

**A summary of service user and carer
experience of Northamptonshire
Healthcare NHS Foundation Trust
(NHFT)**

September 2013 - June 2015



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Summary

Northamptonshire Healthcare NHS Foundation Trust (NHFT) delivers over 100 services, many of which are provided out of a hospital setting and in the community. The Trust also provides inpatient care for people with acute mental health problems and people with dementia, as well as clinical care with the two hospices in the county and community rehabilitation. The significant majority of feedback we have received about NHFT services relate to mental health services, particularly community mental health services and child and adolescent mental health services (CAMHS).

This report is an overall summary of the information we submitted to the Care Quality Commission (CQC) in January 2015 to inform the CQC inspection of NHFT in February 2015. We have also added in additional information that we received from service users and carers between February and June 2015. The information contained is an analysis of feedback we received between September 2013 and June 2015.

We have received some comments relating to mental health services which could relate to other providers. As there are many different providers responsible for some of the services detailed in the report, some of the feedback is not wholly contributable to NHFT. While NHFT is a significant provider of CAMHS and adult acute and community mental health services; other providers also have a role in delivering care for people experiencing mental health problems - including primary care (GPs), voluntary and community organisations providing early intervention and support, and services that provide support in crisis situations, such as the ambulance service and Accident and Emergency (A&E).

We heard a range of views about services including a mix of positive and negative feedback from the people we spoke to, which we have taken at face value. Across all the services we heard about, there were some common themes to the feedback:

Caring inpatient services

Feedback from inpatients at St Mary's Hospital in Kettering was very positive - residents felt safe, comfortable and happy in the environment and were also happy with the attitude of staff and felt at ease with them. The patients we spoke to at Berrywood were also generally satisfied with the care they received and there was some positive feedback about the staff, particularly those who were friendly and helpful.

Communication and listening to service users and carers individually and collectively

People told us that they did not think changes to services and restructures of services, particularly to the Community Mental Health services, Favell House (former respite service for people with neurodegenerative conditions) and Podiatry, had effectively involved service users and their families or been well communicated. While Nene and Corby Clinical Commissioning Groups (CCGs) are ultimately responsible for the services they commission, it is essential that commissioners and providers (i.e. NHFT) ensure that when service change, which may result in people who have previously received a service having the service cut (podiatry) or changed (community mental health services) there is robust and meaningful engagement with service users, carers and patients. Some patients, service users and carers told us that they felt, in relation to specific service changes, there had been a lack of meaningful engagement. We also heard examples of people not knowing where to go to get support or receiving adequate or accessible advice. At an individual level, some people told us they thought there had not been adequate consultation with them and that they were not listened to well or involved in decisions about their own care and treatment.

Waiting times and staff capacity

Long waiting times for appointments, particularly for Child and Adolescent Mental Health Services (CAMHS), Community Mental Health services, Musculoskeletal services and Podiatry, were frequently mentioned and we also heard examples of appointments being cancelled without saying why or without people being advised in advance. There was often a feeling that inadequate staffing contributed to waiting longer for an appointment than was satisfactory. We have been working collaboratively with NHFT and the CCGs over the last 18 months to improve CAMHS and some of our data included in this report is from engagement activity during Autumn 2013, so is now over 18 months old, although we also have more recent feedback. We are planning to find out from children, young people and families how the changes to services have made a difference.

Discharge and joined up working

A number of mental health inpatients at Berrywood Hospital told us that they had concerns about being discharged too soon and not receiving enough ongoing support once they were home. This raises concerns about how the different mental health services communicate with each other to coordinate patient centred care and to look at the 'whole picture'. We also heard from a person who did not feel that Isebrook Hospital had worked well with social care to arrange the discharge of an elderly patient.

Recommendations

Many of the issues raised in this report, particularly those concerning mental health services, could be addressed by:

1. Ensuring a person centred approach that considers all the needs and holistic circumstances of a service user.
2. Working across teams, services and organisations and improving channels of communication.
3. Linking treatment with prevention to meet the wider wellbeing needs of patients, particularly those with more complex mental health needs.
4. Prioritising meaningful patient, service user and carers involvement in changes to individual care and service redesign.
5. Future support to the voluntary and community sector both in terms of funding and support to voluntary and community services.

Sources of information

Visits to St Mary's Hospital and Berrywood Hospital

Healthwatch Northamptonshire visited the two NHFT mental health hospitals. St Mary's Hospital (Kettering) was visited in March 2014, December 2014 and January 2015 (the Forest and Welland Centres), and Berrywood Hospital (Northampton) twice in December 2014 (Harbour, Bay and Cove wards and the Riverside, Brookview and Wheatfield units). Our staff and trained volunteers (authorised representatives) observed the care, conditions and interactions between staff and service users. We spoke to 20 patients about their experiences, to staff, and to other visitors where possible. Ward managers and matrons gave an introduction to each ward. A full report giving further details of the visits is available on our website¹.

Issues and complaints

Since September 2013, Healthwatch Northamptonshire has been keeping a log of unsolicited complaints, issues and comments about all health and care in Northamptonshire, given to us from members of the public.

We heard 25 negative comments and received one piece of positive feedback about services provided by NHFT between September 2013 and June 2015 (excluding the survey responses).

Make Your Voice Count campaigns and surveys

From September to October 2013 and October to December 2014, Healthwatch Northamptonshire ran a public engagement campaign called “Make Your Voice Count”. The aim of the campaign included finding out people’s views and experiences of health and social care and suggestions for improving the quality of care. Over the two year period, 1,028 people responded to our survey about what health and social care services they were using, how they rated them and any good or bad experiences. They also highlighted what they felt they wanted Healthwatch Northamptonshire to focus on.

A total of 80 respondents commented as part of the “Make Your Voice Count” survey on mental health services, 42 of those gave us specific comments about their experiences of services provided by NHFT. Of those, 14 mentioned good experiences and 28 of these mentioned poor experiences. A full report with further details is available on our websiteⁱⁱ.

Feedback from Mental Health workshops

Healthwatch Northamptonshire hosted a workshop about Mental Health and Wellbeing for service users, carers and stakeholder organisations (including NHFT, Mind, Samaritans, Voiceability and Rethink) in May 2014, 52 people attended the event. Those attending shared their thoughts about where they thought there were gaps in the current services and what an effective and integrated mental health services might look like in the future.

Mental Health Questionnaire

Early in 2015, we undertook a survey of mental health service users and carers to understand their views and experiences of local mental health and wellbeing services. This involved speaking to 45 people at five different service locations, Mind offices in Rushden and Daventry, The Daylight Centre in Wellingborough and two visits to The Bridge in Wellingborough. Up to seven questions about their experience of local mental health services were asked.

Engagement with children, young people and families - surveys, focus groups, meetings and workshops

In February 2015, Healthwatch Northamptonshire ran a Health and Wellbeing Conference for young people between the ages of 12 and 18 to enable them to engage with other young people and professionals, open the debate about health and wellbeing issues important to them, and think about how young people want to work with Healthwatch Northamptonshire. The event was attended by 70 young people and 71 adults. Feedback was collected about what young people thought was important to them about health and wellbeing and what they wanted more

information on, which highlighted some of the issues they faced in accessing health services.

From September 2014 to January 2015 HWN in conjunction with Northamptonshire County Council (NCC) Young Leaders carried out a survey of 11-25 year olds across the county. The survey was designed with the Young Leaders to find out how young people felt about their wellbeing. A total of 527 young people responded. The survey was generic to emotional wellbeing and did not ask about specific NHFT services.

Between October and December 2013, Healthwatch Northamptonshire attended a range of events to hear the views and experiences of children, young people and families, particularly about children's community health services. The survey was completed by 53 people and we held three focus groups.

Full reports and further details are available on our websiteⁱⁱ.

Health Visitors

In January 2015, Healthwatch Northamptonshire volunteers conducted a street survey of parents with children aged from 0 to 5 years old in eight locations across the county. The volunteers spoke to 221 parents to find out about their experiences of the local health visiting service. A full report and further details are available on our websiteⁱⁱ.

Occupational therapies (OT) and Physiotherapy services (as part of HWN Musculoskeletal services survey)

Healthwatch Northamptonshire spoke to 165 people using musculoskeletal physiotherapy services and 35 clinical staff across Northamptonshire during April 2014.

75% of the respondents of the HWN survey on musculoskeletal services (of which Occupational Therapy and Physiotherapy are part of) indicated that they have used musculoskeletal physiotherapy services delivered by NHFT.

The following NHFT physiotherapy clinics were visited: Kettering General Hospital, Highfield Clinical Care Centre - Northampton, Towcester Medical Centre, Danetre Hospital - Daventry, Isebrook Hospital - Wellingborough, Nene Park - Irthlingborough, Nuffield Diagnostic Centre - Corby.

A full report and further details are available on our websiteⁱⁱ.

What we heard

Adult Mental Health

NHFT provides a number of Mental Health services. There are other mental health providers in the county including primary care (GPs), voluntary and community organisations providing early intervention and support, and other services including A&E and Ambulance services providing support in crisis situations. Most of the feedback and experiences we have heard relating to NHFT were about Mental Health services.

Our 2014 “Make Your Voice Count” survey asked people what they thought Healthwatch Northamptonshire should take action on. Mental health was cited as the third top priority by 10% of the respondents (specific issues mentioned included: quality of commissioning and provision of mental health services in the county, mental health services for young people, access to support, availability to emergency mental health services, addiction support and help in understanding changes in mental health services).

The survey also asked people to rate services they, or someone they care for, had used in the previous 12 months. Overall, 80 survey respondents rated mental health services: 33% rated them ‘poor’ (the highest percentage of ‘poor’ for all the services rated), 28% ‘good’, 25% ‘satisfactory’ and 14% ‘excellent’.

Inpatient mental health

We spoke to over 20 residents and patients at St Mary’s Hospital and Berrywood Hospital.

The experiences we heard about can be grouped into the following themes:

Care, dignity and staff

Everyone we spoke to at St Mary’s was satisfied with the care they received, felt safe, and comfortable. They also appeared to be happy with the attitudes of the staff and at ease with them. Examples of what we were told by services users, carers, residents and staff and saw included:

- A relative told us that they were very satisfied with the care given to their family member at The Forest Centre. They couldn’t find fault with the centre and were full of praise for the help and support given to their relative, who was enjoying their time there and felt safe and comfortable.
- Another Forest Centre resident said they were comfortable, felt safe and enjoyed their surroundings. They were satisfied with the activities in place and the opportunities to join in with things if they wished.

- Another said the staff were always thoughtful and helpful and gave time or assistance if required.
- We spoke to several service users on Kingfisher ward (Welland Centre) and all appeared to be happy with their care and the attitude of staff. It was evident that the service users were at ease and comfortable with the staff, aided by the calm atmosphere and good interpersonal skills demonstrated. We observed positive interaction of staff with service users on Kingfisher Ward.

The patients we spoke to at Berrywood were generally satisfied with their care and attention they received, although one mentioned a lack of dignity issue (a person of the opposite sex had allegedly watched them getting changed). Examples of what we heard included the following:

- One patient who had spent 14 months on Bay Ward felt that staff were now listening to them and involving them in their future plans more than they used to.
- Another said the ward had a nice feel to it and they felt safe and comfortable. They had been involved in planning an overnight home visit and had felt in control of that and that their voice had been heard.
- Other patients on Brookview weren't happy about having to give in their phone charger on arrival, meaning it was difficult to use their phones.
- A patient appreciated the medical attention they received and thought that there was good monitoring (4 times a day), help with sleeping, and follow up to make sure they were doing OK, e.g. after bouts of depression. They also thought that they were listened to if they were not happy with their treatment or medication, etc. They thought that the hospital was good compared to other hospitals they had experience of.
- A respondent to our Make Your Voice Count Survey thought that they received good care on Brookview Unit in November 2014.

We received mixed comments about the staff at Berrywood. The comments from Brookview Unit (functional older adults) were mostly positive:

- One patient said they were impressed when they first arrived on the unit late one evening. They thought the staff had been very polite and had time to care and explain without being rushed.
- Another Brookview patient said the staff were good and caring and they felt that their care had been good.

- One patient said they felt well cared for and liked the staff. They thought the staff were all caring, doing a good job, professional and compassionate, working well together and were ‘there for you’. Their relative thought so too.
- Another thought the staff were friendly and helpful and that there was always someone to talk to.
- One patient had noticed that staff do not always wash their hands and on the morning of our visit, the patient had witnessed a staff member sneezing into their hands several times and then not washing their hands. When administering drugs the service user noticed another staff member sneezing and then dispensing drugs.

The comments from Bay Ward (recovery ward) were more mixed. Patients thought that most of the staff were good and caring, particularly the healthcare assistants (HCAs) and some senior staff, but also told us some less positive opinions of the nurses and some of the doctors. They also thought that the ward was generally understaffed. Comments from Bay Ward included:

- “Some of the nurses are good but some are not and sit around and don’t stand in for the HCAs. Two are amazing but the rest ignore patients.”
- “The nurses don’t understand how frustrating things can be. For example, sometimes a nurse does not answer the office door for 10-20 minutes because they are ‘cleaning a computer keyboard’” (two service users used this example).
- “The HCAs are fantastic but there are not enough of them. I don’t have a bad word about any of them, they are very caring and work longer if needed.”
- “There are enough nurses but not enough HCAs. HCAs can calm patients because they know them but nurses don’t have that relationship.”
- “The psychiatrists are no help. They are not caring and just look at the disease as a puzzle rather than looking at the person.”
- “Staff focus on the past rather than the present or future.”

Safety

Whilst safety policies and procedures appeared to be in place at both hospitals, we did hear about some serious safety issues at Berrywood, which we reported to the Ward Manager at the time of the visit. The patients we spoke to on Harbour Ward felt safe during their stay, as did two from Bay Ward and one from Cove Ward, but two other patients on Bay Ward did not think the ward was safe and raised the following concerns about safety:

- One patient told us they had become physically ill during a previous stay. They claimed that Berrywood said they were well/not ill enough despite having low blood pressure, blood sugar, heart rate, and potassium levels. Their parent took them to A&E with extremely low blood sugar, resulting in them being admitted to hospital for one month.
- A patient said they were able to take paracetamol from a cupboard and told us they had overdosed on it. The paracetamol had been handed in by a visitor.
- Another patient told us that an ex-patient had allegedly stolen and drunk a bottle of spirit that had been left in the staff office after being confiscated (it should not have been kept there). They also thought it was too easy to get dangerous items onto the ward as they are not searched when they return from outings, including unescorted outings. They had brought in a number of potentially harmful items. NHFT policy does not advocate searching all service users following leave from either Bay or Cove as they are recovery wards, unless the care plan dictates that should happen.
- A patient was allowed into the room where all the prohibited items were stored and left alone. They told us they went on to drink nail varnish remover.
- One patient thought that the room searches carried out missed harmful items even when they were not well hidden. Another found a razor in their room when they arrived on the ward and harmed themselves with it.

Activities

The activities available to residents/patients depends on the type of unit or ward they are staying on. Most were satisfied with the activities but there were some criticisms and suggestions.

Positive comments included:

- A resident at St Mary's (Forest Centre) was satisfied with the activities in place and the opportunities to join in with things if they wished.
- An ex-resident returned to the unit frequently on a social basis to help and chat to the service users. They had also volunteered to be on the patient forum which the unit use on a regular basis to consult residents on any changes to the unit.
- A patient on Brookview Unit, Berrywood was glad they could get up when they wanted to within reason.
- Another patient particularly enjoyed the activities, especially the cooking.

- A Berrywood patient was pleased they could use the onsite gym but thought that 30 minutes per day was not enough time.
- A patient we spoke to on Harbour Ward enjoyed the activities (especially the craft based activities) as it kept them busy during the day.
- Patients on Bay and Brookview Wards (Berrywood) thought it was good that walks around the site were organised every day.
- One patient who had been on the ward for 14 months appreciated being allowed to go out for six hours on Fridays and thought the process of being able to build up leave privileges and move from escorted to unescorted leave worked well.

Criticisms and suggestions included:

- A resident at St Mary's (Forest Centre) felt that as their condition improved, the days became longer and it was difficult sometimes to fill the time with things to do. They felt that activities were based mostly around those that were more poorly and not on those waiting to go home. Being able to take short walks around the hospital site would prepare residents more for their return to their own home.
- Two residents at St Mary's (Forest Centre) wanted to be allowed more time to relax in their own room, as they would do at home.
- A patient on the Brookview Unit, Berrywood felt that there was too much television and that it was on most of the time even if no one was watching it.
- One Bay Ward patient (Berrywood) was bored as they thought they were put in a lower level activity group despite being more able.
- Another told us that there were only occupational therapy activities and that the activities did not change so were not so good for frequently admitted people.
- One Bay Ward patient thought that there were not always enough staff to open the activity room or to facilitate going out.

Discharge

Both hospitals told us how Occupational Therapists are involved in preparing residents for discharge. A service user at St Mary's (Forest Centre) who was awaiting a discharge date was happy with how they had worked with the discharge planner and were fully involved in the arrangements for discharge. Extra support

was being put in place to assist them in coping at home and they were feeling confident about returning home.

However, some patients and relatives from Berrywood told us they felt unsupported and had concerns about their discharge and the support and care they would get afterwards.

- A patient on Harbour Ward was anxious about their discharge and the support available to them once back home. They wanted to go home but wanted to have some reassurances that the support they needed would be in place and also if they wanted to come back to the hospital they could.
- Two Bay Ward patients did not think they were ready to be discharged and said that even if they threatened to overdose when discharged, they would still be discharged.
- One patient said that the psychiatrist decided they were ready to be discharged but that the nurse and therapist disagreed. They told us the psychiatrist told them they “would never be cured”, which was discouraging and troubling. The patient lives alone and thinks the doctors believe they have a larger support network than they do. They felt they were not being given advice they asked for and were being “pushed out to depend on the crisis team”. They were worried that the short-term support would not be enough. The patient also felt they needed a more phased discharge process.
- The parent of one patient was also concerned about whether the crisis team was sufficient to support their child after discharge as they had not managed to provide effective support previously. Allegedly they gave the service user sufficient medication for them to overdose. Both the patient and parent think that the time on the ward had not been long enough for proper assessment before discharge. The patient told us they were desperate for help, but were still waiting to see a therapist or psychiatrist following a referral three months previously.
- Another patient’s parent appreciated that the matron was trying to help with their child’s discharge situation.

In September 2013, we received a letter from the parent of someone being treated at Berrywood Hospital complaining that the patient was being discharged too soon, without sufficient treatment of the underlying issues. They were also concerned about the lack of support on discharge for the vulnerable person. The patient had a number of issues and their parent felt that that no one was looking at the whole picture and that there was lack of communication and cooperation between those trying to help.

Community Mental Health Services

We have heard from 32 people about their experiences of using community mental health services, 24 of which were negative.

Positive feedback

We heard eight examples of positive experiences, including:

- “Northamptonshire Mental Health Services are excellent, I couldn’t ask for more appropriate care and support for my son. I couldn’t ask for anything better.”
- “The Crisis Team were good.”
- “Within the last 12 months I have accessed a good service from Campbell House and from my care manager based in Northampton.”
- “In the main, I have positive experience with care support from the Community Mental Health Team”.
- “The Memory Clinic (as part of dementia care provided by NHFT) helped us and was lovely with my mum.”
- A good experience with a talking therapy service through Changing Minds and floating support and Personal Health Budget support provided by Bromford.

The main negative issues we heard about were:

Difficulties accessing ongoing support

This seemed to be particularly an issue around June 2014 when NHFT was going through a restructuring process in community mental health services, when no support workers or care coordinators were being allocated and patients were being transitioned to the Wellbeing Team, GP-led care and personal budgets. People thought there was poor communication about the changes in services, a lack of listening to patients about what would most help them, and a lack of understanding of long term problems.

- One patient struggled to get ongoing support rather than just crisis support. Another was unhappy that they had lost their support worker, who they could always contact if they needed to be seen urgently.
- Two other patients told us about the detrimental health effects of losing their NHFT care coordinators and the central electronic notes recording system (ePEX). Both were distressed and made complaints. Comments included:
 - They were happy with the previous system but did not feel they would get the right support without a care coordinator at NHFT.

- They were unhappy about how NHFT had communicated with them and did not feel involved in the decisions.
 - One patient was temporarily given a Wellbeing Navigator but did not find these meetings helpful and said that “without warning or reason these meetings stopped during a reorganisation”. The patient was then given a Primary Care Liaison Worker, but did not find this useful and was told they needed to find and pay for their own psychological support despite this need having been previously identified.
- A patient who was involved in the consultation process for the restructure still did not have a clear idea of what was going to happen and felt that the changes were being rushed through.
 - A patient transferred to a personal budget had been waiting nearly two years for it despite being eligible and assured they would get it.
 - A patient said they had been helped by services such as N'Step (Northamptonshire service for the treatment of early psychosis) but that the service was only available for a limited period of 3 years and they were worried about not having follow-on support.
 - The parent of an adult patient with schizophrenia told us that changes to social worker involvement and reorganisation within the Community Mental Health Team had reduced the quality of professional support the patient received. At the same time the adult service user received less support at home due to the birth of a child. This placed the patient under increased personal stress and affected their behaviour.
 - Five other people mentioned long waits for assessments, appointments and/or referrals and one thought that mental health services in Northampton were “poor..., massively oversubscribed and inadequate”.

Treatment or care plans not meeting people’s needs.

- One person with agoraphobia told us they were refused home visits from a counsellor despite them not being able to make face to face sessions.
- One person said they had no care plan and no suitable care and that the staff at Campbell House would not get back to them when they made contact. They were waiting for an appointment with a clinic and had not been given any advice, and thought they had been given wrong advice by the Community Psychiatric nurse. This person felt unsupported, was finding the situation stressful, and did not have confidence in the complaints process.

- A patient's carer said the patient only got half of the psychological therapy they had been referred to before the service ended and then had several inappropriate referrals before being discharging back to primary care.
- One person told us they have received 14 years of poor care from Clarendon House, including numerous diagnoses and medication for conditions they said they never had. Another person thought they had inappropriate referrals and medicines.
- Two people thought that the Eating Disorders Team was poor, one person told us that the team was "unprofessional, under-trained, patronising, under-staffed and did not provide any standard of care".
- One person thought that the Crisis Team was particularly bad.
- Three people thought that there was not enough specialist support for people with depression or that it had not helped.
- One person thought that the limit of six weeks of counselling through GP practices was not long enough for a deep-seated issue.

Communication issues

- We were told by a carer that their relative had waited eight months to get a medication review whilst the GP and Campbell House lost letters and argued over who should pay for the medicines.
- Another carer felt that Campbell House children's service staff were uncaring and dismissive and that they did not understanding the carer's concern and need for information on the care of their child.
- One person told us that the Community Mental Health Team at Clarendon House Kettering had allegedly treated them "in an appalling manner" and that staff had "sent me abusive emails, lost their temper with me, cancelled appointments and never re-arranged them".
- A psychiatrist was described as "rude" and unhelpful by a care home nurse who had tried to make an appointment for a colleague in crisis.
- In June 2015, a patient's appointment with their community psychiatric nurse was cancelled on the day due to illness but the patient was not told and made an unnecessary journey (costing time and money).

Feedback from Mental Health questionnaire and workshop

The survey of 45 mental health service users and carers undertaken in early 2015 asked participants about their experience of local mental health services. Prior to this Healthwatch Northamptonshire collected feedback on mental health service reorganisations plans from a workshop with service users, carers and stakeholder organisations in May 2014.

Although the participants of the survey and workshop had a diverse variety of experiences as service users or carers some key themes emerged. The feedback applies to all providers delivering services for mental health service users, including NHFT, and should be read in that context.

Issues raised included the importance of GPs, long waiting times for services, involvement of the voluntary sector, access to information and communication, training A&E staff and supporting carers. Gaps in the approach and recommendations were also made.

GPs have an important role in providing care and information to service users and carers. Those people who were confident in the services and support that they received found it important to know that their GP and practice staff understood mental health issues and could explain or signpost them.

Where GPs and/or practice staff do not understand mental health and the services and support available, service users and carers lack confidence in all their care and look for other providers of primary care. In these circumstances there also appears to be reduced access to non-medical treatments, such as counselling and talking therapies.

Recommendations included:

- To improve GP and practice staff knowledge and skills about mental health issues through GP training and better information.
- Provide a member of staff within each GP practice to act as a 'mental health lead' or sign poster.

The importance of information

Information is really important for both service users and carers. Those people who knew where to go for information and advice, not just for their immediate health needs but for wider support, were more likely to talk positively about the support and services that they received or had received in the past. However, very few survey respondents were aware of new approaches such as the opportunity to have and use personal budgets or support through primary care. The survey highlighted that some people were not accessing services because they were unaware that they existed.

Recommendations included:

- “Improvements could be made in terms of psycho-education, publicity and much better communications.”
- “Better use of the media - better to keep people informed and involved in change.”
- “There is not enough detail or information about supporting carers to care - carers time may be limited and sometimes they have no choice or no notice.”
- “Look at and offer different ways to keep people informed and involved.”
- “Being very clear with the service user about timescales that can be expected.”

Secondary and crisis care

Whilst some of the people we spoke to had not used secondary care services, those people who had were critical of their experiences. We were concerned to hear from a number of respondents that they regularly had appointments for referrals cancelled, resulting in having to wait months to access services. A number of people also questioned the appropriateness of some of the group therapies that they had experienced. E.g.:

- “The use of counselling services - appears to be a big gap, services are there but there are long waiting times.”
- “Long delays in getting appointments with little support during those waiting times - people get lost in the system.”

Most people who used crisis services felt that they were treated appropriately.

One person raised concerns about what support is available out of hours, including from the 111 service:

- “There is little mention of out of hour’s services and what is available. The 111 service lacks mental health questions.”

Working across the system

Many people we spoke to thought that an effective and integrated mental health service should involve the voluntary and community sector more and include referrals to voluntary organisations/clubs. A more holistic approach between health and social care was also suggested. E.g.:

- Better working across the system from primary care to secondary care and with external agencies such as the Police and voluntary and community sectors.

- More funding and better promotion for voluntary sector services.
- More support groups and drop-in services.

One person also thought that there was a lack of training of A&E staff in mental health issues, e.g. that self-harm was very often not recognised and linked to a mental health issue.

Other suggested improvements regarding NHFT included:

- “Integrate and embed service users and their experiences into the system and all processes.”
- “Consider the patient journey.”
- “Empower the service user for self-management.”
- “Consider anxiety and fear caused by changes.”

Child and Adolescent Mental Health Services (CAMHS)

Thirty respondents to our the 2014 “Make Your Voice Count” survey rated CAMHS as follows: 33% rated them ‘poor’, 40% ‘satisfactory’, 13% ‘good’ and 13% ‘excellent’. Nine respondents gave us specific comments about CAMHS, one was positive:

“Newland House, Northampton was very useful, responsive and informative.”

Requests for help and advice

Twelve families have contacted us for help or advice or to tell us about a poor experience since September 2013, six since January 2015. Many of these families and their children were distressed and didn’t know where else to go for help.

Ten of these families mentioned difficulty in getting an assessment by CAMHS or having to wait a very long time for assessment. We have heard of cases where CAMHS would not accept referrals (from a paediatrician because the child was too young, from a GP because the child had a diagnosis of ADHD, and from a GP and Social Services repeatedly) or did not think that the children needed to be seen urgently, despite the parents and GPs thinking otherwise. This left parents and children/young people distressed (some feeling at risk of harm), unsupported and not knowing where to turn.

We heard of young people being referred between different services (CAMHS, Educational Psychology, Psychiatrists, Paediatricians, etc.) but not getting support from any of them or have to wait a long time for support. There seemed to be a

particular issue for children and young people seeking an assessment for Autism Spectrum Disorders and/or ADHD (nine of the families). There was often a lack of clarity over which service was responsible.

Some of the other families that have used CAMHS thought the service was unsatisfactory. Amongst issues raised were the following:

- waiting lists too long
- assessment criteria too tight
- poorly carried out assessments (sessions too short, only one session, not listening, questions or discussions not thorough, not in line with guidelines)
- CAMHS deciding there is not a problem or ending treatment despite families thinking otherwise
- insufficient support after CAMHS decide to stop treating (including other services no longer being available to them)
- unfriendly or unhelpful staff and confrontational appointments
- not enough clinical staff

Previous feedback

During our engagement activities with children, young people and families from October to December 2013, Healthwatch Northamptonshire heard the following views and experiences about CAMHS. We have since worked with NHFT and other local health and social care partners on a Transformation Programme Board to improve the quality of CAMHS. We have welcomed this opportunity and welcome the demonstrable commitment from NHFT to improving services. We are working with NHFT to assess the impact of the improvements put in place, since we delivered our engagement during 2013, and will be talking to children, young people and families.

Access was a problem

We heard very widespread concerns about the limited availability of CAMHS in Northamptonshire. People said CAMHS were usually good once they have been able to access the service, but the issue was getting that access. Many people said that waiting times for CAMHS were unacceptable and could feel like a very long time when there were urgent mental health needs. This was a view echoed by nearly all the children and young people who spoke to us about CAMHS. For some this resulted in having to seek a diagnosis privately. One person commented:

- “Everywhere I go there is a long waiting list which is very hard to cope with when I am suffering from depression.”

Problems with access to counselling services and early intervention /preventative services

Children and young people were not aware of where to go to for support. Children and young people with urgent needs talked to us about being turned down or contact with services not being followed up. Several people talked about a lack of continuity of care. We heard from one young woman who had 12 counsellors in 4 years. For example:

- “My mum contacted (a serious assault counselling service) but they didn’t get back to us and I didn’t get any help for two years.”
- “When I asked to get a different counsellor they sent me to another service provider. I didn’t get a proper counsellor, so I left.”

Mental health issues highlighted at young people’s health and wellbeing conference

We recently worked with the Northamptonshire County Council (NCC) Young Leaders on a health and wellbeing survey and held a young people’s conference on 18 February 2015 where young people (aged 12-18) were consulted on what health and wellbeing issues were important to them.

Accessible information

The biggest theme coming from the comment cards was that young people wanted more information about where they could go to for help with a mental health issue which was available in a format they could understand. Comments included:

- “I found the waiting rooms in general were not very child friendly, you couldn’t understand posters.”
- “Not getting the right information from social workers.”
- “Access to information about where help can be obtained for emotional problems.”
- “Services aren’t advertised enough.”
- “I know that there is help out there, however, would like to be aware of where to go!”
- “More information for deaf people using BSL in mental health”
- “To be able to understand the treatments/medications a bit more”
- “Make information more child friendly as it can seem confusing and can result in children worrying when they do not need to”

CAMHS and counselling

We also received comments about CAMHS and the counselling offered by the service:

- “CAMHS were terrible in my experience with them - ruined my faith in young people’s mental health workers”
- “CAMHS being accessible and actually help people and just respect them from start”
- “Help for children with parents who have mental health conditions (depression/post-traumatic stress disorder (PTSD)/bipolar etc.)”
- “More face to face support rather than media/IT/web”
- “Counselling services should be made available to come into schools and fit around school hours (evenings and weekends)”

Other children’s services

General themes

Nineteen respondents to our 2014 “Make Your Voice Count” survey rated Children's and Family Services (including Health Visitors). The feedback was mixed: 32% rated them ‘poor’, 21% ‘satisfactory’, 21% ‘good’ and 26% ‘excellent’.

Between October and December 2013 Healthwatch Northamptonshire attended a range of events to hear the views and experiences of children, young people and families, particularly about children’s community health services, and collected survey responses from 53 people.

- 36% of people said they found the services they were using to be very helpful, 32% said services were OK, 21% said services were not helpful (11% didn’t answer).
- 43% of people surveyed said they needed more support. These included a range of responses from “real help” to responsiveness in services, emotional support and signposting among others.
- 43% of people had found it difficult to get support.
- Staff were identified as the most appreciated part of services - in 43% of responses to the survey

We heard some positive views about how services did meet need:

- children, young people and families appreciated staff who took time to explain things
- staff who made children and young people feel relaxed

- organisations with clear rules about confidentiality
- staff who engaged children during appointments
- good information and signposting
- good social and emotional support
- “feeling listened to” and being treated as an individual
- co-ordinated care and support
- friendly and hard-working staff.

The key negative themes we heard during the consultation were:

- Many children and young people did not get the right support at the right time. Several young people and parents described the “struggles” or “fights” they have had to get services. Many people talked about the high level of need they had to demonstrate in order to get any support. The impact this had on the lives and wellbeing of children, young people and families was significant, at times overwhelming, and made it difficult to plan for independence. The following factors were highlighted:
 - lack of continuity of care between different services
 - lack of continuity in the transition to adult services
 - lack of professional time or perceived commitment, interest and sensitivity on the part of professionals
 - gatekeepers/criteria which block or limit access to services
 - services being inaccessible
 - weak partnership working with some ethnic minority groups and organisations
 - difficulty accessing the right services for children with complex behavioural issues
 - lack of information on support available - not knowing where to go to get support was a recurrent theme
 - inadequate social support to prevent crisis or deterioration
 - long waiting times for services during which time the child/young person’s health and wellbeing can decline
 - lack of meaningful involvement in service design (a representative explained that young people, who had been asked to gather the views of their peers, didn’t feel listened to when they had gathered views and made recommendations for service improvement).
- There were concerns about health transitions for young people moving from child health services to adult services, including anxieties about continuity of care and a consistency in the level of support, as young people become more reliant on social care.

- Many families talked to us about a lack of co-ordination of services between health, social care and education to meet the needs of families of children with complex needs.
- Universal and tiered training to support children and young people with Autism Spectrum Disorders (ASD) was an issue. Representatives and parents gave examples of the need for more awareness within all agencies.
- Families of children with autism said they had experienced a varied range of processes and diagnostic practices from varied agencies and providers and families weren't signposted to other appropriate services where there wasn't a diagnosis. One local advocate had concerns that NICE guidelines were not being followed with regard to the diagnosis of ASD, with varying practices within the county.
- There was concern about the quality of health and wellbeing support within schools. One counselling provider wanted better relationships between school nurses and community and voluntary counselling agencies in order to maintain continuity in school holidays.

Health Visitors

In January 2015 Healthwatch Northamptonshire spoke to 221 parents about their experiences of Health Visitors.

- The majority of parents we spoke to were positive about the advice and support they received from their Health Visitor in general and when there were specific concerns about their babies.
- Some parents were critical about the quality of care, including a lack of consistent advice between health visitors and midwives and not enough visits at key stages in their child's development.
- Only 44% of parents said they had received advice on weaning and there were significant variations across the county.
- There was a lot of variation between areas on whether mothers had been asked how they were feeling before and after the birth. In Kettering, a third of new mothers (34%) had not been asked how they were feeling after the birth.

Positive comments included:

- "We know they are there when we need them."
- "I saw my health visitor and she helped me with my post-natal depression."

Negative comments included:

- “Not enough visits with my second child.”
- “It was a vague appointment - she was in a rush so didn’t explain the questionnaire I had to fill in.”

We also heard two poor experiences through our “Make Your Voice Count” Survey:

- “I felt totally let down by my health visitor with my son’s lack of sleep and behaviour issues. At the time, I was suffering mental ill health and had no response to my calls for six months...I was not offered any support or advice.”
- “I found health visitors not to be the most helpful and a bit judgmental if you are struggling to breastfeed, etc. and didn’t want to go to peer groups.”

Speech Therapy

One parent contacted us because they were concerned their autistic son was not getting as much speech therapy as a relative in another part of the country.

Community Paediatric Nurse

One person told us they had a “fantastic Community Paediatric Nurse”.

Orthotics Service

One person told us their child generally received a good service once they were seen but that the recall and reassessment was often severely delayed and that the delay between sizing and fitting sometimes meant that the child had outgrown the equipment by the time it was provided. “More timely appointments for growing children/young people would be a more effective use of resources.”

Other adult services

Community Nursing

Community/District Nursing was rated by 35 respondents to the 2014 “Make Your Voice Count” survey, with the majority rating the service as ‘excellent’ (43%). 17% rated them ‘good’, 23% ‘satisfactory’, and 17% ‘poor’.

We received two comments about community nursing, one positive and one negative:

- “Six weeks of home care after a two week stay in hospital was very good. Personal care support was good and the district nurse service was excellent. It made my role as a carer much easier.”
- “We were told that there is a long wait for a Community Nurse”.

Podiatry services

Podiatry services were rated by 72 respondents to the 2014 “Make Your Voice Count” survey, with the majority rating the service as ‘excellent’ (38%) or ‘good’ (42%). 11% rated them ‘satisfactory’, and 10% ‘poor’. (These figures include private providers so should be read in that context as they will not all relate to NHFT podiatry services.)

We received five further comments about podiatry services, three negative and two positive.

The positive comments we received were about specific clinics:

- “I had to take my elderly uncle to the Podiatry Clinic for a very bad problem with his toe-nails. He was treated with great care and respect and I was very impressed by the staff at the time.”
- “Great podiatry service at Rectory Road Clinic, Rushden.”

The first two negative comments relating to NHFT and one comment referring to Nene CCG highlighted long waiting times and dissatisfaction about the closure of clinics and cuts to funding:

- One parent contacted us when their child with special needs had been waiting for treatment for an infected toenail for over three months and did not have an appointment for another five weeks.
- “Funding for foot problems - how can you get better when they won't help you!”
- One member of the public felt that the decision to close podiatry clinics over a year ago was taken without enough consultation and the changes were not well communicated to patients - they no longer know where to go for help without travelling and thought they and others were no longer eligible for free treatment. They were also concerned that diabetics would be less well monitored.”

Untimely discharge from Isebrook Hospital

We recently heard from the relative of an elderly inpatient at Isebrook Hospital about difficulties in arranging discharge and home care. Northamptonshire County Council (NCC) were having problems arranging a care package but the family also thought that Isebrook hospital was not working together with the NCC care manager and that they didn't attend the same meetings. The patient had deteriorated while at Isebrook due to the environment and the doctors all agreed that he should go home as soon as possible.

Musculoskeletal Services

Physiotherapy or Occupational Therapy was rated by 96 respondents to our last "Make Your Voice Count" survey, with the majority rating the service as 'excellent' (35%) or 'good' (40%). 13% rated them 'satisfactory', and 13% 'poor'. (These figures include private providers).

In April 2014 Healthwatch Northamptonshire spoke to 165 people using Musculoskeletal services across Northamptonshire (including some provided by both acute hospitals). NHFT provides musculoskeletal physiotherapy and occupational therapy, which includes assessment, diagnosis and treatment for patients with musculoskeletal pain and dysfunction. They deal with a variety of musculoskeletal problems, such as pain, stiffness, muscle weakness, instability and reduced mobility of joints and muscles.

75% of the people we spoke to used physiotherapy services.

Positive comments

The top three most appreciated aspects of the service were:

- Clinical staff and good rapport with patients - 92% of patients said they felt able to ask questions about their condition and felt listened to by their clinician. 86% felt that they were involved in decisions about their care.
- Text appointment reminders.
- The quality of care and treatment received.

The three most common issues patients told us were about waiting times for appointments, communication, and cancelled appointments.

Waiting times for first appointments, follow up appointments and at the clinics

- Waiting times for first appointment varied from one day to seven months (at the pain clinic) and the average waiting time for a follow up appointment was four to six weeks.

- Patients told us about clinic waiting times of up to two hours and the lack of receptionist services at a number of sites.
- The impact of waiting times on people’s lives was significant: 17% of people surveyed were on sick leave due to their condition (this may have been because of an elective procedure or an accident). A further 14% stated they were in pain but had no choice but to continue to work.
- Patients also told us that appointments were cancelled but they were not told why.

Communication between departments, GPs and Consultants

- Nearly 50% of patients using more than one clinical service were frustrated at perceived poor communication between departments, particularly where treatment involved using services in another County.
- Communication between departments and the reported lack of knowledge by the Patient Contact Centre were raised as concerns both by patients and clinical staff.

Additional comments

- One person told us that they had a good experience of Adult Community Physiotherapy at St Mary’s Hospital (John Notley Unit).
- The parent of a child with complex health needs told us they had an excellent physiotherapist who “understands the situation well and seems keen to assist if at all possible” and “has a great relationship with our child who likes the consistency of knowing who the therapist working with us is”. They also implied that funding and caseload pressures limited the physiotherapist’s ability to assist them.
- One person told us they had experienced long waits for both occupational therapy and physiotherapy and that waiting times are increased by the services referring to each other.
- Another was unhappy about being told they had to wait 26 weeks for physiotherapy having self-referred.
- A parent recently received a letter wrongly claiming that their child had been seen by Occupational Therapy for a seating review and would therefore be taken ‘off the list’. A new occupational therapist had to be allocated.

Intermediary Care Team

The multidisciplinary intermediate care team (ICT) prevents avoidable admissions to hospital by supporting people within their own homes and facilitating early discharge from hospital where a health monitoring or rehabilitation need has been identified.

We have received positive comments about the intermediate care team (ICT) team and their role in supporting people. The local charity for deaf people, Deafconnect reported problems a deaf patient, referred by their GP to the (ICT), experienced. We were told about examples of poor communication with the patient, a lack of interpreters, and how the patient was left confused by the team on a number of occasions. The ICT relied on a staff member from Deafconnect to communicate with the patient rather than providing an interpreter.

Community dental services

NHFT provide dental treatment service for children and adults who would not or could not, because of their special needs, use a general practice dentist. They also provide oral health promotion services in a wide variety of community settings, including community groups, care home settings and support for teachers in schools.

We received positive feedback from the parent of a child seen by the St Giles community dental clinic. They said they received “excellent service from a dentist who appears to really understand the complex picture of diagnoses presented and interacts well with our teen, helping to manage anxiety and ensure consent is given as treatment is required”.

In 2014 Healthwatch Northamptonshire heard concerns from the Safeguarding Adult Board User and Carer forum about poor access to dental care for people living in care homes and people in need of domiciliary dental care services. The User and Carer forum had become aware that elderly people in care homes, and some receiving care at home who were not able to attend a dental surgery, had extremely poor dental health and were not having either check-ups by dentists or necessary dental work. We have been pleased to note that the NHFT Oral Health Promotion Team has been working with care homes to offer them training and support and we have worked with the community dental lead and Public Health at NCC to prepare a joint paper on the issues.

Thanks and acknowledgements

Healthwatch Northamptonshire would like to particularly thank:

- All the people who shared their experiences of care provided by NHFT
- The staff at Berrywood Hospital and St Mary's Hospital who assisted with the planning and promoting of our visits and for taking the time to show us around
- Our volunteers who have assisted with conducting enter and view visits and gathering people's experiences

ⁱ <http://www.healthwatchnorthamptonshire.co.uk/entter-and-view-reports>

ⁱⁱ <http://www.healthwatchnorthamptonshire.co.uk/about/docs>