SWEET! 3

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healthwatch Essex

Contents

Introduction

Since 2014, Healthwatch Essex has gathered the health and social care lived experience of young people in Essex through the YEAH! and SWEET! projects. The SWEET! (Services We Experience in Essex Today) project has focussed on accessing the voices of seldom heard groups who are not always engaged through traditional consultation platforms.

We know that young people from these groups often have a poorer experience of the health and care services they use and therefore their lived experience is key in improving existing services or creating new ones.

Across our three YEAH! and two SWEET! reports, young people have consistently told us that mental health is an area of largest concern within their health and care priorities. Therefore, it seemed logical to dedicate the third and final instalment of our trilogy of SWEET! reports to this issue. In partnership with Poplar Adolescent Unit Education Centre, based in Rochford Community Hospital, we have produced what is, to our knowledge, the first study of its kind in Essex. In this report, young people being treated in a secure inpatient mental health setting share their lived experience of mental illness, the surrounding services, and the factors they believe could make the biggest difference to their recovery.

Our study took place over six months, in which time patients shared their lived experience within group discussions or one-to-one conversations. This report undoubtedly makes for difficult reading at times, but we hope that conveying the experiences of these young people, which have not traditionally been heard, can lead to increased awareness of their needs, a better understanding of how prevention and early intervention can make the most difference, protection of the services or treatments that are working well and general positive changes in the mental health landscape.

How we engaged

While young people who are experiencing, or recovering from, severe mental illness will require a sensitive and responsible approach to discussing their experiences, this does not exclude them from safely participating in conversations around improving the services they use, or relating their needs to commissioners, professionals in charge of their care, and other decision makers. However, young inpatients of mental health units have not traditionally been engaged through the usual feedback platforms.

Throughout our study we worked closely with Poplar Adolescent Unit Education Centre staff to ensure our engagement would not be detrimental to patients' recovery, and ensured compliance with safeguarding, confidentiality and patient safety procedures. By carrying this out appropriately, we hoped that patients who shared their experiences with us could feel empowered by being heard – especially as many reported commonly feeling ignored or powerless in their journey through services.

At the recommendation of staff, the initial period of our involvement was simply to become familiar to patients, explaining the purpose of our engagement and how we hoped it could produce positive change. We welcomed questions about the study and made clear that participating was voluntary. We also explained that Healthwatch Essex was an independent charity and that talking to us would not impact the care they received, though could potentially change the care young people receive in future.

Patients were welcoming and became comfortable and familiar with our presence at the ward. This beginning stage of our study involved joining patients in activities such as art and cooking or accompanying them on trips into the community such as to the beach or the gym. Throughout the six months of our study we visited Poplar Adolescent Unit two days each week and were able to gain the trust of participants to discuss issues such as diagnosis, mental health services and stigma.

Around halfway through our study it felt appropriate to offer the young people the option to self-select for a one-to-one discussion. These discussions would begin with us reminding participants they could opt out at any time and didn't have to talk about anything they didn't want to. One-to-ones were conducted in a quiet place where Healthwatch Essex staff and patients were in view of Education staff, who would be able to intervene if a patient became distressed (although this did not happen). We also made the young people aware of our safeguarding duties, and in accordance on one occasion a hospital safeguarding form was completed and escalated. At the end of one-to-one discussions, we checked that patients felt well, and able to return to the Education Centre.

While the nature of their illness or lived experience meant these young people were vulnerable, their treatment at Poplar Adolescent Unit was designed to reintegrate them with everyday life, which included talking to people and being open about how they were feeling. The young people we engaged with in this study were enthusiastic and passionate about sharing their experiences, but felt they rarely got the chance to have their say. Done in this way, engaging with seldom heard groups of young people can be helpful not only to the purpose of such a study, but to the young people themselves.

All names have been changed.

Background

Poplar Adolescent Unit provides inpatient services for people under the age of 18 requiring specialist mental health services. The ward has 15 bedrooms across two gender segregated wings and provides short-term rehabilitation for those between 11 and 17. The Education Centre has two main classrooms, where most of our engagement took place, and a study room where we often conducted one-to-one discussions.

Within this study we spoke with 45 patients and 11 members of staff at Poplar Adolescent Unit.

On average, patients were aged between 15-16; the youngest patient we spoke with was 12 and the eldest was 17.

While a small study such as this cannot claim to be representative, it is important to note that of the 45 patients we spoke with, only 3 were male. Requirements for gender segregated corridors meant if female patients were in the male corridor, males could not be admitted. Staff told us this dynamic could also be reversed so that at some points most patients could be male. For this reason, we were unable to achieve a weighted balance between male and female patients in our study.

Some patients were receiving inpatient mental health care for the first time, though others had been in an inpatient setting before. Most patients lived in Essex, though some were being treated out-of-county and came from London, Norwich and Hertfordshire. For this reason, we use the term 'CAMHS' to encompass all CAMHS services young people had encountered across the county, including in Essex where CAMHS has become EWMHS (Emotional Wellbeing and Mental Health Services).

Patients were being treated for a range of conditions, and many had not received a formal diagnosis. Diagnosed conditions included anxiety and panic disorders, depression and low mood disorders, eating disorders, conduct disorders and attachment disorders. Treatments included medication, family therapy, group therapy, one-to-one talking therapies and animal therapy.

The length of participants' stays at Poplar Adolescent Unit could be from one week to several months.

Abbreviations and terminology

A&E
Accident & Emergency department

ADHD
Attention Deficit Hyperactive Disorder

ASD
Autism Spectrum Disorder

CAMHS
Child and Adolescent Mental Health Services

EWMHS
Emotional Wellbeing and Mental Health Services

GCSE
General Certificate of Secondary Education

GP
General Practitioner

HDU
High Dependency Unit

LGBTQ
Lesbian, Gay, Bisexual, Transgender and Queer (or Questioning)

NELFT
North East London NHS Foundation Trust

NHS
National Health Service

PE
Physical Education

PICU
Psychiatric Intensive Care Unit

Admission
When we talk about a young person being admitted to hospital, we mean the point at which a person is assigned a bed in hospital and 'lives' there until discharge. A person who stays in hospital to receive treatment is referred to as an 'inpatient.'

Crisis
Mental health crisis is generally understood to be the point at a person is no longer able to cope with their illness or the aspects of life which can aggravate their illness. A person experiencing crisis may feel suicidal or experience hallucinations or hearing voices.

Discharge
The point at which a patient is deemed to be well enough to return home, or to another setting in the community, and can therefore leave the hospital.

Education Centre
The Education Centre at Poplar Ward is a facility that provides patients with ongoing education during their stay in hospital.

Leave
While receiving inpatient care it was possible for some patients to temporarily leave the inpatient setting with planning or supervision. Also called 'therapeutic leave,' this allowed patients to visit members of their family or attend education at school or college.

Patient
In the context of this study, 'patient' refers to a young person in receipt of care at the hospital.

Participant
We use the term 'participant' interchangeably with 'patient' to indicate a person who was receiving care at Poplar Adolescent Unit and taking part in our study.

Sectioned
Being 'sectioned' refers to when a person has been placed under the Mental Health Act. Being sectioned can allow someone to receive mental health care or to be kept in a place of safety against their wishes. Being sectioned is a last resort when community care is not appropriate, or an at-risk person does not voluntarily agree to receive care. Generally, sections are used when such a person could be a risk to themselves or others.

Section 136 suite
People who have been sectioned under the Mental Health Act (section 136) can be taken to a Section 136 suite. This is a place of safety where the person sectioned can be assessed, and arrangements can be made for the next steps in their care.

Staff
In the context of our study, 'staff' or 'mental health professionals' is used as a general term to include mental health workers such as nurses, counsellors, therapists, psychologists and psychiatric doctors. While these roles are all different, the young people in our study were not always able to differentiate between the professionals they spoke about, hence the use of a more generalised term.

Key Findings

Accessing services

Although some mental health services allowed for self-referral, the majority of young people in our study had not referred themselves to services. Our study found four common criteria that influenced young people's ability to access mental health support:

- The young person needed a basic understanding of mental health to recognise symptoms, and needed to feel confident and comfortable in talking to an adult about the issues they were experiencing
- The adult the young person chose to speak to (usually a parent or teacher) needed an understanding of mental health that enabled them to identify when a young person needed support from services
- Typically, in our study, the parent or teacher made an appointment to speak to a health professional with the young person
- The health professional (usually a GP) needed to agree that the young person needed support from services, and knew where to refer them to

If any of these stages was unsuccessful, participants experienced a delay in accessing support for their mental health.

Deteriorating mental health

When we asked young people if they felt anything could have been different in their care, that could have prevented the need for hospitalisation, they often spoke about the importance of timely treatment. For example, several of the young people who had faced longer waiting times to access services told us their mental health had deteriorated during the wait, sometimes to the point of crisis. Other participants reflected on the time it had taken for them to gain the courage to speak to someone about their mental health, or for someone to notice that they were struggling. These participants felt that a lack of awareness, and negative stigma, could cause a delay in seeking support and therefore also contribute to a deterioration in their mental health.

Lack of consistency

One of the largest commonalities within the young people's lived experience was the number of services they had used, or professionals they had seen within each service. There was a sense that the care they received, and the professional it was delivered by, was always changing without any satisfactory explanation. Some had experienced services being taken over by new providers, being assigned several different workers within the same service, and changes made to their treatment or medication that could vary from professional to professional. A lack of consistency within care could contribute to feelings of hopelessness, or helplessness, toward their own recovery prospects.

Feeling out of touch

Participants in our study often felt they played a passive role in their treatment – that the care they received was something that was done to them, rather than done with them. The following factors, especially if experienced in conjunction with one another, could lead to feelings of not being involved in decisions about their care:

- Being referred from service to service
- Changes to their assigned therapist, counsellor or social worker
- Not being told of the diagnosis they were receiving treatment for
- Not knowing why certain treatments or medications had been prescribed
- Their parents having more knowledge of their diagnosis, treatment and recovery pathway than they did

Understandably, a combination of these factors could lead to anxiety about their illness and the likelihood of recovery, as well as a sense of receiving treatment without really knowing what they were being treated for.

Social factors

While not the case for all patients, many participants in our study felt their mental health problems arose in response to social stressors including:

- Insecure living arrangements
- Bullying
- Difficulties in education
- Abuse and/or neglect
- Bereavement
- Troubled family life
- Identifying as LGBTQ

For some, support or resolution around these factors was as important to their recovery as receiving talking therapy or medication. Sometimes participants who had made progress in hospital feared they would become ill again on returning to their community life. Participants who had been treated as an inpatient on more than one occasion often felt the support had not been in place to continue their recovery after discharge, particularly if the circumstances that had contributed to their illness (such as home life or housing) had not been resolved.

Complex case working

As mentioned above, young people in our study rarely experienced mental health in isolation from the rest of their lives (including their physical health, education and social factors). Therefore, it was not uncommon for participants in our study to be working with multiple agencies that addressed their needs across areas such as housing, social care, physical health, education and so on. Patients in these situations could often feel 'stuck' while waiting for the various aspects of their care to come together and did not always know which agency was responsible for which part of their care, or which professionals were being assigned to work with them.

Recommendations

High quality engagement
Feedback from seldom heard groups of young people can be an important tool when designing, improving or commissioning the services they use, or need. But more-traditional methods of engagement such as surveys, listening events in schools or community settings, and youth panels often do not reach those with seldom heard lived experience. To conduct meaningful engagement with such young people can require a significant commitment of time and resource, but as these young people often have the highest need of services it is always worth the investment to gain their valuable insight. As ever, Healthwatch Essex recommends that when seeking the lived experience of young people in our county, seldom heard groups are considered when methodology is in the design and planning stages.

Early intervention and prevention
Young people in this study who had experienced longer waiting times following a referral into CAMHS, told us their mental health had deteriorated during the wait, sometimes to the point of crisis. While we know that such waiting times are a national issue, and that achieving parity of esteem between physical and mental health could help address this, it is crucial to remain proactive in early intervention and prevention programmes. Being able to identify mental health issues early, and, where appropriate, know how and where to refer, improves the chance of identifying and treating mental health issues before the need arises for more intensive treatment. Part of this work entails increasing the mental health literacy of those involved in the lives of children (such as parents, teachers, health professionals, social workers, and so on), so that they can recognise when a young person needs support and where support can be found.

Consistency of care
Throughout our study, young people described varied experience of care from when they first sought help for their mental illness, through to the care they received following discharge. One of the biggest areas of inconsistency reported was the turnover of staff participants saw within a service, such as a CAMHS worker or social worker. Young people told us that being assigned multiple workers could cause them to disengage, feeling that they weren't being taken seriously. They also found it difficult to invest trust in a new worker, as they didn't know how long they would be involved in their case. As well as this, changes between services and professionals meant the retelling of often difficult experiences, and a sense of "starting from scratch" each time. This made it hard to achieve the sense that progress was being made or believe that recovery was possible. Services in high demand risk higher vacancy rates, and the increased case work across health and social care is well-known. While there is no immediate solution to address staff turnover in these roles, we want to emphasise the importance of consistent professionals in the young people's lives, and encourage commissioners, providers and frontline staff to work together to develop solutions.

Shared decision making
Feelings of distrust, disengagement and dissatisfaction can arise when young people do not feel empowered by the services they use. Young people in our study wanted to be active participants in decisions made around their care, but sometimes felt they were being passed from service to service, professional to professional, or treatment to treatment. Wherever appropriate, they wanted to be the "first to know," and explained that when their parents or other professionals knew about a change to their treatment before them, they felt important information was intentionally being kept from them. Young patients can be empowered through open discussions, in language that is easy to understand, about aspects of their care such as diagnosis, treatment and discharge. Having knowledge about their illness and its treatment can equip them with the confidence to feel involved in discussions and decisions around their care. Participants were also concerned when a new professional they hadn't met before was going to be making decisions about their care planning. Young people like those in our study, who experience a change of mental health professional or social worker, should have the opportunity to get to know them so that they can feel confident that these professionals can represent their best interests when decisions are made.

Taking a holistic approach

Our study demonstrated common links between physical health and social factors (such as housing, family life and education). However, the young people in our study often reported their mental health being treated in isolation from the broader aspects of their wellbeing. For example, we heard from young people who had attended A&E following self-harm or crisis may have had their physical needs met, but their mental illness was not always discussed. This study also demonstrates that factors such as abuse and neglect, insecure housing, substance misuse and education pressures can be exacerbating factors for young people experiencing mental illness, and therefore the resolution of such factors should be considered health outcomes and recovery milestones. This could be key to reducing a number of re-admissions, such as when a young person is discharged from hospital back into a stressful home environment where they risk relapse.

Systemwide collaboration

Participants in our study often had complex needs that were addressed by multiple agencies across the fields of education, social care, health care, housing and so on. The more agencies involved in a young person's care plan, the more potential there was for complications to their discharge and successful reintegration to their communities. This was particularly problematic if a patient was being treated out-of-county. The more we can move toward a systemwide approach, wherein single professionals can coordinate and manage multiple factors of a young person's case, the better chance we have of addressing the root cause of some mental illness, as well as accelerating recovery and, in turn, discharge from the hospital setting. There is also the potential to explore the benefits a care navigator could bring to such cases as a point of liaison between the young person and the multiple services involved in their care.

Case Studies

There were many similarities in the experiences the patients shared with us, but their stories and lived experience were also unique. These young people came from different parts of the county (and country), had different ages and family circumstances. Therefore, in order to portray a snapshot of these young people's journeys from when they first began to experience mental illness to their admission to Poplar Adolescent Unit, we have included the following case studies.

Shannon

“I WANT TO BE HAPPY AGAIN, LIKE THE OLD SHANNON. I THOUGHT I’D FIND HER IN HERE.”

Shannon told us she’d experienced mental health issues all her life but had faced a very difficult year where she experienced bereavement, sexual assault and bullying. This had a negative impact on her mental health, and she was diagnosed with Conduct Disorder.

According to the NHS, conduct disorders are the most common mental and behavioural problem in children and young people, and are characterised by repeated and persistent patterns of antisocial, aggressive or defiant behaviour. Five percent of the UK population aged between five and 16 have been diagnosed with the condition.[1]

This was Shannon's second admission to the Poplar Adolescent Unit, both times following an intentional overdose, with a three-month interval between discharge and re-admission. Her first stay on the ward lasted for four months.

Throughout the course of her life, Shannon had been bullied about her weight and sexuality. While at Poplar Adolescent Unit, Shannon had begun a college course, but stopped attending due to comments from classmates at the college about her mental illness.

Three months into her second admission, Shannon was told she was ready to be discharged. However, the aggressive and disruptive behaviour she had displayed at home resulted in her parents deciding she would not be able to move back in with the family. Therefore, Shannon's discharge was delayed as Poplar Adolescent Unit staff and her social worker tried to find her suitable accommodation.

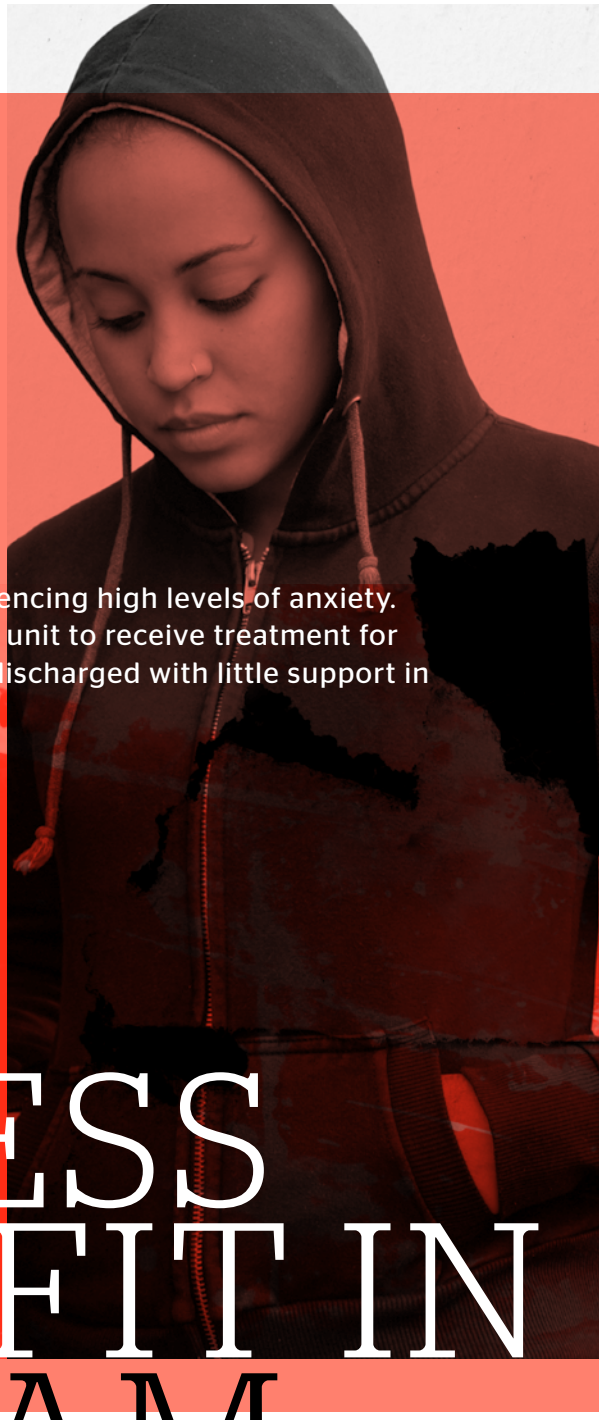
Shannon's housing application was rejected by a charity who felt she was too 'high risk' to be housed by them, yet Shannon was not seen to be at enough risk to justify hospital treatment. This resulted in Shannon being 'stuck' between services and therefore occupying a bed at the ward at a time when mental health beds were in short supply. Shannon felt frustrated by the mental health, social care, housing and education systems that surrounded her.

Shannon attempted to further her search for accommodation by writing a letter to her social worker and visiting the council. When she received no response to her enquiries, she wrote a letter of complaint. At the end of our study, Shannon had been on delayed discharge for two months and had not received a response to her letter or been discharged to suitable accommodation.

Shannon told us her hopes for the future included joining a gym, learning to drive, finding work, training as a beauty therapist and starting a family.

1 http://www.nhs.uk/news/2013/03March/Pages/New-guidelines-on-child-antisocial-behaviour.aspx

Yemi



Yemi's parents separated when she was 12, and she began experiencing high levels of anxiety. Soon after, her mother was admitted to a mental health inpatient unit to receive treatment for her own mental health problems, including alcoholism. She was discharged with little support in place, and so Yemi became her mum's carer.

"MY ILLNESS DOESN'T FIT IN WITH A 9AM-5PM, MONDAY TO FRIDAY SYSTEM."

Yemi said that the negative stigma surrounding mental illness prevented her from seeking support for the anxiety she experienced. After three years of struggling with this anxiety, Yemi approached a member of staff at her school, but the staff member was not aware of any services to refer her to.

Sometime later, Yemi attended an appointment with a private counsellor who told her she would be able to self-refer to CAMHS. Yemi was under CAMHS for two months but said that over this period she was seen by four different counsellors. She told us she had found this stressful, and as though she was not being listened to. Yemi often felt most unwell during evenings and weekends, but the service was not available for her at these times, and she felt her mental health was getting worse.

Eventually, Yemi reached crisis point. However, she was told by CAMHS that they had no space for her in their inpatient facility. This meant Yemi was treated as an outpatient, attended the inpatient facility each day, but returned home in the evenings. She also received visits from an outreach team who kept in touch with her daily.

After her week of attending the facility as an outpatient, it was temporarily closed, and Yemi was admitted to Poplar Adolescent Unit as an inpatient. This meant she was moved out of the county she lived in, and her family found it difficult to visit her or attend the family therapy sessions that were part of her recovery. It also made it difficult to reintegrate with education in her home community.

However, Yemi told us that the treatment she received at Poplar Adolescent Unit made her feel better able to cope with her home life. Although she still struggled with the thought of attending college where she wanted to study vocational skills, she faced some resistance from her family who hoped she would pursue more academic studies.

Toward the end of her stay at the ward, Yemi made the decision to study Resistant Materials at college and was discharged soon after.

Maggie

Maggie first experienced mental health problems in secondary school as a result of bullying. She had also experienced a relationship breakdown and difficulties in her home life, which caused her mental health to deteriorate.

"I HAD TOO MUCH TO DEAL WITH, AND NO-ONE TO TALK TO."

Maggie had been attending sessions with her school counsellor, but as her mental health worsened the counsellor referred her to CAMHS in November 2016. The date of Maggie's first CAMHS appointment was for four months later, in March 2017. Maggie tried to cope with her mental health problems alone in the four months leading up to her appointment, but in January 2017 she reached crisis point and was admitted to Poplar Adolescent Unit. Maggie felt that if she could have been supported sooner, her crisis could have been avoided.

Since being admitted to the hospital, there had been a delay and Maggie had not seen a doctor or had the opportunity to discuss any treatments during her first week at the ward. She explained that although she initially felt relieved at being admitted to hospital, where she believed she would begin to get the help she needed, she was feeling disappointed. As well as this, Maggie had experienced feeling isolated by other patients. A culmination of these factors meant that Maggie was considering discharging herself. She said that she did not know what to do for the best.

Later in our study, Maggie told us she had begun treatment and was feeling more positive about her stay at the ward and the progress she had made. She felt enthusiastic about returning to a new secondary school and hoped to go on to study Biochemistry in her future. Maggie was discharged soon after this discussion.

Nicole

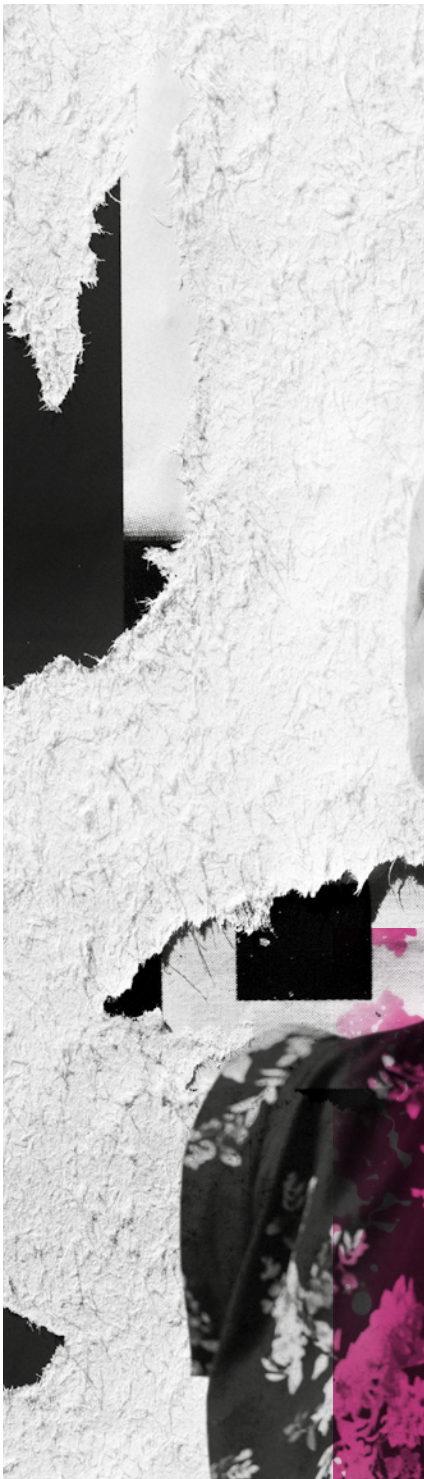
In 2013, Nicole began to self-harm, and her friend urged her to speak to a member of school staff who in turn referred her to CAMHS. She did not hear back about the referral, and so the school wrote to her GP who was able to refer her again. After her second referral, Nicole received an appointment.

"I FEEL FAILED."

Nicole continued to be a CAMHS service user for the next three years. At first she had been discharged after one year in the service, but had later reached crisis point and was taken to A&E. Following this, she was seen by the Crisis Team and eventually admitted to a High Dependency Unit (HDU).

Nicole told us she felt the staff at the HDU had ignored her and she was not recovering. With her mum's agreement, Nicole discharged herself in December 2015. One month later, she was assigned a crisis worker who she saw once a week. Nicole told us that this crisis worker had provided the best mental health care she had ever received, and she got on well with her. She said that her support had been consistent, and that she had established a good system with Nicole's school whereby everyone was in regular contact about Nicole's current mental health.

Later in 2016, Nicole was admitted to another mental health unit. This time she had a positive experience as she was closer to home and found staff to be caring and passionate about young people's mental health. After 6 months as an inpatient at this hospital, Nicole was discharged. However, during her stay in the hospital, CAMHS had changed to EWMHS and Nicole was told she would no longer be able to see this crisis worker. She described feeling as though she had lost the only person she could trust throughout her experience of mental illness.



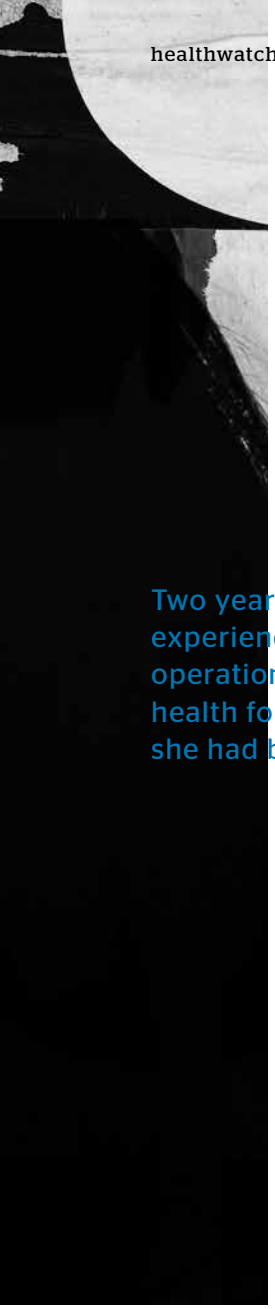
Following her discharge, Nicole's care-coordinator had told her she would be seen 2-3 times a week by EWMHS. However, some time passed and she had only been seen once, and three weeks later was still waiting to receive news of her second appointment. She had also been told she would receive crisis visits at her home twice a week, but this had not happened. Nicole was also assigned a new care coordinator but said that after meeting with her three times he told her, "I feel hopeless with you."

Nicole soon reached crisis point again and spent several nights in general hospital before being admitted to Poplar Adolescent Unit, the third mental health unit she had been admitted to since 2015. She said that she felt that her care coordinator had "abandoned" her, as he had not attended any of her meetings at Poplar Adolescent Unit.

Nicole felt there had been a lack of consistency across her care experience, which she said made it difficult to build the necessary trust to engage with treatment. She felt that a lack of support in community care settings led to her becoming an inpatient three times, and said she felt failed.

Rosie

“IT’S HARD TO STAY HOPEFUL WHEN YOU’VE TRIED EVERYTHING.”



Two years before being admitted to Poplar Adolescent Unit, Rosie began to experience mental health issues when she was due to have a complicated medical operation and was isolated by her friendship group. After struggling with her mental health for several months she began to self-harm. Rosie said her parents found out she had been self-harming but didn't understand.

Her parents encouraged her to see several counsellors across private and voluntary organisations, but Rosie explained she did not want to open up about the issues she was experiencing, and little progress was made. Rosie felt unable to speak openly to her parents and began to confide in other relatives more and more until she began to feel dependent on their care and felt suicidal when separated from them.

One morning Rosie felt so anxious about going to school she described being unable to move. Her mum booked her a GP appointment for the next day, and the GP referred her to the crisis team. The crisis team told Rosie she had 24 hours to decide to voluntarily admit herself to hospital. Rosie was told that if she did not admit herself voluntarily, she would be sectioned. Rosie felt extremely fearful of going into hospital but agreed to admit herself to avoid being sectioned.

After some time at Poplar Adolescent Unit, Rosie concluded that hospital was, in fact, the best place for her, as she had received treatment such as psychological therapies and medication in a safe environment. Family therapy had also been beneficial in helping Rosie feel able to talk to her parents about her mental health.

Rosie said she wished she had had more information about being admitted to hospital in advance, as if she had known what treatments and facilities were available she would have agreed to be admitted much sooner.

However, despite the progress she had made, Rosie said that it was still hard to feel optimistic about recovery as she felt she had "tried everything."

Jenny

Jenny recalled a long history of struggling with anxiety in which she had spoken to many mental health professionals across a range of services. She told us she found these experiences repetitive, and that she often had to repeat her story to each new professional she encountered. Jenny also felt that each professional had used the same counselling techniques, which did not improve her mental health. Jenny felt disempowered by these experiences, and rarely knew which services she had been using, or why.

Jenny told us she eventually encountered a mental health professional who realised Jenny's previous counselling had not been working and referred her to Poplar Adolescent Unit. However, Jenny told us she had not been told why she was being admitted until after she had arrived, so the admission had been a shock.

Jenny felt that staff at Poplar Adolescent Unit listened to her, which had finally enabled her to make progress in her recovery. Her previous experiences of mental health services had made her feel passive, explaining she felt like a much younger child. Jenny's previous experience of services made her feel anxious about returning to the community care setting.

Jenny told us she did not feel she had been taken seriously in the past, and felt that if she had been seen by one consistent professional who listened to her she might have received the help she needed sooner, without having to be admitted to hospital.

Alex

Alex had witnessed a violent attack on a close family member and had herself been sexually assaulted in the same attack. Following this, she received counselling from CAMHS for 18 months, but felt pressured by counsellors to recall stressful details of the assault. Alex was also seen by the crisis team, and was eventually admitted to Poplar Adolescent Unit following an overdose.

"I OVERDOSED TWICE, BUT THE SECOND TIME WAS BECAUSE I NEEDED SOMEWHERE TO STAY."

After seven months at Poplar Adolescent Unit Alex was discharged, though two months after her parents told her that she was no longer able to live in the family home due to aggressive and disruptive behaviour. Alex told us she did not know where to go, and so took another overdose in the hope of being readmitted to Poplar Adolescent Unit.

Alex felt that her experience could have been better if the mental health professionals she had seen had given patients information about the choices available to them and felt passionate about helping everyone in their care.

During our study, suitable accommodation was found for Alex and she was discharged. Alex had been a young carer for her grandfather from as early as age five and hoped to have a career caring for older people in the future.

Maddison

“IT FEELS LIKE I DON’T WANT TO RECOVER. IT’S TOO MUCH HARD WORK. IT’S SO DIFFICULT. . . THERE ARE BAD HABITS AND OLD WAYS.”

Unlike many other patients we spoke to in our study, Maddison said her illness had not been triggered by events in her life but had seemingly “come out of nowhere.”

Maddison began to struggle with her mental health around age 12, when she started self-harming. She told us she did not confide in anyone until she experienced suicidal ideation. She told us that she was seen by a private psychiatrist for a while but felt her mental health was not improving. Her mum made an appointment with a GP who referred her to CAMHS, but CAMHS referred her back to a psychiatrist who prescribed medication.

Since this time, Maddison explained she had reached crisis point several times and had been seen by A&E, the community mental health team, the police, section 136 suites and the general hospital. During her last crisis, Maddison told us she took an overdose and was admitted to Poplar Adolescent Unit. She felt that the ward was the safest place for her as it prevented her from making further attempts at her life.

Unlike many other patients we spoke to in our study, Maddison felt unsure whether anything could have been different that might have prevented her from being admitted to hospital. However, she did feel that a reduction in mental health stigma, particularly in school, would have made her journey easier.

Maddison was being treated for depression and was still an inpatient by the time our study had finished. She hoped to pursue a career in animal care, or mental health care, in her future.

Jess

“I’M GETTING WORSE, NOT BETTER.”

Jess told us she had encountered bullying throughout her school education, and she began to experience hearing voices from the age of 11. It wasn’t until Jess was 14 that anyone knew about the mental health issues she faced, as her mum discovered that Jess had attempted suicide.

Since then, Jess told us she had reached crisis point on numerous occasions and had made several more suicide attempts. Following her first admission to A&E, then general hospital, after one of these attempts, the crisis team referred her to CAMHS.

Jess was discharged from CAMHS following six months of counselling, but attempted suicide again a week later. On this occasion she was restrained by police and taken to a section 136 suite before being hospitalised for a week. After being discharged from hospital she overdosed again and was sectioned. This time Jess was assigned a social worker and admitted as a mental health inpatient.

Jess told us that she had been able to bring items into the unit to harm herself, as well as overdose from medication that had not been secured in the hospital. She was discharged from this unit, attempted suicide again three weeks later and was next admitted to Poplar Adolescent Unit following a week in general hospital.

While far from her home, Jess was told that Poplar Adolescent Unit was the only facility that had space. Although Jess had received weekly counselling and new medications, she felt her mental health was worsening.

Later in our study, Jess was transferred to another mental health unit and we were told her behaviour at Poplar Adolescent Unit had negatively influenced both the mood and actions of other patients.

Max

Max told us he had been experiencing anger and low mood for two and a half years. In this time he had arranged to see his GP on numerous occasions to ask for help, but his GP had not referred him to services or explored treatment such as talking therapy or medication. Yet Max said his mental health continued to worsen which impacted his behaviour in school, and he was permanently excluded in December 2016.

After this, Max was admitted twice to A&E as he had self-harmed.

Max lived out-of-county but said he had recently learned that his nearest CAMHS service accepted self-referrals. Max referred himself to the service and described feeling relieved when the service got back to him within a week and made two close appointments for him to speak to professionals. CAMHS had begun telling Max they wanted to test him for Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD).

However, Max was never able to be tested for these disorders as his mum had left him at home on his own for a fortnight, and he was taken into foster care. Max ran away from his foster home and was found by police who took him to a section 136 suite. Max's mum had said she did not want Max to be returned to the family home and having nowhere to go he was sectioned. Poplar Adolescent Unit was the nearest available inpatient bed that could be found for him at the time.

Being so far away from his family, girlfriend, social worker and CAMHS service compounded Max's anger. He told us that as soon as his section was lifted, he would discharge himself and return home.

Max believed that if his GP had offered him support during the two and a half years he was struggling with his mental health a lot of these events could have been avoided and he may not have been admitted to hospital.

Max told us that he wanted to begin an apprenticeship in window fitting and live with his girlfriend in future.

"I'M SO ANGRY WITH DOCTORS"

Poppy

“PEOPLE MAKE DECISIONS FOR ME.”

Poppy told us she had experienced problems with her mental health all of her life. Poppy told us that she was born when her mother was 15 and living in a young offender’s institution. Both of Poppy’s parents were addicted to heroin, and Poppy was left at home on her own as a two-week-old baby and taken into care.

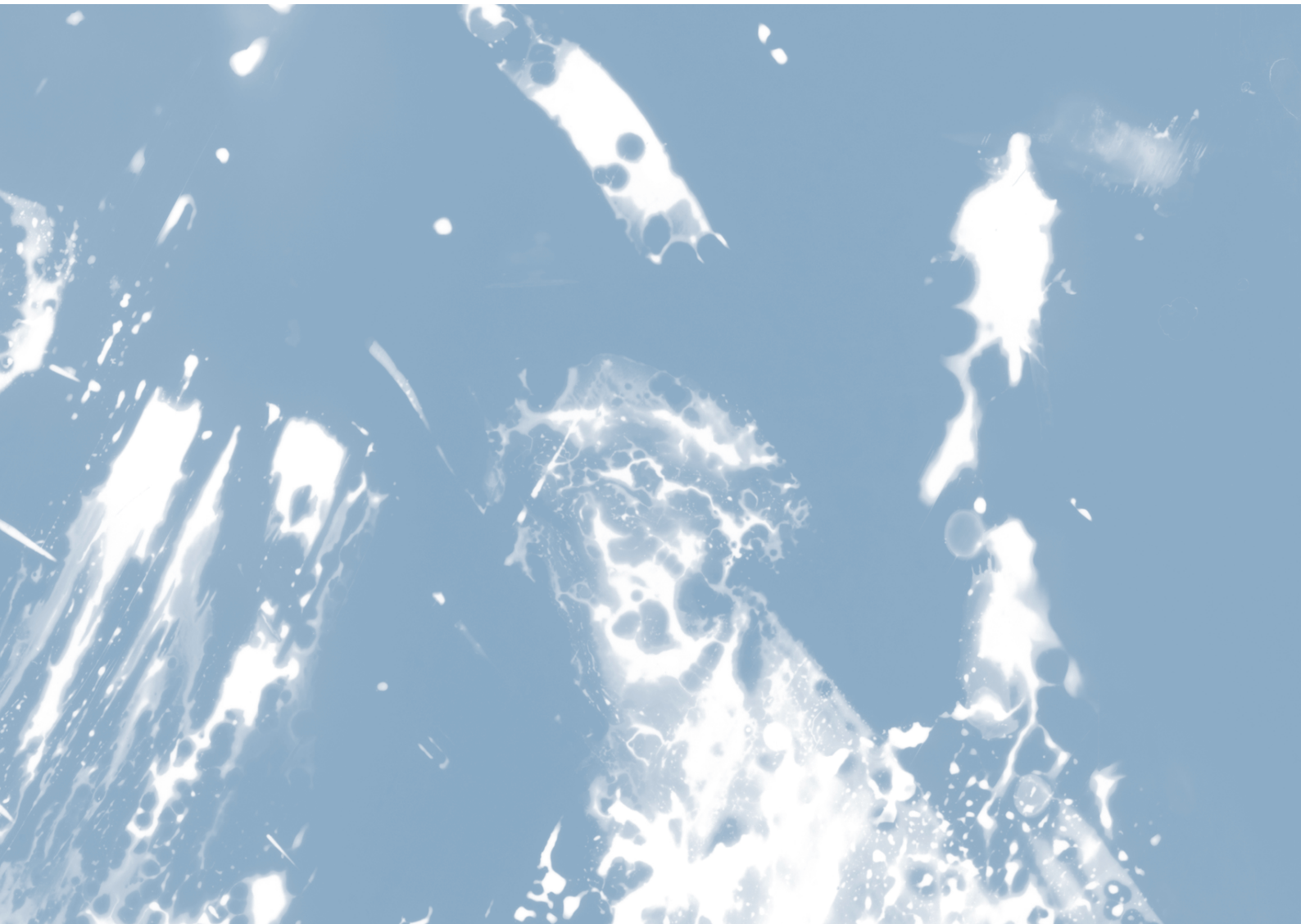
When Poppy was one, she was adopted but said her home life with her adoptive parents had been difficult. She said she had experienced emotional and physical abuse at home, and her parents had asked her to hide the abuse from Children's Services. Poppy felt that this had led to services not believing her when she speaks out about the abuse.

Poppy was referred to CAMHS when she was nine, and in the course of three years she was assigned four different counsellors. Poppy had been diagnosed with Disinhibited Attachment Disorder and Emotionally Unstable Personality Disorder and had previously been an inpatient at a PICU unit after being sectioned.

CAMHS had recently told Poppy she would receive specialist therapy from Great Ormond Street Hospital (GOSH), but when the service changed to EWMHS, she was told this therapy was not affordable and would not be going ahead.

Poppy told us she had been to A&E on numerous occasions following physical and emotional abuse at home, and while she had had two social workers, one left and the other said he would not work with her because of the amount of times she presented at A&E. Poppy was admitted to Poplar Adolescent Unit not long after being discharged from the PICU unit when she had run away from home and been sectioned by the police.

During our study, Poppy was transferred to another PICU unit where she would receive more intensive care than was available at Poplar Adolescent Unit.



Maya

At the age of five, Maya moved in with her grandma while her mum was admitted to a mental health ward. Maya lost contact with her dad around the same time and began to experience her own mental health issues.

Four years later, Maya's GP referred her to CAMHS as she was experiencing low mood and insomnia. Maya recalls being moved to the beginning of the waiting list and being seen by the service quite promptly.

Maya had been a CAMHS patient for several years but told us she had lost trust in the service because the professionals she was assigned to kept changing and she therefore had to repeat problems from the beginning every time.

When CAMHS changed to EWMHS, Maya told us she felt that any remaining consistency had been lost. Following this change, Maya reached crisis point and overdosed on several occasions to try and end her life. This usually resulted in her being admitted to general hospital, where she said she was sometimes seen by the crisis team. However, Maya told us that it was not until her fifth suicide attempt that she was admitted to Poplar Adolescent Unit.

Maya had been diagnosed with Clinical Depression and Anxiety, and experienced hearing voices. The anxiety she experienced prevented her from attending college, and she had spent her days habitually smoking marijuana.

Maya felt that she was recovering at Poplar Adolescent Unit and found it beneficial to have consistent help around her which allowed her to rebuild a sense of trust in mental health professionals. She told us that the hospital treatment had helped her develop a healthy routine and re-establish contact with her dad.

Maya was eventually able to attend college by managing her anxiety and was discharged not long after. Maya went on to study Beauty Therapy.

"THE MAJORITY OF US HERE HAVE GIVEN UP ON CAMHS."

First contact with services

We asked the young people in our study about the first time they spoke to somebody about their mental health problems to help us understand which referral pathways were working effectively, but also where young people encountered delays and barriers in accessing support. We appreciate that not every young person who opens dialogue about their mental health needs to be referred to services, but for the young people in our study, being able to access support was a vital part of their recovery.

Most participants were able to identify when they needed help with their mental health but often delayed speaking to someone through fear of stigmatisation. It was common for participants to have been experiencing mental health issues for some time before reaching out to someone, usually at the point where they felt unable to cope on their own. Therefore, the fear of stigmatisation was the first barrier most young people faced in accessing support.

Yemi's fear of being stigmatised prevented her from talking about her mental health problems for several years, in which time her condition worsened. She believed many young people did not get the help they needed because of the stigma they feared they might face.

For some participants the mental health issues they had been experiencing only came to light when someone noticed behaviours such as self-harming or planning for suicide attempts.

As our previous reports have found, young people are usually unsure if they are able to make their own doctors' appointments or self-refer to services, and even less clear on their confidentiality entitlements. Therefore, the first adult a young person speaks to about their mental health or notices the signs of distress, plays a crucial role in their ability to access the appropriate support in a timely manner. However, this is contingent on multiple factors:

First, the adult a young person first confides in needs to assess the seriousness of the issue in order to decide how to act. Without an understanding of the mental health issues that can affect young people the situation can be misjudged, and this can delay the young person's access to services. For example, some patients felt that an adult had not taken their problems seriously, which highlighted how missed opportunities can prevent us supporting young people sooner.

Feeling they had been taken seriously was also an important part in the next step of the journey to accessing support which most commonly was a GP appointment. Some participants praised the fact their GP had been quick to understand the problem and make a referral to CAMHS or the crisis team.

Maddison tried to speak to a parent about her mental health several times, but felt she was only believed after she had been admitted to a mental health inpatient facility.

Some participants sensed their GP felt uncomfortable discussing mental health, which in turn caused them to feel embarrassed or ashamed.

"He didn't have much to say to me. He made me feel like I'm crazy." **MADDISON**

Previous studies by Healthwatch Essex found that mental health issues in young people were sometimes put down to exam stress or teenage hormones (though both issues have the potential to require intervention in themselves), and participants in this study also felt assumptions about their age added a barrier to their illness being recognised.

Max sought support for his mental health for two and a half years by making multiple GP appointments, but was repeatedly told no help was available. On one occasion Max became so frustrated that his GP called an ambulance to take him to A&E, though he said he only wanted to be listened to.

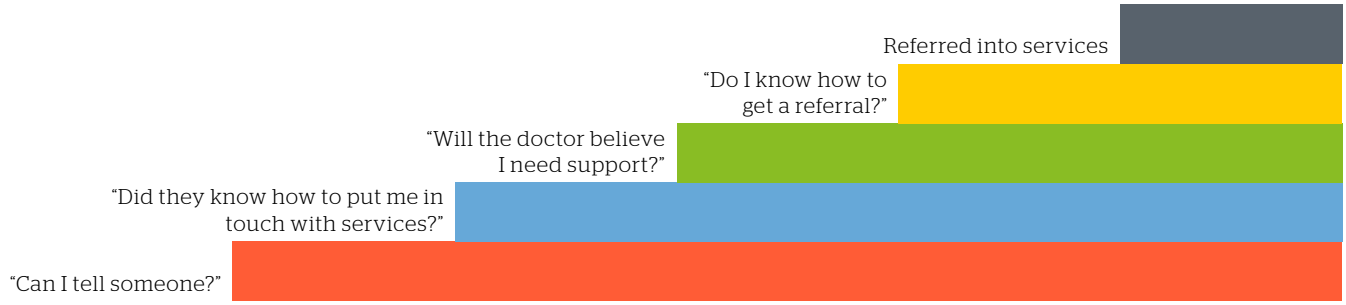
However, even patients whose GPs recognised their mental health needs may have faced further problems if the GP did not know which services were available, and what they offered (the same is true of parents and teachers).

In conclusion, a young person might face multiple barriers to connecting with mental health services when they need them. While young people and the adults in their lives can self-refer to EWMHS, the need to continue to raise awareness of this feature is apparent. In broader terms we have undoubtedly made progress in raising awareness of mental health problems but still have some way to go before young people feel completely comfortable talking about their mental health when they begin to experience symptoms themselves.

When Poppy visited the GP, her parents received a referral to a support group for parents of children with mental health problems, though Poppy herself was not referred to any support.

Maggie's GP gave her a number to call to make an appointment with a therapist but was told that she needed to be 18 years old to access the service.

Part of this would be to continue raising mental health literacy among relatives, teachers and to some extent peer groups who are often the first to learn about a young person's issues. With increasing pressures on time and patient numbers, GPs do a remarkable job in keeping abreast of the changing nature of service provision and accessibility. However, we know that many GPs practicing today did not receive mental health training as part of their medical education. We would recommend that these GPs have the time and ability to access up to date mental health training, including mental health amongst young people and the services available.



Community mental health care

Most commonly, young people in our study had been referred to Child and Adolescent Mental Health Services (CAMHS), with few participants having received no mental health support prior to their hospital admission. For this reason, we wanted to understand, from the young people's perspective, how the service had assisted their recovery, and how it could be improved.

Waiting times

Unsurprisingly, given that it has been a subject of national news in recent years, waiting times were a big factor in young people's experience of the service. Given that young people had often been struggling with their mental health for a long time prior to getting a referral it was upsetting to then wait longer to get support.

Three participants felt they were given timely access to the service, which was particularly a relief for those who had been trying to access support for a long time.

After trying to get a referral from his GP for over two years, Max found out from a friend that he could self-refer to his local CAMHS. Once he had done so, he said he was contacted by the service within a week and began receiving support soon after.

Participants who encountered longer waits described a sense of hopelessness, believing they were unlikely to get the support they needed and often reported that their mental health worsened during the waiting period. One participant told us her school had referred her to CAMHS, but she never received contact and some time later her doctor referred her again. Another participant had been referred to the service on four occasions before she was accepted as a patient.

Continuity

We also heard how continuity within services was as important to participants as receiving timely care. The young people felt impacted by the consistency of the service provision, as well as the staff who treated them.

Maggie's school referred her to CAMHS, and she was given an appointment date three months away. After one month, Maggie's mental health deteriorated to the point she reached crisis and needed to be admitted to Poplar Adolescent Unit.

She described feeling hopeful and relieved when she was referred to the service but remembers feeling 'let down' when she was unable to cope on her own any longer.
"I had too much to deal with and no one to talk to."

It was Maggie's belief that if she had been seen sooner, she might have avoided being sectioned and sent to an inpatient facility. In her words, she felt that the situation could have been "fatal."

Some patients described the impact that a change of their CAMHS provider had on their treatment. For example, one participant told us she had been due to receive specialist therapy at Great Ormond Street Hospital but was told this would not be available under the new provider as the treatment was too costly.

The relational aspect of mental health treatment such as talking therapy meant that staff consistency was highly valued by participants. As mental health recovery tends to be a gradual process that involves working through issues over time, trust and familiarity were key to patient's ability to embrace the full benefits of treatment.

In two months, Yemi was seen by four different CAMHS workers. She attributed the stress this caused to a decline in her mental health.

Yet patients often described experiencing a frustrating turnover of the staff involved directly in their treatment. They explained that it was hard to invest the trust and time required of them to share details about distressing experiences, and they wanted to believe that the person treating them would be 'there' for them. With each change of staff, patients felt they were 'starting from scratch', often having to re-tell their stories and rebuild trust. Participants told us this made it harder to stay fully engaged in therapy when they did not know how long their current therapist would be around.

Maya said the high turnover of staff assigned to her caused her to disengage with the service.

"I didn't always attend my appointments. I thought 'Why make the effort?'"

She strongly believed that this impeded her mental health from improving, and that having received a consistent service could have prevented her from needing to be hospitalised. She told us this sense of apathy was common among Poplar Adolescent Unit patients.

"The majority of us here have given up on CAMHS."

The young people also felt disempowered when their service or assigned professional changed without these changes being explained to them.

Jenny felt that after having spent so much time repeating her story to different professionals it should be explained why the staff or service were changing. This caused her to feel she was being 'passed around.'

She said that if she had been treated by the same member of staff, she might have been able to make progress with her mental health and avoid the need for inpatient treatment.

Two of Poppy's CAMHS workers left shortly after they began working with her, and the third left when the service provider changed. She told us that as each professional wanted to focus on different aspects of her mental health, or had different methods, she was unable to make significant progress.

We regularly hear how overstretched and underfunded community mental health services are and recognise that the frustrations patients report are often shared by providers and professionals alike. Staff turnover in any profession is inevitable but can be a particular challenge in the NHS (where recruitment is a national issue) and where changes to services, increasing workloads and stressors can all contribute to vacancies. We also know that not every young person accessing mental health services faces the same turnover of professionals as participants in our study reported, but perhaps the fact that this is an experience commonly shared by mental health inpatients highlights the important role of consistency in preventing inpatient admissions.

There will always be the need for inpatient care for those young people whose mental health requirements exceed what can be safely provided in a community setting. However, we know that effective prevention and early intervention plays an important role in treating mental illness before it escalates to the point of crisis.

Experiencing crisis

NHS England describes mental health crisis in the following terms: "A mental health crisis often means that you no longer feel able to cope or be in control of your situation. You may feel great emotional distress or anxiety, can't cope with day-to-day life or work, think about suicide or self-harm or experience hallucinations and hearing voices."[2]

Most patients at Poplar Adolescent Unit had experienced crisis on at least one occasion before receiving inpatient care. Therefore, we wanted to understand how young people interacted with services during and after crisis, and the role that effective crisis care could play in preventing inpatient admission.

NHS England explains that people experiencing mental health crisis can contact 111 if the crisis is not life-threatening or make an emergency appointment with their GP practice, acknowledging that "a mental health emergency should be taken as seriously as a medical emergency." However, most of the young people in our study first interacted with services by being taken to A&E or placed under Section by police.[3] Even though experiencing crisis was distressing, participants in our study often praised the compassionate care they received from ambulance staff and police in taking them to a location where they could access help.

Young people who had been placed under Section 136, or who had attended A&E, should then be assessed by a mental health professional to determine the most appropriate support.

NHS England says:

"Whether you experience a sudden deterioration of an existing mental health problem, or are experiencing problems for the first time, you'll need immediate expert assessment to identify the best cause of action and stop you getting worse."[2]

Following mental health assessment, a young person might be admitted to inpatient care or referred to Crisis Resolution and Home Treatment (CRHT) services. CHRT services can play a key role in preventing hospitalisation, as NHS England explains:

"CRHTs treat people with severe mental health conditions who are currently experiencing and acute and severe psychiatric crisis that, without the involvement of the CRHT, would require hospitalisation."

Nicole told us that being assigned a crisis worker was the most beneficial mental health support she had received. She said it had always been easy to get in touch with her crisis worker when she needed support, and her crisis worker frequently liaised with her school to ensure she was well.

After reaching crisis Yemi was told she needed inpatient treatment, but there were no beds available. While she waited for a place, she was visited at home several times a week by the crisis team, to monitor her safety.

Some participants felt that the mental health care they received during crisis had not enabled them to recover sufficiently to make it safe to discharge them, and they had gone on to reach crisis again soon after seeing services.

Poppy was admitted to a mental health inpatient ward following crisis but was discharged the next day.

Maddison had been taken to a section 136 suite after taking an overdose but was discharged shortly after and went on to overdose again.

Maya explained that while she was seen by the crisis team during some of her stays in general hospital, following taking an overdose, she felt disappointed that she was not treated as a mental health inpatient until the fifth time she had overdosed. She felt she should have received this support sooner.

The young people who presented at A&E often had physical care needs that were connected to their mental health crisis (for example, if they had harmed themselves). NHS England says that both physical and mental aspects will be considered in deciding the best course of care:

2 https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/dealing-with-a-mental-health-crisis-or-emergency/

3 Section 136 authorises police to take a person seen to be in extreme distress and in need of immediate care, or who may be at risk of harming themselves or others, to a place of safety (such as a Section 136 suite) for up to 24 hours, in which time they may be assessed by a mental health professional.

"Once at A&E the team will tend to your immediate physical and mental health needs. Many hospitals now have a liaison psychiatry team (or psychological medicine service) which is designed to bridge the gap between physical and mental healthcare."

Five participants told us they had been discharged from A&E without any physical or mental health treatment, and another eight told us that they received treatment for their physical symptoms only, despite saying it would have been obvious that these issues were self-inflicted.

Three patients who had stayed in general hospital following crisis told us they received no mental health treatment during or after their care. All three participants reported being discharged from the hospital when their physical symptoms recovered, even though their mental health crisis was not resolved.

Max received stitches after having harmed himself, and was discharged without his mental health being discussed. On another occasion Max recalled being taken to A&E in an ambulance but was quickly discharged after being told there was nothing they could do.

The A&E environment was said to be distressing for those in mental health crisis, with young people in our study telling us that the stigmatisation or misunderstanding of mental illness could cause them to feel worse. They explained that during crisis they might be crying, shouting, resisting or attempting to leave, and might also be visibly bleeding. They recalled that other patients in the A&E department or hospital were visibly alarmed or disturbed by these symptoms.

Maddison was taken to children's A&E during crisis. She felt worried that she would upset the younger children in the waiting room. When she was admitted to general hospital she was the oldest patient on the children's ward and the only patient experiencing mental illness, and her mum had asked her not to frighten the children.

One participant was admitted to the children's ward following crisis. In her presence, the mother of another patient complained to ward staff that her son had been placed in a bed next to a 'mental patient' and wanted him moved.

The experience of these young people demonstrates that there is still a way to go in achieving parity of esteem between physical and mental health, and their experiences do not always align with the expectations of care set out by NHS England on mental health crisis.

We are aware of the pressures facing A&E departments across the UK and many of the young people in our study have benefited from crucial, and sometimes life-saving, physical health care from A&E and hospital staff. However, as mental health was the root cause of these young people's admission into services a failure to address and treat mental illness could lead to repeat crises, with the possibility of deteriorated mental health.

We also understand it is unfair to expect all A&E staff to be mental health experts but do believe an ongoing commitment to upskilling staff in spotting the symptoms of mental health, and the most appropriate courses of action, could play a significant role in young people accessing the relevant treatment earlier.

It is understandable to wish to avoid admitting young people to mental health inpatient care, not least because of the possibility of bed shortage within that person's county. However, most young people at Poplar Adolescent Unit believed they needed this level of specialised treatment sooner.

Experience of Mental Health Treatment

While the key aim of our study was to understand the factors that could prevent some young people from needing inpatient mental health care, patients naturally wished to talk to us about their experiences of care across both community and hospital settings. In this section, we describe common factors young people voiced in these experiences and the impact these could have on their care and recovery.

Diagnosis

Most of the patients receiving treatment in the ward had not been diagnosed with a specific mental health condition. Yet patients claimed that having a diagnosis was important to them, as it would allow them to learn more about their illness, the treatments that might be available, and help them to gain an overall sense of control over their health management. The patients we engaged in our study described a broad range of symptoms including hearing voices, suicidal ideation, anxiety, low mood and depression, anger, and visual hallucinations. Understandably, these symptoms could be distressing, and many felt that knowing the name of the condition they experienced could normalise their symptoms and cause them to be less frightening.

Maddison told us that without a diagnosis she felt unable to control her treatment or recovery. She said that she couldn't understand why she was unwell, and had been unwell for such a long time, and that without a diagnosis she worried she would be viewed as attention-seeking by society.

Some patients had been given 'unofficial' diagnoses, as particular diagnoses could not be given until a person reached the age of 18 (due to factors such as ongoing development of the brain).

Max told us he was due to receive a diagnosis from CAMHS, but in hospital was told it was too soon to discuss diagnosis. Max told us he wanted to discharge himself from inpatient care so he could return to CAMHS and receive a diagnosis.

Not receiving a diagnosis caused several participants to self-diagnose based on their own research. Patients had varying degrees of knowledge about diagnosable mental health conditions, which was often based on the experiences of their family, or what they had read online. Therefore, while we must value these young people's understanding of their own symptoms, many of the sources they access online might be unreliable or inaccurate. For example, ward staff told us that patients who heard voices or experienced hallucinations often believed they had schizophrenia, but these symptoms can also occur in anxiety disorders.

In instances where diagnoses had been given, patients did not always feel they were clear on why this diagnosis had been reached. Two participants told us they had received a diagnosis but did not feel the diagnosis matched their symptoms. We also discovered that some patients' diagnosis had been disclosed to their families, but not to them. This caused them to feel excluded from conclusions made about their health, and not consulted on their personal experience of living with mental illness daily.

We acknowledge that mental health diagnoses take time and conditions can be difficult to diagnose. However, it may be beneficial to patients and professionals alike if a mental health diagnosis could be reached collaboratively, allowing patients to ask questions about a diagnosis they don't feel fits their symptoms. This would require recognition that the person experiencing the symptoms may be the best-placed to describe them. Even if a diagnosis cannot be reached, this study would suggest that being involved in decisions around diagnosis would give patients a greater sense of control and empowerment over the symptoms that can cause them distress.

Terminology

Participants also explained feeling bewildered by the medical terminology that was used when addressing their mental health needs. Within the field of mental health, there were a broad range of acronyms used to describe mental health conditions (BPD, Borderline Personality Disorder; ADHD, Attention Deficit Hyperactive Disorder; OCD, Obsessive Compulsive Disorder), service provision (NHS, National Health Service; NELFT, North East London Foundation Trust; EPUT, Essex Partnership University Trust; CAMHS, Children and Adolescent Mental Health Services; EWMHS, Emotional Wellbeing and Mental Health Services), hospital protocol (CPA, Care Programme Approach; CRM, Clinical Risk Management) and even types of hospital setting (PICU, Psychiatric Intensive Care Unit; HDU, High Dependency Unit).

For a young person visiting their GP for the first time about their mental health, or a new admission to an inpatient setting, this could be overwhelming. Patients told us that at a time that was already confusing for them, they did not always feel confident asking for terminology and acronyms to be explained. Several patients asked Healthwatch Essex the meaning of these acronyms in our one-to-one discussions, stating that when staff and patients seemed to understand the meanings of these acronyms it could feel isolating and embarrassing.

On top of this, the young people were not always clear on the differences between counsellors and psychiatrists, psychiatrists and psychologists, psychologists and doctors, and so on. This confusion, or feeling of 'not getting it' could cause mental health treatment to feel like something that happened to them, as opposed to happening with them.

We know that this issue is not unique to the field of young people's mental health care, and confusing terminology can be found at all levels of health and social care. We also know that patient outcomes are improved when they feel like active participants in their care, and so making details of care and care provision clearer for young people could help them feel more empowered in decisions made about their care. This could be as simple as producing a list explaining abbreviations and terminology when a patient begins treatment, or simplifying the language that patients are exposed to.

Proximity to home

Shortages of mental health beds for young people close to where they live has made national news, particularly in cases where a parent must spend several hours travelling to visit their child. In this section of our report we wanted young people to describe what this was like in their own words to understand how they benefitted from being treated close to home, and what it was like for those who lived further away.

Three participants who lived in Rochford, Chelmsford or Southend told us their parents visited them every evening, and one patient from Braintree said she was visited by her mum once a week.

One participant who lived further away said her mum could not afford the expense of travel to visit as often as they would both have liked, and another participant from Southampton said she had not seen her family for three months.

One participant was granted leave for ten hours but needed to spend eight hours of that time travelling to and from home, which only allowed him a short time to visit his mum and girlfriend and he had not been able to visit his relatives who were too young to visit him at the ward.

Another participant who came from London said that her parents could not always attend the family therapy sessions that were part of her treatment, and the distance also made it harder for her to reintegrate with her education.

Receiving fewer family visits was not the only negative aspect of being treated further from home. We also heard the impact that distance could have on the progress that could be made for a patient with multiple agencies.

One participant lived in Norfolk and said his social worker and CAMHS worker had not been able to travel to Poplar Ward for a meeting where decisions about his care were due to be made.

One participant who lived in Sheffield had found it difficult to work through the issues within her family because of the distance.

We know that services do their best to place patients close to home, and that bed shortages can affect all areas of the NHS. Hearing the young people describe the benefits of receiving care close to home, in their own words, demonstrates what a key part location can play in their recovery.

Not only does being placed further from home make it difficult to receive visits or involve community services, when a bed does become available closer to home they can re-experience uncertainty on what to expect from the service, will need to repeat their experience to professionals and to establish trust and rapport with staff all over again. We hope that measures of prevention and intervention can play a part in freeing some capacity within inpatient care so that those young people who do require treatment in hospital are able to be admitted within their own county, if not their own town.

Negative stigma

Being an inpatient, or former inpatient, of the hospital could often be met with negative stigma that some patients had already encountered in the community. Staff commented that the general perception seemed to be that mental illness was permanent, and that it was not possible for mentally ill people to recover. Therefore, it was felt that having received inpatient care could be life-limiting for these young people who may be affected by negative stigma for the rest of their lives.

One participant told us about an occasion where uniformed Poplar Ward staff accompanied them on an excursion into the community. When a member of the public saw the staff uniform, she remarked to her partner "Oh look, they're walking them again!" This participant felt that the woman had viewed the young people as if they were dogs.

As part of her recovery, Shannon had been attending a college outside of the hospital. Once her classmates at the college found out she was receiving inpatient care, however, stigmatising remarks had been made and Shannon decided to stop taking the course.

Maya was also fearful of the negative stigma she might encounter when starting a college course. The anxiety she experienced as a result hindered her recovery, and she believed this had delayed her discharge.

We observed an occasion where patients were able to enjoy their trips into the community without being stigmatised, as Education Staff did not wear identifying uniforms. On this occasion, which took place at a nearby beach, one participant remarked: "People were talking to me, no one avoided me, and they let their children near me because no one knows!"

While societal attitudes toward mental health have clearly been improving, those who have been in inpatient settings may still be particularly affected by stigma. Such stigma could pose a barrier to such young people's ability to build a stable future, achieve their potential, and recover in general. We must continue all work to destigmatise mental illness, including work to undo the legacy of asylums that can continue to contribute to misunderstanding around mental health inpatient settings.

The ward environment

Negative stigma in society and the media can create an image of mental health inpatient settings that more closely resembles the 'asylum' conditions of the past, which does not do justice to how care looks. For this reason, patients often described feeling frightened when they learned they would be admitted to inpatient care and remarked wishing they had known sooner the type of environment they could expect.

Jenny told us that the hospital had helped her more than any other mental health service she had used. She said the treatment, strategies, information and awareness she received had helped her make progress with recovery. She also felt the staff, environment and education were better than she had experienced outside of hospital.

Rosie had envisioned being 'taken away and locked up' when she learned she was going to hospital. Once she was used to the setting, she said she felt and believed she was making good progress. She wished that she had known sooner what the hospital would be like, as it would have relieved her anxieties about being admitted.

Being treated as an inpatient offered more protection from harm to themselves or others, and access to more intensive treatment, than could be provided at a community level. However, certain aspects of life as an inpatient of a mental health ward were perceived by patients as detrimental or aggravating to their mental illness.

For example, during evenings and weekends patients told us they had little other than colouring-in, playing card games or watching TV to occupy their thoughts.

Yemi also said that being restricted to the ward and not being able to partake in the Education Centre made it difficult to focus on recovery. She said that after three weeks indoors on the ward it was difficult to find diversions to take her mind off how she was feeling.

One participant had not been able to leave the ward for two months during the summer holidays. She told us she had spent the entire six weeks in the ward while the Education Centre was closed for the holidays. As the ward was on the first floor of the hospital, patients under section could not go outside or access the garden.

Many of the young people at Poplar Ward had previously hidden the symptoms of their mental illness and had found it hard to reach out for support through fear of stigmatisation and isolation. Often for the first time, patients shared an environment with other young people who had similar experiences. This could encourage the young people to begin opening up about their mental health and feel acceptance and understanding.

"You can take the mask off." **MAYA**

However, for young people experiencing this level of mental illness, relationships and friendships could lead to unhealthy attachments that hindered recovery. Staff said that while close friendships could give the young people a new confidence, they could also be detrimental to the young person's recovery as they could isolate themselves from others. For this reason, staff at Poplar Ward discouraged the formation of these types of bonds. However, in an environment such as Poplar Ward, where young people are removed from their usual peer groups, it is an impossible challenge to be able to constantly prevent attachments from forming.

Staff told us that a particular problem for young people who had previously struggled to form friendships was finding friendships and a sense of belonging for the first time at Poplar Ward. Regardless of whether the young people formed attachments with other patients, staying at Poplar Ward could be the first time a young person has experienced having their own bedroom, eating three meals a day and being treated with care. This could, unfortunately, create a dependency whereby patients could undermine recovery to avoid discharge, or attempt to be readmitted following discharge.

Participants told us that whilst patients in good spirits could have a cheering effect on other patients, it also meant that low mood could be 'infectious'. Maya told us that when she returned to the ward after a period of leave she could be feeling cheerful, but after being among other patients she would begin to feel unwell again.

This environment could also trigger young people to feel inclined to partake in behaviours they were working to recover from.

Maya said that before being admitted to Poplar Ward she had not self-harmed for two years. However, being around people who self-harmed had given her new ideas on ways to harm herself.

Participants and staff also told us that patients could learn new methods of self-harm or suicidal methods from being exposed to other young people dealing with high levels of mental illness.

While the young people often shared many common experiences with poor mental health some patients still experienced exclusion or a sense of isolation.

Overall, patients understood that hospitalisation aided their recovery, and acknowledged they were making progress under treatment. Maddison, Rosie and Felicity felt that they were safer on the ward than they would be at home. Maya said that patients benefitted from constant access to support, which she said had built her confidence in asking for help and talking to professionals.

However, unpreventable factors in the ward environment could often make recovery difficult. During one particularly difficult period, patients told us alarms were frequently sounding, including overnight. Having interrupted sleep, feeling affected by the low mood of other patients and not having much to occupy their minds outside of Education Centre hours caused some patients to tell us they were feeling worse.

"I'm getting worse, not better." **JESS**

"I feel like I'm being pushed back." **MAGGIE**

This reinforces the importance of effective prevention and early intervention, through responsive community mental health services.

Discharge

Discharge for inpatients at Poplar Adolescent Unit required planning to ensure young people could reintegrate into life in the community after spending time in hospital.

For some of the young people with more troubled backgrounds, returning to turbulent family life, insecure housing or a pressurised educational setting was a source of anxiety. For reasons like this young people often felt resistant to being discharged despite having been assessed as medically fit to leave hospital. The families or carers of inpatients could also feel anxious about the return of a child they feared might experience crisis again.

Poppy and Maggie felt that returning home could make them unwell again.

Yemi recalled feeling she would never recover enough to return to community care, but her discharge had been planned for a while. She explained there were a 'few setbacks' which prevented her from being discharged. Staff at the Education Centre told us that young people who didn't feel ready to leave the hospital were prone to self-harming or relapsing, which delayed their discharge date.

Given these examples, it is understandable that many patients in our study felt strongly about the importance of being involved in all decisions surrounding their discharge, including timescales and the support in place to help them return to education and home life. Unfortunately, the participants who discussed their discharge with us felt that details of their discharge were unclear, which could compound their anxieties. For example, one participant told us that when she asked a member of staff about being discharged, she felt she was not taken seriously and did not receive an answer. This caused her to contemplate discharging herself as she did not feel confident her release from hospital was being given appropriate consideration.

Shannon wanted to understand how likely it was that she would be discharged before turning 18. As she was 17 at the time of her discussion, this was a particular concern for Shannon who understood that she would be transferred to adult mental health inpatient services if she turned 18 before discharge.

"It feels like the decision's in someone else's hands, but it should be in mine."

She told us she had asked staff about the discharge timescale but had been met with vague and unclear answers. Shannon had seen another patient turn 18 on the ward and be moved to an adult's ward and was worried that this might happen to her.

This perceived lack of clarity sometimes caused patients feelings of betrayal or having been misled. One participant said that she was told she would be discharged after one week at Poplar Adolescent Unit, but at the time of our study had been there for five months.

Jess told us that when she was first admitted to Poplar Adolescent Unit she was told she would be discharged within 24 hours, though at the time of our discussion she had been there for more than five weeks.

The fact that some patient's parents seemed to understand more about their discharge than they did, added to the sense that something was being withheld from them, and that decisions were being made without their input.

When Shannon spoke to her mum, her mum told her that the hospital had said Shannon was ready to be released, though this was the first Shannon had heard of it.

Alex was told she was ready to be discharged and phoned her dad to share the news. She said that when she told her dad he explained he was already aware.

Poplar Adolescent Unit had a duty of care to patients which required certain measures to be in place before they could be discharged. Such measures included secure housing, continued mental health care in place in the community and a planned return to school or college. Without these in place, it could result in a patient, who no longer required inpatient care, being unable to be discharged, and consequently remaining in the ward. One participant told us that she had experienced two discharge dates that had come and gone because the appropriate community support was not in place. Another participant who had been given a discharge date, and had planned to partake in some work experience accordingly, told us that her CAMHS worker had quit and her discharge was therefore delayed.

It was housing that perhaps caused the longest delay to the discharge of a medically fit young person. During our study, three young people whose discharged was delayed had been waiting for accommodation.

Several months into our study, Shannon learned she was on delayed discharge. As a suitable housing placement had not been found for her, her discharge was delayed for two months (by the end of our study Shannon was still on delayed discharge). Shannon was aware that at this point in our study she no longer required inpatient treatment and told us she felt bad about remaining in hospital, saying: "Someone could have my bed by now."

Delayed discharge was problematic for several reasons. As Shannon noted, there is the national shortage of mental health inpatient beds and high demand for inpatient mental health services. The quicker discharge could move for a mentally well person, the sooner those resources could be freed up for young people needing important treatment.

Secondly, every day a person who was well enough for discharge spent among peers who were experiencing mental ill health increased the risk of that person becoming unwell again and undermining their recovery. Some patients in these situations described feeling 'trapped' or 'in prison.'

Also, an inpatient mental health setting is not suitable to someone who has made such significant progress in recovery. During our study, participants on delayed discharge expressed boredom and frustration that sometimes caused them to disrupt the recovery of those at greater risk.

Leaving Poplar Adolescent Unit did not always mean being discharged from inpatient care. Some patients needed to be transferred from the Ward to a more intensive setting, with increased levels of security and observation (such as a PICU – Psychiatric Intensive Care Unit). Patients who lived out of county could also be transferred if an inpatient placement became available closer to home, as this would better support them in reintegrating with their home life, education and community-based services.

Patients in these circumstances shared the same anxieties as patients who were facing discharge soon – concerns about what to expect from the new setting, or where in the country they might be based.

We recognise the dilemma of trying to answer questions about discharge when there are so many varying factors. Patients with mental health conditions respond differently to different treatments, and recover at different rates, and with the variable social factors such as community provision, education and housing, no two cases will be the same - making discharge predictions difficult. We also understand that in some instances the parents may need to know about discharge in advance, particularly if the patient is due to return to their care. It was clear from our study that hospital staff worked hard to maintain the wellbeing of each patient while also recognising that staying in hospital when it was no longer the most appropriate setting could hinder the ongoing recovery of that patient and other patients of the ward.

In short, there are numerous reasons that can prevent a discharge conversation from being as straightforward as patients might like, and these reasons are there to ensure their safety. At the same time, our study identified that many patients are unclear on what these reasons are. We would encourage, wherever possible, that patients can ask questions and voice their concerns about discharge and are given a clear understanding of the factors on which theirs hinges. Feeling involved in their care is important for young people, particularly those who have lived experience of not feeling listened to, taken seriously or in control of their lives and futures.

Furthermore, telling patients they will be released after a short stay may not be conducive to their recovery if it transpires that more time in hospital is required, as this can lead to feelings of distrust, or personal concerns that their recovery has failed.

Being Readmitted to Inpatient Care

Many of the patients we spoke to at Poplar Adolescent Unit were not experiencing inpatient mental health care for the first time. We spoke in detail with nine participants about their history of inpatient care and discharge; six had received inpatient care on two occasions, and three were on their third inpatient admission. We asked these young people what, in their opinion and experience, had prevented them from being able to live healthily in the community following their first discharge.

We know that realistically some patients will need to receive inpatient care on more than one occasion, even with strong support surrounding them in the community. Yet it was clear from our discussions with patients that some readmissions could be prevented if more support had been in place for them following discharge. For example, one participant had been permanently excluded from school following discharge from Poplar Adolescent Unit. Over the following months, she had been studying for her exams alone under great amounts of pressure and was readmitted to Poplar Adolescent Unit.

Nicole had been admitted to a high dependency unit (HDU) for three months where she felt she was not recovering. With her mum's consent, she discharged herself but there was no care plan in place to support her in the community. She soon experienced crisis again and was admitted to a different inpatient unit and discharged six months later. Again, she felt there had been a lack of follow-up mental health care, and four months later she experienced crisis once more and was admitted to Poplar Adolescent Unit.

Most commonly, patients told us that having more support in the community following discharge could prevent them reaching crisis again. This support did not necessarily have to come from mental health services, but from an ongoing approach that considered the young person's housing and education needs along with their mental health needs.

Alex was first admitted to Poplar Adolescent Unit for over seven months. After being discharged she was told by her parents that she would no longer be able to live with them in the family home, and with nowhere else to go Alex reached crisis and was readmitted to Poplar Adolescent Unit less than two months after being discharged. Staff at the hospital were working to find her suitable accommodation.

The nine participants who had received mental health inpatient care on at least one occasion before, had all been readmitted within three months of their last discharge; some in as little as three weeks. The consensus among these young people was that the broader issues that had contributed to their crises had not been resolved (such as issues in their home life, family dynamic, education or housing). This makes a strong case for a holistic approach that considers finding resolutions for these factors alongside the treatment of a young person's immediate mental health needs. It raises the question of the likelihood of an individual making a good recovery if they return to the same circumstances that resulted them being taken into hospital in the first place.

Young people who are being treated in hospital are missing education in their own schools or colleges, the chance to develop and maintain healthy social relationships and opportunities in their local communities (particularly if they are being treated out-of-county). The problems with shortages of patient beds can also mean that a patient who is readmitted to inpatient care is not certain to return to the setting at which they were treated before, with different staff, routines and treatments. Readmission can therefore contribute to feelings of disruption or unpredictability in a young person's life, and each admission risks complicating the young person's reintegration with their communities.

Being taken into hospital repeatedly can inadvertently enforce in a young person the idea that things cannot 'get better,' or that they are not capable of living a healthy life outside of hospital.

As we have said, some patients will need to return to inpatient care following discharge and we are not discouraging this. However, in speaking to young patients at Poplar Adolescent Unit it was clear that unless social factors such as issues in housing, family life and education can be resolved there is a chance that they will reach crisis again. The recovery of young people such as these requires the support of services that address these factors, often as much as the support they need from services that address their mental health.

The link between Mental Health and Education

Significant progress has been made in recognising that some young people with mental health conditions have special educational needs, as do some young people with learning disabilities. The UK Government defines Special Educational Needs and Disabilities (SEND)[4] in the following way:

Special educational needs and disabilities (SEND) can affect a child or young person's ability to learn. They can affect their:

- behaviour or ability to socialise, for example they struggle to make friends
- reading and writing, for example because they have dyslexia
- ability to understand things
- concentration levels, for example because they have ADHD
- physical ability

Many of the young people we spoke to discussed the difficulties they had experienced in mainstream educational settings.

Jenny had an eating disorder and experienced high levels of anxiety. She was very self-conscious and did not want to be noticed, or have attention drawn to her. This made daily school life incompatible with recovery where it was mandatory for Jenny to participate in PE. She also told us that aspects of daily school life, such as crowded or noisy classrooms, could cause panic attacks.

Jenny became avoidant of attending school because when she had a panic attack she was usually removed from the classroom which drew attention to her and the mental illness she was experiencing, causing her to fear she was judged negatively by staff and students.

Healthwatch Essex has previously spoken with young people about the impact academic pressure can have on their health and wellbeing, even for those who are not receiving treatment for their mental health.[5] The pressure to excel academically can sometimes be overlooked as a necessary part of teenage life, something you must become 'resilient' to. However, each young person responds to this pressure differently, and for some it can contribute to ongoing mental health problems or be a time when mental health symptoms become hard to control. For instance, one participant had achieved excellent GCSE exam results and felt overwhelmed by the pressure to achieve just as highly in her A-Level studies. Her mental health deteriorated, and she found it difficult to engage in treatment at Poplar Adolescent Unit as she felt it detracted from her intensive studying routine.

Another participant explained that the pressure to achieve academically directly caused her mental health crisis. She explained that the head teacher at her college regularly motivated students by telling them without academic success they would not be employable and would face bad futures. This participant had already become mentally unwell during her secondary school exams, and she said this continued pressure to excel in college caused her condition to deteriorate. Soon, she told us, she was having frequent panic attacks at college. She said the head teacher had told her that she shouldn't attend if she continued to 'make a fuss,' and she chose to leave her college education.

Jess explained that her mental illness became exacerbated in pressurised academic situations such as exams. She told us her symptoms had first begun during her SATs exams when she began to hear voices that told her to carry out violent acts. Later in her education she also experienced severe panic attacks during exams.

Education Centre staff, who maintained contact with patients' schools, told us that many schools were flexible and hardworking in trying to accommodate the needs of these young people when being reintegrated with their education. However, even with adjustments in place it was common for patients to fear a return to school.

4 https://www.gov.uk/children-with-special-educational-needs
5 SWEET! 2

Five participants said they were worried that when they returned to mainstream education things would not be different, and they would become unwell again.

Overcoming this fear and returning to mainstream education was often the final stage in a patient's recovery before discharge. In several instances during our study, patients that coped well with a return to education were often discharged soon after.

Several of these young people had already missed large parts of their education through illness. Both Jenny and Poppy told us they had missed over a year of mainstream schooling through hospital admissions.

Although inpatient facilities for young people came with educational facilities, they were not always well enough to participate. Three other patients had been permanently excluded from school, or taught in seclusion, due to the anger they experienced as part of their illness.

Another participant had re-joined education following discharge from a different inpatient unit but was unable to cope with GCSE pressure. She began hearing voices, having distressing hallucinations and soon stopped attending school before reaching crisis and being admitted to Poplar Adolescent Unit.

Mainstream schools work hard to address the special educational needs of their students, though not every child's needs can be met in a mainstream environment. Significant progress has been made in recognising that some mental health conditions are disabilities, and appropriate adjustments are required to ensure a young person can participate in education in ways that are not detrimental to their health.

Jenny wanted the option to complete her schooling in her school's learning centre for students with special educational needs. She wanted recognition that her illness did mean she had special needs for her learning, which included the need to be able to study in a much quieter, calmer setting.

Other patients recalled a lack of mental health awareness in their schools among staff and students that could sometimes mean they didn't get the appropriate support when unwell.

Maddison told us her school found the medicine she had been stockpiling, with the intention of taking an overdose. As a response to this her school sent her home for the day, but no other action was taken and Maddison carried out the overdose the following day.

Jenny said her school counsellor often shared details of their sessions with Jenny's mum and asked her to consider the impact her mental health problems had on the family. Jenny said this caused her to feel guilty for being ill.

Continuing ongoing efforts to remove the stigma attached to mental health problems is a sizeable task but is a necessary part of early intervention and prevention and has a place in education where young people spend most of their time. Patients told us that increased mental health awareness in schools, the place they often experienced the first symptoms of poor mental health, would make a difference to their ability to reintegrate with education and recover.

Maddison told us that increased mental health awareness in school would make the biggest difference to her recovery. She said: "School hasn't caused my illness, but it's added to it."

Shannon did not want to return to college because of the stigma she had faced from other students about being an inpatient of Poplar Adolescent Unit.

The Education Centre at Poplar Adolescent Unit allowed patients (who were well enough to do so) to continue their learning while receiving treatment. The environment of the Education Centre was able to address some of the barriers to learning that participants previously struggled with, such as providing a calm, quiet space with small class sizes and the opportunities for one-to-one learning with an assigned key teacher. Furthermore, this was an environment where staff and students alike understood mental health, allowing patients to learn without experiencing stigma.

Jenny felt able to engage in learning at the Education Centre. She said that the small number of pupils made for a calmer, quieter environment.

Alex told us that Education Centre staff had worked with her to manage her anger and taught her ways to behave politely even when she was finding learning difficult. She told us that managing her anger and behaviour in mainstream education had been far harder, and as a result she felt she had not learned as much as her classmates. At the Education Centre, Alex discovered that she enjoyed learning and that there were subjects she could do well in.

"I've had the best time of my life in education here."

Most patients at Poplar Adolescent Unit traditionally had negative experiences of education, whether because of bullying, stigmatisation, a lack of mental health awareness or learning environments that exacerbated their mental illness. Observing patients engaging with learning through the Education Centre, and hearing their feedback, demonstrated how young people who had struggled in mainstream settings could have a positive experience of schooling with some adjustments.

Most young people who experience mental health problems will not need alternative provision, though those who do would benefit from an increased ability to identify these needs. For other young people, continuing our efforts to increase mental health awareness and reduce stigma could make a positive difference to both their mental health and their educational attainment.

The link between Mental Health and Social Factors

Before we began our engagement with patients, we asked staff at Poplar Adolescent Unit about social factors that patients could be affected by. While we know that mental health can impact anyone, and is often said to not 'discriminate,' staff told us that many patients shared experiences of abuse, bereavement or bullying. During our study, we also learned that housing, home life and identifying as LGBTQ were also common themes emerging from our discussions with patients.

Abuse and neglect

Two participants spoke to us about their experience of sexual abuse and the impact this had on their mental health.

When Shannon was younger, she was sexually assaulted by an adult. The aftermath of the assault was too much to cope with, and Shannon said she reached crisis and tried to end her life. She told us she still encountered frightening flashbacks, which manifested during night time checks at Poplar Adolescent Unit which entailed a flashlight being shone into her room while she slept. After waking in this way, Shannon said she felt too afraid to be able to go back to sleep and often felt tired and unwell the following day as a result.

Shannon had previously been supported by a rape clinic. She said that some of the therapy she received since the assault required her to repeat details of the incident that made her feel worse, but that she had also received therapy that did not discuss this incident at all.

Shannon said she had struggled to move on from the assault due to the fact she believed her attacker had 'gotten away with it,' as he was not convicted. Shannon described feeling she had not been listened to or believed.

Shannon's experience is similar to that of Lindsay, a case study shared by Healthwatch Essex in our SWEET! 2 report. Like Shannon, Lindsay told us about dealing with memories of the assault on a daily basis and felt the counselling she received had not helped address the trauma. Lindsay recalled being told that a 'lack of evidence' meant that no charges were bought against the man who attacked her, and she felt she was not believed.

Alex relayed a similar experience. She had witnessed the violent sexual assault of a relative and was then also sexually assaulted by the same group of men. Like Shannon, Alex reported difficulty sleeping, and a sense of feeling betrayed because her assailants did not face charges.

We understand that criminal justice processes will not always result in satisfactory outcomes for victims, particularly where there is a lack of permittable evidence. However, when communicating the outcomes of such processes we must be mindful of the message this can send to victims and ensure victims can access support to address the ongoing impact of the events.

Other participants also described the neglect or abuse they had experienced in their home life.

As a baby, Poppy's biological parents left her at home on her own when they went away. Poppy was taken into care after being discovered alone and was adopted at the age of one. Poppy told us that this had not been the end of her problems at home, as her adoptive parents were verbally, physically and emotionally abusive to her.

Max also told us he had been left at home on his own. His mum told him she couldn't cope with his mental illness and checked into a hotel for several weeks. Max's social worker had discovered he was living alone and took him into foster care. Max ran away from foster care but was found and taken to Poplar Ward.

For these young people, environment was a factor in their mental illness. While it is not possible to decide if the home environment caused the mental illness, or only contributed to it, the connection is clear. For this reason, mental health is not just the remit of the NHS but must be addressed where possible across housing, children's, and social care services.

Bullying

Another common factor in the lived experience of patients was having been bullied. We know that children who are bullied have a higher likelihood of developing a mental health condition.[6] At present, there is no legal definition of bullying in England. However, the Government suggests bullying can be defined by repeated, intentionally harmful or discriminatory behaviour such as physical assault, teasing, name-calling, making threats and cyberbullying.[7]

Maggie told us she had been consistently bullied for three years of her secondary school education. She told us she had requested to change schools several times but felt that her mum hadn't listened to her. Maggie began to experience anxiety and depression connected to the bullying, and although she was finally permitted to move to a new school, the effect of the bullying on her mental health continued.

Elsewhere, this definition of bullying is expanded to include behaviour that is isolating, humiliating or coercive,[8] including sexual behaviour, and wherever an imbalance of power exists.[9]

Seven participants spoke to us about being the victims of bullying, and the long-lasting impact this had on their mental health.

Shannon told us she had been bullied throughout her education, and her weight and sexuality had been targeted by these bullies. Even though her parents regularly attended her school in attempts to have the bullying stopped, she felt the school had failed to take meaningful action to stop the bullying.

Healthy attachments and the ability to make and maintain friendships are crucial to the emotional development and mental health of young people. In our study, some participants spoke to us about the harmful impact the breakdown of friendships or difficulty forming friendships could have on their mental health, even though these were not explicit examples of bullying.

Rosie explained her mental health issues began at a time when she felt her friends had rejected her, and she was finding it difficult to make new friends.

Maddison said she had hated secondary school, and felt she never fitted in with her peers. She said this had resulted in low self-esteem, and she now prefers to avoid close attachments to protect herself from being rejected. When Maddison began experiencing mental illness she explained the majority of her friends had stopped speaking to her, and thought she was fabricating her illness.

Commendable progress has been made in protecting young people from bullying, and warnings from research on the life-term effects of bullying is now generally accepted. By law, all state schools must outline the measures they take to prevent bullying in their behaviour policy, and legislation exists with the aim of preventing bullying and harassment of a discriminatory nature, such as that which Shannon reported.

While it may be impossible to completely eradicate bullying both in and out of schools, and it is likely that much bullying goes unreported through fear of repercussions, when bullying was reported appropriately, either to parents or to schools, patients were not satisfied that action was taken in a timely manner. Respect Me acknowledges that "a child's experience [of bullying] will be directly affected by the response they get from the adult."[10] Continuation of bullying can indicate to the victim that adults are either powerless to support them, or do not care, increasing feelings of helplessness and low self-esteem that can be prominent in young people experiencing mental illness.

6 https://www.kidscape.org.uk/media/1050/preventing_and_tackling_bullying.pdf It is also worth noting that children who bully others are also likelier to develop depression or anxiety
7 https://www.gov.uk/bullying-at-school/bullying-a-definition
8 https://children.wandsworth.gov.uk/education/reu/acm2.asp?p=Public/ReferencePages/How%20To%20Guides/BehaviourManagement/Wandsworth%20Anti-Bullying%20Guidance.pdf
9 https://www.kidscape.org.uk/media/1050/preventing_and_tackling_bullying.pdf
10 http://respectme.org.uk/anti-bullying-practice/

Examples of best practice offer solutions to minimise the harmful effects of bullying such as specialist support for the victims of bullying, working with the victims' families on the ongoing monitoring of the situation, and working in partnership with appropriate agencies. To this we would also suggest working proactively with the victim of bullying themselves, to understand their ideal outcomes and how these might be achieved, and to ensure that all parties feel a satisfactory solution has been reached.

Identifying as LGBTQ

Several participants had also experienced a connection between bullying and identifying as LGBTQ. However, they had not just experienced homophobia from school peers but from other parts of society. Seven participants of our study spoke openly to us about identifying as lesbian, gay, bisexual, transgender or questioning.

Shannon said close members of her family and her girlfriend's family were homophobic. This had made living in the family home difficult.

People who identify as LGBTQ are more likely to experience poor mental health because they may experience discrimination, bullying and negative stigma based on their identity. These negative attitudes can be particularly difficult for young people who are often dependent members of their households.

Poppy told us her family were also homophobic and had stopped her from being allowed to see her girlfriend.

Others had encountered homophobic attitudes in school or in health services.

One participant told us that homophobia had been rife in her school, and there had been no LGBTQ awareness sessions to counteract any of the stigma.

Another participant told us that on one occasion she had overheard mental health staff expressing homophobic attitudes which made her worried about how they may treat her.

As we have found in other Healthwatch Essex reports, the absence of information on LGBTQ people can cause further feelings of alienation or invisibility.

Bereavement

Bereavement was another common factor in the lived experience of patients in our study. While bereavement itself can be a highly distressing experience, for several participants bereavement had come at a time in their life where they were also struggling with other traumas, often causing patients finding themselves unable to cope.

In the space of a year, Shannon had been sexually assaulted and was also twice bereaved. She told us the culmination of these events had led her to crisis and she attempted end her life, feeling she could no longer cope.

Around the time Maggie's sister moved far away for university, she also went through a relationship breakdown and a bereavement. Her sense of loss was overwhelming, and her mental health worsened to the point of crisis.

Poppy, who had been adopted as a baby, told us she had only recently been informed that her biological father had died some years ago. Poppy told us that as well as feeling bereaved, she also felt angry that she had only just found out.

NHS England acknowledges that bereavement can be particularly hard for young people who can feel isolated by the fact that few of their peers can relate to their experiences. When this is combined with other life stressors the impact of bereavement on a young person's mental health can be exacerbated.

Mental illness in the family home

Participants often spoke about mental illness within their families. Of the bereavements patients told us they had experienced, four were the suicide of a relative. Three participants told us they had a parent or sibling who had been treated as a mental health inpatient, and four told us they had a parent or sibling who received ongoing treatment for a diagnosed mental health condition. Two participants had experience of being young carers for parents who had been discharged from mental health inpatient services.

Thirteen participants told us their mental health had been affected by issues arising in their family lives. This could include parental separation, being a young carer and other problems that complicated the family dynamic.

Where health services operate a whole-family approach, the intention is to consider the impact of an adult's health and care needs on children living in the same home. We would encourage this approach to be rolled out, where appropriate, across services to help identify where a young person may need support as a result of their home life.

Housing

The NHS and Mind point out that having secure and suitable housing is one of the greatest factors in mental health recovery.[11] Several patients on the ward were uncertain where they would live after being discharged from hospital.

While being treated at Poplar Ward, both Shannon and Jess's families had also told them they would not be able to return to the family home.

Alex told us she had had taken an overdose with the intention of being admitted to Poplar Ward. She told us that she had needed somewhere to stay as her parents told her she could no longer live at home.

In these instances, Poplar Ward staff would work across agencies to try and find a housing solution for these young people. Staff told us that shortages of suitable housing often led to delays in a patient's discharge.

Shannon was assessed as being medically fit to be discharged, but without a housing placement she could not be discharged. Shannon was aware that if housing had not been found by the time she turned 18 she would be transferred to adult mental health services. There was also the possibility that adult mental health services would not accept her as an inpatient because she did not need mental health inpatient care.

Shannon had applied to a young people's charity that housed people with complex needs. Shannon's application was rejected because she was considered too high risk to be supported by the charity. Being too high risk for housing but not 'high risk enough' for inpatient care meant Shannon was 'stuck' between services for several months.

The shortage of appropriate housing is another nationwide issue with no immediate solution, but until this problem is addressed, we cannot expect to solve the risk to young people's mental health and the strain this can cause to health care services. We must consider housing as a health outcome and continue a collaborative multi-agency approach that considers all aspects of a person's health and care.

Social workers

Five participants spoke to us about their experience of being assigned social workers. As we have found in other work with young people, it was not uncommon for a young person's social worker to change frequently.[12]

Poppy told us that she had been assigned three different social workers who had each worked with her for short periods of time. She said that her first social worker had told her he couldn't work with her any longer because she frequently reached crisis and presented at A&E. Her most recent social worker had left and was due to be replaced.

Having a social worker for a short amount of time could be a concern for patients, as social workers were required to contribute to decisions made about a patient's care following discharge.

Max had previously been assigned three different social workers. Since being admitted to Poplar Ward, he had been assigned a new social worker who he had not yet met. He explained feeling concerned that the social worker would be contributing to decisions made about his future when they had not had a chance to get to know one another.

11 Mental Health Taskforce (2016)
12 SWEET!, SWEET! 2, YEAH! 2

As social workers could play an important role in arrangements for the young people following discharge, a negative experience with a social worker could have a negative effect on other aspects of the young person's care.

Shannon had been medically cleared for discharge but needed a housing placement to move into. Her social worker had agreed to find Shannon suitable housing, but neither Shannon nor staff had received any updates. Shannon's discharge was delayed as nobody knew if housing had been found for her. With the help of staff, Shannon had written to her social worker, and when no response came the staff helped Shannon write to children's services. Again, there was no response and Shannon's discharge was delayed by several months.

Shannon told us she felt that important information about her care was therefore being kept from her, and she was not involved in decisions being made about her future.

Later in our study staff told us that Shannon's social worker was applying for a housing placement for her. Shannon told us later that the application had not been submitted in time, and she experienced a further discharge delay.

Staff took Shannon to the council in the hope of speaking to someone who could update her on her housing situation but were told that Shannon's social worker oversaw this. Shannon's social worker said she did not deal with housing, so Shannon and the staff had to go back and forth between services to try and move the process forward.

Other reports by Healthwatch Essex have gathered the lived experiences of young people who have been assigned social workers. The issues mentioned above are not new ones, and we know social work has seen increasing pressures and workloads, which in turn can lead to a high turnover of staff.

As ever, we encourage measures that can incentivise dedicated social workers to stay in the profession in order to provide the best possible quality of support for the young people who need it.

While a degree of turnover in any profession will always be unavoidable, young people need to feel that decisions made about their care by those who know them, are aware of their history and understand the wishes of the young person they represent. Involving young people in discussions about their care and ensuring they are clear on why certain outcomes are reached can prevent them feeling the system is not listening.

While not all young people who become mentally ill have experienced the social issues highlighted in this section of the report, we cannot deny the connection between distressing life events and poor mental health. This is not simply a case of building resilience in our young people, but ensuring that the system, as a whole, is able to support them in a timely and appropriate manner. Continuing efforts to tackle bullying and stigma, as well as expanding appropriate housing options and supporting those who have been abused or bereaved, are all important factors in resolving poor mental health in our young people.

The link between Mental Health and Physical Health

Existing research has established links between mental health and higher rates of smoking, higher rates of alcohol and drug misuse and so on. Many of these studies have been focused on the adult population, and we wanted to explore some of these issues from the perspective of the young people, in their own words.

Participants at Poplar Adolescent Unit seemed to be treated holistically, with measures in place to improve or maintain their physical health while they were recovering in hospital. There had been a gym facility for patients to use, but this was now out of bounds as some patients had been over-exercising, which can be a negative symptom of an eating disorder or other mental health condition. However, patients well enough to do so were encouraged to exercise by using gym, swimming or tennis facilities in the local area.

In previous studies by Healthwatch Essex, young people have spoken about the relationship between food and nutrition, exercise, and body image. Participants at Poplar Adolescent Unit highlighted how poor body image and/or negative self esteem impacted their mental health and their ability to take care of their physical health.

Poppy said she had never questioned her weight until one of her relatives called her fat. She began to think that she was overweight and eventually this belief became solidified in her mind. She told us: "I don't want to go back to school because I'm too fat." She also said she had not addressed this with the mental health professionals at Poplar Adolescent Unit as she felt too embarrassed to mention it.

Shannon told us that she had been overweight since childhood and had been part of a weight loss programme at a young age. She said she had been consistently bullied about her weight throughout her life and had been on a variety of diets to attempt to lose weight. She said her weight was a great source of unhappiness for her, and she had stopped taking care of her appearance and personal hygiene as she felt there was "no point."

Maddison said that many young people had a negative sense of body image, which she attributed to a pressure to meet certain beauty standards perpetuated through the press, the entertainment industry, and social media. Even though Maddison was told her weight was healthy she believed she was "too fat," and said that many of her peers outside of hospital restricted their eating to meet these beauty ideals. Maddison felt this pressure could be overcome if young people were taught from an earlier age how to maintain a positive body image and feel confident even if they looked different to the "norm."

For other young people, improvements in their mental health allowed them to take better care of their physical health. For example:

Maya had previously been diagnosed with an eating disorder, before being admitted to Poplar Adolescent Unit, as she was underweight. However, she told us that the symptoms of mental illness that she experienced often caused her to forget mealtimes and skipping meals had not been a conscious decision for her.

"You forget to look after yourself when everything's going on."

Maya told us that at Poplar Adolescent Unit staff had helped her develop a healthy routine, which included meals at set times. The positive effects of a daily routine, she told us, had also assisted her mental health recovery.

A large proportion of patients at Poplar Adolescent Unit smoked, although all were under the legal age to do so. We know that people with mental health conditions are more likely to smoke than the average person.[13] In fact, it is claimed that 1 in 3 cigarettes smoked is smoked by someone with a mental health condition.[14]

13 smokefreeaction.org.uk/smokefree-nhs/smoking-and-mental-health/
14 http://smokefreeaction.org.uk/smokefree-nhs/smoking-and-mental-health/smoking-and-mental-health-partnership-resources/

Maddison began smoking when she was 14, during her first admission to Poplar Adolescent Unit. Before she received inpatient care, Maddison told us she used to self-harm to relieve some of the symptoms of her mental illness. In an inpatient setting where patients were monitored, Maddison told us that smoking had replaced the release she used to find in self-harming. Maddison told us that, at the time of our discussion, only one patient on the ward was a non-smoker.

Many smokers claim that smoking relieves some of the symptoms of mental illness, such as stress, but NHS England notes that quitting smoking actually boosts mental health as it can improve mood, relieve stress, anxiety and depression.

Smoking was tolerated by the hospital when patients were on ground release or extended leave, and staff were aware that patients smoked. Poplar Adolescent Unit provided access to nicotine replacement therapy, such as nicotine patches, to help patients manage their cravings. The young people usually obtained their cigarettes from adult relatives during visits to the hospital. Those whose relatives did not bring them cigarettes would get them from other patients or patients and visitors from other parts of the hospital.

Acknowledging the harmful effects of smoking and prescribing nicotine replacement therapies was a good example of how the hospital treated mental and physical health holistically. Both the government[15] and NICE[16] have published guidance aimed at assisting mental health inpatients in quitting smoking. Such guidelines include suggestions like commissioners using contracting levers to support services in becoming smoke free, and Healthwatch Essex would also advocate a family-wide approach that informs relatives about the negative impact of smoking on mental health and recovery and discourage them from illegally supplying young patients with cigarettes.

Use of drugs and alcohol can contribute to, and in some cases – research has indicated – cause, poor mental health. However, people who use these substances are not necessarily ill because of them but may be self-medicating to relieve the symptoms of a mental illness.[17] Six patients of Poplar Adolescent Unit opened up to us about their relationship to drugs and alcohol, and how this impacted their mental health.

Maya told us she frequently smoked cannabis before being admitted to Poplar Adolescent Unit and was working alongside professionals at the hospital to understand if her use of cannabis had contributed to her hearing voices, or if she had started using the drug to mask these voices.

Maya would begin smoking cannabis as soon as she woke up in the morning. It would be hard for her to quit, she said, because almost everyone in her friendship group smoked it too. Maya felt that cannabis use was common among young people and was no longer viewed as a taboo the way it had been in previous generations.

All patients were below the legal drinking age. We were told by some that before being admitted to Poplar Ward, they had previously been supplied with drugs or alcohol by friends or relatives. One participant who smoked tobacco and cannabis told us he had first been given the drug by his parent when he was age seven.

15 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/576434/Promoting_cessation_of_smoking_in_children_and_young_people_for_Tier_4_CAM-HS_commissioners.pdf, p7

16 https://www.nice.org.uk/guidance/ph48

17 https://www.rcpsych.ac.uk/healthadvice/problemsdisorders/mentalillness,offending.aspx

Poppy told us that her sister had bought alcohol for her when she was eleven, and she had become ill after binge drinking neat spirits on several occasions.

Poplar Adolescent Unit seemed to be proactive in helping patients change their attitudes to drug use. An external drug and alcohol service ran programmes on the ward, which lasted several weeks, for young people who had been engaged in substance misuse. The only disadvantage to this was that some patients might be discharged before they had completed the programme.

Having learned about the negative impact that cannabis had on their mental health, both Alex and Maddison had decided not to use the drug again after being discharged.

Our time at Poplar Adolescent Unit reinforced the need for holistic treatment that addresses the connection between mental and physical health. Unlike the experiences some patients reported about time spent in general hospital, at Poplar Adolescent Unit physical health and mental health were treated together (staff also helped patients arrange and attend appointments related to aspects of their physical health that could not be treated at the hospital). Working with young people to address nutrition, exercise and issues of substance misuse furthered their chances of improved mental and physical health, and as patients experienced improved mental health, we witnessed their ability to make healthier decisions in other aspects of their lives.

Research consistently links people with mental health problems to poorer physical health outcomes. Treating mental and physical health in conjunction with one another is a necessary part of redressing health inequalities for this demographic, but the lived experience shared with us in this study shows that areas of physical health and mental health are often still treated in isolation.

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Healthwatch Essex has been delighted to support the resourcing of welcome packs for Poplar Adolescent Unit patients, as arranged by the Education Centre, that provide new patients with hygiene products and objects of therapeutic use on admission to the ward.

Most of all, we would like to thank all patients of Poplar Adolescent Unit whose voices are central to our report. We realise it can be difficult to talk about such personal, and sometimes painful, experiences and to invest the time and trust it takes to do so. We will do our best to ensure your voices are making a difference to the way in which services are designed and delivered in Essex.

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