

Grenfell Community Assembly

Theme Health and Wellbeing

Notes from Grenfell Community Assembly Held on 24 September 2019

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THE ROYAL BOROUGH OF
**KENSINGTON
AND CHELSEA**

Introduction

The Grenfell Community Assembly has been established to ensure that Grenfell related matters are openly discussed and provide the place for statutory and non-statutory partners to respond to local concerns, that fall outside of the remit of the Council's Scrutiny function and jurisdiction.

An Assembly will take place approximately every eight weeks in North Kensington, bringing the conversation closer to residents. The Assembly is not a replacement for Grenfell Scrutiny, there will be ongoing scrutiny of Grenfell issues through the Council's Overview and Scrutiny Committee and four Select Committees.

September 2019 Grenfell Community Assembly

The first Assembly took place on 24 September 2019 at Avondale Park Primary School and was well publicised to local residents, with a specific aim to attract residents who do not normally engage with the Council. This included a variety of methods: North Kensington News, leaflets, social media and the Council's website.

The topic of this first Grenfell Community Assembly was 'Health and Wellbeing'. The Assembly provided an opportunity for residents to discuss important topics that matter to them with relevant and responsible organisations who are best placed to respond and create services to meet local needs. Organisations represented included the local Clinical Commissioning Group (CCG), Central and North West London NHS Foundation Trust (CNWL), Public Health England and local voluntary organisations such as Together for Grenfell, One You Kensington & Chelsea, Everyone Active, Kids on the Green and Latimer Community Art Therapy.

More than 40 residents attended.

Assembly agenda

The Assembly took place between 5pm and 8pm, with the following agenda:

Time	Item
5pm	<ul style="list-style-type: none">• Opportunity to visit stalls on local services
6pm	<ul style="list-style-type: none">• Welcome, introductions and purpose of the Assembly
6.30pm	<ul style="list-style-type: none">• Table discussions focused on key themes, followed by feedback
7pm	<ul style="list-style-type: none">• Opportunity to visit a second table and discuss an additional theme, followed by feedback
7.30pm	<ul style="list-style-type: none">• Table discussions to identify future themes for the Assembly to focus on• Thoughts on the Assembly and ideas for improvement
7.50pm	<ul style="list-style-type: none">• Next steps and closing remarks
8pm	<ul style="list-style-type: none">• Meeting closed

Table discussions

The main body of the agenda gave residents the opportunity to take part in table discussions covering the following health and wellbeing topics:

- Mental health
- Children and young people's health
- Primary care and local GP services
- Self-care and prevention
- Respiratory
- Soil and air
- Long term health monitoring

An external facilitator chaired the Assembly. Table discussions were facilitated by health and wellbeing professionals with direct experience of providing services in the topic being discussed.

This report does not include personal identifiable data, and we have not published information that is sensitive or names of individuals that were put forward during the table discussions.

This document

This document contains a summary of feedback from the Assembly, as well more detailed feedback generated at each table. We hope that this document is read by people who did not attend the event and encourages more people to take part in future Grenfell Community Assemblies.

We have included the detailed feedback notes of the comments and views expressed by individual residents at each discussion table, it does not necessarily mean that each comment is endorsed by the majority of attendees or the many residents who were not present for those discussions.

Next steps

In partnership with our colleagues in health, mental health and the voluntary sector, we are working on responding to all the issues raised by the end of October.

The response will include the actions we are already taking, the actions we have planned and potential new actions that have been identified by the community. The response plan will also include ways in which the community can be involved as well as ways the community can contribute to improving services locally. The Grenfell Community Assembly will review the response plan at the start of the next meeting.

As the Assembly becomes more established, we hope to train some local residents to facilitate table discussions to allow for greater resident involvement.

The next Assembly will take on Tuesday 19 November, further details will appear on the Council's website.

Acknowledgements

The Council would like to thank everyone that attended and participated in the Grenfell Community Assembly and to all the partner organisations that attended, assisted and facilitated discussions.

Summary of the Assembly

Summary of discussions

This section of the report captures the key points of the discussions held on the seven themes at September's Grenfell Community Assembly. Full details of comments made in relation to each theme can be seen on subsequent pages.

Primary Care and Local GP Services

- Not all residents are receiving the support they need as they do not recognise the impact of trauma on their lives
- Need for closer service design with residents
- Need to improve GP access and referrals to secondary care

Self-care and prevention

- Need to increase communication beyond Lancaster West Estate
- Waiting times for Enhanced Health Checks
- Need to improve access and reduce barriers to take up of services

Children and young people's health

- Better integration of CAHMS and Grenfell Support needed
- Schools/teachers lack recognition of anger/trauma impact on students
- Community/voluntary sector services available for young people – not being utilised by schools

Soil and air

- Need to provide clear information on testing and reporting of findings – residents particularly wished clarity about the quality of tests undertaken, what was being tested and the time being taken to do these
- Residents are concerned about the 'Grenfell cough' and other health symptoms
- Concerns on contamination still present locally and what the consequences of this might be, e.g. health impacts, safety of pets, food growing and local honey
- Concern regarding health checks – where to get Enhanced Health Checks, whether all GPs were doing these and whether they covered everything

Long-term health monitoring

- Long-term health conditions to be monitored and data used to understand patterns and trends in health conditions
- Some concern on collecting culturally sensitive data from people who might not engage with the Council
- More help is needed for people with additional needs such as high functioning autism, MS or hoarders

Mental health

- Need for better relationships between the NHS and residents and resident associations
- Opportunities to co-design of services to support those with mental health needs and make use of existing local community organisations
- Referral waiting times an issue for some services including cognitive behaviour therapy
- Need for greater recognition of the impact on the mental health of young people and work to reduce school exclusions

Respiratory issues

- Residents raised concerns in relation to the 'Grenfell cough' and the links to toxins, air quality and pollution related to the tragedy and the environment such as the Westway
- Residents questioned how testing would be taking place and how samples are being collected and a need to communicate the process widely; residents would prefer blood and fluid sampling
- Need for additional GPs who proactively promote Enhanced Health Checks
- Need to focus on housing impact on health

Table discussions: Themed discussions

Themed discussions

This section of the report puts forward detailed notes captured by scribes at each of the themed table discussions.

The detailed feedback notes capture the comments and views expressed by individual residents at each discussion table who attended on the night.

Primary Care and Local GP Services

Discussion points and comments made/questions raised by individual residents in attendance

- Request to describe services and challenges faced by GPs.
- Is there a fast track if patients indicate Grenfell issue?
- Is there value in addressing those who think they are fine? We need to be aware of the future need for services of those that do not recognise they have been affected by trauma.
- Need to ensure services are promoted to the whole community.
- People are using self-triage. But they need help too.
- For some, it's not obvious they are in need.
- Self-care group was mentioned as a useful resource.
- Difficult to see a GP, receptionist can be guardian.
- Use of locums was flagged as an issue.
- Some people are being asked to speak to GP over the phone, but some people can't do that.
- GP Service in North Kensington is excellent.
- Before Grenfell, residents took for granted GP coverage in North Kensington.
- People congregated near the GP surgery after the fire. Went to a place of safety.
- Restoring trust has to be through the GP.
- Needs are complex in Notting Dale.
- SPACE played an important role (214 Freston Road).
- Trauma experts worked from The Space.
- Signposting of services.
- Work with local community to get responsive GP services.
- Want to co-design services.
- Important to have a link to past with Doctors.
- Why are GPs reluctant to refer to consultants?

Self-care and prevention

Discussion points and comments made/questions raised by individual residents in attendance

- Genuine co-design led by the community.
- Recovery needs to be community led and co-production/co-design is crucial.
- Outreach is important.
- Suicide prevention – where is the monitoring? Compared to national average?
- Community needs proper help from all statutory agencies.
- Comms issue. Communications is focused on Lancaster West Estate: wider North Kensington residents not aware of many services.
- Ensure there are no barriers to access.
- Listening to residents, engagement is not far reaching enough.
- How can residents help each other?
- What's the best way to offer time?

Table discussions: Themed discussions

- How do you know what's needed?
 - Clear local directory of services
 - Better communication between NHS and residents
 - Awareness raising of check-ups.
- Service take up:
 - Need to increase take up of services especially amongst those whose first language isn't English.
 - More translators.
 - Speed of access is an issue.
 - Informal contact/approach works better in many cases.
- How can we ensure we are targeting self-care messages to where they are most needed?
 - Social prescribing is really effective too.
- How well are these services working and how are they being monitored?
 - I.e.: Grenfell Health and Well Being service, waited eight weeks for first assessment to first appointment.
- How can the outcomes be better for whole population?
- Enhanced Health Checks:
 - Did not come back to back with an appointment after first call.
 - Who is keeping an eye on these? Is more money being paid into mainstream services?
 - Why waiting so long for an appointment? Communication needs to be clear on waiting times.

Children and Young People's Health

Discussion points and comments made/questions raised by individual residents in attendance

- Services available for 18+ years old?
- 'Young people' age category is unclear.
- Not enough information is available.
- There is an age gap. Kids on the Green supports up to 21 years old, but 21-year olds are not kids.
- Continued support needs to be available
- Support has been taken away – Lack of 'Grenfell Response'.
- Grenfell Fire has isolated one resident aged 18. A concerned parent wanted someone to visit her. [This was taken forward at the meeting].
- Mental Health Awareness - Grenfell has allowed people to talk more, normalizing mental health.
- There are two services available – CAMHS and Grenfell Support. Not integrated enough.
- 15 to 21 years old are most vulnerable.
 - There isn't enough funding available for this age range.
 - Number of services stop at 18.
- Calming Cards - Should be created/designed to help with anxiety, stress and depression.
- Anger relief exercises for children. Teach techniques for life.
- Schools do not seem to understand that young people who are struggling with anger, anxiety need 'time out'.
- Teachers to be made aware of where support services are outside of school for children and young people to assist them.
- Kids on the Green find it difficult to get into secondary schools and support young people.
- Group discussions in schools would be good.
- More mentors are needed.
- Young Adults suffering in silence.

Table discussions: Themed discussions

- Children need options.
- Outside activities for young people. Young people are not accessing these options.
 - How can we encourage children to access options?
 - Providers should come together. Provide joint working opportunities.
- Call for event for children and young people which includes stalls.
- Organisations are sometimes resistant to partnership working.
- Dad's House - This service needs to be brought up to the north of the borough.
- Encouraging young people to attend events/assemblies like this in future to feed into this.
 - Should happen within school time
 - Engagement through: Youth forum, youth parliament, youth participation team. These groups should co-design this discussion.
 - Future assembly on Young People solely: Covering sports, arts, etc

Soil and air

Discussion points and comments made/questions raised by individual residents in attendance

- Latest Update on Soil and Air:
 - Tier 1 scoping/investigation.
 - Plume and previous land uses.
 - Pilot soil sampling.
 - Residents feel that this is two years too late.
 - How do PHE suggest we are tested and how?
 - Why are the gardeners wearing hazard suits to work now?
 - Crucial - List of toxicants for health checks
 - Of the toxins known to have been vented to air, which ones were deposited on the soil in North Kensington? I'd like a breakdown of toxins to air and toxins to soil.
- AECOM Liaison - incorrect analytic methodologies.
- Results:
 - Lead, BAP
 - Typical urban background
 - Where were the samples taken?
 - Deeper samples. Higher levels of dioxins and furans from historic sources.
 - Tests were recorded back in July – now, not until October.
 - How should we be tested? I.e.: Bloods, tissues, bodily functions.
 - Soil sampling results taking too long – three years on, promised in July and we are now in October.
- Professor Stec's work and chemicals of concern. Work has been replicated.
- Grenfell cough - Concerns about coughing blood (residents advised to see their GP).
- Eye problems - Eye irritations and acid acrid smoke.
- What happened to debris inside Grenfell Tower, Cladding, furniture? Test for toxins. Could this not be done now? Did Grenfell United do their own testing?
- Enhanced Health Checks.
- References to waiting for soil reports – consistency in messages is required.
- Concerns about ongoing deposition of dust on walkways.
- Will Phase 2 look at more specific background levels typical of West London?
- Lead – Atmospheric from burning
 - Tetra ethyl lead: Was this tested?
 - Lead soldering?
 - Pipes to bathroom?
 - Copper oxides
 - Metallic oxides in air – need to check

Table discussions: Themed discussions

- Eye irritations and acrid smoke
- Report has not looked at enough chemicals of concern.
- Final Published tier 1 report due in October.
 - Want confirmation from Independent Source that the right chemicals of concern have been analysed.
 - Waiting for contamination to get better before testing.
 - Requesting advanced biomonitoring.
 - There was no air sampling for the first 10 days.
 - More joined up working within agencies.
- What is being measured? Only diseases, not coughing up blood.
- Health checks:
 - Where are all the health checks happening? Some GPs are unaware.
 - Some GPs do them or can go to The Curve. (Request to update leaflet).
- Pets:
 - Bees on roof: Is honey safe to eat as they routinely travel three miles. (Mead also available). Honey available from recent years. Could this be tested as an indicator.
 - Query with food STD Agency
 - Would need to identify toxicants to test for.
- Deep clean - Why was deep cleaning only available in Lancaster West?

Respiratory issues

Discussion points and comments made/questions raised by individual residents in attendance

- Need to have more GPs in the area. Need to bring into Notting Dale three or four more GP surgeries.
- Need to be more proactive with health checks.
- Advertising is powerful especially about health and safety.
- Current tests should give assurances – but need continuous testing.
- Premature testing which will help with health conditions in the future but may not show anything at the moment.
- Resident report has difficulty breathing especially at night, was given an inhaler and pump for heart.
- Grenfell Cough
 - How do you establish a baseline?
 - What fire might have produced which may impact on health?
 - We live in a polluted city and how much do we put down to the fire?
- Grenfell Fire Toxins
 - Of the toxins known to have been vented to air, which ones were deposited on the soil in North Kensington?
 - Resident would like a breakdown of toxins to air, toxins to soil.
 - List of toxicants for health checks requested.
- Why are the gardeners wearing hazard suits to work now?
- Tests recorded in July -now not until October
- How does PHE suggest we are tested and how?
- How should we be tested? I.e. bloods, tissues, bodily functions.
- Pollution
 - Many people dying every year due to pollution and impacts on lungs. Initiatives such as 'no car days'. Maybe as time goes on pollution goes down. Trying to address pollution. No one addressing accommodation which cause lung and breathing conditions.
 - Basement properties (all pollutants go to basement properties)

Table discussions: Themed discussions

- Ceiling height: low (1m90 is illegal) Council should ban this because of accommodation problems.
 - Live across to motorways and there are no barriers. Nothing diverting pollution and noise pollution.
 - Ladbroke Grove very dirty area
 - Portobello under bridge – filthy (urine/excretion)
 - Anxiety
 - Anti-social behaviour. Behaviour of people on the bus – bad behaviour should be enforced to make sure people are behaving. Manners.
 - How can we all help each other?
 - Based on issues such as soil
 - Is there a potential to play down the harmfulness to anxiety levels?
 - Inter relationship between anxiety/depression and respiratory condition.
 - Issues within properties:
 - Housing associations and Council don't clean the carpets – this should be a requirement due to dust mites (especially in basements).
 - Humidity and mould
 - Damp and pollution – lung disease.
 - Ban basement flats.
 - Council doesn't check sizes of private properties and conditions of properties.
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Mental Health

Discussion points and comments made/questions raised by individual residents in attendance

- To learn and create solutions we need to know what has happened.
 - SPACE have engaged with 4,000 residents. Had to change their mindset and haven't seen that change of mindset from statutory services.
 - What happened on the night of the fire, was not just a burning tower and people dying, but a system (safety net) that collapsed and has not been restored. There is a need to rebuild lives, but also a community.
 - Need to engage with local community
 - What trauma are we dealing with? So many broken promises, no honour, makes trauma worse. Promise to include residents by NHS has not been followed through – that wound needs to be addressed.
 - What would 'good' look like? Co-creation of services with residents.
 - Trauma counselling on offer does not suit everyone. Everyone is referred to the same service and there's a queue.
 - The SPACE has addressed this need.
 - Learn from community initiatives like the SPACE.
 - Residents Associations should not be undermined – NHS Services should have a direct relationship with Resident associations, not just the voluntary sector as a proxy.
 - Resident association network already exists
 - There is a consensus about this.
 - Co-design with Resident Associations: Need to get engagement right to shape services.
 - Better communications from services
 - Comms is 'diabolical'. Needs to be linked up across different services. Co-ordination between statutory and voluntary organisations.
 - A need to remind/refresh about services available.
 - School Exclusions
 - Schools' do not have an appreciation of the impact of Grenfell; thus puts pressure on parents.
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Table discussions: Themed discussions

- School not considering the effect of Mental Health problems and how therapy sessions can affect emotions and attendance at school. Giving detentions for trying to excuse self from class.
- Lack of support for people with high functioning autism (especially children)
 - Full of Life doesn't deal with high functioning autism.
- Someone trained in Mental Health support should be in schools
 - Lots of children in the area suffering.
 - Better support and understanding of mental health needs in schools.
- Several survivors and bereaved trying to get cognitive behavioural therapy (CBT). Waiting list is three to four months. There are two services:
 - Community Living Well (which has quite a long waiting list)
 - Grenfell Specific
- How does follow up on referrals work?
- There is a grey area between 18 to 21-year olds.
- Some people who access services are quite slow to come forward through their children's experiences.
 - People are falling through the gaps.
 - Different models for different people/cultures
- Talking Therapies
 - How can you help people whose first language is not English?
 - Therapy pets.
- Different models for different people/cultures.
- Different stigmas attached to going to NHS vs a Community Service. Some people would rather access help away from the community.
- Wide range of organisations delivering wide range of healthcare services.
- Disproportionate number of people already had mental health problems. Resources equals resilience.
- Do survivors/bereaved have latitude in who they engage with (in terms of talking therapies) in the service

Long term health monitoring

Discussion points and comments made/questions raised by individual residents in attendance

- Long term conditions need to be monitored.
- Asking for enhanced checks and data populated from individuals to establish patterns and trends in conditions.
- How do we collect culturally sensitive data from people who may not engage with the council? (Local partner delivery survey for residents in North Kensington was mentioned).
- Solutions and actions rather than monitoring which can be easier to address in the short term.
- Monitor what is not being resolved.
- Linking of services – more joined up approach asked for.
- We need proper tests for toxicity and then we can have long term monitoring. Grenfell cough needs to be investigated.
- Self-health referrals?
- Secondary conditions coming from primary conditions:
 - There is no support in this borough for people with high functioning autism.
 - People with long term conditions like MS need more integrated support.
- No support for hoarders in the borough.

Table discussions: Topics for future Assembly meetings

Topics for future Assembly meetings

Residents gave suggestions for future Assembly discussions. These suggestions will be used to plan future Assembly topics. Below is the full list of suggestions made.

Suggested topics

- Adult safeguarding
- Meals on wheels for the elderly and vulnerable
- Community Safety – crime, drugs, gangs, anti-social behaviour etc.
- Changes to mobility scooters will impact on those housebound
- Funding for voluntary sector
- Housing/Housing repairs
- Data sharing and GDPR
- RBKC Public Health monitoring of presentation of symptoms, diagnoses
- Suicide and death by unexplained injury
- Sheltered accommodation – housing accountability: As property developers or social housing providers, Housing associations – terms of reference
- Social and wider determinants of health
- Social services
- The Grenfell Health and Wellbeing Service manual of engagement
- What is true resident led co-design?

Many of the suggestions made are linked to each other and are likely to be discussed in one or more future Assembly meetings. Some suggestions made are the detailed content of specific topics that will be explored in more detail during future Assemblies.

The next Grenfell Community Assembly will take place on Tuesday 19 November 2019.