have been recognised and acted upon.

The reliable transfer of patient casefiles and the importance of keeping up to date, accessible, contemporaneous notes and care-plans including in electronic format, which make clear when new information is added, cannot be overstated and has been highlighted in a previous Commission good practice guide⁵¹. This extends to case note entries and correspondence made after a patient's death.

6. The SAER process and duty of candour responsibilities conducted across two boards

Good practice - conducting an SAER across two boards

We asked the SAER reviewers about their experiences of working jointly on their review. There were many positives – the opportunity to see at close hand how other services operate and to learn from respective approaches to undertaking SAERs was clearly valued. Helpful reflection was offered as to how the joint significant adverse event review of Mr D's care and treatment could have been conducted better such as the review team coming together more, jointly writing the report and accepting joint ownership of the report's findings.

The Chair maintained communication with Mr D's family and all relevant staff were included and kept informed, however the potential for subsequent shared or individual board-level actions was adversely affected by restrictions due to the Covid-19 pandemic.

Engagement with family unbalanced

We were told by Mr D's family of their experience of being presented with the SAER report and having the contents explained to them. Their view was the report got to a number of the key details of the care and treatment which was provided to Mr D which, had they been done differently, may have effected a different outcome. The report was presented to them by the SAER Independent Chair with management representatives of both boards present. They observed that when outlining the conclusions, one board appeared to explain away a finding in the SAER report.

Mr D's family felt had the services any doubt about a finding from the SAER then this should have been resolved ahead of the report being issued to them. The Commission agrees it was inappropriate for a service to present a qualified view of a finding from the SAER at that point. This affected the family's sense of the boards' 'buy-in' to the SAER findings and associated learning.

Divergence of action plans post-event

It was suggested to us by staff who conducted the SAER that in future scenarios where two care-delivery sites or services jointly undertake an SAER, the process should clearly identify

⁵¹ PersonCentredCarePlans_GoodPracticeGuide_August2019.pdf (mwcscot.org.uk)

where there were care-delivery failings and assign the reporting of these as separate reports, which can then be brought together and responded to. The divergence between the boards of action plans following this SAER, with each focused on a sub-set of the findings limited the scope and reach of the learning opportunities.

Observations by the Commission

For learning to be effective both boards should accept the learning points in totality. Mr D's admission and the risky psychosis-driven behaviour which led to his death could have occurred at any inpatient site where staff, if working with a boarded-in patient in the absence of key clinical details, might similarly fail to recognise the significance of observed behaviour.

The Commission will ask NHS A and B for a further update on the action plans they implemented in response to the SAER to ensure commitments therein have been met and account taken of all learning points from the SAER and this investigation.

Staff involvement and support limited in Board A

We were struck by the difference between staff from the two boards in their experience of Significant Adverse Event Reviews. We were told staff in NHS B had been offered support around the event and had known about the SAER review process and spoke about the process in positive terms. Staff in NHS A were less well informed and had limited knowledge of the SAER's findings or those of a previous SAER report for this service, following which recommendations had led to a change in clinical processes.

The National Framework for Scotland: Learning from adverse events through reporting and review includes in its overarching principles the 'just culture' approach, which supports staff to recognise, report and learn from adverse events⁵².

Recommendation

NHS A to ensure staff are sufficiently aware of and supported during the process of an SAER involving their care area or patients under their care.

Organisational duty of candour⁵³ obligations not fully addressed

All health and care professionals must be open and honest with patients in their care when something goes wrong that has caused them harm or has the potential to do so. This is known as professional duty of candour. Regulatory bodies such as the General Medical Council the Nursing and Midwifery Council and the Health and Care Professions Council provide guidance for staff in how to respond when things go wrong. ⁵⁴, ⁵⁵ The professional duty of candour (DOC) obligation to offer, as soon as possible, an explanation and an apology to Mr D's family was discharged in person at the time of Mr D's death by General Adult Consultant E NHS B, letters offering condolences and explaining there would be a review were sent by Clinical Directors from both boards, and some staff offered their sympathy directly to Mr D's parents.

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^{52 20191216-}AE-framework-4th-Edition (2).pdf p8

⁵³ The Duty of Candour Procedure (Scotland) Regulations 2018 (legislation.gov.uk)

⁵⁴ Openness and honesty when things go wrong: the professional duty of candour (nmc.org.uk)

⁵⁵ The duty of candour | (hcpc-uk.org)

The opportunity to discharge organisational duty of candour responsibilities was compromised in the meeting with Mr D's family to discuss the SAER findings as in their opinion one board came across as defensive. Our view is the more appropriate response was for both boards to have provided a co-ordinated and unqualified apology for actions identified as having contributed to the death of Mr D.

The organisational duty of candour non-statutory guidance⁵⁶ published by Scottish Government makes clear that although it is the legal responsibility of the board in which an incident occurred to fulfil the legal responsibilities, it is not unusual for more than one organisation to be involved in the provision of healthcare, therefore "all parties are expected to co-operate fully throughout the duty of candour procedure and share lessons learned and necessary actions identified by the procedure".

Observations by the Commission

We believe an apology needs to be fulsome and meant for it to provide families with the reassurance their views and concerns were taken seriously and that lessons would be learned which could reduce the likelihood of recurrence.

Recommendation

Both NHS A and NHS B must complete their responsibilities under organisational duty of candour to offer an explanation for Mr D's unexpected death and an apology where indicated, and ensure local policies fully reflect Scottish Government's non-statutory guidance⁵⁷.

All health boards must raise awareness among staff of the organisation's obligations under duty of candour and related local policies. This should include a focus on organisational duty of candour when training staff to undertake SAERs and especially the requirement for a full apology (which is not the same as an admission of liability or blame).

⁵⁶ Organisational duty of candour: guidance - gov.scot (www.gov.scot)

⁵⁷ Organisational duty of candour: quidance - gov.scot (www.gov.scot)

Conclusion

The investigation concluded there were aspects of the care and treatment delivered by each board that had they been conducted differently might have prevented Mr D's death while detained under the 2003 Act. A more assertive approach to the treatment of Mr D's psychotic illness in the two years before his death was warranted. The failure to impart key clinical details to the treating ward staff during his final admission both in the provision of all relevant casefiles and the creation of an informed and updated risk assessment and care plan meant Mr D was able to engage in risky and ultimately fatal psychosis-driven behaviour (the consumption of excessive amounts of water) without mitigations having been put in place.

The findings and learning points are of relevance to NHS and social work across Scotland which is why we are publishing this investigation report. Acknowledgement must also be given to the difficulties staff face when service delivery arrangements are undergoing change, where service structural arrangements introduce added barriers to the timely and effective delivery of care, and where difficulties exist in accessing inpatient beds when urgently needed – whatever the reasons behind this.

The Commission recognises many of the learning points from this case are not novel, for example, the importance of maintaining good standards of treatment, note-keeping and risk assessment and risk management. However, by bringing together the learning points in addition to the recommendations for both boards, we are highlighting the importance of monitoring and maintaining already established evidence-based standards of good practice, and that boards and individual clinicians should regularly assess and reflect on their collective and individual performance against established standards of care.

Appendix 1 - Glossary

2003 Act – Mental Health (Care and Treatment) (Scotland) Act 2003 – the provisions of this act are intended to ensure that care and compulsory measures of detention can be used only when there is significant risk to the safety or welfare of the patient or other people.

AMHS – adult mental health services - these services assess and treat people aged 18-64 who have mental illness.

ASD – autistic spectrum disorder – is a developmental disability of uncertain cause that affects the brain and how it works. People with ASD often have problems with social interaction.

BAP – British Association for Psychopharmacology – promotes research and education in drug treatments for mental disorders, bringing together people in academia, health services and industry.

BFT - behavioural family therapy – an evidence-based approach to promote positive communication, problem-solving skills and stress management within families.

BMJ – British Medical Journal – a weekly peer-reviewed medical journal.

Care manager – employed by a HSCP to assess care and support needs for people and work with them and their families to arrange how these needs are met.

CAMHS – child and adolescent mental health services – provide mental health assessment and treatments to young people in the age range up to 18 years.

CAMHS-PS –child and adolescent mental health service (psychosis service) - a team which works specifically with young people with a diagnosis of psychosis.

CBT – cognitive behavioural therapy – a talking therapy that can help to manage problems by changing thoughts and behaviours.

CPD – continuing professional development – the process of tracking and documenting skills, knowledge and experience and used as a record of learning.

Crisis team - provides short-term intensive community based care as an alternative to hospital admission for people who are experiencing a mental health crisis.

DIDR – Death in Detention Review –a review by the Commission on the recommendation of the Scottish Government of deaths of people detained under the Mental Health Act.

DNA – did not attend; did not turn up for a planned clinical meeting.

Depot injection – a long-acting injection (of antipsychotic medication) given at 2-4 week intervals as maintenance treatment of psychotic illness.

Discharge coordinator – Member of health staff responsible for coordinating the discharge of patients from hospital.

DoC - duty of candour— organisational duty of candour is a legal duty that sets out how organisations should tell those affected that an unintended or unexpected incident appeared to have caused harm or death. Organisations are required to apologise and to involve those affected in a review of what happened. Professional duty of candour applies to professionals in health and social care and encourages openness when things go wrong.

HSCP - health and social care partnership - organisation formed as part of the integration of health and social care services provided by NHS boards and local authorities; jointly run by the NHS and local authority.

ICU - intensive care unit in an acute hospital.

MDT – multidisciplinary team meeting – a meeting at which professionals from various disciplines contribute to decisions about the assessment and treatment of individuals.

MHO - Mental Health Officer – A specialist social worker with additional training, who has specific roles under mental health and adults with incapacity legislation.

MSE - mental state examination – A detailed and structured examination of a person's current state of mind including symptoms and behaviour that might indicate the presence of mental illness.

NES – NHS Education for Scotland – the education and training body for NHS-Scotland.

OOH— out of hours service in mental health services. Available when patients are in mental health crisis out with usual working hours.

OP – outpatient department – part of a hospital designed for the treatment of outpatients, people with health problems who visit the hospital for diagnosis or treatment, but do not require a bed or to be admitted for overnight care.

OT – occupational therapist - helps people of all ages overcome challenges completing everyday tasks or activities (referred to as 'occupations').

Practitioners – professionals such as social workers, nurses, occupational therapists, physiotherapists etc.

RMO - responsible medical officer - a consultant psychiatrist in charge of patients' treatment.

SAER – significant adverse event review – carried out by NHS boards following events that have resulted in unexpected death or harm. These analyse factors that have contributed to the circumstances of the adverse event and make recommendations for change and learning.

SCR – social circumstances report –a statutory report by a mental health officer that examines the interaction of an individual's social and family circumstances with their mental health condition, when planning care and treatment under the 2003 Act.

Service manager – senior member of HSCP staff who has responsibility for a particular part of HSCP service.

SPSO – Scottish Public Services Ombudsman – the public body that handles the final stage for complaints about the NHS and local authorities.

SPSP – Scottish Patient Safety Programme – a national quality improvement programme that aims to improve the safety and reliability of care and reduce harm to patients.

STDC – short term detention certificate – the preferred 'gateway order' of the Mental Health Act 2003 when a person needs compulsory care and treatment in hospital against their will and can last for up to 28 days.

Team leader - member of HSCP staff; would usually report to service manager. A team leader can be from any professional discipline.



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Mental Welfare Commission 2023