Patient Experience to inform the JSNA listed by content

Introduction

The following is a summary of the recently collected patient experience that we hold under each of these headings. This represents 2200 experiences collected through around 250 visits to community groups across the geographic and demographic range of Richmond as well as the findings of focussed reviews of services where relevant to the JSNA topics.

Section 1.1: Population prevention programmes

Sub sections:

- NHS childhood vaccination programmes uptake
- E.g. MMR, HPV
- Antenatal and Newborn Screening
- Health visiting (ages and stages)
- Smoking in pregnancy

Patient Experience Summary

Antenatal and Newborn Screening

Healthwatch Richmond gathered the views and experiences of 103 local women with due dates ranged from August 2015 to May 2018 who had received care during pregnancy (antenatal care). The project and the choice of questions used were discussed with local hospitals and partners. Report HERE

Women were asked if they felt involved in the decision of where to have the screening checks. 51% felt involved, 33% neither felt or not involved and 15% did not feel involved. A person would have benefited from "more information around screening and the interpretation of results". 100% of women who took the survey were not smokers.

86% of respondents rated their care as very good (44%) or good (42%).

The majority of women across all providers reported good access to information, emotional support (although more should be done to ensure that all women are informed about emotional support).

About 1 in 3 women self-refer to hospital (29%) for their initial antenatal appointment. Those that do reported better experiences and fewer mistakes.

The majority of women said that they received the right amount of written (77%) and verbal (80%) information, that this was given at the right time (93%) and was understandable (90%).

The area where most women reported not receiving enough information was in relation to feeding their babies. Of those who did receive information about feeding from Kingston Hospital, 26% reported that they did not receive sufficient information about feeding their baby until during or after the birth of their child.

Overall, 72% of women were told about emotional changes to expect during pregnancy, with more women reporting this at Kingston Hospital (75%) than at West Middlesex Hospital (62%). Few of the women we spoke to had needed support and feedback was mixed about the support available for those who had accessed it.

An experience about gestational diabetes care was mixed and the patient felt they only had adequate care after moving to West Middlesex Hospital (from Kingston Hospital).

Another experience of Gestational Diabetes had poor follow up care from their GP. They did not receive their follow up blood test 6 weeks after birth to check if their blood sugar had returned to normal range.

Health Visiting

There are 26 experiences about Health Visiting and 4 experiences about the Well Baby Clinics from 2017 to April 2020. Health Visiting is provided by Central London Community Healthcare. A sentiment was assigned to each experience and the breakdown of the 27 Health Visiting experiences is as follows: 13 positive and 13 negative experiences. Out of the 13 negative experiences, there were 4 experience that occurred in the past year.

Parents felt supported when the Health Visitor had the time needed to understand the baby's individual needs were given individualised guidance. Positive experiences were when support was responsive for example when parents could not get a same day GP appointment they turned to their Health Visitor for help. They also valued getting efficient referrals to services that they need. Guidance around feeding and sleeping issues was appreciated.

Negative feedback occurred if the advice was conflicting between the health visitor and the midwife. Secondly if the advice given was felt to be too general and not specific to them, or if their concerns were not being taken seriously which made them feel "inferior" or that they were "over-anxious". Women did not always feel they were given good information and support about breastfeeding. Two experiences detailed how the Health Visitor just gave them information leaflets that they did not feel were useful. This made this mother feel like a failure when their problem didn't resolve. Around a quarter of the negative experiences had problems contacting the team or had Health Visitors not turning up at agreed appointment time.

There were 4 experiences collected about the Well Baby clinics that operate out of the borough's Children's centres. Some clinics operate as a drop in clinic while others required the person to make an appointment before attending. All 4 experiences were negative and related to the difficulty in accessing the service. There were two experiences detailing the challenge in the service change from a drop in clinic to appointment only. They found it difficult to get through on the phone to make an appointment. Conversely there is an experience explaining about the difficulty they experience with their clinic being a drop in service and the long waits (up to 2 hours) they have had. Coordinating the care of their other children around the uncertainty of the waiting time is very difficult. There was also a problem if the parent's lived on the Borough's border and they were registered at a Hounslow GP practice they were not able to access the baby clinic that ran out of their GP practice and instead had to travel to their local Children's centre which was inconvenient.

Section 1.2: Unintentional injury and accidents

We are not aware of any feedback related to this heading that we can share

Section 1.3: Childhood Obesity and risk factors

Sub Sections:

- At reception and year 6
- Healthy eating
- Physical activity
- Dental health (cavities)
- Breast feeding correlation (see previous section)
- Fast food restaurants near schools

• Deprivation and obesity

Patient Experience Summary - not divided into subsections

From YOL! discussions with 14 school-aged children and young people we found that they generally understand what healthy eating is. It is also understood that the lack of physical activity and excessive sugar intake/processed food may lead to becoming overweight, obese or dental issues. Young people explained that schools have generally taught them how to eat healthily, but the environments in which they live do not support them in making positive choices. One said: "Schools have lessons on balanced diets but nothing changes", meaning that young people may understand the importance of a wider determinants approach to improve healthy eating.

However healthy foods were not always a viable option for children at schools. Cheaper snacks/lunches at school are highly calorific and poor in nutritional values, while fruit and vegetable options were viewed as less affordable. Young people at YOL! and Kingston and Richmond Youth Council (KRYC) understood that not all pupils may be able to afford them and added that healthy options are often unappealing, unavailable or insufficient. Moreover, they mentioned that measures were taken around some of their schools (all in Kingston and Richmond) to decrease fast food and sweets purchased outside of school hours. Nonetheless, they remarked that young people in general will happily walk further from the school to eat unhealthy foods. One young person mentioned speaking to a friend who often went to eat at McDonald's with their family because it was cheaper than buying or making healthy meals at home.

Young people added that PE hours or other opportunities to be active are very limited in comparison to the time spent sitting at other lessons and studying at home. The time spent being inactive seems to increase further as they progress further in their education. They suggested step (i.e. fitbit) competitions to encourage young people's movement.

Some young people spoke positively about their parents' influence in incorporating healthy eating and physical exercise into their routines. However, not all said that they or their parents were able to cook healthy as well as tasty food, therefore wished to be taught healthy cooking skills.

Section 1.4: Children and Young People's Mental health

Sub sections:

- Prevention
- Under 5's emotional wellbeing
- Tier 2
- Tier 3
- Tier 4
- CAMHS transition to Adults
- Hospital admissions

Patient experience

Tier 2

Back in 2016, Healthwatch Richmond collected experiences from parents and schools on Richmond's CAMHS services. The report, available to download <u>HERE</u>, found that many of the 1580 young people who sought help wished for better emotional wellbeing services in and out of school.

The report found that local young people who access helpful services report levels of emotional wellbeing on a par with those who have never needed to seek help.

There were many barriers to seeking support however. Many (44%) were put off from seeking help due to the stigma around mental health, a lack of understanding of their own needs and the difficulties experienced in explaining a particular state of mind.

Accessibility to services was described even more as an issue for those whose sexuality, ethnicity or gender made them less likely to access a service. Young people recently remarked that exam stress, lack of confidence and peer pressure remain the main reasons for them to suffer with anxiety or low mood.

Long waiting lists and high thresholds for CAMHS were and remain a significant barrier to accessing care. In 2019, young people at KRYC and Youth Out Loud! explained that Off the Record is a safe and useful place to seek help or even just ask questions about mental health. Those who went there described staff as "friendly and helpful". However, if one was to request counselling they would be on a waiting list for months. This seems to put young people off from seeking support.

The 2016 report found that online services are also useful to children and young people. Throughout 2019/20 YOL! has been working closely with local public health and mental health services to find how those who are self-harming can get the help they need. They found that some online resources can be very useful to discover new information safely, as well as for getting in contact with someone who may be able to help remotely. We have put together a list of services that YOL! finds useful and safe to use <u>HERE</u>.

Prevention

In terms of prevention, young people at YOL! and KRYC think that a "working together" or "whole school" approach will help them develop resilience, as well as better mental health. Where schools and other agencies communicate with each other effectively and where there is friendly staff, being able to openly talk about mental health, young people feel prompted to share their feelings.

CAMHS transition to Adults

Finally, Healthwatch Richmond has attended three groups in the community where parents of young people and the young people themselves who are transitioning to adulthood, shared their experiences. In total, we spoke to 18 parents and 5 young people. Among all services, mental health is one of those where young people and their parents do not feel well supported enough for transitioning to adult services. Parents spoke about the difficulty in identifying an appropriate pathway for preparing their children to adulthood and specifically, to independence in seeking or getting the right support. Please see the "SEND" section for more.

Young people's suggestions for improvements also include support around exam pressure and a more serious approach to the mental health problem. Extra-scholastic activities are greatly valued to "take their mind off things" as well as find trusted adults to talk to.

Section 1.5: Risky Health behaviours / Crime -Teenage years

Sub sections:

- Young people not in education, employment or training
- Smoking alcohol and drug use
- Young people's sexual health, including STIs (e.g. chlamydia), contraception, (e.g. LARC & EHC), under 18 & repeat conceptions and TOPs & repeat TOPs
- Crime

Patient experience

Young people's sexual health, including STIs (e.g. chlamydia), contraception, (e.g. LARC & EHC), under 18 & repeat conceptions and TOPs & repeat TOPs

During YOL! Meetings we have discussed sexual health thoroughly with professionals from local providers. From our discussion we found that the young people have many unanswered questions and are not sure where to get them answered. They feel embarrassed to talk about taboo issues with adults so the first places they go to are friends and the internet. They feel their friends don't necessarily have the right answers, while the internet is hard to navigate.

Young people at YOL! have discussed the use of online resources to get information about risky behaviours, in particular sexual health.

One YOL! member would only generally use NHS sites for health information as they find other information often extreme/creating anxiety/ not trustworthy.

On Google they searched -sexual health - then skip over the adverts (mistrust, expensive), ignore 'bots'. Nhs.net came up first - looked at FAQs and found it is a text heavy site but NHS logo means its reliable.

On Google they searched- sexual health for young people. Brook site looked good. Specific locations of services useful (eg add bus routes/ stops, supermarket next to clinic etc)

Important key words included - free, confidential

They wouldn't trust instagram or facebook for health information (and definitely not Tic Tok).

The young people liked Young Minds website - clear and to the point, not patronising, don't try too hard, statements. Other sources of information were not known to young people.

Young people understand that locally, Off the Record is useful to get free condoms but are not sure what other support they could get there.

School nurses are useful to get the young people's questions answered, but they are not always available and don't seem to announce when they are in at the school. Therefore young people often miss out.

Young people explained that schools deliver sexual health information but they do not find this helpful because:

- it is very general information
- they don't feel free to ask questions (it is embarrassing, there's no confidential way do this)
- often too focused on STIs and very little on other topics such as porn, healthy relationships, self-eroticism, "what is normal" etc...

Smoking alcohol and drug use

Young people at YOL! and KRYC have noticed others smoking, taking drugs and abusing prescription medication at school. They were surprised that so many young people misuse substances and believe that they are getting hold of drugs easily. YOL! perceived this as a safety risk because they feel drug users do not fully know what they are taking and what risks are connected to what they are doing.

Crime

We heard from both parents (at outreach sessions) and young people that knife crime and muggings concern them a lot because people in the borough are increasingly targeted. Young people do not know how to protect themselves and would not usually report a crime.

Section 1.6: SEND

Sub sections:

- Prevalence of needs (autism)
- Demand SEN support, EHCPs, residentials
- Transitions to adult services

Patient Experience

Healthwatch Richmond spoke to 27 adults and 11 young people in 2019/20. While some parents were very happy about their children's EHCPs, a considerable number of others expressed concerns. For instance, EHCPs were not carried out properly by the school, others did not manage to have regular reviews and others felt the ECHP did not reflect their children's needs.

Some parents provided feedback on their child's ability to attend mainstream education but children and parents explained that anxiety and the challenges presented by mainstream schools can make attending mainstream school challenging.

Children with ADHD or autism whose learning difficulties are not formally diagnosed, face significant struggles with accessing support via schools. Some people told us that their children had dropped out of education as a result.

Transitions from childhood to adulthood represents a great concern for these parents. The transition process from child to adult services can be a vulnerable time for young people (YP) and their families. During this period, children stop receiving health services that they may have had since a very young age and move on to equivalent adult services (where available) which can be structured and funded differently.

Problems highlighted within the current transition system include:

- Some children stop receiving care before the equivalent adult service has been organised
- Some children transitioned to adult services that did not meet their needs
- When services are working well it is often because carers take on the professionals' jobs.
- Families feel confused and distressed by the lack of information and support given to them during the transition. This is generally due to gaps in support and services arguing about who should be giving support, and in the meantime people are left without support

Local experiences support the CQC's recommendations that:

• Commissioners and providers must listen to, involve and learn from YP and their families and understand what they want from their care

- Existing national guidance must be followed so that YP are appropriately supported through their transition. NICE has published updated guidelines in 2016
- GPs should be more involved at an earlier stage in planning for transition. This is particularly relevant for CYP transitioning from CAMHS
- Services must be tailored to meet the needs of YP transferring from children's health services and include extra training for health care staff in caring for YP

Section 2.1: Healthy Lifestyles and behaviours

Sub sections:

- Tobacco Control
- Smoking Cessation
- Healthy Eating
- Physical Activity
- Screening uptake
- Sexual health including contraception, (e.g. LARC & EHC) STIs (e.g. HIV), TOPs and repeat TOPs
- Substance Misuse

Sexual Health Service delivery and performance

Patient Experience

See Obesity section 1.3 and Risky Behaviours section 1.5.

Section 2.2: Long term conditions

Sub sections:

- Respiratory COPD-
- Type 2 diabetes
- Mental health
- CVD
- Flu Vaccinations
- Cancer

Living with long term conditions and complex

• More than 2 co morbidity

Patient experience

CVD

We have 19 experiences related to heart (cardiovascular) disease from 2017 to April 2020.

Five patients had positive feedback about the information and advice about how to manage their condition they were provided with following their first adverse cardiac event (e.g. heart attack). The patients were most grateful for the "helpful" cardiac rehabilitation classes they were referred to, and one patient described how it improved their confidence.

Patients were generally positive about the care they had while a patient on a ward except one patient who felt during their 1 week stay their personal care/hygiene was not well looked after. Two patients who were admitted onto a ward after attending A&E with cardiac problems described extended waits for their discharge prescriptions from the West Middlesex Hospital pharmacy. One patient reportedly waited 8 hours for the medication. Both patients were positive about the care they received while a patient on the ward. A patient had been discharged from St George's Hospital following treatment for a heart attack and discharge they struggled accessing the anti-coagulant medication they required. The medication they needed was a hospital prescribed drug, therefore their GP could not prescribe this for them when they ran low and they struggled to access medication they needed.

There were two experiences where the patient and/or family were shocked when their condition deteriorated or the patient passed away without the patient or family being informed of the risks that their condition presented.

Diabetes

There were 26 experiences relating to diabetes care since April 2018. 8 experiences were about care from their GP. A theme emerged that information and support needed improving at the pre-diabetic stage of the disease. A focus on prevention was not felt to be present and people expressed regret/anxiety about this. In one case a patient felt the out of borough GP they were registered at did not provide the necessary intervention they felt was needed when they were told they were pre-diabetic.

Once diagnosed with diabetes most patients felt well supported and had had good quality care. The one instance of poor diabetes care by a GP related to an administrative error in repeat prescription that meant a 3.5 week wait for insulin, this formed part of a wider complaint about poor care at this practice.

One person who was recently diagnosed with diabetes referred to the Richmond Wellbeing Service to get support for their mental wellbeing. They did not meet the criteria and were "told they were not unwell enough" to get support.

There were 6 experiences relating to diabetes community services, the care was spoken of very positively and this included diabetic specialist nurses, district nurses and podiatry. The patients value these services and they were happy with the support this gives them. The experiences also indicate that they were able access the services, for example booking podiatry appointments.

A person with diabetes found it difficult to find an affordable exercise class that was suitable for their medical history. There was a positive experience of 'MyTime Active' at St Mary's University. There was negative experience about 'Healthier You' at Richmond Adult College they did not feel it gave any information that was not available on the internet.

Experiences of the retinal screening at Teddington Memorial Hospital and Kingston Hospital described that it was hard to book appointments.

Two inpatient care experiences detailed the difficulty being a diabetic with food/drink in hospital.

Substance Misuse

Significant experiences from people with substance misuse have related to the difficulties of accessing mental health care (see Mental Health in Adults section 2.3)

Section 2.3: Mental Health in Adults

Sub sections:

- Depression
- SMI (crisis care)
- Links to perinatal mental health
- Parental Health issue of parents has effect on children's well being

Patient Experience

Between 2017 and 2019, Healthwatch Richmond spoke to 586 patients and carers about their experiences of mental health services. 55 came from patients and carers of Recovery and Support team (RST) service users and 110 from the Richmond Wellbeing Service. Among all the experience, 150 statements were relevant to crisis care, an issue of significant importance with around 1 in 4 of the people that we spoke to as part of our service reviews or outreach work raising it. <u>See all Mental Health Reports HERE</u>

Depression (<u>IAPT Report here</u>)

We found that for most people, the Richmond Wellbeing Service provided high-quality IAPT therapy that was in line with NICE recommendations for their needs.

People praised staff's ability to pace sessions appropriately and create supportive conditions to share their experiences. Those with long terms conditions were particularly happy about the service designing specific courses to help them cope with the concerns that came from living with a long term condition.

Nevertheless, issues were mentioned around access, limited upfront information on how the service runs and being triaged to the right level or type of treatment.

Crisis Care (<u>REPORT HERE</u>)

Overall, people told us that they struggled to access crisis care when they needed it. Many people experience problems with accessing care because of the thresholds for referral into services. This means that people approaching a crisis are unable to get help to avoid it escalating. An inevitable result of this is that more people will experience a crisis and that more of the people who do access care will have higher levels of need. Accessing care at an earlier stage would help many people approaching a crisis however, people who misuse substances continue to have particularly limited access to mental health care and crisis care (see next section for more).

The requirement for enhanced out of hours care was another strong theme emerging from the feedback. This was evident through the lack of services that people have access to out-of-hours, but also through the expectations placed on it and the feedback that people gave on the Mental Health Support Line (Crisis Line). The Mental health Support Line was viewed by 20 people as a caring service, but ultimately one that is not always responsive or able to provide the support necessary to meet the needs of people who use it. Conspicuous by its absence are NHS 111 or 999 and the need for a robust point of access for urgent mental health support. 1 in 5 people told us how GPs play a vital role in supporting many with mental health needs. The value of the care that they are able to provide both as professionals and as a service that can see people urgently, was clear from the patient's comments. Improvements to the environment and care provided in A&E during the lifetime of this project are likely to have a significant impact on the patients who present there.

Finally, it was clear from a third of our findings that during recovery, and to prevent relapse, people need support to rebuild their lives after a crisis. Where people get the support they need they talk about making meaningful changes to their lives to secure their recovery. Too many people however experienced difficulties with finding the support they need to better care for themselves.

It was clear that the newly emerging Social Prescribing service has a role in promoting wellbeing after a mental health crisis.

Perinatal Mental Health

We have 15 experiences of perinatal mental health with around half for care given during pregnancy and half for care given postnatally. Mental health support in the antenatal period was positively reported with timely access to support that was valued and helpful. Staff caring for this person at the time consistent and caring and the Bridge team of midwives at Kingston Hospital were particularly praised. Mental health support given after birth was more mixed. Some had a positive experience while others felt the specialist support they needed was not available to them as they lived in Richmond. Secondly the length of time support could be given was reduced compared to a previous area they had lived.

Health visitors provided support where they could but some felt the advice they gave was "misguided". Advice to eat steak was given when a new mother told her health visitor she was depressed. A second mother was told they could not take antidepressants due to breastfeeding her baby and were given no alternatives to help. They felt the health visitor was expecting her to "suck it up" and when she was given the tablets she was told to "take them at her own risk". They decided not to take them as they felt unable to weigh up the benefits and risk without guidance from a professional.

There were two experiences of being referred to the Richmond Wellbeing service after birth. One mother reported their therapy was cancelled several times due to either staff illness or the group size not being big enough to warrant running it. Over a period of 7 months, the patient told staff they were feeling increasingly desperate and needed more therapy or medical intervention. Unfortunately, they did not feel staff were responsive as they were only given basic self-care tips such as "have a long bath". This culminated in the patient ringing a crisis line saying they felt suicidal, where thankfully they received immediate intervention from the community mental health team the next day. The second experience reported the difficulty they had accessing help as they were not permitted to bring their 2 week old baby with them to the therapy session. Therefore they felt unable to engage with therapy as they were still breastfeeding and felt unable to leave their baby at that time.

Section 2.4: Substance misuse support for dual diagnosis (integrated care/treatment)

Service delivery and performance

Between 2017 and 2019, Healthwatch Richmond spoke to 586 patients and carers about their experiences, collecting 150 statements that were relevant to crisis care. Of those, 1 in 6 (25) highlighted difficulty accessing care, especially as a result of tight thresholds, even after being referred for support. The common theme within these experiences was around referrals not being accepted by a provider because of previous treatment, a pre-existing mental health condition or problems with substance misuse and addiction. [See <u>IAPT Report</u>, <u>Crisis Care report</u>]. It is notable that we believe these issues also relate to the Recovery & Support Team, however our methodology for the service review may not have included people who were unable to access the service and so we do not have such strong evidence of this.

People described gaps between services where they did not meet the threshold for one team, but are deemed too high risk for another service. Conflicting service thresholds are especially significant for people with dual diagnosis as it can be impossible for them to access care. In particular, six people reported that they were denied access to the Richmond Wellbeing Service (RWS), as a result of RWS's assessment that their use of alcohol or drugs was prohibitive to engaging with psychological therapies. One patient who significantly drank 2-3 times a week said that RWS had "put their own label on" this and consequently denied them access to treatment. Two other patients said it felt like they were being "fobbed off" and "we were someone else's

problem" because of substance misuse issues that they didn't believe should have prevented them from engaging with the service. Patients who had been turned away by the RWS also reported inconsistent messages and variation in referral thresholds for accessing the service. People who were using the same substance were told that they would need to demonstrate differing periods of stability or abstinence before they could be reconsidered.

Patients and professionals told us that they would also benefit from a publically available RWS policy on patients with substance misuse to ensure consistency of care and equal access.

Being denied access to services can be extremely detrimental for people and these issues can be clearly described through the experience of "Jane", who was admitted to hospital following a suicide attempt. On her discharge, the hospital referred Jane to community mental health services who assessed her and decided that they couldn't see her because of a substance misuse issue, which meant she did not meet the criteria for their service. Jane's GP referred her to a substance misuse service for help with this but they were not able to provide support because of a significant underlying mental health condition. For the final weeks of her life, Jane bounced back and forth between unsuccessful referrals and her GP.

Section 2.5: Violence against women and girls

Patient Experience

We are not aware of any experiences relating to this.

Section 2.6: Living with Disabilities

Sub section:

- Adults with Learning Disabilities
- Physical and Sensory Disabilities
- Links to SEND

Patient Experiences

Adults with Learning Disabilities

5 outreach sessions reaching 35 people with learning disabilities have highlighted some outstanding needs. Many of these are covered well by Mencap's Treat Me Well campaign and we are very supportive of the recommendations from this:

- People appreciate healthcare staff understanding and adapting to their needs including, speech impediments, motor skills, wheelchair users, difficulties in expressing their needs and feelings.
- Longer GP appointments remain important to ensure the above is explored appropriately. Some people expressed the importance of being talked through what is going to happen while others prefer not to. This highlights the importance of checking in with people and identifying their preferences.
- People find disability passports useful when presenting at the GP or at hospital appointments
- Autistic people expressed their difficulties in attending hospitals, especially A&E, which are noisy or have bright lights or strong smells. They often experience sensory overload and feel put off from visiting these environments, even when they need them. Reasonable adjustments such as quiet spaces would help with this.

- Counselling services are very important to some people with disabilities, to process feelings in a way that is tailored to their needs. Therapists and mental health services who understand disabilities are important.
- Independence is very important to people with disabilities however, during child-adult transitions people report struggling with having their needs fully met. Please see SEND section 1.6.
- Sexual health is important for many people but the taboo means that many people are not aware of the support available to them (e.g. CONNECT in Kingston).
- People find that paperwork is a big barrier to living independently. Third sector support is very important for this but not everyone is aware how they can get the right support.

Section 2.7: Homelessness and Rough sleepers

Patient experiences

We have 23 recent experiences of health and social care from those experiencing homelessness. Securing stable accommodation was an issue raised frequently and this has a significant impact on the ability of people to access support for their physical and mental health.

A major issue identified was concern over care for those with mental health problems (9 experiences). It is difficult for a person to successfully engage with the Home Treatment Team while homeless, it was suggested that appointments with this team should take place at local community centres to provide a location where mental health staff can meet with the patient for treatment. For these people, communication and coordination of care with the community mental health team was challenging. Additionally, accessing medication took longer due to not having no fixed address. There are also issues relating to accessing mental health services when a person has substance misuse problems that are a common barrier for homeless people.

Patients are often discharged to temporary accommodation, such as hostels and B&Bs, and this was cited as the cause of many relapses for people with mental health conditions. It is a particular challenge to those in crisis, as often they will be discharged from A&E back onto the streets as they do not meet the criteria to be sectioned. Unfortunately, this means they are not in a safe environment to recover.

There was concern from professionals and individuals that access to primary care was challenging for those who are homeless despite proof of address not being required for this. The Vineyard Community Centre has developed a strong relationship with The Vineyard Surgery (local GP surgery) so they can signpost clients there, and they allow them use the community centre's postal address to overcome this issue.

There were also problems accessing dentistry with most not registered with an NHS dentist. Many in the homeless community suffer from very poor dental and oral hygiene health and it is area that is neglected. Local solutions, probably through the Community Dental service, are necessary solutions as local dentists feel unable to meet the needs of patients with complex needs resulting from chaotic lifestyles and rough sleeping and will often not register homeless patients. Unfortunately there are barriers to accessing this service as it requires a referral is needed from a primary care dentist.

Section 3.1: Dementia prevention and care

Patient experience

We reviewed 75 experiences collected via community outreach from those with dementia, their carers/family members and also professionals who care for those with dementia.

We have 20 experiences of dementia care in hospital. We have also reviewed inpatient care at local hospitals and found, with a few exceptions that we believe have been addressed, inpatient care can meet people's needs. Staff reported strain in providing good care on a ward due to high numbers of dementia patients at West Middlesex Hospital. The experiences from patients/family members showed that some staff had a lack of awareness and did not understand the capacity of patients with dementia. Some felt there should be a way to visually identify patients with dementia, and the suggestion was a Forget-me-not bracelet. There were other challenges for dementia patients while on the ward. Disorganised or even chaotic care was reported at times on the ward. Carers also felt there was a further need to keep patient's active (both physically and mentally) during their inpatient stay. A lack of support for patients/carers following discharge was identified as a problem in the experiences. Irrespective of if dementia patients attended A&E or were inpatients there was still a reliance on carers for effective communication with staff and for carers to advocate for them.

There were 8 experiences of dementia care from GP services. There was only 1 experience that was negative and this was because the GP had "insensitively" given them their dementia diagnosis over the phone. Good care was provided by GPs who were sensitive and understanding to the individual's needs, and they were reactive in providing urgent care when it was necessary. A carer of those with advanced dementia described their difficulty in getting to their GP surgery as they do not have an accessible vehicle and the visit is unsettling, but they had to attend for the flu jab. They have struggled to get the flu jab to be administered by the district nurse during their daily visits, as the district nurse reports not having access to the vaccine.

Feedback from Clinical Dementia Specialists, highlighting the following issues: inconsistency in the quality of social workers for patients with dementia, a lack of information following diagnosis, a lack of support for carers and a lack of information on the criteria for accessing NHS Continuing Healthcare. The quality of support and information provided by the Richmond Memory Service was good but there was doubt about how easy it was to contact/access the service.

Other issues identified in the patient experiences were difficulties accessing assessments from the Occupation Therapy team. There were also delays with Adult Social Services in providing support. People who had gone through a social care assessment process would have welcomed more information about what would happen next.

For those receiving social care, carers did not arriving on time caused significant disruption to the person with dementia as a routine could not be kept. It also meant care needs could not always be met due to the short visits. The more negative experiences were from those ineligible for social care support despite feeling they needed help, and another person felt they needed to be in crisis before help was given. Carers/family members also struggled to coordinate different services and highlighted a lack of communication between services which meant each service did not take full responsibility for that patient.

Two experiences detailed issues with the procedure for applying DOLS (deprivation of liberty safeguards) for residents of sheltered accommodation schemes and residential/nursing homes. One person described that because DOLS was not yet in place they couldn't put up bed rails, which was essential to keeping that individual safe. The process of applying for DOLS was also described as "frightening and intrusive".

Carers of those with dementia felt they needed more support and were "left on their own" to cope. A carer needed more respite care to help them care for their spouse. They currently get this for a few hours once a month. Carers felt they lacked the information they needed to ensure their

'cared for' person had the necessary support. Despite being in regular contact with medical services, one carer was not told about the access team or the voluntary care support available in the borough.

Wider support in the community that was valued by those with dementia was Kew Garden Dementia walks for the peer support that this offered. The importance of peer support was echoed in others experiences. A person with dementia valued the use of apps to help them day-to-day, for example it was reassuring to them that they had 'Find my Friends' function on their iPhone so if they were to get lost or confused their family could find and help them.

Section 3.2: Social isolation and loneliness

Patient experience

We were unable to identify experiences to share relating to this but do recognise that isolation and loneliness plays a significant part in our signposting work.

Section 3.3: End of life care

Patient experience

We reviewed 25 experiences regarding End of Life Care.

End of Life Care could be improved by setting a clear and agreed care plan when the possibility of death is recognised. The patient's family members can then feel very burdened and responsible for helping with the patient's physical and emotional needs, and this does not leave them space to look after their own wellbeing.

Furthermore, this care plan is carried out efficiently and without delay, and services act in a coordinated way to deliver the best care for that individual. Any delays in accessing care can mean that the patient suffers a poorer quality of life in the final period of their lives, and it can also cause avoidable admissions to hospital. For example a carer could no longer lift the patient out of bed while waiting for changes to care plan the patient was admitted to Hospital with pressure sores due to extended periods in bed.

The main complaint about GPs in End of Life care were that they did not providing home visits and there was poor coordination of other community services. This would have been valuable to those having their end of life care at home.

Two experiences expressed concern over the quality of care provided by domiciliary care providers, which included carers not arriving on time which meant double up care could not be given, and carers not providing good personal care. This pushed one relative/friend to conclude that "the neglectful care contributed to their death".

Experiences around Hospital care indicates a need to improve the ability of clinical staff to recognise the possibility of death. There were a group of experiences from relatives expressing shock after their death of their loved one. For example, a spouse was advised to go home after their partner was admitted to hospital when they had been told their partner was currently stable. They then received a phone call at 5 am the following morning informing them their partner had a cardiac arrest and had died during the night.

The lack of recognition of how unwell the patient is can lead to inappropriate actions being taken in their care. In one experience the patient was not given palliative care until 3 days before their death, and this meant they were on a shared ward which gave the family no privacy at this difficult time. A very unwell patient had an unaccompanied hospital to hospital transfer in a taxi, they passed away a few days later and their family member felt the stress of this journey contributed to their death. One experience highlighted that hospital staff were not communicating effectively when a relative was towards the End of Life and what this meant for their care. An example was seen in an experience where the family did not understand why their relative was transferred to Teddington Memorial Hospital (TMH) for palliative care, and poor referral information had been given as staff at TMH were reportedly equally unclear why this referral had been made (i.e. they were told it was for rehabilitation).

There were three experiences of end of life care on NHS continuing healthcare. Two experiences highlight delays in getting equipment or changes in care packages while receiving this funding. Calls and emails went unanswered which meant they could not be responsive to the individual's evolving care needs. This made it challenging to provide good end of life care. The final experience explained how they were given little notice when NHS continuing Healthcare was reduced leaving some nursing care was not funded. The short notice period meant alternative funding arrangements were not arranged in time and the family had to pay these costs.

Section 3.4: Healthy aging (Falls, Fractures and Frailty)

Patient experience

We have 47 experiences from those who had suffered a fall or from their carer/family member. We heard how falls were being caused by an, sometimes undetected, infection that triggered delirium.

Patients who had a fall that necessitated a call to 999 and an ambulance being sent reported they experienced very long waiting times (~3 hours) for an ambulance to arrive.

Many people were positive about the care they received after being taken to hospital following a fall, they were provided with clear information about their injury and the necessary treatment. The problems that were identified were that if they had an extended inpatient ward there was not enough activity or entertainment available to elderly and frail patients. Inactivity and long periods in bed hindered their recovery and concern was raised by family members. Secondly, we heard of experiences of patients being discharged following a significant fall without the necessary reablement package put in place on their return home. Help with daily tasks at home is needed to keep this patient safe in their recovery, but referral to social care did not happen. Equally, a referral to the Richmond Response Rehabilitation Team was not always made, and a referral would ensure access to physiotherapy and occupational therapy as needed in recovery. There were long waits to get adaptations at home such a shower rails, stair handles and hoists.

Feedback about the Falls and Balance course run by HRHC was very positive, with patients finding that it was helpful and it made a difference to their physical health. We have had signposting requests asking whether this type of support existed, this suggests that people who would benefit from the service are not being referred for it.

We had contact from members of the community concerned for their elderly neighbours who have had multiple falls and appear to be becoming frailer. They asked for information about how to get support for their frail neighbour. They felt that the falls could have been avoided if support was offered earlier to a person who is at risk of falls. This suggests that the community is able to identify someone at need of support at home but they do not know how to get them help.

We had two experiences of the difficulty in caring for residents who are a fall risk in a care/nursing home environment. A care plan for one resident stated that they should be offered opportunity to walk with assistance and have a transfer to a chair, but this was not being done routinely. A dementia resident repeatedly got out of bed at night and would then fall, this posed a risk to their health but bed rails could not be placed without DOLS in place. From the care staff's perspective this meant that they could not keep this resident safe.

Section 4.1: Air quality

We do not hold this information

Section 4.2: Climate change

We do not hold this information

Section 4.3: Healthy neighbourhoods - creating sense of place to people's wellbeing

Sub sections

- Active Travel
- LINK TO Childhood Obesity and risk factors

We do not hold this information

Section 4.4: Healthy environments and physical assets including those promoting wellbeing e.g. libraries

Sub sections

- Parks
- obesogenic environment / out-of-home meals/food environment aspects: land use surveys and locations of hot food takeaway
- LINK TO Childhood Obesity and risk factors

We do not hold this information

Section 4.5: Healthy Communities- working with wider determinants

Patient experience

Supported by the Strategic Community Partnership Fund, we ran two events aimed at promoting mental health and signposting people to the right services. Through discussions with participants we gained a lot of information on how the wider determinants of health affect their mental wellbeing.

Determinants of Mental Health: 65+

Our Strawberry Tea party was aimed at 65+ (and/or their carers) with experience of mental health issues or an interest in it. This highlighted that to people building resilience is important and elements should be put in place to maintain it. Events such as loss, bereavement, health setbacks can affect their resilience, and this impacts their wellbeing negatively. People also spoke about

ageing as associated with a loss of confidence. Although they did not make specific remarks on the reasons, the focus was on how to access support to address this. People were aware that support is available but long waits for referrals made access to counselling difficult. Moreover, people mentioned that CBT can help readdress behavioural issues but they felt it is not effective for long-term depression and anxiety.

Positive views on Richmond's healthcare services were collected. Nonetheless, people spoke about long waits for face-to-face or phone GP appointments, which may negatively affect someone who is suffering with mental or physical health problems. Many people were aware of the possibility of going into a care home however, they had concerns with the associated fees. Those who already were a resident of a care home said that moving from independent living into a care home is very unsettling. Others who had visual impairments felt that staff in care homes have little understanding of the needs of people with visual problems.

In order to improve mental health for people over 65, people were asked what new services would be useful. Suggestions included: improving social connections, better access to mental health services, bereavement support, and services supporting independence at home in particular after hospitalisation. Better public transport and IT courses were also seen as enablers to independence.

Due to the physical changes and challenges that older people encounter, it was agreed that better access to physical therapies would ease pain and progression of common diseases like arthritis. Nutrition was also mentioned as important to prevent, reduce or manage pain and illness, indicating the need for a tailored dietician service. The availability of male workers would be appropriate to assist some older men who have this preference.

Wider determinants of Mental Health at work

Our event focused on promoting mental health in retail workplaces. This event was held as retail workers are often exposed to a fast paced environment, with tight deadlines and high competitiveness. These are known to negatively affect mental health, and therefore productivity. Speakers for our event shared data that highlighted how a third of the retail workforce consider themselves to be stressed and this leads to absenteeism, presenteeism or high turnover. Promoting mental health in retail workplaces makes sense and starts from teaching employers what would help their employees. In particular, mentally healthy workplaces involve tapping into all elements of Maslow's hierarchy of needs, and 8 steps:

- 1. Making a commitment
- 2. Building the approach
- 3. Positive culture
- 4. Support and training
- 5. Managing mental health
- 6. Providing the right support
- 7. Helping people recover
- 8. Going further

Spotting the signs of mental health problems is important in the workplace and people should be enabled to share how they really feel, in order to improve it.

Wider determinants of Mental Health and Crisis Care

Most local services are really good at meeting the needs of most of their patients. Some are struggling with workforce issues but despite the fact the individual services and staff work hard to provide good services the system doesn't always work for patients. For most people, at a certain point, the only thing that will prevent a crisis is getting prompt access to appropriate clinical services.

This means that we need services that are:

1. accessible 24 hours a days 7 days a week

- 2. provided in a comfortable environment
- 3. provided by compassionate staff who are able to access medical records
- 4. enable the first point of contact to coordinate care options to ensure that everyone gets the care they need when they need it and that no one falls through gaps between services

There are initiatives that may prevent people from reaching a crisis. Crisis cafes show potential and patients believe that they might work. Community groups create social networks and peer support. This reduces the isolation that exacerbates symptoms and makes seeking support more difficult. Having peers to speak to, can help people to access care sooner and avoid crisis. However, people believe these initiatives are underfunded and not provided out-of-hours.

After discharge, people want to get back to their lives. This is dependent on thei health but also the wider determinants of health: finances, welfare & benefits, driving, employment, housing, meaningful occupations, routine, purpose and leisure. Support groups and the voluntary sector can help people get back to their lives and can signpost to other sources of support. People sometimes experience gaps in care at discharge and sometimes they are lost in the system.

People's expectations are not always managed and this can lead to frustration, loss of faith and increase the likelihood of relapse.

Please see section 2.3 for more on crisis care and our full report.

Section 4.6: All Carers

See section 1.6 on some of the impacts of caring for children with SEND on their parents/carers. Secondly section 3.1 Dementia for the impact on carers of those with dementia.

We hold almost 700 carer experiences. These could be analysed however we would require a framework to analyse them against. The following issues however were identified and fed back to LBRuT as part of the Carers Strategy engagement work:

- Needing additional emotional support, someone to talk to about the challenges that they experience.
- Needing support in relation to specific challenges with services including
- Mental health services where the service does not have consent to provide confidential information about the patient. Carers often report challenges with supporting their cared for people to engage with the trust e.g. calling up to cancel an appointment but also in not knowing how best to care for the patient at home.
- Carers whose cared for people drop out of mental health trust services do not have access to mental health trust support and we typically refer them to the carers centre to pick up the slack.
- NHS Continuing Care there are challenges with this service but often the patients are most unwell and need significant help from carers to engage with the system.
- Social services. Some carers have shared experiences that would benefit from advocacy or complaints advocacy. We currently refer to Cambridge House where the advocacy service is commissioned. We don't have feedback about whether services are effective but have no reason to doubt their effectiveness
- Carers have sometimes experienced challenges with engaging with Council housing services on behalf of their cared for person.
- A need for financial and benefits advice (including council tax) for carers has come up in our feedback. this may be because people don't know where to start looking. We don't have feedback about whether services are effective but have no reason to doubt their effectiveness.
- Concerns about what will happen to their cared for person when they are unable to continue their caring role.
- Seeking additional support for their cared for person around wider determinants of health, NHS care or social care.

Section 4.7 Community voice

Patient Experience

Healthwatch Richmond carries out an extensive programme of community engagement in order to understand people's experiences of health and social care and be able to take action on what is important to the community. Since April 2019, we delivered 75 face-to-face outreach sessions targeting 4 demographic groups: under 21s, over 65s, working age population and disadvantaged and seldom heard. This map shows where we have been and which groups we have visited. In these sessions we spoke to 1007 people and collected 933 experiences of health and social care. We were able to provide signposting information on 144 occasions that answered queries and connected people with a service that can help them. Our database is, therefore, a rich resource to have insight into the community voice.

To determine our work plan for the upcoming year, an analysis of all the experiences collected in the preceding years is undertaken. This enables us to identify trends and see what is important to the community at that time.

From 2018/19, projects were undertaken in '<u>urgent and emergency care</u>' and '<u>inpatient care</u>' as they were high priorities for local people.

Urgent and emergency care

From the feedback we received regarding A&E, waiting times and unsympathetic reception staff were identified as the most common concerns. Clinical care was often praised, although this praise was not entirely universal with some patients speaking of their concerns of not being taken seriously. People said that if they were ill at the weekend and needed medical treatment, or if they could not get a GP appointment within a reasonable time - something several people reported - that they would either go to Teddington Memorial Hospital (TMH) or call 111. Feedback about TMH is largely positive with regards to the quality of care provided and it was clear from the feedback how much this local service was valued by Richmond residents.

Inpatient care

Inpatient care experiences highlighted, in some instances, poor quality care and problems with the communication between clinical staff and the patients. Another issue that was highlighted was noise and disturbances at night caused by other patients, patient transfers and from staff. Hygiene and ward environment issues were also a concern.

From experiences collected in 2019/20 the following areas were identified: GP (appointment booking), postnatal care and health visiting, transitions from Children's to Adult services and NHS Continuing Healthcare. Other areas identified for future activity is homelessness and access to primary care, dentistry(oral health) in care homes and annual Health Checks for those with a learning disability.

GP appointment booking

Appointment booking was the most common theme for GP experiences that were negative. The national GP survey supported our experiences that there was significant variation between the Borough's GP practice in the patient's experience of booking appointments.

Postnatal and Health Visiting

We collected poor experiences of postnatal wards that were described as "stressful", and staff who were "overstretched" which meant they were not able to help when needed. There were sometimes problems when new parents were transferred to community midwife care. Support offered by health visitors was not always individualized to that person and baby's individual needs.

Transitions from Children's to Adult services

Please see Section 1.6

NHS Continuing Healthcare

A significant number of negative experiences showed a strong need to review this area. Contested changes to care plans was a common theme in the experiences, and was usually accompanied with poor communication from Richmond CCG and difficulty in contacting them. An equally common theme was a lack of information/support with the application process. There were difficulties as agreed care plans were not delivered and promised funding was not received, and this was exacerbated by a lack of/slow response from Richmond CCG after queries or complaints were made.

Homelessness and access to primary care

There is an established need for homeless people to have improved access to primary care in Richmond. There were problems with registering with practices (both without proof of residence and on a temporary basis) and also in communicating with the practice (by phone and booking appointments via GP Online). See section 2.7.

Dentistry (oral health) in care homes

Our reviews of care homes in 2017/18 identified concerns from home managers about the ability of their residents to access to dentistry. The CQC report 'Smiling matters: oral health care in care homes' identified that residents were not always being supported to maintain and improve good oral health. The damaging effects of this are substantial and will impact our local community.

Annual Health Check for those with learning disability

Health inequality is stark for those with a learning disability. There is evidence of significant variation in the percentages of people with learning disabilities registered with GPs receiving a annual Health Check. People with Learning Disabilities and the organisations that support them have also told us that the services/support that they need to address lifestyle issues (e.g. Mainstream smoking cessation and weightloss services) are not accessible to people with learning disabilities.