An independent investigation into the care and treatment of a mental health service user James in Essex

November 2020

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Our Report has been written in line with the terms of reference as set out in the Terms of Reference on the independent investigation into the care and treatment of James. This is a limited scope review and has been drafted for the purposes as set out in those Terms of Reference alone and is not to be relied upon for any other purpose.

Events which may occur outside of the timescale of this review will render our report out-of-date. Our Report has not been written in line with any UK or other (overseas) auditing standards, we have not verified or otherwise audited the information we have received for the purposes of this review and therefore cannot attest to the reliability or accuracy of that data or information.

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1 Executive Summary

1.1 NHS England, Midlands & East commissioned Niche Health and Social Care Consulting (Niche) to carry out an independent investigation into the care and treatment of a mental health service user, James. Niche is a consultancy company specialising in patient safety investigations and reviews.

1.2 The independent investigation follows the NHS England Serious Incident Framework[1] (March 2015) and Department of Health guidance[2] on Article 2 of the European Convention on Human Rights and the investigation of serious incidents in mental health services. The terms of reference for this investigation are given in full in Appendix A.

1.3 The main purpose of an independent investigation is to ensure that mental health care related homicides are investigated in such a way that lessons can be learned effectively to prevent recurrence. The investigation process may also identify areas where improvements to services might be required which could help prevent similar incidents occurring.

1.4 The underlying aim is to identify common risks and opportunities to improve patient safety and make recommendations for organisational and system learning.

1.5 On the evening of 15 December 2017 James killed his partner Heidi by stabbing her multiple times.

1.6 We would like to express our condolences to the families. It is our sincere wish that this report does not add to their pain and distress and goes some way in addressing any outstanding issues and questions raised regarding the care and treatment of James.

Mental health history

1.7 Mental health care was initially provided to James by North Essex Partnership NHS Foundation Trust (NEPT). This Trust merged with South Essex Partnership University NHS Foundation Trust in April 2017 to form Essex Partnership University NHS Foundation Trust (EPUT). References to 'the Trust' should be seen as referring to NEPT up to April 2017, and EPUT thereafter.

1.8 James described the onset of mental health issues when he was 17 and he started taking illicit substances to overcome being bullied at school, and said his mental health worsened when he moved to University to study geography and continued to take illicit drugs. His first presentation to mental health services was in 2000, aged 19 when he was admitted voluntarily to an acute inpatient unit in Harlow for two weeks. The diagnosis at the time was drug

[1] *NHS England Serious Incident Framework March 2015. https://www.england.nhs.uk/wp-content/uploads/2015/04/serious-incident-framwrk-upd.pdf*

[2] *Department of Health Guidance ECHR Article 2: investigations into mental health incidentshttps://www.gov.uk/government/publications/echr-article-2-investigations-into-mental-health-incidents*

induced psychosis. After discharge he was referred to Harlow community mental health team (CMHT). Following an assessment, it was concluded that James was not showing evidence of a psychotic disorder but was struggling to cope with various stresses in his life.

1.9 He had four admissions to hospital between 2006 and 2008 and received treatment in the community for the following 10 years. Although there were changes of psychiatrist during his care under Harlow CMHT, he had the same care coordinator from 2008 to 2017.

1.10 James had a diagnosis of:

- F10.26 Mental & Behavioural disorder due to the use of alcohol;
- F20.0 Paranoid Schizophrenia
- F41.1 Generalised Anxiety Disorder

1.11 He received psychological therapy and medication for his mental health issues, including being treated with clozapine[3] from 2008 along with other antipsychotic medication.

1.12 Heidi and James had been in a relationship since 2007 and had lived together in their flat at first in Harlow and since May 2017 in Braintree.

1.13 Heidi supported James at mental health service meetings about his care and was noted to be his carer.

1.14 James and Heidi moved to Braintree in May 2017, and his care was transferred to a new team in October 2017. Shortly after this he had blood test results which meant that clozapine had to be discontinued (known as a 'red result, see paragraph 1.28) and he was advised to increase his other medication (quetiapine)[4] until clozapine could be reinstated.

1.15 Over the next few weeks there were changes in his mental state which indicated he was relapsing.

1.16 On 15 December 2017 James was found to have stabbed Heidi at their flat and was arrested. Heidi died at the scene.

1.17 James was found unfit to plead in January 2019 and was given a hospital order under Section 37 of the Mental Health Act 1983,[5] with a Section 41 restriction on discharge. He remains in a secure mental health hospital.

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[3] *Clozapine is prescribed for the treatment of schizophrenia in patients unresponsive to, or intolerant of, conventional antipsychotic drugs. https://bnf.nice.org.uk/drug/clozapine.html*

[4] *Quetiapine is prescribed for the treatment of schizophrenia. https://bnf.nice.org.uk/drug/quetiapine.html*

[5] *Mental Health Act 1983 Section 37: Powers of courts to order hospital admission or guardianship, Section 41: restriction on discharge. https://www.legislation.gov.uk/ukpga/1983/20/section/37*

Internal investigation

1.18 The Trust conducted an internal serious incident investigation which was completed in October 2018 and adjusted after family comments in May 2019.

1.19 The internal investigation made four recommendations:

- When a known patient under CPA shows significant relapse signatures, a review of the current care plans ought to be carried out in order to establish whether the patient will benefit from new interventions and additional support from different disciplines.
- When there is a transfer of care between teams, the transition needs to be clear and done in a timely manner in order to optimise opportunities to develop therapeutic relationship
- The allocation of care coordination of patient needs to be delegated according to the need of the patient.
- When a patient history demonstrates inadequate symptom control despite the use of combinations of anti-psychotics, medical reviews should aim at collaboratively working with the patient to promote insight into how treatment with medication needs to be optimised when one of the anti-psychotics is stopped.

1.20 A review of the internal investigation has been carried out, detailed below at Section 6.

Independent investigation

1.21 This independent investigation has been conducted in co-operation with the Domestic Homicide Review (DHR) into the death of Heidi, which has been commissioned by Braintree Community Safety Partnership. We have reviewed the internal investigation report and studied clinical information and policies. The team has also interviewed staff who had been responsible for James's care and treatment and spoken to his current responsible clinician.

1.22 The investigation was carried out by Dr Carol Rooney, Associate Director, Niche, with expert advice provided by Dr Huw Stone, consultant forensic psychiatrist. The investigation was supervised by Nick Moor, Partner, Niche.

1.23 From our analysis of the issues we have identified eight findings in relation to care and service delivery issues. These have been synthesised into three overarching themes: patient care, service delivery and Trust oversight. and Accordingly we have made seven recommendations.

Findings and recommendations

1.24 It is clear that James had a serious mental illness that was treated over many years by the Trust. He was never symptom free but had access to medical and psychological care which supported him to maintain a level of wellbeing and independence. He was provided with consistent care by CCO1 for over 10 years.

1.25 He continued to abuse alcohol until October/November 2017, and his engagement with psychological care tended to focus on coping skills rather than attitude change. He continued to question his diagnosis and suffered ongoing anxiety as a consequence of his paranoia.

1.26 James had a supportive partner and family who provided emotional and practical assistance. He was able to maintain independent living with his partner, although the choices he made about the use of alcohol could be said to be unwise.

1.27 The move to the Mid Essex team took place months after they moved house, and this was largely because of James' anxiety about change. The handover was not structured and was not supported by a full care plan and risk assessment review. Because of service changes, he did not have a medical review between September 2016 and October 2017.

1.28 The management of the cessation of clozapine following the 'red result'[6] in October 2017, did not in our view offer sufficient support to James and Heidi. It was recognised that he was relapsing in November and December 2017, and we consider this should have triggered MDT discussion, and a clear care and risk management plan that considered the presenting risks.

1.29 A thematic diagram of the issues is at Appendix E.

1.30 We have listed below the findings that we have developed through our analysis of the care and service delivery issues. We have made the following seven recommendations to improve patient care accordingly.

[6] *A clozapine 'red result' requires further testing to be carried out, and a review of the prescription. of clozapine.*

Finding 1

Family education and interventions; as in NICE guidance '*Psychosis and schizophrenia in adults: prevention and management (2014)*'; was not provided by the Trust

Finding 2

An up to date risk assessment with risk mitigation plans was not undertaken in either specialist psychosis teams.

Finding 3

Systems to manage escalation in a patient's risk with respect to the need for potential admission to inpatient mental health beds were unclear.

Finding 4

Service changes contributed to a lack of timely CPA[7] and medical review in Harlow in 2017.

Finding 5

The transfer of care between teams was not carried out in a timely manner, with appropriate detailed handover and plans for continuity of care.

Finding 6

After the sudden cessation of clozapine, neither appropriate professional monitoring of physical health or education and guidance for service users and families were provided.

Finding 7

Recording of clinical information was not carried out consistently within and between teams.

Finding 8

The serious incident investigation report did not meet the timeliness standards expected by NHS England guidance, although an extension had been agreed by the CCG.

[7] *The Care Programme Approach (CPA) is a package of care for people with mental health problems. https://www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/care-for-people-with-mental-health-problems-care-programme-approach/*

Theme 1 Patient care

Recommendation 1

The Trust must ensure that NICE guidance for the care and treatment of patients with psychosis is adhered to, including specific reference to structured family education.

Recommendation 2

The Trust must revise their clozapine administration guidance to include the education of patients and families, and the management of risk if clozapine is stopped suddenly.

Theme 2 Service delivery

Recommendation 3

The Trust must ensure that community teams have structures and processes to ensure that the CPA policy is adhered to, and systems in place to monitor compliance.

Recommendation 4

The Trust must provide clarity about protocols and responsibilities with respect to responding to increased need for interventions, zoning, and the process for considering and effecting inpatient admissions from the community.

Recommendation 5

Standards for note keeping must be monitored by the Trust, to include how medical consultations are recorded.

Theme 3 Trust oversight

Recommendation 6

When going through large-scale service changes, the Trust must ensure that risks to patient care are assessed, documented and mitigated.[8]

Recommendation 7

Serious incident investigation reports must meet the timeliness standards expected by NHS England guidance.

[8] *We suggest using the Quality Impact Assessment methodology as proposed by the NHS National Quality Board "HOW TO: Quality Impact Assess Provider Cost Improvement Plans".*

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212819/How-to-Quality-Impact-Assess-Provider-Cost-Improvement-Plans-.pdf

2 Independent investigation

Approach to the investigation

2.1 The independent investigation follows the NHS England Serious Incident Framework[9] (March 2015) and Department of Health guidance[10] on Article 2 of the European Convention on Human Rights and the investigation of serious incidents in mental health services. The terms of reference for this investigation are given in full in Appendix A.

2.2 The main purpose of an independent investigation is to ensure that mental health care related homicides are investigated in such a way that lessons can be learned effectively to prevent recurrence. The investigation process may also identify areas where improvements to services are required which could help prevent similar incidents occurring.

2.3 The overall aim is to identify common risks and opportunities to improve patient safety and make recommendations about organisational and system learning.

2.4 The investigation was carried out by Dr Carol Rooney, Deputy Director, with expert advice provided by Dr Huw Stone, Consultant Forensic Psychiatrist.

2.5 The investigation team will be referred to in the first-person plural in the report.

2.6 The report was peer reviewed by Nick Moor, Partner, Niche.

2.7 The investigation comprised a review of documents and interviews, with reference to the National Patient Safety Agency (NPSA) guidance.[11]

2.8 NHS England made contact with James's clinical care team at the start of the investigation, explained the purpose of the investigation and sought his consent to access the relevant records. James's clinical team confirmed he was unable to respond and therefore NHS England sought consent from the Trust Caldicott Guardian for his records to be released for this investigation.

2.9 We used information from the Trust, and James's GP surgery to complete this investigation.

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[9] *NHS England Serious Incident Framework March 2015. https://www.england.nhs.uk/wp-content/uploads/2015/04/serious-incident-framwrk-upd.pdf*

[10] *Department of Health Guidance ECHR Article 2: investigations into mental health incidentshttps://www.gov.uk/government/publications/echr-article-2-investigations-into-mental-health-incidents*

[11] *National Patient Safety Agency (2008) Independent Investigations of Serious Patient Safety Incidents in Mental Health Services*

2.10 As part of our investigation we held a group meeting, which included:

- Care coordinator, West area team
- Consultant psychiatrist, Mid area team
- Social work lead, Mid area team
- Advanced Nurse Practitioner, Specialist Psychosis Service, Mid area team
- Clinical Manager Specialist Psychosis Service, Mid area team
- Clozapine clinic nurse
- Head of Safeguarding, EPUT

2.11 A full list of all documents we referenced is at Appendix B, and a full chronology is at Appendix C. Appendix D lists questions for the independent investigation provided by James' family after the internal report, and our responses.

2.12 We have adhered to the Salmon and Scott principles as outlined below:

'The Salmon Process is used by a public Inquiry to notify individual witnesses of potential criticisms that have been made of them in relation to their involvement in the issue under consideration. The name derives from Lord Justice Salmon, Chairman of the 1966 Royal Commission on Tribunals of Inquiry. The Salmon Report set out general principles of an adversarial process for conducting an inquiry, similar, in essence, to what may be expected in a court of law. However it was recognised by Lord Justice Scott, during his 1992 inquiry into the sale of arms to Iraq, that it is not practicable or appropriate in all cases to conduct an inquiry with a full adversarial process. Whilst recognising that it is proper that all witnesses must be able to adequately present their evidence, and have access to legal advice if required, it is not necessary to allow a full process of examination and cross-examination by legal counsel in order to achieve fairness in the course of proceedings. In many cases, the financial and logistical implications of such a process would have a significant detrimental impact on the ultimate aim of the inquiry; to reach conclusions on the issue under consideration'.

2.13 The draft report was shared with:

- the Trust;
- the GP surgery;
- NHS Mid Essex Clinical Commissioning Group
- NHS West Essex Clinical Commissioning Group
- NHS England.

2.14 This provided opportunity for those organisations that had contributed significant pieces of information, and those whom we interviewed, to review and comment upon the content.

Contact with Heidi's family

2.15 Heidi's family agreed to meet us with the DHR Independent Chair in October 2019. They said they had heard that James should have been sectioned as soon as the clozapine was stopped. We clarified that this would not have been the case, but the expectation would be that he would have closer monitoring in the community by the clinical team.

2.16 Heidi's family requested some changes to the detail of the report which were made.

Contact with James's family

2.17 James's parents were travelling abroad, and initial contact with them was by telephone. They provided information from their perspective on James' care, and a list of questions which they hoped that independent investigation may be able to address. These and our responses are at Appendix D.

2.18 The lead investigator and DHR independent chair met James' parents abroad in March 2019, to hear their perspective.

2.19 We shared the report with them prior to completion. They would like to say that they thought the report was thorough, and they hope the recommendations are being implemented.

Contact with James

2.20 NHS England attempted to contact James via his responsible clinician at the secure hospital where James was detained. It was confirmed that he would be unable to participate in the investigation process, and was too unwell to meet us.

2.21 We had a telephone interview with his current responsible clinician, who confirmed that James was not well enough to participate in the investigation or meet with the author

2.22 Through his clinical team we offered James the opportunity to meet with us prior to publication of the report, but he remains too unwell.

Structure of the report

2.23 Section 3 provides detail of James' background.

2.24 Section 4 sets out the details of the mental health care and treatment provided to James.

2.25 Section 5 examines the issues arising from the care and treatment provided to James, including comment and analysis.

2.26 Section 6 provides a review of the Trust's internal investigation.

2.27 Section 7 sets out our overall conclusions and recommendations.

3 Background of James

Personal background

3.1 James was the only child of his parents and was brought up in Essex. He has said he feels he was mentally unwell as a child, but was not diagnosed. He left school at 19 with 9 A-C grade GCSE's.

3.2 He was at Birmingham University for a year studying geography, but left after a psychotic episode. He has had various jobs, including investment banking until 2003. Latterly he has focused on less formal employment, such as a window cleaning round.

Relationships

3.3 James had been in a stable relationship with Heidi since 2007, and she moved into his rented flat in Harlow in 2008.

3.4 He kept in regular contact with his own parents. He went along with Heidi's contact with her family and allowed her niece and nephew to stay at weekends.

3.5 The couple moved to Braintree in May 2017, after buying their own flat. Heidi continued to work in Harlow, and James worked cleaning windows.

Contact with the Police

3.6 James was arrested in July 2006 for smashing an ex-girlfriend's window and spent the night in police custody. He said he had deliberately smashed the window because he believed the woman was an impostor and was part of a conspiracy to harm him. He described feeling paranoid and had some beliefs that appeared delusional but did not want to discuss these. There is no information about any further police action.

3.7 In June 2007, there is an incident referred to in the clinical notes when he reportedly hit his parents, but there is no detail available.

3.8 In December 2007 James reported to his consultant psychiatrist that he had been in a fight about three weeks earlier and was 'in trouble'. He had drank six pints and got into a fight with people whom he felt were following him. He had some scratches to his face but no other injuries. He said that no one was seriously hurt, and no weapons were involved. The police were called but no one appears to have been charged. He admitted he had been drinking alcohol and using cocaine for the month before the fight.

4 Mental health care and treatment

2000 onwards

4.1 Mental health care was initially provided to James by North Essex Partnership NHS Foundation Trust (NEPT). This Trust merged with South Essex Partnership University NHS Foundation Trust in April 2017 to form Essex Partnership University NHS Foundation Trust (EPUT). References to 'the Trust' should be seen as referring to NEPT up to April 2017, and EPUT thereafter.

4.2 James described the onset of mental health issues when he was 17 and he started taking illicit substances to overcome being bullied at school. He said his mental health worsened when he moved to University to study geography and continued to take illicit drugs. His first presentation to mental health services was in 2000, aged 19 when he was admitted voluntarily to an acute inpatient unit in Harlow for two weeks. The diagnosis at the time was drug induced psychosis. After discharge he was referred to a community mental health team (CMHT) in Harlow. At this assessment, it was concluded that James was not showing evidence of a psychotic disorder but was struggling to cope with various stresses in his life.

4.3 At aged 18 James was discovered in a compromising position with a girl in bed by the girl's mother. They were part of a group that had been drinking, and neither apparently had any recollection of events. He was however reported to the police by the parents and then arrested on suspicion of rape. Nothing further came of this allegation, but James remained shocked and extremely anxious.

4.4 James went to University in Birmingham. His second psychotic episode related to fears that two men who ran a club in Birmingham had found out about the rape allegation, and he was going to be kidnapped, tortured and killed by these people. He believed they may have recruited others, and he thought Chinese 'triads' may be involved. These delusional beliefs continued through until 2017.

4.5 He was referred for stress and anxiety management training via the occupational therapist within the CMHT. He attended two outpatient appointments initially in 2000 where it was documented that he had continued to misuse both alcohol and drugs. He failed to attend follow-up appointments offered between December 2000 to March 2001 and was eventually discharged from the CMHT back to the care of his GP.

4.6 James had a diagnosis of:

- F10.26 Mental & Behavioural disorder due to the use of alcohol;[12]

[12] *International classification of diseases (ICD10).* https://apps.who.int/classifications/apps/icd/icd10online2004/fr-icd.htm?gf20.htm+

- F20.0 Paranoid Schizophrenia
- F41.1 Generalised Anxiety Disorder

4.7 James disputed the diagnosis of paranoid schizophrenia, stating his psychosis was initially drug induced. Below we have summarised his care between 2000 and 2016 and focused in detail on the last year of his treatment in 2017. The full chronology of his care is at Appendix C.

4.8 The events surrounding his initial breakdown at University continue to disturb him, and he was regularly preoccupied with concerns about people who had been involved in clubs and drug use in Birmingham. He spoke of wanting to move to other towns, hoping to make a fresh start and avoid the people he believed were following him. He made at least one trip to Cambridge while considering a move there, but said he saw a Chinese man who gesticulated at him.

4.9 James continued to use alcohol, up to 60 units a week at times. He reported that he smoked heavily and drank large amount of tea, coffee and caffeinated drinks. He was referred to substance misuse services in Harlow in 2007 for drug abuse, and in 2013 for alcohol abuse. He attended substance misuse services in Braintree in 2017, and he stopped drinking alcohol in October 2017.

4.10 Although there were changes of psychiatrist during his care at Harlow CMHT, he had the same care coordinator from 2008 to 2017.

4.11 James was prescribed clozapine from 2008 to 2017. Clozapine is the only effective drug for treatment-resistant schizophrenia, that is, a patient whose schizophrenic illness has not responded fully to treatment with other antipsychotic drugs. Treatment resistance occurs in about a third of people with schizophrenia. The latest guidance[13] from the National Institute for Health and Clinical Excellence (NICE) in 2014 stated that clozapine should be considered for patients who had failed to respond adequately to separate trials of two other antipsychotic drugs. Clozapine is unique in that a so called 'therapeutic threshold' has been identified with a specific level of the drug in the patient's blood. This means that if a patient does not appear to be responding to treatment with clozapine, the level in their blood can be measured to ensure that a sufficient dose has been prescribed.

4.12 Unfortunately, clozapine has a number of problematic side-effects, principally neutropenia,[14] which requires long term monitoring of the patient's white blood cell count. If the blood test shows a low white blood cell count (known as a 'red result'), then it is advised that they discontinue treatment with clozapine. However, sudden discontinuation of clozapine is very often followed by rebound psychosis, which can be severe and very difficult to treat. This can

[13] *Psychosis and schizophrenia in adults: prevention and management. https://www.nice.org.uk/guidance/cg178*

[14] *Neutropenia means having a very low number of neutrophils in the blood. Neutrophils are white blood cells, which are normally found in the blood in large numbers. They help fight infection, particularly bacterial and fungal infections. https://www.nhs.uk/conditions/low-white-blood-cell-count/*

also be complicated by cholinergic rebound,[15] which can cause nausea, vomiting, diarrhoea, headache, sweating, restlessness and agitation. This is because clozapine has a specific effect on the cholinergic system in the body. Therefore, clozapine discontinuation should take place gradually, unless this cannot be avoided (for example, if clozapine has to be stopped abruptly because there is neutropenia).

4.13 Our analysis of clozapine prescribing and management is discussed at section 5 below.

Table 1 - Overview of James's care between 2000 and 2016

Dates	Service	Summary
2000	Acute admission, Harlow	Two weeks admission, offered counselling and stress management, did not attend follow-up appointments
December 2002	Harlow CMHT	Referred by GP to CMHT psychiatrist, at the same time his father raised concern that James's mental health was deteriorating and he was low in mood. The GP prescribed an antidepressant, fluoxetine.[16] James confirmed feeling low in mood with some delusional beliefs such as his computer had been hacked and that his personal details had been shared. He did not feel suicidal and did not feel he needed to be seen urgently. He was referred for a follow-up in the outpatient clinic in early 2003.
January 2003	Harlow CMHT	Seen by consultant psychiatrist in the outpatient clinic. James reported feeling people were watching him, checking his computer, sending messages and planting his garden lawn with microphones. The impression was a possible diagnosis of paranoid schizophrenia and that he needed to exclude drug induced psychosis due to the previous drug history. Fluoxetine was discontinued, and James was started on olanzapine[17] 5 mg.
3 February – 12 March 2003	Stort Ward Derwent Centre	Admitted informally to Stort Ward in Harlow, on 3 February 2003. At the time he was observed to be suffering with paranoid delusional ideas and was also having persecutory delusions in the nature that people were after him and messing with his head. He also believed that people were using computers to monitor him. He was

[15] *Cholinergic rebound syndrome is induced in susceptible patients after an abrupt discontinuation of a drug that blocks muscarinic acetylcholine receptors. Its central component is characterized by agitation, confusion, psychosis, anxiety, insomnia, hypersalivation and extrapyramidal manifestations.*

[16] *Fluoxetine is a type of antidepressant medication, known as selective serotonin reuptake inhibitors. SSRIs are the most widely prescribed type of antidepressants.* https://www.nhs.uk/conditions/antidepressants/

[17] *Olanzapine is a type of antipsychotic medication. Antipsychotic medicines are usually recommended as the first treatment for psychosis.* https://www.nhs.uk/conditions/psychosis/treatment/

Dates	Service	Summary
		prescribed Olanzapine 10 mg at the time. He was diagnosed as suffering with persistent delusional disorder.[18]
2003/2004	CMHT Harlow	On CPA and monitored by outpatient appointments and CCO1, and sessions with clinical psychologist started. He was prescribed antipsychotic and antidepressant medication with variable compliance. A depot medication, flupentixol,[19] was prescribed for the first time.
2005	CMHT Harlow	Continued to be monitored in the community via the CMHT and outpatient clinic reviews and his treatment included: carbamazepine, olanzapine, flupentixol and trifluoperazine.[20] He did not always take his oral medication. James disclosed he had been using illicit substances (magic mushrooms and cocaine) and this had brought on an increase in hearing voices and feeling paranoid. It was noted by the consultant psychiatrist that James would be susceptible to ongoing psychotic relapses of marked severity through stress or life changes, and if he discontinued his medication.
2006	CMHT Harlow	Seen in outpatient clinics for routine monitoring and titration of medications. Continued to express paranoid ideas, affecting his day-to-day functioning. He reported feelings of being followed by strangers, people watching him and had been isolating himself as a way of coping and using alcohol to the excess at times. He continued to use recreational drugs and consume excess alcohol.
29 July – 16 August 2006	Stort Ward Derwent Centre	After his arrest on 28 July for smashing an ex-girlfriend's window, he was seen on 29 July by CRHT and admitted informally to Stort Ward; struggling to cope in the community with his paranoia and delusional thoughts. Admission was to stabilise mental state and medication. Initially very paranoid after discharge, settled with increased oral medication, stable by end of September, seen by CMHT.

[18] *Delusional disorder , is a type of serious mental illness in which a person cannot tell what is real from what is imagined. The main feature of this disorder is the presence of delusions, which are unshakable beliefs in something untrue, characterized by the development either of a single delusion or of a set of related delusions that are usually persistent and sometimes lifelong. The content of the delusion or delusions is very variable. Clear and persistent auditory hallucinations (voices), schizophrenic symptoms such as delusions of control and marked blunting of affect, and definite evidence of brain disease are all incompatible with this diagnosis. However, the presence of occasional or transitory auditory hallucinations, particularly in elderly patients, does not rule out this diagnosis, provided that they are not typically schizophrenic and form only a small part of the overall clinical picture.* https://icd.who.int/browse10/2016/en#/F22.8

[19] *Depixol (Flupentixol) is an injectable (depot) medication used for maintenance treatment in schizophrenia and other psychoses.* https://bnf.nice.org.uk/drug/flupentixol-decanoate.html#indicationsAndDoses

[20] *Trifluoperazine is an antipsychotic medication.* https://bnf.nice.org.uk/drug/trifluoperazine.html

Dates	Service	Summary
3 November – 15 November 2006	Stort Ward Derwent Centre	Concerns were expressed by his parents and care co-ordinator, stopped taking oral medication, paranoid and suspicious. He felt he was being watched and people thought he was a rapist and had bugged his mobile phone. He admitted taking cocaine and cannabis. Advised to contact ADAS,[21] and accepted trifluoperazine. Asking to leave so was discharged after some leave, on 15 November.
18 November 2006 – 31 January 2007	Stort Ward Derwent Centre	Readmitted four days later, finding it difficult to cope at home and distressed by paranoid thoughts, consumed a large amount of alcohol. Frightened to go out, referred to psychology, switched to quetiapine 250 mg and flupentixol 100 mg fortnightly, with lorazepam to address agitation.
2007	CMHT Harlow	Continued to have paranoid thinking that people were following him, being under surveillance and listening to him on his mobile. The outcome of the outpatient clinic review in February resulted in his flupenthixol being reduced due to side effects. James reported using cocaine two months before. A new care coordinator (CCO2) was appointed and he was engaging with ADAS with regards to his substance misuse. In March, his depot of flupentixol was changed to risperidone consta due to severe side effects.
2008	CMHT Harlow	Severe side effects of current medication. Psychiatrist discussed clozapine prescription, which he initially refused. He agreed in May 2008, and this was prescribed and gradually increased over the next few months. He had stopped using illicit drugs by this time.
20 August 2008-17 September 2008	Chelmer Ward Derwent Centre	Deterioration of mental health, frightened when he is out, people know about him and his past, delusions of reference from Ceefax. Highlighted words appear on the TV which he believes are from computer people trying to 'screw his head up'. Admitted informally to Chelmer Ward. Various changes made to medication 'to lessen the impact of symptoms', and had short term psychological work.
2009-2010	CMHT Harlow	Seen as outpatient for medical review, care coordinator allocated. Referred to substance misuse service. Fluctuating anxiety and paranoia, specialist psychological therapy for paranoia introduced.

[21] *ADAS is the West Essex Alcohol & Drugs Service. http://www.adasuk.org/*

Dates	Service	Summary
April 2011	CMHT Harlow	Red result for clozapine, deemed to be green on repeat analysis, therefore it was not necessary to discontinue clozapine treatment.
2011-2012	CMHT Harlow	Low levels of clozapine found, thought to be linked to smoking and drinking a lot of caffeine, abusing alcohol. Paranoid thoughts and anxiety but working actively with psychology. Drowsy in the mornings so dosage of clozapine changed to increase at night. Asking for diagnosis to be changed to drug induced psychosis.
2013-2014	CMHT Harlow	Panic attacks, paranoid thoughts, drinking 40 units alcohol a week. Liver function tests improved.
2015	CMHT Harlow	Increasingly anxious after two triggers, grandmother died, and Heidi had a serious health issue. Depression symptoms, clozapine levels increased after he stopped smoking, antidepressant prescribed.
2016	CMHT Harlow	Plans to move to Braintree shared with CMHT. Still abusing alcohol, clozapine at therapeutic level. He was informed he would be referred to the local team when he moved.

Up to October 2017

4.14 James was last seen as an outpatient by the Harlow CMHT psychiatrist in September 2016. He spoke of moving to Braintree and was advised he would be referred to the local team when he moved.

4.15 He continued to be seen in the clozapine clinic monthly for blood tests and health checks, and CCO1 saw him two to four weekly until October 2017.

4.16 In February 2017 at the clozapine clinic he reported feeling low in mood and drinking heavily. He expressed concerns about his physical health, having started statins for cholesterol and abnormal liver result. His weight at this time was 109 kg, and he was encouraged to exercise and eat healthily. He continued to report low mood, citing his impending move to Braintree as stressful. He complained of hyper-salivation as a side effect of clozapine, and was still taking hyoscine hydrobromide 300 mg at night, since it was prescribed in 2014.

4.17 In March 2017 he described stressors to CCO1, around the purchase of the flat in Braintree which was taking longer than anticipated. He had however started attending the substance misuse service, had cut down his drinking and lost nine lbs in weight. He reported ongoing paranoia, being less anxious at that time, but he was preoccupied with things he saw on the ground, feeling as though they relate to him. He was also expressing suspicion about a friend who is an estate agent, although he trusted him to help with the flat purchase.

4.18 James attended the clozapine clinic on 14 March 2017 and was reported to be well engaged. He reported that he had a bad week the previous week and had been drinking heavily. He was worried about his liver function and cholesterol. He said he was low in mood on and off, but Heidi helped him. He reported that he was still experiencing hyper-salivation at night. James was then seen for blood samples to be taken, because of his concerns, and was told that his cholesterol had improved, and liver function results had worsened.

4.19 He did not attend his next appointment on 23 March with CCO1, and a follow up call was made to him that day. He called on 24 March, asking to speak to his care coordinator urgently. In the call he said he had tried to call to let her know that they were with the solicitor the previous day, hence missing the appointment. He was very worried about his liver function results and said he had not been drinking much for the previous three weeks. He wanted to stop the statin, hyoscine and clozapine. He was encouraged not to stop the clozapine in particular but was persuaded to consider reducing it only. James asked if he could stay with the current team in Harlow rather than move to the Braintree team, and CCO1 advised she would discuss this with the managers concerned. He was informed that his consultant psychiatrist had changed due to a Trust restructure, and he was noted to seem unconcerned. The outpatient appointment that had been arranged for April 2017 had to be moved to May 2017 as a result of this. There were no further face to face medical reviews in Harlow.

4.20 CCO1 then wrote to the new consultant in the Harlow team, and the manager in the Braintree team to advise and discuss. She also asked the consultant to consider the possible effects of James reducing his clozapine by 25 mg a day, and for advice on managing his worsening liver function tests (elevated ALTs,[22] at 17 March 2019). There was no record of discussions with management about whether James could stay under the care of the Harlow team.

4.21 The consultant reviewed James's blood results over the previous year. His view was that his alcohol consumption could certainly have contributed to his elevated ALT levels, also his Mean Cell Volume.[23] The fact that he was taking quetiapine and clozapine could also be contributing to the raised ALT. However, it was noted that although it had been gradually creeping up, it was felt this was not a major concern (ALT can go up to 1000s & is currently 148) but needed to be monitored. Liver function usually recovers after stopping consumption of alcohol, and it was noted his other liver functions were normal. The consultant agreed to reduce the clozapine by 25 mg to 400 mg, without seeing James.

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[22] *Alanine aminotransferase test (ALT) is a blood test for liver disease. https://labtestsonline.org.uk/tests/alanine-aminotransferase-alt-test*

[23] *A red blood cell count is a blood test that measures red blood cells. Red blood cells contain a substance called haemoglobin, which transports oxygen around the body. The red blood cell size is recorded as the mean cell volume (MCV).* https://www.nhs.uk/conditions/red-blood-count/

4.22 James was seen at his usual monthly clozapine clinic in Harlow on 11 April 2017. He confirmed he had spoken by phone to the new Harlow CMHT consultant who had explained about the possible causes of his raised liver function test, and how his liver function could improve. He said he felt reassured by this and had tried to cut down his drinking, saying he had just gone three weeks with no alcohol. He told the clozapine clinic nurse that he thought he was staying under the care of the Harlow team, and he was advised that plans would have to be made to move across to the Braintree team, and the Braintree clozapine clinic, and that this would be discussed in the forthcoming team meeting. He refused to have his liver function checked, asking if this could be done next time.

4.23 His clozapine blood results were green,[24] and he was encouraged to maintain his reduced use of alcohol, and drink plenty of water, and healthy eating and positive coping methods were reinforced.

4.24 CCO1 saw James on 27 April 2017. He said that he and Heidi had completed the purchase of the flat, but he was becoming very anxious about other aspects. These were worrying they might be burgled, concerns about drinkers hanging around outside, and, his neighbours also having fishing gear so thinking they are '*being funny'* with him. He wondered whether they had made the right decision to move, but also said he does like the flat and they had plans to change things such as the kitchen. He reported ongoing anxiety and paranoid thoughts but agreed these were longstanding concerns. He reported he was drinking more, having been reassured by the consultant that his liver function was not of serious concern. At this time, he reported drinking 12-14 units per day, most days. He was advised to stop drinking and he agreed he was aware of the risk of continuing. He had not started attending ADAS again because he was moving. Transferring his care to a Braintree team was discussed, and James expressed concern about this, worried that he would not get on with whomever he was allocated to. He was advised this could be done gradually once he was more settled, and the team would discuss this.

4.25 James and Heidi moved to Braintree in May 2017, to a flat that they bought with family help. He called to let CCO1 know this had happened, and left a message saying he was anxious but coping.

4.26 He was seen by CCO1 on 8 June 2017, after attending the Harlow clozapine clinic. Future attendance at the clozapine clinic in Chelmsford was discussed with him, and he seemed unsettled by this. He told CCO1 that since the move about four weeks earlier he had been feeling '*about the same*' but also feels better about himself now that he is a home owner. He said he felt more able to be free in Braintree, as he felt '*under siege*' in Harlow and felt less worried about who he may bump into. He did however still express anxiety and concern about being stopped by the police and followed by Chinese people. He apparently saw a Chinese person when driving back to Harlow after picking up the flat keys and wondered about this. He continued to sleep until lunchtime most days, then usually watched TV until Heidi came home from

[24] The clozapine manufacturers use a traffic light system (green, amber, red) for guiding dispensing on the basis of full blood count results. https://www.hcpinfo.clozaril.co.uk/en-gb/clozaril-connect/cpms

work. He asked about having diazepam re-prescribed to manage anxiety, feeling it would be better than alcohol. Pros and cons of diazepam were discussed, and James was able to accept it would not be a good idea, and that other ways of managing difficult feelings were encouraged. Goals were discussed; James had considered joining a gym in Braintree and had thought about taking up running but was reluctant to commit himself to anything at that time.

4.27 James attended the Harlow clozapine clinic on 4 July 2017, for blood and health checks. He had been working and although a little unkempt, appeared relaxed. He said he thought his mental state was stable, and things were going well at the new flat and between himself and Heidi. He was advised he was being referred to the clozapine clinic in Chelmsford, and his next appointment would be there, and the next fasting blood test would be done there. The clozapine blood result was green. He said he was drinking more since the move, and was again advised to reduce his alcohol intake, exercise and eat and drink healthily. The next appointment was booked for 1 August 2017, to be adjusted if transferred to the Chelmsford clinic.

4.28 There were phone calls to CCO1 in July, advising he had forms to fill in for benefits, and giving his new GP details. An appointment had to be rearranged because James was away on the planned date in July.

4.29 CCO1 saw James on 3 August 2017. He reported feeling very anxious, which they agreed was usual for him. However, he reported feeling that this anxiety was different somehow; he appeared more aware of the physical symptoms of anxiety such as dizziness and shortness of breath, rather than due to his usual paranoid thoughts. He had had blood test by his new GP and was pleased his liver function tests were normal. The only abnormal result was triglyceride cholesterol, which he was to see his GP about.

4.30 James disclosed some personal relationship issues between himself and Heidi. He was asked if it would be helpful for them to be supported to discuss this as a couple. James was noted to say they don't talk about it, and he said he might talk to his GP about seeing Relate locally.

4.31 The stressors he was reported to be feeling at the time were around his parents travelling abroad, and Heidi having an upcoming operation. He said he was unsure how he felt about this, as it may impact on their ability to have children. He said Heidi was optimistic, although he said that he was '*barely able to look after myself*'. The amount of caffeine he was drinking was discussed and how it might impact on his health. He was feeling unable to leave the flat, and could not go fishing. Coping mechanisms discussed, and James said he did not want to start CBT again, but would '*see how things go'.* A further appointment was booked for three weeks, and he was advised that the referral to the Braintree team was to be explored, and he remained very anxious about stopping the contact with CCO1.

4.32 He was seen again on 31 August 2017 by CCO1. He reported ongoing severe anxiety, and difficulty getting to sleep, although then sleeping late. He had been referred to a gym by his GP which he was due to start, and he was

looking forward to. He reported trying to reduce his alcohol intake, and that he had not drank any that week so far, and was doing some part time window cleaning. He was also anxious about a planned operation for Heidi and visiting his parents abroad; he said he did not like flying or going on the Eurostar.

4.33 He was referred to the Mid area[25] Specialist Psychosis team in August 2017. At his next meeting with CCO1 on 21 September 2017, he expressed concern about going to the Chelmsford clozapine clinic as planned on 2 October. He spoke of a number of people he knew who had died of cancer recently, and that life was short so he was thinking of proposing to Heidi at Christmas. He appeared aware that although he had some anxieties, these were based on anticipation rather than experience, and how to manage this by various techniques was discussed. A further appointment was booked for three weeks, and he was given the phone numbers of the Mid area Psychosis Team in Braintree. He said he had not gone to the gym as he felt would be pointless, but said he was planning to go to the ADAS[26] walk in clinic for support with alcohol.

October - December 2017

4.34 James was first seen by the Mid area Psychosis team in the clozapine clinic on 2 October 2017. He appeared settled in mood and mental state and was given seven days clozapine while awaiting initial blood test results. His bloods came back as amber on 4 October, and he was asked to attend for a repeat test. He called CCO1 on 4 October saying he was finding this stressful and asking if he could attend the previous clinic or just fill in a form.

4.35 He attended on 5 October for a repeat blood test and was reassured about his anxiety. The blood result was in fact red, and this was repeated, and a further result was also red. Clozaril® Patient Monitoring Service (CPMS) [27] was contacted, and they advised to do a further blood test on 6 October, followed by one on Saturday 7 October. On 6 October James attended the clinic, and a further red result was received.

4.36 James was called, advised to stop clozapine immediately, and bring his remaining medication into the clinic the following day. His parents were contacted by phone to let them know, and James was to attend on the 7 October with Heidi, bringing his clozapine in to the clinic.

4.37 The Mid area Psychosis team consultant, Dr L, was contacted and informed. Dr L had not yet met James and advised that he be asked to increase his quetiapine to 600 mg should he have any concerns about a deterioration in

[25] *Refers to the Mid area of the North Essex part of the Trust*

[26] *In fact this was Open Road*

[27] *Clozaril® Patient Monitoring Service (CPMS)is the manufacturer's system for regularly monitoring the blood results of patients on clozapine – clozaril is the brand name*

his mental state. An appointment with Dr L was arranged for the following week.

4.38 On 7 October a further blood test was done, which was again red. CPMS were contacted, and their advice was documented as that he was now prohibited from taking clozapine. He was advised to attend The Gables clinic on the following Monday (9 October) to have post treatment health monitoring, and to see Dr L. At this time James said he was feeling mentally and physically ok. He also said he had an appointment at Open Road[28] for support with alcohol use.

4.39 On 9 October Heidi phoned CCO1, advising that James had had a bad week and explaining about the red results. James was spoken to on the phone and said he did not feel good at all. This was his fifth day without clozapine. CCO1 called the clozapine clinic and asked for an update, advising that it was planned to hand over to a care coordinator at Braintree in two weeks' time. An amber result was obtained that day.

4.40 Dr L saw him on 9 October as an emergency because of the red blood results. It was noted that the result on that day was amber. He had been asked to return on Thursday 12 October, and if the blood test was green, may go back on clozapine.

4.41 He disclosed that was drinking about 60 units of alcohol per week until recently and stopped alcohol when he was told that the combination of clozapine and alcohol could be affecting his white blood cell count. It was thought that this may be the reason his recent blood test had returned to amber. Dr L strongly advised him not to touch alcohol at the moment as he could be putting his life at risk.

4.42 Dr L suggested that if he starts to become unwell he should double the dose of quetiapine until the clozapine could be reinstated. No signs of relapse were noted, and he reported that the move to Braintree had been a positive one for him and Heidi. It was noted that he '*did not voice any risk concerns'*. A prescription of three weeks of additional quetiapine 300 mg per day if required, but if not required, the plan was that he go back on clozapine '*when the blood result is green'*. A review appointment was planned for six weeks' time.

4.43 On 11 October CCO1 called James as planned. He said he had been feeling very anxious and was unable to sleep, he felt panicky and was not going out. He was managing to stay off alcohol but felt very '*up and down'*. He said he did not have any thoughts about harming himself, and had been looking up the effects of stopping clozapine on the internet. He said he had gone from sleeping for 12 hours at a time, to three and a half hours a night. He said he was taking the extra 300 quetiapine daily and had a further blood test the following day. The date and time of his first meeting with the new care coordinator (CCO2) was given to him, and it was agreed that CCO1 would

[28] *Community Drug & Alcohol Team, Harlow, now provided by a different company: Open Road Essex. https://www.openroad.org.uk/*

phone him on the following Friday. CCO1 emailed the Braintree clozapine nurse, reporting that James said he was pacing and restless and sleeping poorly. Dr L was phoned, who agreed to prescribe additional medication and leave the prescription (for diazepam 5 mg three times a day) at the Gables for James to collect.

4.44 On 13 October CCO1 spoke to James, who said he had been having night sweats and nightmares and was pacing the flat all day after a night of little sleep. He said his last blood result was green, but he was not sure when he might be able to go back on clozapine. CCO1 agreed to speak to the team at Braintree to see if he could be prescribed night sedation, and was given zopiclone 7.5 mg. He called the out of hours team at Braintree that night, saying he could not sleep even though he had taken zopiclone. He reported he had a panic attack earlier but felt better now and was proud of the fact that he had not had an alcoholic drink for nine dyes. He was advised his concerns would be handed over to the Mid area Psychosis team in the morning.

4.45 On 16 October he attended the clozapine clinic for a repeat test, which was amber. He was noted to appear anxious and reported having minimal sleep despite taking zopiclone. The next clinic appointment was arranged for 19 October 2017. The clozapine nurse called Dr L to convey his presentation and advise he had an amber result; he was very anxious; including being very anxious about clozapine being restarted; he was sleeping only three to four hours a night and was struggling to carry out his usual routines. He was requesting diazepam short term. James was advised that Dr L had agreed to prescribe diazepam short term, and he was to collect a prescription from the Gables. He was advised to call the out of hours team if he need further support and was to be called on 18 October to remind him to attend on 19 for a blood test.

4.46 He attended the clozapine clinic on 19 October, with a green result. It was noted that he appeared to be managing his anxiety with the help of diazepam. He said he was considering not starting clozapine again, there was a lengthy discussion about this, and he was advised to discuss this with Dr L on 30 October. He had arranged a GP appointment that afternoon to discuss medication. A request to prescribe a further course of diazepam 5 mg twice a day was faxed to the GP. The provisional plan was for James to start clozapine retesting on 23 October with a view to restarting. Dr L was away on leave at this point.

4.47 James saw his GP that day, who called the clozapine clinic to confirm his medication. The GP stated that he could not prescribe zopiclone due to the amount of medication he was on, and the absence of a previous history of zopiclone use. The zopiclone he had been taking earlier had been prescribed by the consultant psychiatrist, not the GP.

4.48 James became annoyed by this conversation and asked the GP to call CCO1. The GP refused on the grounds that he had already spoken to a mental health nurse. James then called CCO1 himself and also expressed concern that the GP could not use his own phone, and he appeared suspicions about this. The GP clarified that they *would not,* not that they *could not*. The diazepam was

prescribed at three times daily after discussion, along with procyclidine, and he was advised to see his usual GP for a medication review.

4.49 James called CCO1 later that day, angry and upset, complaining about the clozapine nurse and the GP. He had also just noticed that he had only been prescribed diazepam and procyclidine, and not his other usual physical health medication. CCO1 tried to reassure him that it was communication difficulties about his transfer of care, and the main difficulty was around him having to stop clozapine suddenly. He said he was due to see his regular GP the following morning. James also said the he had started to get side effects of the quetiapine; dry mouth, sweating, restless legs and jaw clenching. It was agreed he would call CCO1 again after he had seen his GP.

4.50 James called CCO1 the following day to say the GP had been very helpful, had prescribed everything he needed including zopiclone, and he felt much better. He was still expressing concerns about the clozapine clinic and it was agreed to discuss this again.

4.51 On 23 October James attended the clozapine clinic, with a green result. CPMS suggested that a final blood test should be done in one weeks' time, with a view to restarting.

4.52 On 24 October James called NHS111 stating he was worried because his feet were ice cold and had been for three days, and he had unexplained bruises on his shin. He was advised to see his GP in the next three days. He saw his usual GP on the 25 October, nothing untoward was found and he was advised to wear thicker socks.

4.53 A meeting took place on 25 October between CCO1, James and CCO2, who was to take over as care coordinator. It was noted that James was well dressed and his mood was even. He reported feeling stressed after the move to Braintree and nervous about working with a new care coordinator. He said he had been on clozapine for ten years but recently had red results and now did not want to continue with it. It was agreed he would see CCO1 for a final meeting but would be transferred to CCO2 within the following week, and it was noted he had an outpatient appointment with Dr L for 30 October.

4.54 He said he had stopped drinking and having caffeine after his red blood tests and had cut down to one diazepam a day. He said he was feeling better, his personal issues were resolved, and he was not at all sure he wanted to go back on clozapine. It was agreed to discuss this further.

4.55 At the clozapine clinic on 30 October his blood results were again green. Dr L saw him on 30 October. He reported that he had not been free of paranoia while on clozapine, and had had side effects such as constipation, tachycardia (and sexual issues). He said that they had all now improved, and Dr L noted that it *'did not seem a good idea to restart clozapine*'. James said his mood was stable and he 'd*id not voice any active thoughts of wanting to harm himself for anyone else'*. James requested psychological treatment and it was planned to discuss this in the MDT meeting. Heidi had apparently been taken ill recently but was alright now. He said he had a mixture of good and

bad days and was still suspicious of people. The move from West to Mid area teams had been really difficult for him. He did not appear to be thought disordered or psychotic. It was planned to see him in six to eight weeks' time, with the CCO2 '*keeping an eye on him*', the frequency of this was not recorded.

4.56 James called CCO2 on 1 November 2017 about his physical health. He said the Open Door advisor would like to speak to CCO2 and it was agreed that they would speak. The Open Door advisor had suggested a joint meeting to discuss plans and possible anti-craving medication. He had been doing some window cleaning work, and said he now had a case worker at Open Road. He acknowledged that prior to his red blood test he had been drinking more than usual. He said he was not craving alcohol and had stopped all caffeine but was a bit disappointed that he did not feel that much better. However, he reported waking earlier, and feeling more motivated. It was left that James would call CCO2 after his final meeting with CCO1.

4.57 James' last meeting with CCO1 was on 2 November 2017. He said he was pleased that Dr L was happy for him not to go back on clozapine, he felt more motivated and was sleeping better. He said he had been doing a lot of research about relapse and medication. He was annoyed that he feels he may have been made worse by clozapine. He said the psychological work had been the most help. He was reluctant to focus on any work with his new team, saying he did not want to do too much at present.

4.58 An MDT discussion was held at the Mid area Psychosis team on 2 November, it was noted that he had moved from West to Mid area and had 15 years of CBT input. He had specifically requested to start psychological work. It was agreed that the Mid area psychologist would discuss an approach to this with the West psychologist.

4.59 CCO2 saw James on 8 November 2017. He reported having a very bad day the day before. He said he had racing thoughts, and was not paranoid but was watching TV without really watching it all day. He felt this may be due to alcohol or clozapine withdrawal. He had spoken to his parents, as he called them frequently, and could talk to Heidi about his concerns. He said he often calls her at work and her employer understands that he has mental health issues. He said he only felt comfortable talking to people he can trust and would be reluctant to call CCO2. He was encouraged to try, and it was agreed they would meet every two weeks to develop a relationship. He was to continue to see CCO1 once a month for psychological work, with a view to handing over to the Mid area psychologist.

4.60 Heidi called CCO2 on 14 November saying he was having a very bad day. CCO2 went to their home to see them, James was visibly anxious and said he feels his mental health has gone downhill. He said he had racing thoughts all day which have turned negative. He was easily moved to tears earlier in the day, and had called Heidi who came home from work to be with him. Possible causes were explored, he said he initially took 600 mg quetiapine when he first came off clozapine but reduced this to 300 mg because he was suffering side effects such as restlessness, teeth clenching, sweating and muscle

spasms. He was still taking fluoxetine 20 mg. He said he had fleeting thoughts of suicide but although not unusual had increased over the last few days. He said he could keep himself safe with Heidi's support, and had no plan or intent. CCO2 planned to arrange an urgent review with Dr L and request further diazepam. Crisis numbers were provided and the couple were advised if they were really concerned about a crisis they could go to A&E.

4.61 CCO2 called James back later that day, advising that Dr L had agreed for the further prescription of diazepam, and an urgent appointment with Dr L had been requested. James called CCO1 the following day, saying he knows CCO2 is his care coordinator but just wanted to talk it through. Reiterated his concerns, and CCO1 advised she would let CCO2 know they had spoken.

4.62 CCO2 called him on 16 November, James said he felt slightly better and with less racing thoughts and planned to write things down to discuss with Dr L. CCO2 called him again after some confusion about the GP diazepam prescription. He was looking forward to the medical review on 27 November to discuss medication, and said Heidi was a big help to him, supporting him with his mental health. He agreed to speak to CCO2 again next week and had the crisis team numbers if needed.

4.63 James saw his GP on 17 November 2017, asking for more medication, believing vitamin D might be helpful. He said he wanted to reduce propranolol, which he thought he was taking because of side effects of clozapine. The GP did not change his medication but gave diet and exercise advice.

4.64 James called CCO1 on 20 November, saying he had tried to call CCO2 but could not get through. He said he felt he was still suffering from the effects of withdrawal from various substances. He said he was struggling to concentrate, cannot watch TV but is able to read and write, and he asked if he could write to CCO1 rather than meet this month. He was very worried about his short-term memory but was encouraged to see this as related to anxiety rather than memory loss. James said his parents had offered to pay for him to be admitted to the Priory, although they have since clarified that they did not offer to pay but merely discussed the possibility. He told CCO1 that he was concerned about the amount of money involved, although he had also been looking for a private therapist in Chelmsford for addictions and anxiety. He was encouraged to discuss with CCO2, and to use resources available to him on the NHS.

4.65 CCO2 had a call from James on 21 November; he was expressing frustration as he had a series of complaints he wanted to make about the clozapine clinic staff. CCO2 said he would forward complaint forms and support him with this, but he was undecided and said he would think about it a bit more. He was very unhappy that he believed his medical a review had been cancelled by the office for 27 November. CCO2 clarified that this was still going ahead and let him know, James said he felt stressed at present, had racing thoughts, although he did not feel he was psychotic. He said he was finding it therapeutic to write things down and planned to bring his writing to the medical review. James said he felt he could cope at the time but was aware of duty numbers if he needed more support.

4.66 James' mother called the West Psychosis team on 21 November, asking to speak to CCO1, as she was concerned about him. CCO1 called his mother back, who reportedly said she thought the changes of moving teams and coming off clozapine had been really difficult for him. His parents thought he seemed to be becoming more obsessive and phoning them a lot to go over and over things, although he did seem less paranoid. James had also said to his parents that he should not have moved to Braintree. CCO1 had noted that although James had worked hard to stop drinking, in CCO1's view he needed to take more responsibility for dealing with and managing his problems, and there was only so much that the service can do aside from give medication if someone does not engage with helping themselves to manage problems. The risk is then that James is prescribed more and more medication. It was noted that CCO1 asked about the suggestion about paying for the Priory, and his parents said they were only trying to help. CCO1 noted that it was acknowledged that they must be finding the situation very difficult.

4.67 A discussion was held at the Mid area Psychosis Team MDT meeting, and it was noted that he had stopped clozapine, was researching other medications and had a review with Dr L on 27 November.

4.68 On 25 November James called the Duty team saying there was a lot going on at the moment and asking for some extra support. There is no record of what support was offered or given. James said he attended A&E in Harlow and was catheterised but with no diagnosis as such.

4.69 He called NHS 111 on 26 November because he had not passed urine for 24 hours, had a lot of pain and felt physically unwell. The call handler spoke to James and Heidi. James' catheter was draining well and he was reluctant to go to hospital. NHS 111 called his GP and asked if a district nurse could review his catheter. It was noted that the catheter had been in situ for two weeks while he waited some tests on his prostate. The district nurse called at 11.00 am that day, and spoke to Heidi as James was asleep. She said she had called NHS 111 because she was concerned that his urine in the catheter bag was an orange colour. She was assured that if it was draining and there was no pain it was working properly, and medication can cause colour change. It was planned that he call his GP the following day.

4.70 CCO2 called James on 27 November asking how his medical review went. James had not attended because he felt physically unwell. James said he attended A&E in Harlow and was given a catheter bag but no diagnosis as such. He said he felt he was '*back to square one'* but was able to acknowledge his progress in terms of giving up alcohol and caffeine. He reported that he had spoken to Dr L and rearranged the appointment for two weeks' time, and she had said there were no signs of relapse when talking to him. It is unclear whether this information came from James or Dr L. An appointment for a carer's assessment was made with Heidi, to take place when CCO2 saw James at home next.

4.71 On 28 November Heidi called CCO2, saying James was anxious because he had accidentally taken double the dose of quetiapine one day last week, taking 600 mg instead of 300 mg. he now felt that the higher does had caused

his bladder problems. CCO2 sought advice from nurses within the team, and advised Heidi that was very unlikely, and in fact Dr L had prescribed 600 mg when he first stopped clozapine. CCO2 asked what the A&E opinion had been, and James said it was either an infection or an enlarged prostate.

4.72 Dr L recorded that James had phoned to cancel his appointment, he said he was feeling unwell and was in Norfolk. He said that at first coming off clozapine he had felt physically and mentally well. He soon after he began to experience strange physical symptoms, insomnia, nightmares, tremors, restless legs, constant anxiety, dry mouth, and constipation. He also said he had constant negative worry thoughts, kept losing things, and experienced bouts of rage which he had not had since he gave up drugs 10 years earlier. He then woke up one day recently and felt like it was a breakthrough because he could block all the negative thoughts. He felt things were improving until this weekend; he had problems passing urine over the previous couple of weeks and then had 24 hours retention and went to A&E and had the catheter fitted.

4.73 He said he wasn't sure of the cause but it could be an infection or an enlarged prostate. He did say he was mentally ok, was not depressed and did not want any medication changes. He asked for a carer's assessment for Heidi, and that CCO2 should be copied into his care plans so it '*takes the pressure off*' Heidi.

4.74 On 29 November CCO2 saw James and Heidi at home. A carer's assessment was completed for Heidi. CCO2 then saw James, who was very anxious, said he was very tired because he could not sleep, as he was anxious if he sleeps he may slip into a coma. He said he had felt dizzy and had a slight increase in hallucinations, and the TV had spoken to him on three occasions that week. He said it had spoken about a new medication he could use, some deep breathing exercises he could try, and his exact address had been read out on TV. He also heard a telephone ringing beside his bed, although there was no phone there. James was able to acknowledge that these experiences were not real. He talked again about making a complaint about the clozapine clinic but remained undecided. Discussed what may help him sleep and other coping mechanism, and he requested zopiclone.

4.75 CCO2 recorded that James was at risk of a decline in his mental state following his physical health issues. CCO2 reminded the couple that Dr L said not to increase quetiapine at present and said Dr L would be asked to prescribe zopiclone if possible, and to check when his medical review was.

4.76 CCO2 phoned on the following day (30 November) informing James that Dr L had prescribed zopiclone for 14 days. James raised the issue of olanzapine, saying he was '*through with antipsychotics*' and would consider a mood stabiliser. He was advised his medical review would be arranged as soon as possible.

4.77 The monthly meeting with CCO1 was planned for 30 November, which James called to cancel at the last minute. Heidi then called CCO1 saying James had seen his GP, his health was ok but the GP thought he was physically and

mentally drained. James then came on the phone and asked CCO1 not to speak to his parents about his care, as they kept calling him asking what was happening. CCO1 said they would pass on this message to the Mid area Team.

4.78 On 30 November Heidi phoned CCO2, saying she had manged to get James a GP appointment that day; he had been having dizzy spells and difficulty sleeping. The GP had told them it was likely to be due to anxiety. Heidi said herself and James were happy with the support they were getting from the Mid area team, but James' parents were not. CCO2 was asked by Heidi not to discuss care with James' parents. CCO2 offered a medical review appointment with Dr L on 8 December.

4.79 The GP notes of 30 November record that he was generally anxious and had not been sleeping well. James said the cause may be urinary retention, prostate issues or constipation, but they were not sure about it. Since then he has had broken sleep, but had some sleeping tablets from psychiatrist. Noted he had an appointment with the psychiatrist the following Monday, he was encouraged to try to relax. He had a slight cough and dry mouth, physical observations were taken, all within normal limits.

4.80 On 2 December James called NHS111 stating he had a rectal lump and swelling. He was advised to drink plenty and see his own GP, with a possible diagnosis of constipation. Later that day he called again saying he had a rectal bleed, and was seen by an out of hours GP at home. The out of hours GP gave advice but James wanted to go to A&E, and he was advised to call back if anything else was needed.

4.81 James and Heidi attended A&E at Broomfield hospital at 19.34 on 2 December 2017. He said he had been lying in bed all week and was now feeling constipated. It was thought the rectal bleed may have been due to straining and he was prescribed lactulose[29] and movicol.[30] He requested a mental health assessment due to his anxiety.

4.82 He and Heidi were seen by a community psychiatric nurse (CPN) on behalf of the Trust access and assessment service (AAS). He said he felt better since stopping the clozapine but now his mind was racing, but it felt like he was waking from a slumber since stopping clozapine. He had been drinking heavily but gave up eight weeks ago. He said he felt exhausted all the time because of his physical health, and feels he is experiencing withdrawal symptoms form clozapine. Hearing the occasional voice but nothing bothersome, but said he has been having mood swings, and feels he lacks control. He said he was angry earlier on and struggles to relax. He said he was not anxious at interview, and was able to manage paranoia through psychological input, but wanted diazepam to help him to relax.

[29] *Lactulose is a medication used to treat constipation.* https://www.nhs.uk/medicines/lactulose/

[30] *Movicol is a laxative medication used to treat constipation.* https://www.nhs.uk/conditions/laxatives/

4.83 Heidi and James were both aware that he had a medical review on 8 December and advised to discuss diazepam and sleeping tablets then. He denied any suicidal ideation, or thoughts of harming others. The CPN noted that he did not appear to be in crisis, was not anxious and was laughing and joking. His main questions were around whether his symptoms were due to clozapine withdrawal. The CPN's plan was that he should contact the psychosis team on Monday, gave him advice on anxiety management, and continue with prescribed medication until his medical review. It was agreed the AAS team would call to see if Dr L could see him sooner.

4.84 On 4 December James called CCO2 and advised he had been to A&E and seen the AAS, and he was diagnosed as having severe constipation. James was aware he had a medical review that week, and said he could manage until then but would like some diazepam. This was prescribed by Dr L, and the prescription was taken to his flat.

4.85 On 7 December the GP received a referral for catheter care. On 8 December James attended his GP for catheter care, he had a trial without a catheter which was unsuccessful, and it was now to be in situ for three months. Tamsulosin[31] was started due to possible swollen prostate. James told the GP he thought the constipation and urinary retention were due to clozapine withdrawal. He was advised to attend the psychiatric appointment as planned.

4.86 Dr L saw James on 8 December 2017, along with Heidi. James presented four handwritten pages, which was his account of things that had gone wrong in his life. He said it had taken him three hours to write and referred to his previous experiences in clubs and at university. Dr L noted that these appeared to be an indicator of him having a relapse. James said he did not believe he had paranoid schizophrenia, but that all his problems have been about substance abuse. Dr L explained that the diagnosis was well established and there was concern in that his current dose of quetiapine 300 mg might not be enough. There was also concern noted about his physical health, and wanting to ensure the urinary retention and constipation were not made any worse. Dr L prescribed aripiprazole[32] which James agreed to. He was very clear that he would not go back on clozapine and he was assured this was not planned at present. Dr L recorded that '*the hope would be that the combination of quetiapine and aripiprazole will contain a full-blown relapse and maintain his functioning in the community short term*'. It was planned that he would have to be '*monitored very closely'*, and CCO2 was copied into the letter to the GP, *'so that [CCO2] can keep a closer eye on him in the community whilst I see him in monthly clinics'*. Dr L also separately emailed CCO2 to confirm this plan. Dr L noted that although there was a paranoid flavour to some of his speech, he was not thought to be at the stage of a full-blown relapse and there was no evidence of any perceptual disturbance. It was noted that James was happy with that plan, and he was prescribed further zopiclone 7.5 mg and diazepam 5 mg three times daily, to provide

[31] *Tamsulosin is used to treat the symptoms of benign prostatic hyperplasia (swelling). https://www.nhs.uk/conditions/prostate-enlargement/treatment/*

[32] *Aripiprazole is a medication used to treat schizophrenia. https://bnf.nice.org.uk/drug/aripiprazole.html*

support management of his symptoms to prevent a full-blown relapse at this point. This was referred to as a short-term plan, although there was no more detail which described possible longer term plans.

4.87 James called the out of hours mental health team at just after midnight on the night of 8 December, saying he was having bad mood swings, which he had not had for 10 years, and wanted to speak to a nurse about medication. He was advised this would be passed to the AAS.

4.88 On 10 December at 14.30 James called the AAS team again and asked if a member of staff could speak to Heidi, because she was saying he was behaving oddly. Heidi came on the phone and told the nurse he had been moving things around the flat unnecessarily, but that he had taken some diazepam and had aripiprazole to take that evening. She was advised that James could take another dose of diazepam to help calm things down. She said she would call the Mid area Psychosis team tomorrow and ask the GP to help.

4.89 CCO2 called James on 11 December 2017 to ask how he was. James said he felt he was becoming suspicious of people and was able to identify this a sign he was becoming unwell. He had not started the aripiprazole but agreed to start this week. He said he had called the out of hours team because he had racing thoughts over the weekend but it had now settled down. Had a good night's sleep last night and now feels better. He asked if Dr L could increase the propranolol, as the GP had decreased it and he was not sure why, and this was causing a racing heart. CCO2 agreed to email Dr L, and to see James at home later in the week.

4.90 James left a message for CCO1 to call him on 11 December. CCO1 called him and spoke on the phone for about 15 minutes. Called to talk about how traumatic he had found it coming off clozapine and caffeine and alcohol, and now was worried about his physical health. He was not keen on taking the aripiprazole but has found it helpful. Again described '*waking from a slumber*' after coming off clozapine. He said he had called the crisis team because he had woken at 3 am and described himself as *'freaking out'*; had hallucinations and heard voices whispering that were soothing, saw colours and later that day had been *'manic'*, calling people; then very angry, shouting and screaming. He also said he had a very high moment, better than any high he had on drugs. He agreed he had some paranoia, some of this was centred on his experience of the clozapine clinic, and feeling suspicious of the new team. He said he had decided he would photograph things that were worrying him, so he could talk about them. James said he had a meeting planned with CCO2 that week. CCO1 asked how his parent were getting on, and he said they were always worried. No meetings were planned because James did not feel able to travel to Harlow at present.

4.91 On 14 December CCO2 called to the flat as arranged by phone, and got no answer. His mobile number was called several times, with no answer. CCO2 called Heidi at work, explaining a home visit was planned, particularly as there was concern regarding his mental state. It was noted that Heidi said he was a *'bit up and down*' but she had no immediate concerns. She was asked to call

CCO2 or the crisis team if there were any concerns, and informed that CCO2 was on leave the following week but that Duty and Crisis teams were available.

4.92 On 15 December James called the Trust contact centre asking for a message to be given to CCO2, which was that James '*wanted to work with him rather than against him*'. He said he was happy for someone to speak to Heidi if he was resting. She had taken that day off to stay at home with him but could not take any more time off, so he really wanted to speak to CCO2.

4.93 On 15 December James' parents called the Trust contact centre from abroad expressing concern. They were advised to request that the police do a welfare check and gave the contact number. The number of the Duty team was supplied.

4.94 On the morning of 15 December, CCO2 went to see James at home. James said he had called the police the night before because he felt someone was moving things about in the flat. Heidi said his memory was very poor and he was forgetting where he had put things. James admitted that he could sound rational but was not thinking rationally, and strange things were happening to him, such as things moving around. He was asked if he would agree he was showing signs of relapse and he was not sure, but he did eventually agree to increasing aripiprazole to 10 mg as suggested by Dr L.

4.95 James was asked about thoughts of suicide or self-harm and reported none. CCO2 noted that James appeared to be suffering a relapse in his mental state. The plan agreed was that Heidi would supervise medication at home, he would take aripiprazole 10 mg, and Dr L would renew the prescription.

4.96 CCO 2 noted that James was to go onto 'stepped care' with the Mid area Psychosis team. He refused daily visits but accepted daily phone calls with one joint visit planned for on Wednesday 20 December. He said he did not want new people in his flat but would answer the door to them. He had a psychology appointment booked for 4 January, and CCO2 planned to see if the venue could be moved to Braintree.

4.97 A call was taken by the out of hours team on the evening of 15 December from James' parents, expressing concern that James had not been answering the phone, and suspecting he may be having problems. His parents were asking the team to visit; it was explained that if they had concerns about his safety or anyone else's they should call the police.

4.98 The homicide occurred that night.

5 Discussion and analysis of James's care and treatment

5.1 The terms of reference require us to:

- Examine the referral arrangements, communication and discharge procedures of the different parts of the NHS that had contact with the service user
- Examine the effectiveness of the service user's care plan and risk assessment, including the involvement of the service user and his family
- Review the appropriateness of the treatment of the service user in light of any identified health needs/treatment pathway
- Review and assess compliance with local policies, national guidance and relevant statutory obligations

Care and treatment

5.2 In order to consider the issues in detail we have approached them under these following headings:

- Care planning, risk assessment and family involvement
- Prescribing and management of clozapine
- Physical health
- Substance misuse treatment
- Referrals, communication and discharge
- Family questions

5.3 We will include compliance with local policies, national guidance and relevant statutory obligations as part of our analysis

Care planning, risk assessment and family involvement

5.4 James had the following diagnoses:

- F10.26 Mental & Behavioural disorder due to the use of alcohol; [33]
- F20.0 Paranoid Schizophrenia

[33] *These are ICD10 codes for diseases, signs and symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or diseases. International Classification of Diseases (10th Revision). https://icd.who.int/browse10/2016/en#!/X*

- F41.1 Generalised Anxiety Disorder

5.5 He was not comfortable with the diagnosis of paranoid schizophrenia, preferring to consider that he had developed a psychotic illness as a result of drug usage. The anxiety was seen as a response to his psychotic and paranoid thoughts, which affected his daily life. He continued to suffer from anxiety and paranoid symptoms, which were never fully controlled by medication or psychological therapy. He believed that he was being watched and followed and had particular concerns about being targeted by the police and by Chinese people. He would not talk to Heidi in their flat if their mobile phones were switched on because he believed they were being recorded by phone. When Heidi was at work or out at her parents he would phone her regularly saying there were people breaking in to get at him.

5.6 His symptoms were not well controlled by antipsychotic medication, and in 2007/2008 he suffered from acute and enduring dystonic side effects. He had botox injections and medication for extrapyramidal side effects[34] but was asked to consider clozapine in April 2007. After some consideration James agreed to clozapine, which was prescribed in conjunction with quetiapine (detailed discussion of clozapine treatment below).

5.7 He was cared for under the care programme approach (CPA) as the policy states: '*An individual deemed to have complex needs, a higher risk profile and/or requiring multi agency input should be placed on CPA*'.[35] Six monthly reviews were carried out as expected by policy. He had a care coordinator (CCO1) who had provided consistent care since 2008, when he was last admitted to hospital. James was seen around three monthly as an outpatient by the Harlow CMHT consultant psychiatrist. He was seen initially by one consultant throughout 2007 and 2008, he saw a locum in 2010, and from 2011 to 2017 he was under the consistent care of one CMHT consultant.

5.8 CCO1 was in fact a consultant clinical psychologist based with the West Psychosis team. The cognitive behavioural therapy approaches that were provided to James over many years have been described in his clinical records in detail. James was provided with a care coordinator (CCO2) after his transfer to the Mid area team in 2017.

5.9 NICE guidance[36] for treatment of psychosis provides evidence-based guidance on the following best practice elements of treatment:

5.10 We have benchmarked James care in relation to these standards in the table below:

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[34] *Extrapyramidal side effects (EPS), commonly referred to as drug-induced movement disorders, are among the most common adverse drug effects patients experience from dopamine-receptor blocking agents.* *https://www.ncbi.nlm.nih.gov/books/NBK534115/*

[35] *EPUT CPA policy CLP30*

[36] *NICE CG178: Psychosis and schizophrenia in adults: prevention and management (2014)* *https://www.nice.org.uk/guidance/cg178/chapter/1-Recommendations*

Standards	Available to James
Service user experience	
Use this guideline in conjunction with service user experience in adult mental health (NICE clinical guidance 136) to improve the experience of care for people with psychosis or schizophrenia using mental health services, and: • work in partnership with people with schizophrenia and their carers • offer help, treatment and care in an atmosphere of hope and optimism • take time to build supportive and empathic relationships as an essential part of care.	Yes, continuity of care coordinator and well-developed relationships with James, Heidi and parents – up until 2017
Race, culture and ethnicity	
Healthcare professionals working with people with psychosis or schizophrenia should ensure they are competent in: • assessment skills for people from diverse ethnic and cultural backgrounds • using explanatory models of illness for people from diverse ethnic and cultural backgrounds • explaining the causes of psychosis or schizophrenia and treatment options • addressing cultural and ethnic differences in treatment expectations and adherence • addressing cultural and ethnic differences in beliefs regarding biological, social and family influences on the causes of abnormal mental states • negotiating skills for working with families of people with psychosis or schizophrenia • conflict management and conflict resolution.	Not directly applicable
Mental health services should work with local voluntary black, Asian and minority ethnic groups to jointly ensure that culturally appropriate psychological and psychosocial treatment, consistent with this guideline and delivered by competent practitioners, is provided to people from diverse ethnic and cultural backgrounds	Yes
Physical health	
People with psychosis or schizophrenia, especially those taking antipsychotics, should be offered a combined healthy eating and physical activity programme by their mental healthcare provider	Yes
If a person has rapid or excessive weight gain, abnormal lipid levels or problems with blood glucose management, offer interventions in line with relevant NICE guidance (see obesity [NICE clinical guideline 43], lipid modification [NICE clinical guideline 67] and preventing type 2 diabetes.	Yes
Offer people with psychosis or schizophrenia who smoke help to stop smoking, even if previous attempts have been unsuccessful. Be aware of the potential significant impact of reducing cigarette smoking on the metabolism of other drugs, particularly clozapine and olanzapine.	Yes
Routinely monitor weight, and cardiovascular and metabolic indicators of morbidity in people with psychosis and schizophrenia. These should be audited in the annual team report.	Yes, carried out by the GP, and clozapine clinics
Trusts should ensure compliance with quality standards on the monitoring and treatment of cardiovascular and metabolic disease in people with psychosis or schizophrenia through board-level performance indicators.	Unclear

Support for carers	
Offer carers of people with psychosis or schizophrenia an assessment (provided by mental health services) of their own needs and discuss with them their strengths and views. Develop a care plan to address any identified needs, give a copy to the carer and their GP and ensure it is reviewed annually.	Yes, to Heidi Difficult latterly as parents were abroad. Contact was maintained but it was not possible to arrange carers assessments
Advise carers about their statutory right to a formal carer's assessment provided by social care services and explain how to access this	Yes, completed
Give carers written and verbal information in an accessible format about: • diagnosis and management of psychosis and schizophrenia • positive outcomes and recovery • types of support for carers • role of teams and services • getting help in a crisis. When providing information, offer the carer support if necessary.	Some information provided, i.e. crisis numbers – no evidence of written information about diagnosis, recovery
As early as possible negotiate with service users and carers about how information about the service user will be shared. When discussing rights to confidentiality, emphasise the importance of sharing information about risks and the need for carers to understand the service user's perspective. Foster a collaborative approach that supports both service users and carers, and respects their individual needs and interdependence	Yes
Review regularly how information is shared, especially if there are communication and collaboration difficulties between the service user and carer.	Yes
Offer a carer-focused education and support programme, which may be part of a family intervention for psychosis and schizophrenia, as early as possible to all carers. The intervention should: be available as needed, have a positive message about recovery	Not provided to Heidi or parents
Include carers in decision-making if the service user agrees.	Yes
Peer support and self-management	
Consider peer support for people with psychosis or schizophrenia to help improve service user experience and quality of life. Peer support should be delivered by a trained peer support worker who has recovered from psychosis or schizophrenia and remains stable. Peer support workers should receive support from their whole team, and support and mentorship from experienced peer workers.	Not available at that time
Subsequent acute episodes of psychosis or schizophrenia and referral in crisis	
Offer crisis resolution and home treatment teams as a first-line service to support people with psychosis or schizophrenia during an acute episode in the community if the severity of the episode, or the level of risk to self or others, exceeds the capacity of the early intervention in psychosis services or other community teams to effectively manage it	Yes
Crisis resolution and home treatment teams should be the single point of entry to all other acute services in the community and in hospitals.	Yes

Consider acute community treatment within crisis resolution and home treatment teams before admission to an inpatient unit and as a means to enable timely discharge from inpatient units. Crisis houses or acute day facilities may be considered in addition to crisis resolution and home treatment teams depending on the person's preference and need	Yes
If a person with psychosis or schizophrenia needs hospital care, think about the impact on the person, their carers and other family members, especially if the inpatient unit is a long way from where they live. If hospital admission is unavoidable, ensure that the setting is suitable for the person's age, gender and level of vulnerability, support their carers and follow the recommendations in service user experience in adult mental health (NICE clinical guidance 136).	Yes
For people with an acute exacerbation or recurrence of psychosis or schizophrenia, offer: • oral antipsychotic medication in conjunction with • psychological interventions (family intervention and individual CBT)	Yes No
For people with an acute exacerbation or recurrence of psychosis or schizophrenia, offer oral antipsychotic medication or review existing medication. The choice of drug should be influenced by the same criteria recommended for starting treatment (see sections 1.3.5 and 1.3.6). Take into account the clinical response and side effects of the service user's current and previous medication.	Yes
Offer CBT to all people with psychosis or schizophrenia. This can be started either during the acute phase or later, including in inpatient settings.	Yes
Offer family intervention to all families of people with psychosis or schizophrenia who live with or are in close contact with the service user. This can be started either during the acute phase or later, including in inpatient settings.	No
Consider offering arts therapies to all people with psychosis or schizophrenia, particularly for the alleviation of negative symptoms. This can be started either during the acute phase or later, including in inpatient settings.	No
Behaviour that challenges	
Occasionally people with psychosis or schizophrenia pose an immediate risk to themselves or others during an acute episode and may need rapid tranquillisation. The management of immediate risk should follow the relevant NICE guidelines.	Not applicable
Follow the recommendations in self-harm (NICE clinical guideline 16) when managing acts of self-harm in people with psychosis or schizophrenia.	Not applicable
Psychological interventions	
Offer CBT to assist in promoting recovery in people with persisting positive and negative symptoms and for people in remission. Deliver CBT as described in recommendation 1.3.7.1	Yes
Offer family intervention to families of people with psychosis or schizophrenia who live with or are in close contact with the service user. Deliver family intervention as described in recommendation 1.3.7.2	No
Consider offering arts therapies to assist in promoting recovery, particularly in people with negative symptoms	No
Pharmacological interventions	

The choice of drug should be influenced by the same criteria recommended for starting treatment	Yes
Do not use targeted, intermittent dosage maintenance strategies routinely. However, consider them for people with psychosis or schizophrenia who are unwilling to accept a continuous maintenance regimen or if there is another contraindication to maintenance therapy, such as side-effect sensitivity.	Yes
Consider offering depot /long-acting injectable antipsychotic medication to people with psychosis or schizophrenia: • who would prefer such treatment after an acute episode • where avoiding covert non-adherence (either intentional or unintentional) to antipsychotic medication is a clinical priority within the treatment plan.	Not applicable
Using depot/long-acting injectable antipsychotic medication	
When initiating depot/long-acting injectable antipsychotic medication: • take into account the service user's preferences and attitudes towards the mode of administration (regular intramuscular injections) and organisational procedures (for example, home visits and location of clinics) • take into account the same criteria recommended for the use of oral antipsychotic medication (see sections 1.3.5 and 1.3.6), particularly in relation to the risks and benefits of the drug regimen • initially use a small test dose as set out in the BNF.	Not applicable
Employment, education and occupational activities	
Offer supported employment programmes to people with psychosis or schizophrenia who wish to find or return to work. Consider other occupational or educational activities, including pre-vocational training, for people who are unable to work or unsuccessful in finding employment.	Yes
Mental health services should work in partnership with local stakeholders, including those representing black, Asian and minority ethnic groups, to enable people with mental health problems, including psychosis or schizophrenia, to stay in work or education and to access new employment (including self-employment), volunteering and educational opportunities.	Yes
Routinely record the daytime activities of people with psychosis or schizophrenia in their care plans, including occupational outcomes	Yes

5.11 Heidi did attend many of his outpatient appointments and CPA reviews, but the table above demonstrates a lack of evidence that she or James parents' were provided with education and supportive family interventions.

5.12 It is clear that James received many years of psychological input. He was provided with an extra element of psychological input to work with his paranoid thoughts, as it was recognised that these were deeply entrenched and interfering with his life. It was noted that he would work on superficial coping mechanisms but would not engage in psychological work which challenged his delusional and paranoid beliefs.

5.13 NICE guidance for psychosis and schizophrenia in adults: prevention and management[37] advises that carers, relatives and friends of people with psychosis and schizophrenia are important both in the process of assessment and engagement, and in the long-term successful delivery of effective treatments.

5.14 It is recommended that carers should be given written and verbal information in an accessible format about:

- diagnosis and management of psychosis and schizophrenia
- positive outcomes and recovery
- types of support for carers
- role of teams and services
- getting help in a crisis.

5.15 In our view psychosocial education should have been provided for James, Heidi and his parents in understanding the nature of his diagnosis, how families could support him, what could be expected in terms of recovery, and how medication may affect him.

Finding 1

Family education and interventions; as in NICE guidance *'Psychosis and schizophrenia in adults: prevention and management' (2014);* was not provided by the Trust

5.16 Risk assessments were reviewed in line with the CPA care plan reviews, as expected by the Clinical Risk assessment and Safety Management policy.[38]

5.17 The most recent structured comprehensive care and risk plan we could find was written on 14 December 2017. There are detailed contingency and risk management plans, a crisis plan which included James' early warning signs of relapse. In the risk section it is noted that there is a risk he will resume drinking, with serious risks to his physical health and mental state. It was noted he does not generally have thoughts of self-harm and suicide, or of harming others, and when relapsing previously he broke a window in a girlfriend's house.

5.18 His relapse signatures included: preoccupation and fixation about past events that happen when he was engaging with drug misuse and how he was treated by people in clubs, difficulty getting out of bed, low mood, not leaving his home, feeling more paranoid and anxious. The triggers identified were

[37] *Psychosis and schizophrenia in adults: prevention and management Clinical guideline [CG178]Published date: February 2014 https://www.nice.org.uk/guidance/cg178/chapter/Introduction*

[38] *EPUT policy CLP28*

stresses e.g. significant change, being away from home, being alone. The contingency measures to prevent a crisis were: regular medical reviews and regular appointments with his CCO.

5.19 After the move to the Mid area team care plan reviews were described in narrative form in outpatient letters to his GP, starting with his first appointment with Dr L on 9 October 2017. A risk assessment was updated by CCO2 on 29 November 2017 within the care plan, and the START structured risk assessment tool was used, as described in the policy.[39] It is noted that these written care plans were discussed with James and Heidi, and a copy provided to him.

5.20 Risks updated at 29 November 2017 were:

- suicide ideation/intent: James reported previous thoughts of suicide and can have fleeting ideation at times. No plan or intent, does not feel he would ever act on this, identified Heidi as a strong protective factor
- violence and aggressive behaviour: no violence or aggression reported
- evidence of neglect/vulnerability: on a good day, [James] is able to care for himself, cook and clean. On a bad day or when unwell, [James] usually neglects these tasks
- physical health issues: reports to have stopped drinking alcohol altogether for last month. Has had catheter bag fitted due to urinary retention.

5.21 There is a section in the risk assessment entitled 'hazards' which notes that James had '*previously been violent when under the influence of drugs. This had not been a problem for several years, although there are times when he feels very angry and thinks about assaulting people*'.

5.22 There are entries during November 2017 when James described experiencing feelings of rage, and of feeling a 'high' which was stronger than anything he had experienced when taking drugs. There is no record of any exploration of these feelings, no discussion of with what or whom he felt rage, and no record of this in the updated risk assessment.

5.23 The Mid-Essex specialist psychosis service operational policy[40] describes a system of zoning, which allows for recording and prioritisation of risk:

Service users are zoned using a traffic light system:

- Red – for service users who need the highest levels of intervention

[39] *EPUT policy CPL28 page 12*

[40] *EPUT Mid-Essex specialist psychosis service operational policy Version 3 2015.*

- Amber – where service users have high levels of need but present with no immediate risk factors at the current time

- Green – where service users are more stable and making a good recovery

5.24 The level of interventions at each stage are not however, prescribed. There is no mention of zoning anywhere in the clinical records made by the Mid area Psychosis team. We consider that James should have been 'zoned' at amber from October 2017, and red from November 2017.

5.25 He was described by CCO2 in the clinical records as changing to '*stepped up*' care from December 2017. We can find no reference to a description of what this entails in the Mid Essex specialist psychosis service operational policy.

5.26 After raising a query about this with Dr L, we were informed that '*stepped up care'*, means:

'intense monitoring by the team. The team offers daily visits to monitor the progress the patient is making and provide hospital care at home. If the risk escalates and patient is identified to be high risk to himself or others, patient referral is made to the gatekeeping team for admission. If the patient is not responding to the stepped-up care, the team can then refer the patient for home treatment and the gatekeeping team for admission. The gate keeping team complete their own independent assessment and their criteria is that the community team should have tried at least 1 week of stepped up care in community to make sure that the patient cannot be stabilised in the community and requires an assessment for admission'.

5.27 The North Essex Specialist Mental Health Recovery Pathway (SMHT) Operational Policy[41] (June 2017), indicates that the SMHT Duty role is to '*deliver and co-ordinate stepped up care for those who have increased needs',* and the SMHT and Specialist Psychosis Team (SPT) Duty System Protocol[42] (undated), states that the role of Duty is:

- 'to provide stepped up care to patients who are in need of more frequent interventions as part of the care plan to prevent admission and who are 'RAG' rated RED. The crisis and contingency plan will outline interventions to be provided by Duty'.

- Patients on 'stepped up' care are RAG rated RED. All cases in RED are discussed in the team zoning meeting, and rationale for stepped up care agreed by the MDT.

- Risk assessment will be completed and a crisis and contingency plan put in place stating the frequency of stepped up care and outcomes to

[41] *EPUT North Essex Specialist Mental Health Recovery Pathway, operational policy June 2017*

[42] *EPUT Duty System Specialist Mental Health Team and Specialist Psychosis Team undated*

be achieved. This is the responsibility of the Lead Practitioner or Care Co-ordinator.

- Support calls, as well as face to face contacts will be provided to deliver the care plan.

- Duty co-ordinator (Band 6 or 7) to make clinical decision to step down, and cease stepped up intervention. This decision is to be communicated with the Lead Professional / Care co-ordinator.

5.28 CCO2 was on leave from 14 December, and it was noted that James and Heidi were told the Duty team was available. We can find no detailed description of what is meant by '*stepped up care'*, and what the Duty team's responsibility in this respect might be.

5.29 We were told that the expectation of gatekeeping procedures around admission to a hospital bed include that a patient would be provided with '*stepped up care'* for at least one week in the community before an assessment for an inpatient bed may be considered. Dr L was concerned about James appearing to be in in the early stages of relapse in early December 2017, but this gatekeeping process was given as part of the reason why admission was not an option open to the team at that time.

5.30 In Dr L's view he was not at that time unwell enough or presenting with significant risk such as to make the team consider an urgent admission. There was also an aspect of building a therapeutic relationship with James and building trust with him as his new team. It was felt that it would have been inappropriate to suggest for him to go into hospital when he was debating the diagnosis, and saying that he did not feel that antipsychotics had ever kept him symptom free.

5.31 The consideration of the therapeutic relationship is a positive aspect, however we found that James was not on any formal '*stepped up*' care plan, and there was no record of zoning. In our view the instruction to the CCO2 to '*keep an eye*' on him was insufficient as a risk management plan, and the Duty team did not have access to an up to date crisis and contingency plan. See finding 2 and 3.

Finding 2

An up to date risk assessment with risk mitigation plans was not undertaken in either specialist psychosis teams.

Finding 3

Systems to manage escalation in a patient's risk with respect to the need for potential admission to inpatient mental health beds were unclear.

5.32 Regular CCO meetings, clozapine clinic appointments and consultant outpatient appointments took place. The consultant input changed in September 2016, which was described as due to a restructure. As a result of this, an outpatient appointment that had been arranged for April 2017 had to be moved to May 2017. Personnel also changed and although he was allocated a new consultant psychiatrist, he was not seen for a face to face medical review between September 2016 and October 2017. Advice on medication management was obtained by phone from within the Harlow CMHT, and James had a telephone discussion with a consultant psychiatrist in March 2017, when James was concerned about liver function. The lack of medical review was noted in the internal investigation, but no recommendation was made.

Finding 4

Service changes contributed to a lack of timely CPA and medical review in Harlow in 2017.

5.33 The expected time frame for a risk assessment and CPA review is a minimum of six months. We could not find a standard regarding medical reviews, but would expect that this would be described in the CPA care plan.

5.34 We could not find evidence of a review of care plans or risk assessments when the transfer to the Mid area Psychosis Team occurred. Dr L's letters to the GP in October and December 2017 are termed '*care review/care plan*'. At 8 December 2017 medication changes were listed as '*started on aripiprazole with a view to increase it to 10 mg if felt beneficial*'. Health advice to remain abstinent of alcohol was noted, and the risk identified was '*deterioration of mental health'* and the risk management plan was '*to see him on a monthly basis'*. The CCO was asked to '*keep a closer eye on him*'.

5.35 In our view this was not an adequate reflection of James' needs or risk. He had recently changed teams after nearly 10 years, had life events such as moving to Braintree, having his parents travelling abroad, and had to stop clozapine abruptly in October.

5.36 There was positive consideration of his wishes not to transfer teams at the time of his move to Braintree in May 2017. However, his care became more fragmented when his need for clozapine bloods to be done locally became more pressing. A referral was made to the Mid area Psychosis team in August 2017, and it appears a gradual move to the local clozapine clinic was arranged. A Mid area team psychiatrist and CCO were not identified until October 2017. There was no formal handover from one consultant to another, which would have been of particular importance given his history of poor symptom control and high doses of physical and psychiatric medication.

5.37 During November and December there were many signs of his relapse warnings, and a significant change in his engagement with services. He made

several calls to physical health services, and out of hours mental health teams. He began writing long letters about his beliefs about his difficulties and became preoccupied with feeling he had been treated unprofessionally by the clozapine clinic. The most significant symptoms of relapse in our view were his description of racing thoughts, lack of sleep and mood instability. James described experiencing feelings of rage, and of feeling a '*high'* which was '*stronger than anything he had experienced when taking drugs*'. There is no record of any exploration of these feelings, no discussion of with what or whom he felt rage. In our view this is a serious omission. See finding 2.

Finding 5

The transfer of care between teams was not carried out in a timely manner, with appropriate detailed clinical handover and plans for continuity of care.

5.38 There is good evidence that Heidi was involved in James' care, and her views were taken into consideration. James gave permission for professionals to speak freely about his care to her, and she often accompanied him to care reviews and appointments.

5.39 James parents were in very regular contact with him whilst they were travelling abroad. There were times when James asked professionals to limit the detail of what was shared with his parents, and this was respected. Concerns expressed by his parents were noted and responded to.

5.40 However, in our view there was not a considered approach to family education, which could have helped both Heidi and his parents to support his recovery and identify when help was needed. See finding 1.

Prescribing and management of clozapine

5.41 James was originally prescribed clozapine in May 2008, following a history of severe extrapyramidal side effects while taking depot medication. He was prescribed quetiapine orally to try to minimise the side effects, but unfortunately this failed to lessen his anxiety and paranoia. At that time a LUNSERS[43] assessment was carried out which demonstrated that he was experiencing severe side effects.

5.42 Physical health investigations were carried out in preparation for clozapine prescribing. The internal report states that James was admitted as an inpatient while clozapine was initially prescribed, but the clinical records do not support this. The notes show that clozapine was started in May 2008, and his next inpatient admission to the Derwent Centre was in August 2008.

[43] *Liverpool University Neuroleptic Side Effect Rating Scale. The Liverpool University Neuroleptic Side Effect Rating Scale (LUNSERS) is self-rating scale for measuring the side-effect of antipsychotic medications.* https://innovation.ox.ac.uk/outcome-measures/liverpool-university-neuroleptic-side-effect-rating-scale-lunsers/

5.43 The therapeutic effects of clozapine were regularly monitored, with discussion about therapeutic levels and changing dosage times when James said it made him tired in the mornings.

5.44 He was seen regularly at clozapine clinics for health checks and blood tests, and monitoring was reduced to monthly blood tests in May 2009.

5.45 Therapeutic levels of clozapine are affected by general wellbeing, smoking, alcohol and caffeine intake. This was regularly discussed with James, and he was encouraged to reduce smoking, caffeine and alcohol intake, and doses were adjusted accordingly.

Traffic light system for dispensing clozapine:

Results	**WHITE BLOOD CELL COUNT (×109/L)**	**NEUTROPHIL COUNT (×109/L)**
GREEN Clozapine can be dispensed	>3.5	>2.0
AMBER Clozapine can be dispensed, but monitor full blood count twice a week	3–3.5	1.5–2.0
RED Stop clozapine. Monitor full blood count daily until results return to normal	<3	<1.5
Clozapine should also be stopped if the platelet count falls below 50×109/L or the eosinophil count measures above 3×109/L		

5.46 James had one ‘red’ result for clozapine in April 2011, which was deemed to be green on repeat analysis, therefore it was not necessary to discontinue clozapine treatment at that time.

5.47 An ‘amber’ then ‘red’ result was received in October 2017. This was followed by further red results on repeated testing. The clozapine policy[44] states the manufacturers advice is that clozapine is ‘*contra-indicated in patients with a history of clozapine-induced agranulocytosis and patients must not be re-exposed to clozapine after a red result’*. The advice from CPMS is clear that clozapine should be stopped and repeat blood tests carried out.

5.48 October 2017 blood results and management:

Date	**Clozapine result**	**Outcome/Event**
2 October	Green	Given 7 days clozapine
4 October	Amber	CPMS advice; repeat tests
5 October	Red	CPMS contacted. Advised to repeat test on 6 and 7 October
6 October	Red	CPMS advice: stop clozapine immediately and repeat tests

[44] *North Essex Partnership University NHS Foundation Trust, Clozapine policy: medicines policy Tab 13 Version 5 January 2016*

7 October	Red	Advice from Dr L who had not met James; increase quetiapine to 600 mg if deterioration in mental health. Appointment given for the following week.
9 October	Amber	Heidi called CCO1. James had had a bad week. Now 5 days without clozapine. Handover planned to the CCO2 at Braintree in 2 weeks' time.
9 October		Emergency appointment with Dr L. Return on 12 October for further blood test if green could restart clozapine. Advised to stop drinking alcohol as putting life at risk. Increase quetiapine to 600mg until clozapine could be reinstated, prescription given. Review appointment in 6 weeks.
12 October	Green	James told CCO1 unsure if he wants to go back on clozapine
16 October	Amber	CPMS advice: Await further tests
19 October	Green	James did not want to go back on clozapine; advised to discuss with Dr L on 30 October. Provisional plan for James to restart clozapine on 23 October
23 October	Green	CPMS suggested further blood test in 1 week with a view to restarting clozapine
30 October	Green	James reported he was not free of paranoia when on clozapine and had experienced other side-effects, so did not want to restart. Dr L noted, '*did not seem a good idea to restart clozapine.'* Mood was noted to be stable and he *'did not have any active thoughts of wanting to harm himself or anyone else.*'
	Green	

5.49 The Trust clozapine policy states that:

Re-use or re-trial of clozapine after a red result is unlicensed so liability for any use, whilst CPMS must be informed for blood monitoring, lies with the prescriber.
The Trust supports a very cautious re-exposure to clozapine in exceptional circumstances subject to the following:

- *a second opinion supporting the need for clozapine,*
- *advice from a haematologist,*
- *collaboration with pharmacy, care-coordinator and the wider MDT,*
- *informed consent from the patient regarding a 1 in 3 chance of repeat dyscrasia against likely benefits (the capacity to consent should be documented or if no capacity, Mental Health Act commissioners should be contacted), and;*
- *involve family or an advocate.*

5.50 Clozapine was therefore stopped immediately, and further blood tests were arranged. An emergency appointment was arranged to see Dr L, who reviewed his medication, and suggested he increase the dose of quetiapine in the meantime. There is no evidence that any education around the potential side effects of stopping clozapine were discussed with James, Heidi or his

parents. The clozapine policy[45] does not describe what support and education should be provided to a service user or family member in these circumstances. The Mid-Essex specialist psychosis service operational policy[46] (2015) does not refer to this either.

5.51 We would expect there to have been detailed discussion with him at an earlier stage about re-initiating clozapine, and some of the ways in which white blood cells can be boosted to prevent a further red result. This is because this was his first true red result in nearly 10 years and he had been successfully treated with it for many years.

5.52 We would also expect there to be investigations into why he suddenly had a red result, for example, getting advice from a haematologist.

5.53 Over the next three weeks James had three green results, and by the time he saw Dr L on 30 October he had been off clozapine since 5 October. He refused to consider taking clozapine again, so it was not in fact re-prescribed.

Finding 6

After the sudden cessation of clozapine, neither appropriate professional monitoring of physical health or education and guidance for service users and families were provided.

5.54 In our opinion the changes in his presentation should have triggered a full review of his risk assessment and care plans. At this point we consider that it would have been advisable to offer an admission to hospital to try to stabilise his mental state and make a full assessment. We were informed at interview that the team felt he had capacity and would have refused admission. It was apparently discussed in the team meetings, but not documented; nevertheless, we believe it should have been offered as an option to Heidi and James, and their responses recorded.

Physical health

5.55 There was good monitoring of James' physical health through the clozapine clinic and GP. The clozapine clinic communicated regularly with the GP requesting appropriate tests and monitoring.

5.56 James was known to experience ongoing side-effects of antipsychotic medication. These were treated appropriately by adjusting doses, prescribing medication to counter side-effects and referral to specialist services for botox injections.

5.57 From October 2017 to December 2017 James contacted primary care services with concerns about his physical health on many separate occasions. Six of these were to out of hours services, and included feeling his feet were

[46] *EPUT Mid-Essex specialist psychosis service operational policy Version 3 2015.*

ice cold, unexplained bruising, constipation, rectal bleeding and catheter problems.

5.58 He also saw his GP complaining of feeling unwell and dizziness. James shared his concerns about his physical health with CCO2 in November 2017, and it was noted that these concerns were also affecting his mental health. There is no record of this being discussed with Dr L, or of any discussion at an MDT meeting.

5.59 In our view there was insufficient attention paid to James' physical health concerns and any potential adverse effects on his mental state. See finding 6.

Substance misuse treatment

5.60 James was initially a user of illicit drugs, and this appears to have been a factor in his first psychotic episode. While he had no recorded use of illicit drugs after 2007, he continued to abuse alcohol, up until October 2017, when he stopped suddenly.

5.61 He was referred to local substance misuse services and encouraged to attend. He self-referred to Open Road in October 2017 after the red blood test. He engaged in initial assessments and agreed that his key worker could contact CCO2 for information about his care.

5.62 He declined any further contact in December 2017, saying he no longer needed any input, as he had not had any alcohol since early October.

Referrals, communication and discharge

5.63 James was provided with consistent care until early 2017, when there was a change of structure in community mental health teams. This meant that he was allocated a different consultant psychiatrist in Harlow, and plans to start outpatient appointments appear to have been delayed. He was not seen face to face by a consultant psychiatrist in Harlow between September 2016 and his transfer to Braintree Mid area team in October 2017.

5.64 There was a long delay between James moving to Braintree in May 2017 and being referred to the Mid area team in August 2017. This was largely at James' request, which is in itself commendable. In practice however this meant that he did not have the opportunity for a medical review, and his care began to become fractured. This was compounded by him not wanting to move clozapine clinics.

5.65 There was no structured handover between consultant psychiatrists, or teams. The handover arranged by CCO1 to CCO2 appears to have been helpful. However, this did not form part of a structured handover to the team, which should have included a review of medication, care plans and risk assessments. We have noted that neither CCO1 nor CCO2 was a qualified nurse, and could not be expected to support James with his medication regime. We have not made a formal finding about this because we have not found any causal link. However we suggest the Trust reflects on the skills

required when allocating a care coordinator for a service user who has a serious mental illness and a long history of instability on medication.

5.66 The internal investigation made a recommendation that any transfer of care between teams, needs to be clear and carried out in a timely manner in order to optimise opportunities to develop therapeutic relationship. We agree with this recommendation and have not repeated it.

5.67 There is evidence of good communication with primary care when James contacted the out of hours and hospital services for physical health issues. Actions recommended by NHS111 were acted on by the GP surgery.

5.68 Outpatient letters were routinely sent to the GP surgery after mental health consultations, with requests for the GP to adjust medication, or carry out physical tests.

5.69 We did not find any evidence of joint working with GP surgeries towards a shared care plan.

5.70 Within the electronic clinical records we found a variety of approaches to recording.

5.71 One care coordinator recorded an unstructured narrative of the discussions with James. Another recorded observations using the 'SBAR'[47] format. It is not clear whether either of these is the accepted format for documentation.

5.72 We note also that medical reviews were rarely documented in the clinical record from October 2017 onwards, and were on all but one occasion, were only noted in GP letters.

Finding 7

Recording of clinical information was not carried out consistently within and between teams.

[47] *SBAR communication tool- situation, background, assessment, recommendation. https://improvement.nhs.uk/resources/sbar-communication-tool/*

6 Internal investigation

6.1 This element of the terms of reference requires us to critically examine and quality assure the NHS contributions to the Domestic Homicide Review.

6.2 In order to do this we have reviewed the internal investigation report, and gathered some feedback about the experiences of James' parents in the process.

Critically examine and quality assure the NHS contributions to the Domestic Homicide Review

6.3 On 16 December 2017 the Trust was contacted by Essex Police, stating that an investigation into an alleged murder has begun and James was the alleged perpetrator and had been arrested. Initial information was shared, and James was seen by staff from the Criminal Justice Mental Health Team (CJHMT), who completed an incident form (Datix).[48]

6.4 As expected by the NHS England Serious Incident Framework, a serious incident investigation was commenced.

6.5 The Trust head of safeguarding became a formal member of the DHR panel, and the internal serious incident investigation became the Trust individual management report for the DHR panel.

6.6 An investigation panel was formed, comprising the director of mental health services, consultant forensic psychiatrist, crisis resolution & home treatment team manager, and the head of safeguarding.

6.7 The report does not record the timeline of the investigation process, nor the reasons for the extensive delay in producing the report. The first iteration of the report was shared with families in October 2018.

6.8 The Trust allocated family liaison officers (FLO) who maintained regular contact with both families individually. Both families were contacted to ask for their input into the internal investigation, and both families responded by either meeting with Trust staff, and/or making contributions in person and in writing. It was noted that access to relevant support had been offered to both families.

6.9 Heidi's family were initially unable to meet, and contact was maintained through the Police Family Liaison officer. A first meeting was arranged in May 2018, and a number of concerns were raised, and later responded to by the Trust. A further meeting with Heidi's brother and sister took place in July 2018.

[48] *Datix is the EPUT electronic incident recording system.*

6.10 James' parents were abroad, and a teleconference was arranged with them in April 2018.

6.11 Comments were received, and a final version which responded to both family questions was sent back to the families in March 2019. There is no explanation in either version of the report for this delay.

Finding 8

The serious incident investigation report did not meet the timeliness standards expected by NHS England guidance, although an extension had been agreed by the CCG.

6.12 The resulting report is repetitive and difficult to follow. There are two appendices (2&3) which give the detail of each families' questions, and a further appendix of queries (4) raised by James' parents after receiving the draft report, with Trust responses.

6.13 Questions and comments were obtained through the FLO via emails from both families, and these were incorporated into the terms of reference and findings. Some factual accuracies were identified which were adjusted.

6.14 James' family provided questions based on the report to this independent investigation, which are discussed in Appendix D.

6.15 The internal report used a structured approach to identifying contributory factors. No root cause was identified, but the report listed a series of factors which are considered to have influenced the outcome. These were:

- Handover between CMHTs
- Medical reviews
- Optimisation of medication
- Consideration of hospital admission
- Optimal resource allocation (considering the care coordinators were a psychologist and a social worker)
- Lack of formalised structure when transferring patients between teams

6.16 We found a contradiction regarding the starting of clozapine. At paragraph 32 it is stated that: *'Whilst under the care of the CRHT in 2008, Patient A's mental state was improving, despite review of his treatment. As such he was started on clozapine and this was monitored accordingly in the community by the CRHT'*. In the answers to the family questions in Appendix 4, it is stated by James' family (page 55): '*this paragraph wrongly states that the Patient started clozapine in the community, whereas he started it as an informal inpatient in 2008 (as stated in paragraph 4 of the Report)*'.

6.17 The Trust response is: '*We acknowledge this, but the report does not say patient started this in the community only monitored in the community*'.

6.18 However, on this point the report does in fact say (at paragraph 32) that clozapine was started in the community, which is factually accurate according to the clinical records.

6.19 There were a number of findings which do not appear to have been taken forward as recommendations, such as inadequate documentation regarding risk and mental state assessments, lack of timely risk assessment reviews, and MDT discussions not taking place when indicated.

6.20 There were four recommendations made:

a) When a known patient under CPA shows significant relapse signatures, a review of the current care plans ought to be carried out in order to establish whether the patient will benefit from interventions and additional support from different disciplines

b) When there is a transfer of care between teams, the transition needs to be clear and carried out in a timely manner in order to optimise opportunities to develop therapeutic relationship

c) The allocation of care coordination of patient needs to be delegated according to the need of the patient

d) When a Patient's history demonstrates inadequate symptoms controlled despite the use of combinations of anti-psychotics, medical reviews should aim at collaboratively working with the patient to promote insight about how treatment with medication needs optimise when one of the anti-psychotic is stopped

6.21 These recommendations appear to us to be targeted at clinical care issues, rather than systems issues.

6.22 There is no exploration of what the factors influencing decisions were; for instance, why policies were not followed, and the factors influencing the lack of risk assessment and adequate documentation.

7 Findings and recommendations

7.1 We have listed below the findings that we have developed through our analysis of the care and service delivery issues, and our subsequent recommendations.

7.2 It is clear that James had a serious mental illness that was treated over many years by the Trust. He was never symptom free but had access to medical and psychological care which supported him to maintain a level of wellbeing and independence. He was provided with consistent care by CCO1 for over 10 years.

7.3 He continued to abuse alcohol until October/November 2017, and his engagement with psychological care tended to focus on coping skills rather than attitude change. He continued to question his diagnosis and suffered ongoing anxiety as a consequence of his paranoia.

7.4 James had a supportive partner and family who provided emotional and practical assistance. He was able to maintain independent living with his partner, although the choices he made about the use of alcohol could be said to be unwise.

7.5 The move to the Mid Essex team took place months after they moved house, and this was largely because of James' anxiety about change. The handover was not structured, and was not supported by a full care plan and risk assessment review. Because of service changes, he did not have a medical review between September 2016 and October 2017.

7.6 The management of the cessation of clozapine following the red result in October 2017, did not in our view offer sufficient support to James and Heidi. It was recognised that he was relapsing in November and December 2017, and we consider this should have triggered MDT discussion, and a clear care and risk management plan that considered the presenting risks.

7.7 A thematic diagram of the issues is at Appendix E.

7.8 We have made the following seven recommendations to improve patient care accordingly.

Finding 1

Family education and interventions; as in NICE guidance '*Psychosis and schizophrenia in adults: prevention and management (2014)*'; was not provided by the Trust

Finding 2

An up to date risk assessment with risk mitigation plans was not undertaken in either specialist psychosis teams.

Finding 3

Systems to manage escalation in a patient's risk with respect to the need for potential admission to inpatient mental health beds were unclear.

Finding 4

Service changes contributed to a lack of timely CPA and medical review in Harlow in 2017.

Finding 5

The transfer of care between teams was not carried out in a timely manner, with appropriate detailed handover and plans for continuity of care.

Finding 6

After the sudden cessation of clozapine, neither appropriate professional monitoring of physical health or education and guidance for service users and families were provided.

Finding 7

Recording of clinical information was not carried out consistently within and between teams.

Finding 8

The serious incident investigation report did not meet the timeliness standards expected by NHS England guidance, although an extension had been agreed by the CCG.

Recommendations

Theme 1 Patient care

Recommendation 1

The Trust must ensure that NICE guidance for the care and treatment of patients with psychosis is adhered to, including specific reference to structured family education.

Recommendation 2

The Trust must revise their clozapine administration guidance to include the education of patients and families, and the management of risk if clozapine is stopped suddenly.

Theme 2 Service delivery

Recommendation 3

The Trust must ensure that community teams have structures and processes to ensure that the CPA policy is adhered to, and systems in place to monitor compliance.

Recommendation 4

The Trust must provide clarity about protocols and responsibilities with respect to responding to increased need for interventions, zoning, and the process for considering and effecting inpatient admissions from the community.

Recommendation 5

Standards for note keeping must be monitored by the Trust, to include how medical consultations are recorded.

Theme 3 Trust oversight

Recommendation 6

When going through large-scale service changes, the Trust must ensure that risks to patient care are assessed, documented and mitigated.

Recommendation 7

Serious incident investigation reports must meet the timeliness standards expected by NHS England guidance.

Appendix A – Terms of reference for the independent investigation

ADDITIONAL HEALTH RELATED TERMS OF REFERENCE FOR 2017/30950

The investigation is to be conducted in partnership with the Domestic Homicide Review into the death of [Heidi]

Terms of Reference

The investigation will examine the NHS contribution into the care and treatment of the service user from his first contact with specialist mental health services up until the date of the incident.

- Critically examine and quality assure the NHS contributions to the Domestic Homicide Review
- Examine the referral arrangements, communication and discharge procedures of the different parts of the NHS that had contact with the service user
- Review and assess compliance with local policies, national guidance and relevant statutory obligation
- Examine the effectiveness of the service user's care plan and risk assessment, including the involvement of the service user and his family
- Review the appropriateness of the treatment of the service user in light of any identified health needs/treatment pathway
- To work alongside the Domestic Homicide Review panel and Chair to complete the review and liaise with affected families
- To provide a written report to NHS England that includes measurable and sustainable recommendations to be published either with the multi-agency review or standalone

Appendix B – Documents reviewed

EPUT NHS Foundation Trust documents

- Clinical records
- Internal investigation report
- Mid Essex Specialist Psychosis service Operational Policy
- Access Assessment Service Operational Policy
- CG 52 Appendix 3 Management of Acutely Disturbed Patients
- CG 52 Clinical Guidelines for the Pharmacological Management of Acutely Disturbed behaviour
- CG 55 Appendix 2 Guideline on Monitoring Psychotropic Prescribing
- Clozapine policy
- Clozapine quick reference guide
- CLP 28 Clinical Risk Assessment, Management & Safety policy
- CLP 30 CPA policy
- CLPG 13-MHJS Appendix 7 High Dose Antipsychotics
- CLPG 28 Appendix 1 Aide Memoire for Assessing Risk and Compiling a Safety Management Plan
- CLPG 28 Appendix 2 Guidelines for Good Documentation
- CLPG 28 Clinical Risk Assessment, Management & Safety procedure
- CLPG 30 CPA procedure
- CLPG 30 CPA procedure Appendix 1 CPA Information leaflet
- Duty Protocol
- Mid-Essex specialist psychosis service operational policy
- North Essex Specialist Mental Health Recovery Pathway Operational policy

Other documents

- GP records and Individual Management Report
- Open Door Individual Management Report

Appendix C – Chronology

Dates	Service	Summary
2000	Acute admission, Harlow	Two weeks admission, offered counselling and stress management
Late 2000	CMHT outpatients offered	Did not attend follow up appointments
December 2002	Harlow CMHT	Referred by GP to CMHT psychiatrist, at the same time his father raised concern that James's mental health was deteriorating and he was low in mood. The GP prescribed an antidepressant, fluoxetine.[49] James confirmed feeling low in mood with some delusional beliefs such as his computer had been hacked and that his personal details had been shared. He did not feel suicidal and did not feel he needed to be seen urgently. He was referred for a follow-up in the outpatient clinic in early 2003.
January 2003	Harlow CMHT	Seen by consultant psychiatrist in the outpatient clinic. James reported feeling people were watching him, checking his computer, sending messages and planting his garden lawn with microphones. The impression was a possible diagnosis of paranoid schizophrenia and that he needed to exclude drug induced psychosis due to the previous drug history. Fluoxetine was discontinued, and James was started on olanzapine[50] 5 mg. he remained in hospital until March 2003 and was discharged having attained 'partial recovery'. He was diagnosed as suffering with persistent delusional disorder.[51]
3 February – 12 March 2003	Stort Ward Derwent Centre	Admitted informally to Stort Ward in Harlow, on 3 February 2003. At the time he was observed to be suffering with paranoid delusional ideas and was also having persecutory delusions in the nature that people were after him and messing with his head. He also believed that people were using computers to monitor him. He was prescribed Olanzapine 10 mg at the time.

[49] *Fluoxetine is a type of antidepressant medication, known as selective serotonin reuptake inhibitors. SSRIs are the most widely prescribed type of antidepressants. https://www.nhs.uk/conditions/antidepressants/*

[50] *Olanzapine is a type of antipsychotic medication. Antipsychotic medicines are usually recommended as the first treatment for psychosis. https://www.nhs.uk/conditions/psychosis/treatment/*

[51] *Delusional disorder is a type of serious mental illness in which a person cannot tell what is real from what is imagined. The main feature of this disorder is the presence of delusions, which are unshakable beliefs in something untrue, characterized by the development either of a single delusion or of a set of related delusions that are usually persistent and sometimes lifelong. The content of the delusion or delusions is very variable. Clear and persistent auditory hallucinations (voices), schizophrenic symptoms such as delusions of control and marked blunting of affect, and definite evidence of brain disease are all incompatible with this diagnosis. However, the presence of occasional or transitory auditory hallucinations, particularly in elderly patients, does not rule out this diagnosis, provided that they are not typically schizophrenic and form only a small part of the overall clinical picture. https://icd.who.int/browse10/2016/en#/F22.8*

Dates	Service	Summary
2003/2004	CMHT Harlow	On CPA and monitored by outpatient appointments and care coordinator, and sessions with clinical psychologist started. He was prescribed antipsychotic and antidepressant medication with variable compliance. A depot medication, flupentixol,[52] was prescribed for the first time.
2005	CMHT Harlow	Continued to be monitored in the community via the CMHT and outpatient clinic reviews and his treatment included: carbamazepine, olanzapine, 64epixol and trifluoperazine.[53] He did not always take his oral medication. James disclosed he had been using illicit substances (magic mushrooms and cocaine) and this had brought up an increase in hearing voices and feeling paranoid. It was noted by the consultant psychiatrist that James would be susceptible to psychotic relapses of marked severity on going through stress or life changes and if he discontinued his medication.
July 2005	A&E Harlow	James presented to the A&E in Harlow where he was assessed by the psychiatric liaison nurse. He complained of auditory and visual hallucinations. He was angered by these and was also annoyed about feeling that his computer had been hacked by a stalker. He reported 3 to 4 weeks before that incident he used magic mushrooms. James became agitated and would not wait to be seen by the on-call psychiatrist in order to discuss his medication but he agreed to take his prescribed medication and contact his care coordinator.
2006	CMHT Harlow	Seen in outpatient clinic for routine monitoring and titration of medications. Continued to express paranoid ideas, affecting his day-to-day functioning. He reported feelings of being followed by strangers, people watching him and had been isolating himself as a way of coping, and using alcohol to the excess at times.
March 2006	CMHT Harlow	Worsening symptoms of paranoid ideas, related agitation, and excessive recreational drug use and alcohol consumption. Trifluoperazine 5 mg twice a day was added and this improved symptoms. He was advised to avoid alcohol & recreational drugs.
July 2006	CMHT & CRHT Harlow	He had been monitored by a care coordinator and involvement of the crisis resolution & home treatment team (CRHT) to enhance his care after an outpatient review where he was showing further deterioration in his mental state. There was also concern about medication compliance

[52] *Depixol (Flupentixol) is an injectable (depot) medication used for maintenance treatment in schizophrenia and other psychoses.* https://bnf.nice.org.uk/drug/flupentixol-decanoate.html#indicationsAndDoses

[53] *Trifluoperazine is an antipsychotic medication.* https://bnf.nice.org.uk/drug/trifluoperazine.html

Dates	Service	Summary
29 July – 16 August 2006	Stort Ward Derwent Centre	After his arrest on 28 July for smashing girlfriend's window, he was seen on 29 July by CRHT and admitted informally to Stort Ward; struggling to cope in the community with his paranoia and delusional thoughts. Admission was to stabilise mental state and medication.
September 2006	CMHT Harlow	Initially very paranoid after discharge, settled with increased oral medication, stable by end of September
3 November – 15 November 2006	Stort Ward Derwent Centre	Concerns were expressed by his parents and care co-ordinator, stopped taking oral medication, paranoid and suspicious. He felt he was being watched and people thought he was a rapist and had bugged his mobile phone. He admitted taking cocaine and cannabis. Advised to contact ADAS, and accepted trifluoperazine. Asking to leave so was discharged after some leave, on 15 November.
18 November 2006 – 31 January 2007	Stort Ward Derwent Centre	Readmitted four days later, finding it difficult to cope at home and distressed by paranoid thoughts, consumed a large amount of alcohol. Frightened to go out, referred to psychology, switched to quetiapine 250 mg and depixol 100 mg fortnightly, with lorazepam to address agitation.
2007	CMHT Harlow	Continued to have paranoid thinking that people were following him, being under surveillance and listening to him on his mobile. The outcome of the outpatient clinic review in February resulted in his flupenthixol being reduced due to side effects. James reported using cocaine two months before. A new care coordinator was appointed, and he was engaging with ADAS with regards to his substance misuse. In March, his depot of flupentixol was changed to risperidone consta due to severe side effects.
December 2007	CMHT and assertive outreach (AOT) Harlow	Seen for urgent review, been in a fight, with people he believed were out to harm him. Using alcohol & cocaine. Lorazepam 0.5 mg added and encouraged to attend the local substance misuse service (CDAT).
2008	CMHT and assertive outreach (AOT) Harlow	Fortnightly outpatient reviews and care coordinator contact. Paranoia variable levels, anxious but depot reduced because of extra pyramidal side effects, mostly neck spams. Depixol stopped and changed to risperidone consta. James refused to consider clozapine until May 2008. Referred to psychology at his request.
May 2008	CMHT and assertive outreach (AOT) Harlow	Seen by CRHT from 24 April to 9 May due to deterioration in mental state. Increased quetiapine failed to address his increased paranoia, clozapine 75 mg started in May, reducing quetiapine gradually. EEG before clozapine showed him to have sinus tachycardia.
June 2008	CMHT and CRHT Harlow	Seen in outpatients for CPA review, and also under the care of CRHT. Clozapine increased to 150 mg morning and 250 mg at night, reporting anxiety and increased paranoia and fearful he is being targeted. Miss C is supportive, he denies using any recreational drugs, no

Dates	Service	Summary
		major side effects of clozapine, but some mild problems with neck torticollis, slowly improving.
July 2008	CMHT and CRHT Harlow	Seen by CMHT consultant with CRHT consultant, quetiapine increased as paranoia and anxiety increased. Delusional beliefs very present. Referred to cardiology for assessment as routine ECG consistent with sinus tachycardia.
20 August 2008- 17 September 2008	Chelmer Ward Derwent Centre	Deterioration of mental health, frightened when he is out, people know about him and his past, delusions of reference from Ceefax. Highlighted words appear on the TV which he believes are from computer people trying to 'screw his head up'. Admitted informally to Chelmer Ward. Various changes made to medication 'to lessen the impact of symptoms' and had short term psychological work.
February/March 2009	CMHT & CRHT Harlow	Medical review - seen with Heidi - paranoid ideation still present, only going out accompanied, continues to feel under surveillance. Quetiapine 300 mg mane and 400 mg nocte, clozapine 200 mg mane and 350 mg nocte. Clozapine increased by 50 mg to 200 mg mane & 350 mg nocte. Side effects of weight gain, in part from quetiapine, but also alcohol use. Torticollis much improved. Discussion about National Psychosis unit if he does not respond well to increased clozapine. Seen monthly by consultant, no change by March 2009, still on fortnightly blood testing. Reluctance to increase medication, now on substantial doses of two antipsychotics. Making enquiries at NPU. Parents seen, appear under stress, carers assessment discussed
October 2009	CDAT (West Essex community drug & alcohol team)	Presented in April 2009 with 2-month history of drug & alcohol misuse. Case closed October 2009, discharged because he no longer needed the service, abstaining from alcohol.
November 2009	CMHT Harlow	Medical review – said he has cut down from 8 pints every night to 2 pints a night (of 4% lager). Paranoid ideas present about people from Birmingham being in Harlow, plans to move to Cambridge for a 'fresh start'. Heidi has had a kidney transplant. Said Heidi is closest to him and while he cares about his parents, it is their decision. Said he does not want to work with AOT as finds them intrusive. Would consider an out-patient assessment at NPU but does not want to be separated from Heidi as an inpatient. No med changes. Seeing psychologist & OT for stress & anxiety management. Said he will remain involved with ADAS.
December 2009	CMHT Harlow	No changes, said he went on holiday and found his paranoid experiences were there, so now decided against moving to Cambridge, possibly another village in Essex. Parents asked for formal care coordinator to be

Dates	Service	Summary
		allocated; actioned. Encouraged to maintain ADAS contact as still drinking. No plans to harm people.
March 2010	CMHT Harlow	Reported continuing anxiety, denied suicidal or homicidal ideas. CMHT declined to allocate care coordinator, so psychiatrist maintaining CCO responsibility. No changes to medication.
April 2010	CMHT Harlow	Paranoid thoughts, asking RC to write a letter to Cambridge council stating that staying in Harlow is detrimental to his physical & mental wellbeing, talking of asking his MP to help. No changes to medication. Using alcohol daily despite contact with ADAS. Suggested referral to National Psychosis Unit again, but he declined the offer. CPA review June 2010.
May 2010	CMHT Harlow	Letter to his mother assuring her he had been referred to ADAS and was motivated to engage with them and talking of abstaining.
September 2010	CMHT Harlow	New psychiatrist in the team. Anxious and guarded, said he had been physically unwell the previous week with diarrhoea and vomiting but was better now. Still drinking regularly, very reluctant to discuss medication, especially Lorazepam. No psychotic symptoms, to be seen regularly in clozapine clinical and by CCO.
November 2010	CMHT Harlow	Seen as OPA with Heidi. Had a relatively good period, and less drinking, but said he had gone downhill. Increased alcohol abuse and increase in anxiety and paranoia. Said he did not have a problem with his mother knowing about his treatment plan, but he did not want her to know about his drinking. Specialist psychological therapy for paranoia introduced, James to meet the psychologist in November to discuss.
May 2011	CMHT Harlow	Finding psychology sessions hard, too intense & can't trust the psychologist. Problems with continuing paranoia and anxiety, thought police dogs were watching and following him- caused him to '*act out physically on the door at home'*. Heidi asked if he could be prescribed lorazepam that she controlled, so he doesn't abuse it. Still tending to use external resources to manage his anxiety eg alcohol, drugs or medication.
December 2011	CMHT Harlow	Seen as OPA with Heidi. James's mother had sent a letter expressing her concerns, discussed. CCO had responded and spoken to his mother which seemed to reassure her. James said he had been feeling more paranoid and found it difficult to use the techniques from psychology sessions. Coping better without lorazepam, physical health better after healthy eating efforts, lipid profile improved. No psychosis, no side effects, asking to come off quetiapine because he is on clozapine, to be discussed further.
February 2012	CMHT Harlow	Seen as OPA with Heidi. Reduction in quetiapine discussed, said he felt increasingly anxious, but has

Dates	Service	Summary
		settled now, and feels less paranoid. Recent plasma levels were 0.29 mg per litre, below normal range, he said he never forgets clozapine or more than 24 hours. Discussed the effects of smoking & caffeine intake. Said he smokes a lot, drinks a lot of coffee & tea, one bottle of coke and one bottle of red bull at least per day. Encouraged to decrease this, and repeat plasma levels.
February 2012	Letter from Heidi to CMHT	Letter of concern after OPA. Concern that clozapine levels have only just been flagged up as low now, and neither agreed to the care plan. Suggests his clozapine be increased at night as he had trouble sleeping. Said he won't communicate with her if their mobiles are in the same room, he'll only write things down- believes his and her phones are tapped. Avoids her family because he believes they are plotting against him Said Dr L only asked about medication and not about his mental health. Asks for plans to be reviewed so that he keeps a diary of this thoughts, and night time medication be reviewed.
July 2012	CMHT Harlow	Seen with Heidi & CCO. Good & bad days, started diet coke again but trying to limit to 500 ml per day. Drinking again, 40 units of alcohol a week, tries to have 3 alcohol free days a week. April 2012 clozapine plasma levels 0.23 mg per litre- less than therapeutic level, but once again discussed that levels depend on his smoking & caffeine intake. Paranoid ideas remain, no SE's. Care plan: James try to resume gym activities, reduce caffeine & fizzy drinks, and reduce alcohol and smoking. Increase clozapine & decrease quetiapine
November 2012	CMHT Harlow	Seen with Heidi. Working actively in psychology sessions, focus on confidence and self-esteem building, one panic attack last week related to thinking a friend's wife was plotting against him. No alcohol on 4 days a week, but 30/40 units per week, 20/25 cigarettes a day. Starting to exercise more, asking for diagnosis to be changed as he hasn't used illicit drugs for 3 years. Forgets mane meds sometimes, and worries that it makes him drowsy, clozapine changed to 100 mg mane & 500 mg nocte.
March 2013	CMHT Harlow	Seen with Heidi & CCO. Panic attacks, especially at night, wakes up unable to breathe. Insistent he did not want to go on any other medication, and wanted to continue decreasing quetiapine. Drinking 30/40 units a week.
April 2013	CMHT Harlow	CPA review with Heidi & CCO. Emerged that he had been drinking far more than the 30/40 units he said at last OPA. Questioned his diagnosis of F10.26, and said alcohol is not a problem. Paranoid ideas.
September 2013	CMHT Harlow	Seen with Heidi & CCO. Listed a number of events that he felt showed people were conspiring against him. Asked that these be put in the care plan, so he could show his parents to provide evidence to his parents that

Dates	Service	Summary
		they could be real. Blood tests showed some improvement in liver function & lipid profile, to be repeated every month at clozapine clinic. Clozapine reduced to 500 mg nocte. Drinking less (12 cans a week) and exercising more, lost 6lbs in previous 2 months.
November 2013	CMHT Harlow	CPA review with Heidi & CCO. Depressed and anxious, anxiety mostly around people acting suspiciously when he is fishing. Believing phones are 'bugged' so need to be switched off while talking to Heidi. Feeling hopeless sometimes that things are not going to get any better, but no anhedonia and reduced mood for 2/3 days a week only. Still drinking a lot of alcohol, ¾ days week drinks 4 to 8 pints of 4% lager. Asking for increase in propanol for anxiety symptoms, especially palpitations. Increased to 160 MR nocte
January 2014	CMHT Harlow	Phone call to consultant from James, increasingly anxious and having a lot of paranoid ideas, requesting benzodiazepines. Long discussion about pros and cons, and how he had come off them after being addicted. Finally agreed to increase nocte quetiapine to 300 mg, for review at Jan OPA, GP informed.
April 2014	CMHT Harlow	Seen with Heidi & CCO. Reasonably stable, manged a holiday to Paris. Noticed he tends to become increasingly suspicious when he is more anxious, but able to manage it better. Still using alcohol, 2 or 3 days a week when he drinks a bottle of 13% wine and 2 cans 5% beer. Asking for some medication to counteract excessive salivation that he was having on clozapine. No evidence of thought disorder, or thoughts of harm to self or others. Agreed to start monitoring lipids & LFTs as he found that motivating in the past. Diet/exercise encouraged.
Nov 2015	CMHT Harlow	Seen alone. Increasingly anxious over the past few weeks. Reduced motivation and anergia. Comfort eating and drinking a bottle of wine & two beers 3 or 4 times a week. Triggers stated as Heidi having a scare about cervical cancer. Also, his grandmother died about 3 months ago, and his mother inherited some money, he thought she would share it with him but she hasn't, now very angry. He had thought parents would help him move out of Harlow by giving money to help buy a place. These making him more anxious with symptoms of depression. Clozapine levels on 22/9 0.76 mg per litre. He said he had stopped smoking completely and was informed clozapine dose would need to be reviewed. Agreed on Fluoxetine 20 mg which had helped in the past.
Dec 2016	CCO Harlow (CMHT)	Letter to mother in response to her letter of concern. Understands that it can be very difficult to know how to help James, and the medication he is taking may take

Dates	Service	Summary
		some time to have a full effect. Offered opportunity to have carers' assessment.
September 2016	CMHT Harlow	Seen with CCO. Informed that he is moving to the Braintree area, probably within the next 6 to 8 weeks. Some anxiety about this but mental state reasonably stable, still having the same amount of alcohol. Clozapine levels (3/3/16) 0.62 mg per litre. Long discussion, eventually agreed to reduce to 425 mg nocte. Asked to keep the CMHT informed about moving and would then be referred to the local team.
May 2017		Moved to Braintree
August 2017	CMHT Harlow	Referred to Mid area Psychosis team, Braintree
October 2017		Accepted by Mid area Psychosis team
9 October 2017	Mid area psychosis team	Seen by Dr L, emergency appt as blood had come back red. Further test this am, amber. Clozapine clinic asked him to have a further blood test this Thursday, if green to go back on clozapine. Drinking 60 units of alcohol weekly until recently, when he was informed it could be a combination of alcohol and clozapine affecting his white blood cell count, go it extremely anxious and stopped alcohol, altogether, which could have been why the next latest was amber. Strongly advised not to use alcohol. Suggested he can double up his quetiapine if he starts to become unwell, until the clozapine is reinstated, extra quetiapine 300 mg daily px if required, but can go back on clozapine if results are green. To see in 6 weeks. Said the move has been positive, they prefer Braintree.
10 October 2017	Mid area psychosis team	Clozapine 400 mg nocte discontinued as had red result.
October 2017		Call to NHS 111 saying feet were ice cold. Said he stopped clozapine 3 weeks ago after having a bad reaction to it
30 October 2017	Mid area psychosis team	Has had three green results, and off clozapine for some time. He explained that clozapine had not adequately controlled his symptoms and he was still struggling with paranoid ideas). Said tachycardia and constipation have also gone, and sexual issues improved. *'It certainly did not appear to be a good idea to put him back on clozapine*'. Somewhat contained on quetiapine, said the move to Braintree had been very difficult for him, very suspicious of people and finds it hard to trust. Mood stable, no thoughts of harming himself or others. Abstinent of alcohol for one month, and has established contact with Open Road. CCO (S/W) keeping an eye on him, James requested psychological treatment and to be discussed din next MDT mtg. Stress from health of partner, Heidi had a blood transfusion and had a bad

Dates	Service	Summary
		reaction to it. Not thought disordered, to see again in 6/8 weeks.
November 2017	CCO Harlow	Saw Harlow CCO for final time, but to see monthly for psychology input until appointment with Mid area team psychologist.
2 December 2017	NHS 111	Has catheter, looks orange, pain in penis where catheter is. Maybe side effects of antipsychotic meds. Spoke to him & partner. Not bypassing, draining normally. Advised to contact a primary care service within 6 hours.
2 December 2017	Prime care OOH Braintree	Constipated, rectal bleeding, advised to attend A&E
2 December 2017	A&E Broomfield Hospital	23.13. Difficulty moving bowels, had PR bleed, possible straining. Has catheter in situ for urinary retention. Recent alcohol detox, MEWS 0. Also requesting mental health assessment for anxiety. Poor mobility, has been lying in bed whole week. Prescribed lactulose and movicol, advice on diet and exercise.
2 December 2017	A&E Broomfield Hospital, EPUT access & assessment service	Seen in A&E, brief advice given on anxiety management, to contact the specialist psychosis team on Monday, to continue with prescribed medication until appt with Dr L next week. Advised that Dr L would do medication next week, they will call to see if there is an appt sooner. Trust line number given.
8 December 2017	Mid area psychosis team	OPA seen with Heidi. Arrived with 4 sheets of paper listing all his previous experiences in clubs etc, referred to in paranoid thoughts. Dr L read and fed back to him that the content was worrying, and Dr L believed he was *'becoming unwell and indicative that he was having a relapse'.* He denied previous diagnosis or any psychotic illness and said any problems in the past were due to substance misuse. Dr L worried about physical health as had catheter in situ for 3 months. Explained to him that quetiapine 300 mg would not hold him '*as I could already see that he was relapsing*'. Recommended Aripiprazole, he agreed, hope was that the combination of aripiprazole and quetiapine will contain a full-blown relapse and maintain him in the community in the short term. Very clear he would not go back on clozapine, and Dr L not planning to do that. '*to be monitored very closely'* and copied to CCO so '*he can keep a closer eye'* on him in the community, and Dr L to see him monthly. Started on aripiprazole 5 mg od, with a view to increasing it to 10 mg, also on procyclidine 5 mg tds. Although a paranoid flavour, he is not at the point of a full-blown relapse and there was no evidence of any perceptual disturbances. Prescribed diazepam 5 mg tds and 7.5 mg zopiclone at night to help. Dr L said not the kind of clinician that would force him, but obliged to outline the risk of not taking medication.

Dates	Service	Summary
16 December 2017	A&E Broomfield Hospital	Catheter problem, no intervention noted.

Appendix D – James' family questions

We have listed the queries raised by the family of James as provided below. Their questions are in italic, and Niche findings in bold.

Issues and Questions arising from the Revised EPUT Report

The Three Red Readings, the care plan and the transfer of care

A) *Were the NICE guidelines followed when the decision to take J off Clozapine was reached? The Report only states that advice was sought from the Manufacturers of Clozapine*.

Niche finding: NICE guidance does not include a detailed approach to the management of clozapine cessation. EPUT's policy was followed.

B) *Did the Trust have guidelines setting out the steps required when a person had to stop Clozapine abruptly? If not, why not. Other Trusts have written guidelines setting out the steps that must be followed.*

Niche finding: EPUT has a policy, although this does not include patient education.

C) How often was J's blood checked after the three red readings? If his neutrophil count fell below 1.0 x 109/L a haematologist should have been consulted as J was at risk of infection because of his low white blood cell count. The notes indicate that J was simply told to rest at home.

Niche finding: Blood tests were done 5 times after the three red readings. Two were amber and three were green. These were his first red results after many years. We agree a haematologist opinion should have been sought.

D) *The Consultant Psychiatrist (CP) suggested restarting J on Clozapine after his blood reading was green – would she have consulted a haematologist before doing this?*

Niche finding: No, CPMS had agreed the reading was green by 30/10/17 and clozapine could be re-prescribed.

E) *Was the CP familiar with patients stopping Clozapine abruptly? Did she have to undertake Continuing Practice Development and keep up to date with medical developments?*

Niche finding: Yes, as all medical staff are expected to do.

F) *Why did the CP not see J after his transfer to Braintree began? He was attending Chelmsford Hospital for his blood readings so the transfer was clearly in place, but the CP did not actually see him until after the three red readings had been obtained.*

Niche finding: The transfer was not planned in a structured way

G) *Why did the CP not read J's medical notes? If they were unavailable at the outset, why did she not request Harlow to send her detailed information about his history? How could she treat J without sight of these? Why did she increase the dosage of Quetiapine without seeing J, bearing in mind that Quetiapine can lower white blood cells and increase the risk of infection. Was this taken into account by the CP?*

Niche finding: All the EPUT notes were available to the CP electronically.

We are unable to answer the questions about why the actions were taken.

H) *Did the CP consult with Harlow about J's medical history and background? The Report does not involve the Harlow team, but they were active in J's care for many years. Were the Harlow team shown the final Report and given the opportunity to comment on it and/or to add anything they thought might be relevant?*

Niche finding: As above. EPUT were responsible for managing internal input to the internal investigation.

I) *How much liaison did the CP have with the newly qualified Care Consultant (CC)? Did she have concerns about his lack of experience and the fact that he was not a medical professional, bearing in mind the complexity of J's case and the fact that his care consultant at Harlow was a Clinical Psychologist?*

Niche finding: We have found no evidence of MDT meetings where J's care was routinely discussed as a team.

J) *How many other people were involved in J's care and why are they not referred to in the Report if they took part in decisions about his care plan?*

Niche finding: The care team including the clozapine clinic staff, the CP, care coordinators and the GP are all referred to.

K) *From 6 October J was showing signs of mental and physical deterioration and he was in regular touch with services who documented his state of mind in particular. Given these very specific clinical indications, why was the care plan not changed as it became clear that J was relapsing?*

Niche finding: We have found no evidence of MDT meetings where J's care was routinely discussed as a team.

L) *Was the CP's decision on 30 October to review J in 6/8 weeks' time within clinically acceptable boundaries bearing in mind all of the symptoms laid before her at the time?*

Niche finding: yes we believe so. An earlier appointment could always be requested by the CCO if needed.

M) *J constantly explained how bad his symptoms were and he voiced his concerns many times, and wrote a letter to the CP explaining how he was feeling. Why did the CP not hear alarm bells ringing and take appropriate action when she read J's letter? Did she speak to Harlow for more information about his background and talk about his decline with them?*

Niche finding: The notes from Harlow were available to the CP. It was noted he was at risk of relapse and medication was adjusted.

N) *The CP states that J did not want to restart Clozapine. However, the Report does not make it clear that J had no idea of the risks that stopping Clozapine could bring. Had he been aware of the risk of a rebound psychosis he would have done anything to make sure that [H] was properly cared for. Why were J and [H] never told of the risks?*

Niche finding: We cannot answer the question with a reason why, our views on the decisions made are clarified in the report.

O) *[H] was ill equipped to look after J as his health deteriorated. She had no experience of severe mental illness – during the 10 years she had known J he had never had the symptoms that he began experiencing after he was taken off Clozapine. How could she*

have known what might happen? The CP had a duty of care towards [H] to make sure that she was not put at risk, but despite acknowledging that J was relapsing she did not amend the care plan.

Niche finding: please refer to the full report, it is however clear that J was never symptom free. We cannot respond to a question about what [H] did or did not know.

P) *The CP said that J was relapsing but it was not a full-blown relapse. What does the CP think a full-blown relapse means? He was seeing and hearing things that weren't real – he was frightened thinking that people were breaking into his flat – he heard voices coming out of the television and telephone. He was living in a world that was unreal and this should have caused concern that he might harm someone. He was not able to make rational decisions because he was unwell and although he had no history of violence the very nature of his psychosis should have rung very loud alarm bells. Why did the CP not do anything?*

Please refer to the full report.

Q) *Why was the possibility of admission to hospital for J never discussed by the CP? Why was the conversation that J had with his mum about the possibility of him going into a private hospital never discussed? J wanted to do whatever it took to get well so why was this not discussed with him? If he had broken his leg or had cancer he would have been given a hospital bed – why was this not available for him as a patient suffering from a very serious mental health illness?*

Niche finding: It was felt that J would refuse if admission was offered, and that a week of 'stepped up care' was necessary before admission could be considered. We believe admission should have been offered.

R) *As J's health deteriorated why was the care plan not reviewed and changed? How much iller did J have to become before steps would be taken to provide him with adequate care?*

See above

S) *Was J's GP informed of the decision to take him off Clozapine? If not, why not bearing in mind that other Trusts list this as one of the key steps in their written guidelines dealing with stopping Clozapine.*

Niche finding: Yes the GP was informed.

Other points:

1. The report seems to suggest that Harlow did not conduct the handover adequately and that there was infrequency of appointments with the Psychiatrist when J was with them. It should be noted that J had a very strong, long standing relationship with his Clinical Psychologist who acted as his care coordinator during the period he was at Harlow. She would speak to him and see him regularly and if she felt he needed more help she would refer him to the Psychiatrist at the Derwent Centre. J's health was stable when he was in Harlow and both he and [Heidi] knew his mental health team well and were able to speak to them when they needed to.
2. Why are different levels of care given to mental health patients? As previously mentioned, if J had broken his leg, or had a stroke, he would have been taken to hospital. Why did his increasingly dangerous symptoms and continuing voicing of his concerns not afford him the right to proper care?
3. Mental health illness is very different from physical illness. The question of capacity in making decisions about keeping carers fully informed about the patient's

diagnosis, treatment and potential problems should not be the same as it is for a person suffering a physical illness. A mentally ill patient cannot always see that he is unwell and can be ill equipped to make decisions for himself when his health is declining. So that carers can act in the patient's best interests they need to be kept up to date and guidelines regarding this should be put in place as a matter of course in the future.

4. All NHS Trusts should have written guidelines setting out the steps to be followed when a patient stops taking Clozapine. These guidelines should include consideration of hospital admission as a matter of course
5. As a direct result of inadequate care, J did go on to suffer a full blown relapse in the form of a rebound psychosis, which as is well documented online for anyone to read, means that the symptoms he suffers are greatly increased from the ones that he suffered from when he was ill in the past. This relapse resulted in the death of [Heidi] and the mental destruction of [James], who remains in the rebound psychosis 15 months after the event. He is still being held on an intensive care ward, subject to 15 minute checks, and is not able to have any possessions in his room because he self-harms, hears voices and sees monsters that don't exist. We liken this to brain damage. The whole set of events is a tragedy which could have been prevented had J received the care that should have been available to him.

   This statement does not refer to the IOPC report because that is not yet available. Once it becomes available a further note will be prepared and sent to all interested parties for further review.

Appendix E – Thematic diagram