



Community Voices

Conversations with North Kensington residents about their health and wellbeing September to December 2018





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Acknowledgements

We would like to thank the bereaved, survivors, local residents, community groups and faith groups across North Kensington for sharing their experiences and reflections. This work would not have been possible without their support and generosity in making time for the much valued conversations.

We would also like to thank Dr Oisin Brannick, Dr Meena Nathan and Dr Yasmin Razak for supporting these conversations and enabling these voices to be heard.



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Introduction

The fire at Grenfell Tower on June 14, 2017 had a devastating impact on many people. 72 people lost their lives; many others experienced trauma, loss and displacement.

The Grenfell Tower fire occurred in an area of huge social and cultural diversity. The area has a rich and vibrant history and is home to communities from many parts of the world, many of whom have profoundly shaped the character of the area. There is a strong sense of community, shaped by many factors including history, population density, migration and faith.

Since the fire the NHS has played a key role in meeting the immediate and evolving health needs of the community of North Kensington. To make sure we were delivering the right type of services in the right way carried out a number of community conversations between September and December 2018 with the bereaved, survivors, local residents and community and faith organisations.

What follows are stories and accounts of local residents told in their own words, demonstrating how they have been affected and the issues that are important to them. Giving voice is an important cornerstone of our engagement approach, and listening and acting on what we hear is critical. This work is a demonstrative example of that approach.

Patient narratives are now being used widely within the health service to facilitate the development of services and clinical knowledge and skills.

The evidence from the patient narratives has helped inform the development of West London CCG's Cultural Competence Framework and the Health and Wellbeing strategy for North Kensington.

Some of the key deliverables that are arising out of the development of the Health Partners Network of local community and faith groups will help us deliver messages and health information to their communities. The conversations also provide an insight into the journey of recovery and what actions we would need to take or contribute towards building greater resilience.

A common thread that emerged among the majority of conversations was that health services needed to better understand the role of culture in their treatment, as clinical services were not necessarily the most appropriate route. Giving the individual the ability to make a choice between a traditional NHS treatment and a more culturally appropriate form of care was seen as critical in empowering and building resilience for patients. Recognition that people grieve differently and heal differently, the role of faith and local support groups was seen as being critical. It is also important to say that many of the issues highlighted within the individual conversations on health services, housing etc have now been resolved.

The conversations provided a rich source of information about the relationship between an individual's culture and their values and how they deal with their health and approach to services.

This has led us to develop a number of recommendations that will be used to shape services being commissioned and our approach to building community resilience.

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What we wanted to do

We wanted “to capture the experience of patients post the fire to better understand the impact and relevance of our services.”

The aim was to collect stories and retell them so we could provide a deeper insight into individual lifestyle, culture, preferences and motivations and how they affected how people viewed and accessed services.

The decision was taken to start the interviews fifteen months after the fire as this was seen as a reasonable period in which to hear and learn of the experiences.

In depth structured conversations were carried out with a total of 60 individuals between September and December 2018. The 60 residents included individuals who were bereaved, survivors and local residents who were directly affected by the fire. Six bereaved and six survivors, 44 residents from Grenfell Walk and the surrounding area and two community advocates shared their experiences. They were from a wide age range that included young people, parents with young children (0-5 years), and people aged 40- 80. The conversations typically ranged from one to two hours in length with individuals and families at a place of their choice.

The participants came from a range of diverse cultural backgrounds. This included people from Morocco, Bangladesh, Syria, Somalia, Philippines, Eritrea, Sudan ,Iraq and the Caribbean.

People were invited to take part in the project through community groups, GPs, faith groups and third sector organisations. A discussion guide containing a list of key themes and topics was used to facilitate the conversations.

Written consent was obtained from all participants prior to the start of the conversation. Participants were given an information sheet that explained the project, how their feedback would be used and a commitment to confidentiality. They were also provided with contact details of the Engagement Lead and Programme Director should they wish to raise any issues after the interviews.



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What we heard

People shared their stories and real-life experiences in the conversations. The conversations were emotional. There was sorrow, pain and grief and anger. There was also hope.

People talked about their own pain and anxieties, but also about their concerns for their neighbours and people in their local community.

The issues and concerns highlighted in the conversations have been shared under different headings below. These have been supported by quotes from the participants to illustrate the point. The stories and quotes have been anonymised to protect the privacy of these individuals.

The findings from the conversations are structured under the following sections:

- _ Impact of the fire
- _ Culture and health behaviours
- _ Children and Young People
- _ Mental and Emotional Health
- _ Primary Care
- _ Self-Care



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Impact of the fire

The fire was a traumatic event which has had a great impact, both emotionally and physically on residents. Their experiences are set out in the following narratives using their words to describe their feelings.

Mrs A's story



Mrs A, 70 years old has lived in the area for over 30 years. She was woken up by her daughter on the night of the fire. The police came soon after and asked her to leave her flat. She

came out of her home and just stood there watching the fire from 1 am until about 5.30 am. She was in a state of shock and described how she felt and how the cladding and debris kept coming towards her. It was intense. She could not go back to her flat and was temporarily homeless. Fortunately, she had her children who lived in the area to look after her for the next three months.

The fire had affected her health. She talked about her eyes burning all the time. She was struggling with her breathing and was unable to sleep because of nightmares for several months after the fire. It took her almost one year before she could go out and do things socially. Her faith and religion was the biggest support during this period. She started volunteering in her church and helping other people. This gave her a purpose. Also, her GP had referred her for counselling sessions and dealt with other physical health issues.

Mrs A was very grateful to her GP for her support and for always being there when she needed their help. She said that they have done everything possible to help her. Despite all the help and support from her family, faith and NHS she was struggling on her recovery journey.

“I haven't moved forward in the last 15 months. I am still there. It is day to day, hour by hour coping. I haven't been sleeping properly. I often jump out of my bed in the middle of the night and pull the curtains to see the tower, which wasn't covered at the time. Sometimes I would find my face wet. I was crying and I didn't even know that the tears were running down my face. I didn't realise how traumatised I was. It is trauma really isn't it?”

Her journey to recovery continues.

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Mr J's story



J was 20 years old at the time of the fire. He was working as a driver and lived with his parents. He had lost relatives in the fire, including his cousin who was also his best friend.

J had to quit his job a few weeks after the fire because he couldn't concentrate on his work. He was having problems sleeping and became very anxious. He stopped going out of the house, stopped going to the gym and even avoided meeting friends. He started drinking to help him get through the day. This continued for a few months.

His family were very worried about him and constantly encouraged him to see his GP. J had initially refused to talk to his doctor. He did so eventually after almost eight months since the fire. His GP referred him for counselling therapy and also for gym sessions. The gym sessions helped him build his confidence and made him feel more positive. He also started going the mosque as this was the only place he got some peace.

All this helped him feel better and he felt a lot more positive and hopeful at the time of the interview.

"My GP is helping me a lot. She has referred me to a gym and it is helping me become stronger. I also have started praying a lot. I feel I get lot of answers to what has happened from God. Going to the gym has helped build my confidence."

His journey to recovery continues.

Mrs B's story



Mrs B is in her 70s and is a carer for her 80 year old husband, who is disabled and suffers from type 2 diabetes. They lost close family friends in the tragedy. The son of the family

that died was not in the Tower at the time of the fire and was on the telephone with them right until the fire took their lives. Mrs B and her family had heard the details of this conversation and were deeply disturbed by it.

Both Mrs and Mr B are non-English speakers. Mrs B was concerned about her husband as he was housebound. He was emotionally disturbed and struggling to control his diabetes. They both wanted information and advice in their mother tongue, but didn't have a computer and had no digital literacy. Mrs B didn't know about local services and where to access information and help because of her lack of English.

They were happy with their GP, but were not receiving any additional support to deal with the trauma caused by the fire.

Mrs B was also housebound because she was a carer and was unable to leave her husband alone. She would like to access some social and physical activities to get them out of the house and help them meet other people. She was happy to speak to someone about her emotional well-being if it was in her mother tongue. She didn't know how to get started.

Their journey to recovery continues.

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Mrs and Mr L's story



Mrs and Mr L, both in their 60's lived in close proximity to the tower and witnessed the fire from their flat. They appeared to be extremely traumatised by the incident. The council had boarded their window facing the tower a few weeks after the fire. As a result they did not get any daylight in their flat.

Mrs L was petrified of the dark. She was scared to go out of the house in the evenings because she had heard stories about spirits of the dead lurking in the alleyways. Mr L felt he constantly had a 'burning smell' around him. They both suffered from anxiety attacks.

"I can see shadows in my sitting room. I am scared of the dark. That is why I keep the lights on all the time. I am scared to go out in the evenings."

The couple were isolated and not engaged with any local services for almost a year after the fire. Furthermore, they had not received any NHS services or additional support to deal with the trauma because they were registered with a GP practice outside the borough. The locum doctor they saw on their visits failed to recognise their health needs and refer them to appropriate services.

The only support they had was from their church.

After one year they were contacted by a voluntary organisation through their church that subsequently referred the couple to NHS services. The voluntary organisation also put them in touch with local activities and groups for the elderly.

Mr L received counselling therapy from the NHS for almost three months. He found this extremely beneficial. It helped him cope with the situation and helped build his confidence. The therapist asked him to keep a diary and got him involved in painting therapy, which he found very helpful. He was very positive about the service he received. The therapist was friendly and supportive, and Mr L appreciated the fact that he could contact them for support at any point, which reassured him. **"Before they came I was down and was struggling. They gave me things to do. I was asked to write down things and I found that helpful. It made me stronger. It took my mind away from the fire. I focused on what the therapist was telling me to do."**

Mrs L was still unsure about accessing mental health services at the time of the conversation. She said she would prefer to be involved in activities and do things in her community to keep her busy. Both Mrs and Mr L continued to be involved in their church and the activities provided by community and voluntary sector groups.

Their journey to recovery continues.

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Mr I's story



Mr I, 67 years old, has lived with his family in the North Kensington area for over 30 years. He and his family lost their close friends in the fire, and his entire family was traumatised and affected by the tragedy. He talked about his mixed emotions of sadness and shock, but also of anger and frustration because of the situation. He had to take time off work and had not worked for 14 months since the fire. He used to be physically active and went to the gym regularly but had lost all interest in going out and felt lethargic after the fire.

There were a number of other factors that had exacerbated his anxiety and stress. The on-going national inquiry was not helping him move forward because it was a constant reminder of past events. All of this was taking a toll on his emotional well-being.

Mr I had been in regular contact with his GP after the fire, but had not considered talking about emotional issues with them. His perception was that the GP was only there for physical health problems, so he didn't talk to his GP about his state of mind and emotional well-being. As a result there was a delay in referring him to services. He eventually had his assessment and received therapy on a regular basis. He found the mental health support extremely helpful. He said, **"The therapist listened to me patiently. I had a chance to share my innermost feelings with my therapist, which helped me to come to terms with the tragedy."**

He strongly believed that his well-being and recovery was closely linked to the well-being of his family. He was concerned about the emotional impact of the tragedy on his children and grandchildren. He was praying for their recovery.

His recovery journey continues.

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Miss G's story



Miss G had been living in a hotel since the fire and was waiting to be rehoused. However the process was taking a long time and she wasn't happy with

the support she had received from her keyworker. She was isolated in the hotel and spent most of her time by herself in the hotel room. She did have a few friends, but she felt too depressed to go out with them.

She was experiencing problems sleeping and talked about 'the hurt in her heart'. She felt that her stress was exacerbated because of the problems she was having with her housing and solicitor. It was 15 months since the fire and she was still waiting for housing to be sorted. She wanted to go to the church as she was hoping her faith would help her deal with the situation, but she struggled to deal with the crowds. She was afraid of the noise and people.

"I can't face too many people. I want peace and quiet to pray."

Her GP referred her for counselling services. She attended six sessions, but decided to stop because she couldn't cope with the constant questions from the therapist. **"She (therapist) is always asking me if I was dreaming and what I was dreaming. She asked me once, then again and again, the same questions every time I saw her. I was so confused. She was not helping me, so I stopped going to her."**

It emerged during the conversation that she hadn't eaten or cooked her own cultural food for over a year. She was in a hotel and was eating only hotel and processed food. She smiled for the first time in the interview at the thought of being able to eat her cultural food.

"I would love to be able to cook my own food. This will make me relax. I haven't eaten my own food for over a year. I miss it."

She was feeling very down and sad at the time of the interview. She was aware of her trauma and felt that it had become worse in the last few months. The only person she trusted was her GP.

Her recovery journey continues.

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Mrs R's story



Mrs R and her teenage daughter had recently shifted to temporary accommodation after living in a hotel for the past 11 months. She was experiencing problems sorting out her housing with the council, which appeared to exacerbate her anxiety and depression.

"I have been through so much after the fire dealing with the housing and council. And I have a sick child. She has now got asthma."

Her daughter was traumatised by the fire because she had lost her childhood friend in the tragedy. The situation was made worse because they were displaced, which made her lose her sense of belonging and her routine. Her daughter was receiving mental health support.

Mrs R was experiencing panic attacks and mood swings. She was feeling lethargic because of her weight gain, due to the hotel food and lack of exercise for almost a year. She was worried about her child and felt overwhelmed by everything she had to deal with. **"I am only thinking about my daughter. I am dealing with so much stress. I can't explain it. Sometimes I am happy, sometimes I am very down. There is so much going on. In order for us to go forward they have to sort out our housing."**

Her GP referred her to the mental health service, but she stopped seeing her therapist after a few sessions because she didn't feel comfortable with her. **"I saw the therapist a few times but I wasn't feeling comfortable with her. She would look at the watch and it felt that she was waiting for the session to finish. You know, I just didn't feel comfortable and I didn't want to go back."** She was subsequently seen by another therapist for a few months and was also offered Talking Therapy, which she found very helpful.

Mrs R was very happy with her GP and felt she could speak with her about any issues related to herself and her daughter. Her GP had referred her daughter for various activities, but the problem was that there was no one to take her daughter to them. **"One of the things that you need to be ready for if you are to self-care, is to have a social network that helps support you to do the activities. I am a single mother and work long hours. I need practical support to take my daughter to activities."**

She was getting the necessary health support at the time, but she felt strongly that her recovery was directly linked to her housing situation.

"In order for me to move forward I need to first sort out my housing. They are stressing me so much for the last year that it is making me feel worse. Our health is not getting better. In fact I am getting stressed. I am getting depressed and scared. I can't even explain it."

Her recovery journey continues.

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Mrs S's story



Mrs S is in her early 30s. She is a single parent and lives with her children who are seven and nine years old. She arrived as a refugee from Syria four years ago. She lives in a

flat opposite the tower. She and her children watched the fire all night. She even took a video of the fire to share with her relatives in Syria. Mrs S didn't realise the seriousness of the situation at the time and was shocked to hear about the fatalities the next day. She couldn't believe that something like this could have happened in England.

The family got back to some kind of routine the week following the fire. They did not know anyone in the tower, but the two children had witnessed the fire and one of her son's class mates had died. She didn't think this would have an impact of her children as they were both very young. After a few months her older son started getting nightmares; he couldn't sleep at night and became very clingy. This bothered her, but she couldn't understand why this was happening. She didn't know who to speak to about this matter. She also didn't speak English, so this made it more difficult to access the right help. She kept praying to Allah to make her child feel better.

Her child's school contacted her after a few months to discuss his behaviour. This came as a complete surprise as she was totally unaware of how her child was behaving at school and the things he was talking about. The school arranged for the child to see a therapist, which really helped him with his nightmares and sleep. The therapist was from the same cultural background which helped both the child and the mother.

"I was contacted by my son's school about his behaviour. I was shocked to find out from the school about the things my son was saying about the fire. I thought he wasn't capable of such a reaction because he was only 7 years old. I thought children this age don't get affected like adults do. As a mother I thought I was doing OK. I didn't realise all this going on inside him. The school helped a lot. There was an Arabic speaking lady helping my child. Even my son doesn't speak English well, so it was good to have someone he could communicate with in his own language. The lady speaks to my son in Arabic. She has helped him a lot. Even I am seeing a therapist now. She speaks Arabic. I feel much better."

Her son is still receiving support and had made good progress.

The family's journey to recovery continues.

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Mrs Z's story



Mrs Z is a long term resident in North Kensington. She has three children between the ages of 15-20 years. She lost her best friend in the fire, which had a devastating impact on her emotionally. Her condition was further exacerbated because of the emotional state of her three children.

“My life changed completely. Everything has stopped. I don’t feel happy. I am always tired. I can’t be bothered to do anything. I have started to forget things. It has also affected my children. They suffer depression.”

She had to sign off work because of her health and state of mind. She and her children just stayed indoors.

She was referred for counselling by her GP, but she stopped attending the sessions because of the problems she experienced with the service. There was a mix up with her appointments initially, which she interpreted as the NHS not taking her seriously. She then started seeing a therapist, but struggled to build a rapport with her, and as a result was unable to trust her.

“I made an appointment with the NHS. The lady didn’t turn up. She didn’t call me. I asked someone to call the NHS on my behalf. They called the office to find out and they said that counsellor was off sick. Two weeks later the same counsellor called me saying she was sorry she couldn’t call me because she was so busy.

So her office told me she is off sick and she is telling me she was so busy. She asked me if I wanted to make another appointment, but I said no. I don’t trust her no more.”

Mrs Z's children were being supported by CAMHS. She was very happy with the support her children were receiving from the CAMHS therapist. Mrs Z approached the CAMHS therapist to discuss her own situation. The therapist put Mrs Z in touch with a community based therapy service. Mrs Z found this very helpful, as she formed an instant connection with the therapist. She was from her own cultural background which made it possible for Mrs Z to talk about her feelings and emotions in her mother tongue. **“My psychologist is so good. I used to forget all my other appointments, but I never forget to see her every Monday. She understands me. I can share my innermost feelings with her. At the end of the sessions she always asks me if I want to hear the Quran or if I want to hear music. It is so relaxing. I look forward to seeing my psychologist. She is exceptional.”**

Mrs Z was very happy with her GP. **“I feel she is part of my family. She is my GP and she cares for me. She has helped me and my family a lot.”**

Their recovery journey continues.

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Mrs D's story



Mrs D, in her 40s, is a single parent who lived with her 17 year old daughter in a flat opposite the tower. They had to be moved to a hotel because of the fire.

The fire had a huge impact on their lives. Her daughter failed her exams that year and became very depressed. Mrs D's health condition also suffered. She developed high sugar and cholesterol levels which she attributed to the hotel food and stress caused by the tragedy.

The delay in getting her housing sorted was causing her lots of stress. She was getting no support from her key worker. **"My key worker was like a postman. She just came and gave me letters and told me this and this. She didn't do anything for me."** They were looking forward to getting into a routine in their own home and starting to rebuild their lives. **"I want to have my own place and settle. I want to be able to wake up in the morning and make my own coffee, take my daughter to school. Bring my aunty home, cook for her. Doing these things will make me feel better."**

She felt well supported by the NHS and was positive about her experience of using NHS services. She was very happy with her therapist and her sessions were helping her cope with the trauma and pain. **"I feel my therapist understands me. I can shout, scream and cry in front of her. I feel comfortable with her. She can feel me. Sometimes she cries with me. She understands my pain."**

She was also referred to the gym on Kensington High Street, but it was a mixed gym, so they didn't go.

She said recovery was a long and painful process. The following activities and services would help her and her daughter in their recovery journey:

- _ Housing issues being sorted
- _ A good therapist who understands them
- _ Somewhere to do gentle exercises and physical activities, as they were stuck in the hotel room for long periods of time
- _ Women-only exercise classes.
- _ Massage and exercise

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Mrs Q's story



Mrs Q lived close to the tower with her husband and three children aged 19, 18 and 9. She was very close to one of the deceased families who lost their lives in the fire, and used to babysit for the family when the children were younger. The friendship continued over the last decade, and the ladies continued to meet every Friday for a coffee and chat.

The fire had a tremendous impact on her entire family and Mrs Q was extremely worried about the impact of the fire on her three children. Her 9 year old couldn't sleep at night because of nightmares and panic attacks. The child was terrified and scared that there may be a fire in their house. She insisted on switching the fridge off every night because the fire in the tower started from the fridge.

Her 18 year old son refused to talk to anyone about his feelings. He was putting up a brave front because he didn't want to worry his parents. But Mrs Q noticed that her son had become short tempered, agitated and stopped going out to meet his friends. He was doing his GCSEs at the time, but couldn't take his exams because of the fire as he was on the site all day. He refused counselling as he said he didn't want to talk to anyone about his feelings.

Mrs Q was experiencing a lot of emotional issues. She was very distressed at losing her best friend. She was also very afraid to use any electrical gadgets at home because she was

terrified at the prospect of a fire and harm to her children. She used to work as a child minder but she had to stop this work because of the trauma of the fire. This has resulted in a loss of income which has contributed to her stress. Her biggest worry was the well-being of her children which she felt took priority over her own health.

Mrs Q was not interested in seeing a counsellor even though her GP was insisting she seek help. Her emotional needs were not a priority for her and her main concern was for her children and their well-being. **"I am a mother and my only interest is my children."** However, she said she would consider seeing a therapist if it was offered in her GP practice. In the meantime, she got her strength from her faith and read the Quran with her children, which provided them with solace and strength.

"I am living on a day to day basis. I can't think what services and activities would help me. My main concern is my children's health. I know that if my children are happy then it will ease my stress."

She was positive about the support her daughter had received from the GP and her school. The child was offered art therapy at school, which seemed to have a positive impact, as she built trust with the therapist and opened up to her. The child told her mother, **"Mum I can draw whatever I feel. It is helping me a lot. I can talk to her and she understands what I feel."**

Their recovery journey continues.

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Ms Y and family – their story



Ms Y lost her sister, brother in law and two nieces in the fire. She became the primary carer of the child who had survived the fire. Ms Y lives in the area with her elderly mother, but had taken a year off work to deal with health issues. She rated her physical health as being good, but hadn't really had time for herself as she has been looking after her niece and her mother since the fire.

She was very positive about the services and support she had received after the tragedy which helped her cope initially, and the support from the hospital was very helpful in dealing with the bereavement. The bereavement counselling provided by the hospital was culturally sensitive and took into account religious and cultural considerations without them having to even mention it. **"They were very aware of our religion even without me having to tell them anything. They did draw religion in it even before I had asked them. It was nice they had already included that in the script without me having to instigate that."**

She added, **"They also brought a Muslim chaplain and she was very helpful as well especially when it came to my mum. The chaplain spoke Arabic, so my mum could express her feelings and emotions. This was all in the hospital. They were absolutely brilliant. They had a huge understanding of people's religion, ethics."**

Ms Y also received support from a voluntary organisation to help her deal with the child's trauma. She found them to be accessible, friendly and available at very short notice. **"They told me what their child was going through and helped me deal with her emotions and feelings. That gave me the confidence that I could look after her and do the right thing."**

Ms Y was positive about the support she and her family had received from her GP. She appreciated the extra appointment time that was offered to Grenfell patients. She found the massage therapy offered at her GP practice very therapeutic as it helped her deal with the stress of the situation. **"It was a break from the daily rush and routine. It gave me a break and a chance to relax."**

Her GP had arranged for her elderly mother to see an Arabic speaking therapist. Her mother found it helpful up to a point, but she stopped the service after two months because she didn't feel she was getting anything more for from it. **"It has been very difficult for my mother. She lost her daughter in front of her eyes. She needs time to come to terms with it. She felt she had said all that she could to the therapist and she had nothing more to share."**

Ms Y had not taken up the counselling offer because she didn't feel the need for it. She said she would consider it in the future, but it wasn't something she felt she needed at this time.

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Culture and behaviours

How people deal with their health depends on their individual culture as this shapes their values and beliefs. Cultural beliefs about their health affect how people think and feel about their health and how they respond to health messages. All cultures have systems of health beliefs to explain what causes illness, how it can be treated and who should be involved in the process.

The insights from the community conversations clearly show the vast influence of culture on people's behaviours to their own health. Culture appears to have affected their perceptions of health, illness and death, and how pain is experienced and expressed, where patients seek help, and the types of treatment patients prefer.

Culture also appears to have significantly influenced the way people experienced loss and grief. The language used by many people to describe their grief focused more on their emotions and their feelings. They talked about a hurt and sadness in their heart and did not associate this with their mind where in their culture feelings reside rather than in the mind. It meant they could not relate to the western therapies

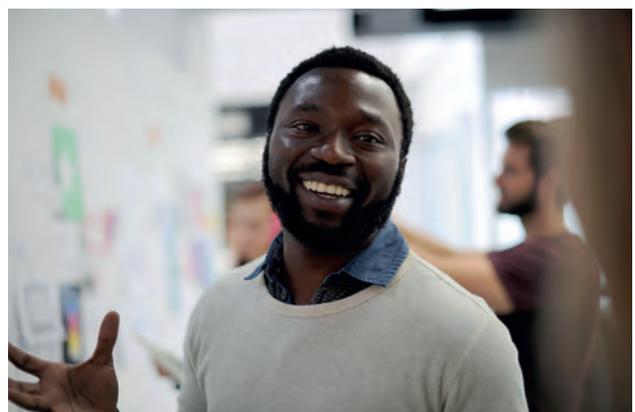
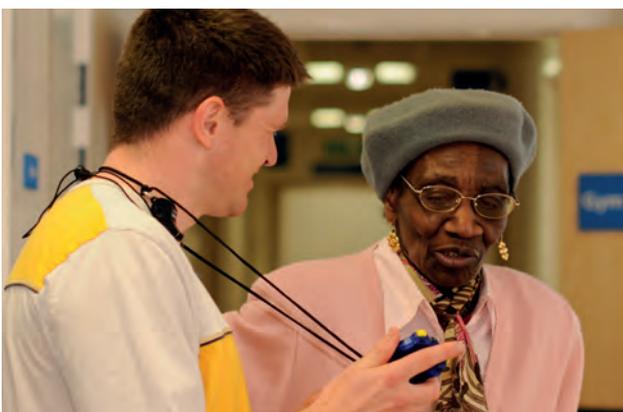
that focused on treating the mind and this had an impact on what they thought about NHS services and their willingness to use them.

"I am in pain and it is hurting in my heart. The only thing that will help me is if there is any medication to help me forget what happened."

"We are people of the heart because the heart is everything. Quran mentions that the creation of the heart was first. Mind was created later. It is the heart that needs healing."

"She (therapist) always asking me if I was dreaming, what I was dreaming? She me asked once, then again and again. Same questions every time I saw her. I was so confused. She was not helping me, so I stopped going to her."

The consequence of this was that a number of individuals either chose not to engage with the services, or where they engaged they did not complete their treatment plan. In cases where the patient and health professional were of the same culture, a good outcome was secured for the individual.



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Health literacy, which is the ability to access, understand, and use health information and services, was a key issue that had an impact on people's health outcomes. There were many cases where people had experienced difficulties in obtaining, understanding and acting on health information that was provided.

As a result therapies like Cognitive Behaviour Therapy (CBT) were not effective because of the way they were structured and required people to have a certain level of literacy and health literacy to engage.

“The lady gave me homework to do. I was so confused. I didn't know what to write. So I asked my son to write for me. But after one week I was more confused about what was happening. It didn't make sense, so I stopped going.”

Mental health has a stigma associated with it and carries different weight in different communities and because of this many people choose not to access these services.

“The lady at the reception gave me a form and it said mental health form. I said my children are not mental; they are having problems sleeping

at night. But the lady said you have to fill the form because it is mental health. This freaked me out. I thought my children will be treated like mental patients. So I took my children and ran away from the reception. I didn't go back. My children are not mental.”

“I was diagnosed with PTSD after an initial assessment. I did a few sessions at St Charles, but then stopped going because I didn't want to be seen by other people from my community as being mental. Once I was sitting in the waiting room and someone I knew recognised me and asked me what was wrong with me. People talk and I didn't want people to say I was mentally ill.”

The conversations showed the challenges for older people from an ethnic minority background, even if they have been settled in the UK for a number of years, around accessibility through language and very poor IT literacy. This was made worse because they did not think they should seek help from their GP about emotional and mental health issues because in their culture such issues are dealt with by a religious scholar or faith leader.



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There was a common perception that GPs were there to deal with physical health.

“It is not usual that you go to the GP to talk about emotions. To me they are there to deal with physical health. I never thought they (GPs) would care for this sort of things.”

“I was seeing my GP regularly, but I didn’t want to share my emotions and feelings with them. This was very private. I thought I had to deal with this on my own.”

One aspect of culture (religion) being seen as a health provision in itself was demonstrated by the comments that people made.

“I am a Christian and I have been praying a lot. This has helped me become stronger. It has helped me a lot. I try and go to the church every week.”

“I would go the church and sit there for hours. It helped me concentrate more on other people’s pain. It helped me focus and gave me strength. I realised that helping others was making me feel better.”



“I was feeling hopeless and didn’t know what to do. I started going to the mosque every day. I was asking Allah for guidance because I know he always shows the way.”

“I am a single parent. Both my children are suffering emotionally because of the fire. I read the Quran with my children. This gives us all strength.”

Another example of culture as a health provision is communal grieving.

“In Africa we talk in stories. It is how it is done in our culture. Stories can be very powerful to educate people, inform them and also engage them in their own health. It is very different to what happens in the West. It is much easier to change behaviour because it is more acceptable if it comes from within our community.”

Cultural appropriateness was a theme that also emerged very strongly in relation to mental health services. These issues are identified under the section on mental health.



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Children and Young People

The conversations with parents and carers about their children demonstrated the difficulties and challenges they faced in understanding behaviour changes and the most appropriate method of securing help and support, but also the impact on parents.

Parents were concerned that their children were not their usual selves and were quiet and low, and this was impacting how they behaved at their primary school. Children discussed the fire in school and often came back home asking parents questions related to the tragedy. One of the key worries the children living near the tower had was whether the tower would fall on their homes. Parents believed that the younger children were deeply impacted but this was not visible in most cases. They were worried that it was only a matter of time when these fears and anxieties experienced by children would manifest itself in their behaviour.

Some parents got support from the local nursery staff. They helped them recognise the trauma and urged them to speak to the GP about their children's behaviour.

“My 8 year old child gets panic attacks. She lost her friends in the fire. She waits for us to go to sleep at night and then switches off all the plugs in the house. She insists on switching the fridge off because the fire started from the fridge. She started bed wetting, but didn't tell anyone because she was embarrassed. I can't sleep at night because I worry so much about my child.”

Parents had observed a change in behaviour of their older children (teenagers) and assumed that this was a delayed response to the fire.

Parents felt that there was an increase in exclusions of boys from secondary schools because of their aggressive and disruptive behaviours which they felt was triggered by their response to the fire. Parents were most concerned that some schools were not trying to understand the underlying reasons for such behaviour and that there was a lack of adequate support.

“This is a posh school. There are not many children in this school from the poor area. The school did not understand trauma. The school head refused to support me. A week later my son's tutor gave my son a number to call. That is when I contacted the Child and Adolescent Mental Health Service (CAMHS). They were brilliant.”

There was a feeling expressed that children of survivors were offered a better service than families and children who lived in the area surrounding the tower. Parents said they have had to step up emotionally to support the children where the schools had failed. However, they were finding this difficult to do as they did not know the best way to support their child in these exceptional circumstances. Parents were looking for guidance and support on trauma and behaviours to be able to help their children.

The biggest concern for the older age group was that many young people between the ages of 16-20 had refused to access any help from health professionals or even talk to their GP about their feelings and wellbeing.

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“My son has not talked about the fire, but I know he watched the fire continuously on YouTube. His school has not offered any help. On the contrary the principal has given warnings for his behaviour. I had requested the principal to consider providing support, but he said, your son is a teenager and this is a typical teenage behaviour. It is the hormones.”

“My daughter is 18 years old and has refused all help. She refuses to speak to anyone about the fire. She lost her best friend in the tower. But she just doesn’t want to talk to anyone. Her school and GP tried very hard. She gets very angry with me for trying to help her. This really depresses me. How can I feel good knowing what she is going through?”

“My 16 year old just shut down in the first year after the fire. He just wouldn’t talk about it. He lost his close friend. I really didn’t know what to do. He just suffered in silence, but I could see he had become more impatient and angry at home. I felt so helpless.”

“My son loves to spend time with me. He helps a lot at home, but when it comes to talk about his feelings he doesn’t. He says mum you have enough on your plate. He is very close to his father, but still he doesn’t share anything even with his dad.”



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Emotional wellbeing and mental health

There were two broad themes that emerged from the conversations regarding access and experience of mental health services:

- The personal and cultural factors which influenced people’s decision on whether to access services.
- The relationship between the service user and healthcare provider such as long waiting times for initial assessment, language barriers, poor communication between service users and providers, and inadequate recognition or response to their mental health needs.

Cultural factors appeared to influence people’s attitudes and expectations of services. People were positive about their experience of the service when it was culturally appropriate.

“I spoke to this therapist in Arabic. She was very kind and understood my feelings. I could express how I felt emotionally about my daughters. I could share my feelings in my language. I could see that she (therapist) could feel my pain. I told her everything in my heart.”

This experience changed from positive to negative when the therapist left and was replaced by a therapist who did not speak Arabic and used interpreters.

“The main thing is the culture. I can feel that he (English therapist) does not feel what I am feeling because he is not from our culture. He was very nice and friendly, but there was no connection emotionally, so I stopped the sessions.”

It appears that whilst the gender of the clinician was not a barrier; it was the language and culture which influenced people’s decision, in some cases, to continue with the service. They felt it took much longer using interpreters and it did not sufficiently allow them to express their feelings.

One of the key issues that emerged from the conversations was that people did not understand what was being offered and the rationale for the service. This was particularly an issue for ethnic minority people using the service.

“My child was getting help in school from a therapist. She was very good and helping my child a lot. My child was having bad dreams and couldn’t sleep at night. She told him to think of superman and batman every time he felt scared and that they would protect him. This really confused me. Because in my faith we believe that it is only Allah who will protect us. What the therapist was saying was completely against my religious beliefs. I almost stopped the therapy, but the therapist saw I was uncomfortable and explained to me what she was doing. She changed her narrative after our conversation. I was happy.”

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Alongside these there were also examples of positive experiences of mental health services.

“We both speak English and she understands me. I can shout, scream and cry in front of her. I feel comfortable with her. She can feel me. Sometimes she cries with me. She understands my pain.”

“He is the only person I can share my innermost feelings with, something I haven’t been able to do even with my wife. “He is the one person on this planet who knows what I am going through. I don’t know if this is helping me, but it has stopped me from getting worse.”

“Before the NHS came I was down and struggling. They gave me things to do. I was asked to write down things and I found this helpful. It made me stronger. It took my mind away from the fire. I focused on what the therapist was telling me to do. They even referred me to Open Age when the therapy finished. It was Open Age

that stepped in to provide on-going support. I go there because it gives me something to do. I need to keep myself occupied so that I don’t think of the fire.”

Child and adolescent mental health services (CAMHS) was regarded highly by parents who were very positive about the services and support provided. The therapists were described as being friendly, understanding and helpful.

“The therapist is wonderful. My child built trust with her and opened up. I could notice a change in my child’s behaviour. He started talking more openly. He said, mum I can draw whatever I feel. It is helping me a lot. I can talk to her and she understands what I feel.”

“What is good about the therapist working with my child is that she is gentle and works at the same pace as my child. She is not pushy and really understands what my child feels.”



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Primary care

Overall people spoke very positively about their GPs and the support they received from them after the fire.

“I felt very good and elated when I got a message from my GP after the fire. I felt there was someone looking out for me. I am very happy with my GP practice. Everything that could be done was done. I was well looked after by my GP.”

“My GP is there whenever I need her. She has done her best to support me and my family. She has referred me to get counselling. She has referred my child to a specialist. But most important is that she listens to me.”

However, people reported a difference in the quality and type of support provided to patients affected by the fire across GP practices in the North Kensington area.

Concerns were also raised that locum doctors did not understand the impact of the tragedy and were not offering the same level of support.

Self-care

The concept of self-care and people taking responsibility for their health was challenging for people. Self-care was seen as a low priority and people did not recognise that it could help their condition.

One of the consequences of the fire was a drop in the level of personal resilience and individual motivation. This had made many people feel depressed and disinterested in the activities they had done before the fire. People talked about stopping going to the gym and not having the energy to do anything.

“The fire has caused lot of people to be lethargic. They don’t know where to turn, what to do and how to start again. They don’t have the motivation to get out and about.”

“We are living on a day to day basis; unable to think about what activities or services would make me feel better.”

“I can’t feel good or think about myself until my children are OK. I have three children. All of them are seeing counsellors. My stress will go only after they feel happy.”

“It is not easy to motivate myself. I really have to push myself. At least I have my family around me. I know so many old people who live alone. They are the ones who need support. The more activities we have the better it is for them.”

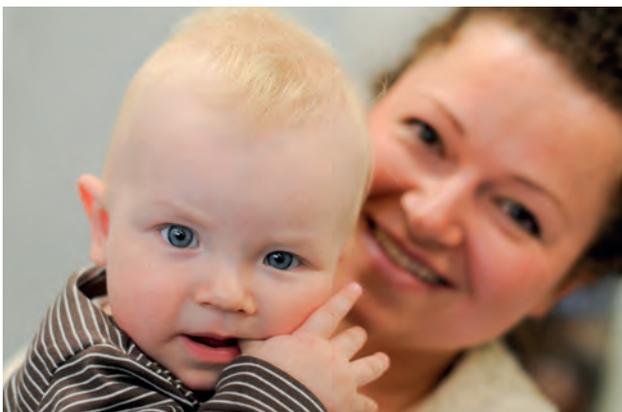
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A number of people said that the community should take the lead on the provision of activities as opposed to the NHS. The need for activities to understand cultural nuances and incorporate this in the future was seen as critical in encouraging more people to look after themselves.

“My husband has diabetes. He is very isolated and does no physical activities. We can’t go out much because he is disabled, also we don’t know about local activities. We are struggling to manage his diabetes as we do not know how to do this. For him it is very difficult to express health concerns and feelings properly via interpreters.”

“The NHS could make swimming and such activities available for people my mother’s age. But they would also need to support them initially. It is difficult for people to start doing things on their own if they haven’t done such things before in their life. It would be nice if somebody could take her there as my mother would never have the confidence to go on her own.”

Views were expressed that self-organised groups should be supported so they could offer culturally appropriate activities rather than rely on the statutory sector providing them, as this was a powerful way to build community resilience. The talking and sharing of idea and issues generated a sense of belonging and worth. This was seen to provide purpose.



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How the conversations have influenced our work

It was inspiring to see that people were willing to share their personal insights to alleviate others' pain and help in any way they could to rebuild their community.

It was evident from the conversations that cultural issues and health literacy were key barriers for many Black and Minority Ethnic Groups (BME) and this was a reason given for many BME people not engaging with mental health services. What also emerged from the conversations were that older people and some first generation residents did not consider seeking help from their GP about emotional and mental health issues, because in their culture such issues were dealt with by a religious scholar or faith leader. The conversations also highlighted the key challenges in providing services and support for children and young people. The need for community based and culturally appropriate activities was identified as a way for local residents to improve their wellbeing.

The conversations have provided evidence that has helped to shape and influence a range of actions that should impact positively on the residents of North Kensington. The insights will guide and inform our approach to designing and delivering care as set out in our Health and Wellbeing Strategy.

The difficult and complex challenge is to incorporate culture and behaviour into all aspects of our work. This is in recognition that inequalities in health are also a major contributor to preventing individuals from taking greater responsibility for their health. We need to link our work on Health Inequalities with our work on Culture and behaviour to get better health outcomes for our diverse communities.

We are developing a number of work streams that will contribute towards the achievement of our goals. The conversations have contributed in the development of the Cultural Competence Framework being produced by West London CCG to ensure that the services commissioned for North Kensington are culturally appropriate.

This has been a huge learning exercise for all of us and we will continue to work with a range of our partners. It is proposed that we scope the need to have a further set of conversations to assess how far we have travelled.

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Recommendations

The aim of this project was to have in-depth conversations with people who had been affected by the Grenfell tragedy and to assess their experiences of services delivered and what would be needed as the community and the NHS moves forward.

This has led to the development to a set of recommendations as set out below.

Recommendations 1 Primary Care

The community feedback highlighted variation in services provided by GP practices in North Kensington. This included access to GP appointments, general GP services and the provision of services introduced as a result of Grenfell. There was also feedback that some primary care providers were not as responsive to the needs of patients that had been affected by Grenfell.

- 1a** It is recommended that urgent steps should be taken to address variation in care within the Primary Care Services to ensure that all patients are able to access the right GP care at the right time.
- 1b** It is recommended that GP practices make sure that locum doctors are well briefed on the local context that patients will present with.

Recommendation 2 Children and Young People

The conversations highlighted the urgent need for emotional and wellbeing services to support 13-21 year old children and young people. There were a number of concerns raised by parents and community members about young people in this age group. Many young people had refused to access any help from health professionals or even talk to their parents or GP about their feelings after the fire.

It is recommended that Children and Young People's services develop a clear plan of engagement with this cohort to help determine needs so that appropriate services can be commissioned on the basis of this evidence.

Recommendation 3 Cultural Competence

Emerging from the community conversations is the need to better understand the way that culture and religion influence the way people access physical and mental health services and support. Lack of cultural and spiritual understanding of their problems by service providers often resulted in people not using services, dropping out of therapy, and refusing to engage with mental health services.

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Cultural issues and health literacy emerged as the key barriers for many Black and Minority Ethnic Groups and was a reason given for them not engaging with mental health services.

- 3a** It is recommended that the NHS needs to do more to recognise and respond to the needs of faith, ethnicity, culture and gender in healthcare.
- 3b** It is recommended that the NHS develop a Cultural Competency Framework in partnership with local communities and that this is then used to commission the best services.
- 3c** It is recommended that the NHS ensures that there are a range of community providers with the relevant understanding and experience to provide mental health and well-being services that are most appropriate.
- 3d** It is recommended that there is more alignment and working together of the engagement function of different parts of the NHS and voluntary and community sector to allow for a greater sharing of knowledge, cultural insights and local intelligence to better support our communities.

Recommendation 4 **Building resilience through social prescribing and self-care activities**

We received strong feedback about the need to support and help the community to build its own resilience through the provision of social prescribing and self-care activities. On top of this self-care (approach and activities) needs to understand cultural nuances in order for the activities to be accessible and appropriate to North Kensington communities.

Furthermore, any self-care should consider a behaviour change approach to change mind-sets as a precursor for self-care. This should be given key consideration when commissioning any social prescribing activities.

A number of people said that the community should take the lead on the provision of activities as opposed to the NHS. It is important to ensure that the recovery and resilience building is not just driven by professionals but by communities 'otherwise we will get more of the same'.

Another issue that emerged from the conversations was about the loneliness and isolation experienced by the elderly. Those living on their own appeared to be more at risk as they were isolated from the wider community and local services, and remained disenfranchised. There were some who were struggling to manage their long term-health conditions. The fire had appeared to have exacerbated their pre-existing health conditions

- 4a** It is recommended that the NHS for North Kensington incorporates a strategic objective on building community resilience within the Health and Wellbeing Strategy.
- 4b** It is recommended that the NHS work with the community to commission and develop a range of culturally sensitive self-care activities services with a focus on local providers to build resilience.
- 4c** It is recommended that NHS addresses the specific needs of the elderly population raised in the report by commissioning services and self-care activities that are accessible and appropriate for this age group.

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The voices of the community within North Kensington who shared their stories and accounts were powerful and moving.

They have taken the time to advise what they believe needs to be done to make a difference, particularly for their children, young people and elderly people.

West London CCG has listened and we are committed to working with the wider NHS and other provider services, as well as local community, voluntary and faith organisations to address the issues raised. We have made a number of recommendations that we will seek to deliver in the coming months and years.

We will also continue to have conversations with the local community so their voices influence any changes to services that are made to ensure the future needs of the North Kensington community continues to be met.



Get in touch with us

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