

## North Kensington Recovery (NKR) Grenfell Health Programme

Insights gained from evidence-based engagement feedbacks by survivor, bereaved and wider-residents of North Kensington impacted by Grenfell Tower fire.

February 2025





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## 1. Executive Summary

This engagement report is firstly with recognition and thanks to Survivors, Bereaved and other residents who have so generously given us their time, energy and engaged with passion, challenge and also support for the NHS. Without these relationships much of this work would have struggled.

Engagement and involvement is central to the North Kensington Recovery programme. Since 2017 there has been engagement with Grenfell Tower fire Survivors, Bereaved and other local residents that includes conversations, focus groups, health partner meetings, patient feedback, and work with organisations representing local communities. In 2018 – 19 the development of the North Kensington Recovery strategy received over 1200 responses. This engagement builds on ongoing learning.

Over this period, we have gained insights into health needs, the challenges of recovery following a major disaster, the need for cultural competence in health. All of this has helped shape and influence health plans. There has also been considerable learning and we continue to learn.

The report therefore develops further insights from our engagement work to date and is intended to specifically inform the next phase of North Kensington Recovery from 2025 -29:



There are a number of inputs to this report. Recent engagements took place between December 2024 and February 2025 and included two surveys, two roundtable meetings and a number of focus groups- all to support understanding of current and changing health needs, and to inform make-up of future Grenfell health services 2025-2029 should be. This report builds on existing insights from engagement and sources including North Kensington Recovery publications. It also acknowledges considerations around the health impacts from recent government announcements on taking down the Grenfell Tower, and the need to continue listening and involvement alongside affected communities. In April and May 2025 further engagement is planned to inform and support development of services in the next phase of North Kensington Recovery.

We recognise there will be many views in a community impacted by a disaster of this large scale and have therefore strived for equity of views and influence. Working effectively requires understanding of the multiple views and perspectives that are shaped by local communities' many experiences.

The key insights from the work undertaken in 2024 /25 that should help shape the next four years of North Kensington Recovery (2025-2029) are with regard to meeting current and future Grenfell affected health needs. These are the priorities expressed by community participants, set out below:







- 1. NHS resources should focus on those residents most in need, with **support directed towards people living near the Tower site**.
- 2. Overall, there are **ongoing issues of low trust** experienced by communities towards the NHS
- 3. Both GP and Community-based Grenfell Enhanced Health Checks (EHCs) are valued, but there are varying expectations around what the scope of an EHC should be. Some people wanted a greater degree of reassurance around their health from EHCs.
- 4. Services and support for **emotional wellbeing and mental health are a priority** for both Survivors and Bereaved and Residents, with, most people preferring this delivered by GP or other NHS services. However, a **mixture of clinical and nonclinical provision** (community led, peer support) was **favoured overall**
- 5. Many people experience challenge in managing long term conditions. These were exacerbated by health inequalities across the locality, and have deepened since the fire
- 6. Significant levels of concern and anxiety linked to the tower being taken down, and what the **impact** of this will be **on people's health**
- 7. A high level of anxiety and distress expressed, influenced by two main issues. Firstly, the capacity for long term health monitoring to address issues around toxicity, cancers and other health conditions that might arise in the future as a result of the fire. Secondly, the state of NHS, including long waiting times for scans, appointments and access to primary care services.
- 8. Community Led Recovery was expressed as meaning greater accountability and transparency by the NHS, including the allocation of resources, improving communication with communities, and genuine involvement of communities in decision making
- 9. The **impact of Housing on health** was a recurrent theme. Persistent themes were unsuitable housing, overcrowding and poor state of homes that all impacted on health and wellbeing

## 2. Context and Background

This report provides an analysis of responses and feedback received from Survivors, Bereaved and other local residents about the state of their health and what people would like to see the NHS do in the future for those impacted by the Grenfell Tower fire. This would help influence and shape the NKR business case (2025). The analysis is also supported with insights drawn from the following:

- Seventh Anniversary Insights (internal document 2024);
- Health Partners minutes (including internal engagement logs.)

In undertaking further engagement in 2025 that consisted of two surveys, roundtable events, and focus groups, it was recognised that there were a number of other pressing issues within the community that would impact on time and energy available for engagement. With this in mind, it was agreed that flexibility and listening to feedback be continued and fed into the







business case process as it progressed through NKR partners and NHS decision making. Useful information for completing the survey was shared with all those who were contacted, and can be found here: <u>Next Steps: NHS North Kensington Major Incident Response</u>

It is also important to recognise that our model of engagement for Grenfell is nontransactional and that there are ongoing conversations with a range of stakeholders that provide valuable insights into local health services and concerns of Survivors, Bereaved and local residents.

Insights gained from engagement are structured into two sections:

- North Kensington Recovery Model of Care and services Concerns and Future Direction
- Health Issues General Health and Grenfell specific health needs

Input is structured around the key themes of:

- A. Area Boundary 500 Meters Proposal
- B. Primary Care
- C. Emotional Wellbeing
- D. Children and Young People
- E. Community-Led Recovery
- F. Long Term Monitoring
- G. General and Grenfell specific health needs

In this context, the totality of insights gathered have been reviewed and summarised below in these headings. The 2025 two surveys also had both common and distinct questions for Survivors and Bereaved, and other Local Residents to respond to.

# **3. North Kensington Recovery Model of Care and services - Concerns and Future Direction**

## A. Area Boundary - 500 Metres Proposal

A significant majority support a focus on some services within 500 metres. There are some concerns about excluding affected individuals beyond this range, with suggestion there should be a principle of reasonable flexibility for people who may not fall in criteria but have relevant needs. Some people want a smaller area size to be considered, whilst others want broader inclusion.

## The survey question asked was:

"We are looking at focusing some Grenfell health services in future for those who live within 500metres of the Tower, for example GP enhanced health checks. Do you agree, disagree or 'other' (Please see map at aforementioned link.)" Answers were either: "yes, no or other"

The responses for focussing some Grenfell health services within 500 meters of the Tower are summarised below:





	Yes	No	Other
Survivors and	32	1	3
Bereaved			
Wider Residents	125	12	15
Overall	157	13	18

Discussion at round table events indicated broad support for the proposal, with several suggestions that there should be a focus on service provision more specifically for people living within closer proximity to the Tower site. Some people suggested 250, 200 and 100 metres as appropriate distances for consideration.

The key themes from "Other" responses were:

- **Survivors and Bereaved:** Concerned about community division, potential exclusion of affected people outside 500 meters, and suggestions to adjust the area (e.g., reducing to 100 meters).
- **Residents:** Some opposed the initiative, citing potential negative health effects. Others supported it with modifications, such as widening the coverage or increasing mental health support.

## **B.** Primary Care

In summary, Enhanced Health Checks are generally well received with a high proportion of those who have had an EHC feeling more assured about their health. However, concerns have been voiced around the comprehensiveness and scope of EHCs to address all health concerns that people have. At round table discussions, concerns were expressed including different community expectations of the scope of EHCs, a reported low level of trust in services and a general theme on improving communication to patients.

**Round Table discussions** focussed both on Enhanced Health Checks and broader primary care, with both EHC specific satisfaction survey data (2024) and the recent survey both concerned solely with EHCs. Satisfaction with the service is high with those who have used it (87% reporting good or very good) and 76% of people reporting that the EHC provided assurances around their health as a result of the Grenfell Fire.

**Survivors and Bereaved** were asked a survey question around whether they usually had an EHC each year, and if so where (at a GP practice or at a community venue). There were 36 respondents for this question. In response to a question on what people would want to see additionally in the health check, responses included counselling, mental health support, and additional blood tests. 34 out of 36 respondents expressed interest in GP services addressing emotional well-being, such as sleep anxiety.

**Residents were surveyed** on a separate question on their level of interest in a GP focussed service on emotional wellbeing and mental health (e.g. anxiety and sleep disorders). 153 responded, and a majority of 73% stated positive interest in this. However, a similar level of respondents (154) showed low support when asked 'who do you feel







should provide support for emotional wellbeing?', with only 17% indicating they feel this should be a GP delivered service. This requires further listening and engagement for clear insights.

Additionally, the round table discussions on primary care generated some specific themes:

Primary Care / Enhanced Health Check	Wider Physical Health Concerns	
Some people report challenges in GP	Several people raised concerns on	
access and a lack of trust in the	toxicity and potential link to illnesses like	
information provided through EHCs	coughing, skin rashes, and hormonal	
	imbalances	
Some people reported concerns on	Some people felt there is insufficient	
comprehensiveness of EHCs, particularly	communication and reassurance from	
for conditions linked to Grenfell-related	health providers in general	
toxicity e.g. digestive issues, thyroid,		
reproductive health, skin concerns		
Noted that some people would like	Some of the health issues that people	
expedited referrals to secondary care/	would like to see addressed include	
specialists for Grenfell-related health	respiratory problems, dizziness,	
concerns.	stomach cramps, and skin conditions	

## C. Emotional Wellbeing

Overall, preference was expressed for services that support emotional wellbeing across different providers and in different ways. For Survivors and Bereaved, the majority prioritised emotional wellbeing support through GP practices, with the second preference for NHS services. The reverse was true for resident respondents who valued NHS services to provide this first, followed by GP practices.

The range of responses on types of support showed preference for a mix of provision including therapeutic and emotional support. Survivor and Bereaved respondents highlighted the importance of peer support, social interaction and physical activity alongside professional support for wellbeing. Resident respondents indicated social support, group activities and social interaction alongside a range of talking therapies as well as listening and other informal opportunities.

There were 36 Survivors and Bereaved respondents to the question '*who should provide support for emotional wellbeing?*'. 20 people felt that this support should come from health providers such as GP practices or from other NHS services and support such as Talking Therapies, with 10 stating from other sources such as faith groups and resident associations. 6 people did not know who should provide support.

In response to the question '*what other kinds of support would be most helpful in meeting Survivor-Bereaved residents*' *emotional needs*', the preferences identified were for peer and community driven support, physical activities such as gym, yoga and







gardening- and other forms of wellbeing support. Several responses prioritised selfreliance.

154 residents responded to the question 'who should provide support for emotional wellbeing?'. 89 people felt that this should be from health providers, with NHS services and support the majority responses, followed by GP practices. A significant minority of 50 people either did not know, did not feel they had emotional wellbeing needs, or else stated 'other'.

153 residents responded to the question '*have you received support through the NHS Grenfell Health and Wellbeing Service*'. 33 said that they had, and 120 had not.

113 residents shared their views on '*what other kinds of support you would find most helpful in meeting your emotional needs*'. Survey responses, focus groups and round table discussions demonstrated that some people were not clear about what and how they could access in order to receive support. With this context in mind, analysis of responses showed four areas of importance:

- **Social Support**: e.g. group activities, physical exercise including walking groups, local gym memberships, and access to community spaces.
- **Mental Health Support**: interest in therapies such as CBT (Cognitive Behavioural Therapy), DBT (Dialectical Behavioural Therapy), and EMDR therapy.
- **Talking and Listening Support**: A recurring theme was the need for someone to talk to, highlighting the value in both talking therapies or informal support systems.
- **Social Interaction**: community groups and activities like gardening, singing, and cooking

## D. Children and Young People

Three quarters of respondents favoured services for Children and Young People (CYP) working better together across health, education, social care and the Voluntary and Community Sector. Two main themes from the priorities are 1) Better coordination and collaboration across services, and 2) Prioritisation of mental health support and long term needs for CYP who continue to feel affected by Grenfell.

## **Survey insights**

There is strong support expressed for better coordination, communication, and collaboration among the NHS, charities, local authorities, and voluntary and community sector organisations. Services should be more integrated and holistic, particularly for children and families affected by Grenfell. Three priorities came through around central coordination and improved visibility of existing services, for trauma-informed and long-term mental health support for children and young people, and thirdly for better communication between schools, NHS, and social services to assist children with mental health challenges and those with limited healthcare access.

## Insights from round tables:







**Expand Engagement:** Use door-knocking and community stalls to reach more people, as current events attract the same participants.

**Support for Children:** Provide peer-to-peer academic coaching (16-18), early intervention for school leavers in poverty, and GP checks at community hubs. **Monitoring & Outcomes:** Track children affected by Grenfell, collaborate with schools on educational attainment, and consider wider community impacts (including those within 200m of the tower).

**Survey Improvement:** Current surveys do not fully capture community needs, requiring better data collection methods.

## E. Community-Led Recovery

Discussion of Community Led Recovery showed several main concerns. The approach must be genuine. Participants described feeling let down by inauthentic involvement exercises in the past, and recommendations made that were over-ridden by authorities. Decision making must involve communities. People also emphasised they wanted to see:

- 1. Greater **transparency and accountability** about decisions made in North Kensington is important, including how funding is allocated and spent
- 2. **Communication must improve** so that Survivors, Bereaved and Residents can be clear about what support is offered and how to access it
- 3. Taking down of the Tower is a major concern and community voices must be heard as part of this. **Assurance of safety** as this is happening is a concern, with particular regard to health

Community led recovery is a <u>priority</u> across the NKR programme. It must be informed by the experience and knowledge of residents, Survivors and Bereaved who have been impacted by Grenfell Tower fire. Discussions at round tables and focus groups explored how the next phase of North Kensington Recovery can better develop and embed transparency and accountability. The following summary brings together the discussion themes:

- Ensure local people of all ages and diverse cultural backgrounds impacted by Grenfell. including children and young people, feel that they will have better involvement in the programme in the coming years.
- Making sure that all decisions made about health services for Grenfell-affected groups are informed by the community.
- Improving the openness and transparency in the programme more generally by, for example, providing more information to residents about service performance and finances.
- Increasing the opportunities for community partners to oversee the services and support put in place.
- Offering opportunities to those affected by the fire to make shared decisions with the NHS in specific areas of the programme.
- Ensuring that community-led recovery is over seen through governance structures of the Programme and Partners held to account.







- Insights from Survivors about their distrust/ frustration with how resources are being used (e.g. concerns about the use of Grenfell funding for services that do not directly benefit them.)
- Engagement during 2024 established insights that in addition to increased transparency and accountability there was a need for greater involvement of key stakeholders in designing and monitoring Grenfell services, prioritising those services that "received the lion's share of Grenfell resources".
- Start the process with the health impact of the deconstruction of the Grenfell Tower communities' concerns should be at the heart of proposals and presented to us so that we can comment, challenge and contribute.
- The Government and the Council have failed to take a community-led recovery: "I am not sure what the NHS would do any better".
- Lancaster West Residents (LWR) Are at the forefront of the Tower decisions "how will the NHS work with us to ensure that we lead on developing measures to address our concerns when we better understand what the Governments plans are".
- Community-led should include residents being able to hold decision makers to account.
- "This is not about Voluntary Community Sector (VCS) funding "they never consult us but take the money".
- "We want a say in who gets funding" so residents can vote.
- Community led recovery should have at its heart accountability and transparency as "want to see" not, "what you want to give us".
- "Faith is important to us" and should be integrated into recovery for those that need it.

## F. Long Term Monitoring

Further understanding is needed around take up of existing monitoring services, particularly with people who have not had appointments to date. The majority of people who have used adult respiratory services are satisfied, with some indications given that will be helpful to explore further with Survivor and Bereaved. For Paediatric monitoring, response numbers were low and do not give any specific insights for service development or improvement. Some wider concerns around future health status were linked to screening and monitoring services in the following section around general and Grenfell impacted health and support needs.

Survey data, round table discussions and focus groups supported insights into adult and paediatric long term monitoring services for Survivors and Bereaved. Wider discussions around current health needs and future concerns helped further with context, and the bigger picture of what matters most to Survivors and Bereaved and wider residents.

The majority of the 34 Survivor and Bereaved respondents indicated they would not attend an annual respiratory monitoring appointment (59%). The majority of those who would not attend said they did not need any more help in this area. Of the 18 people who have used the service, the majority are satisfied (72%). Several areas for inclusion







in the service were suggested. These included provision of x-rays or scans, a greater focus on cancer, more proactive contacting of patient and for the option of MRI scans.

There were 11 responses to survey questions around the paediatric monitoring service. 5 people indicated they were happy with the service, and 6 stated they were not. There were no insights shared in response to what people would like to see included in the appointment.

#### 4. Other General and Grenfell specific health needs

Several survey questions invited responses from both Survivors and Bereaved and Residents on current and future health needs and concerns, alongside a focussed question on specific Grenfell health needs that people wanted to be addressed:

How do you feel about your health in 2025 and beyond? Do you have any Grenfell affected health needs you feel are not being met? What support would you find helpful and why?

Survey responses were supplemented with insights from round table discussions and focus groups that identified priorities and themes on broader health and support.

**33 Survivors and Bereaved** responded to the whether their Grenfell affected health needs were being met. 85% stated that their needs were being met. Unmet needs identified included management of long term conditions, counselling and enhanced cancer screening.

There was a mixed picture of feelings expressed around own health now, and in the future. Many of the responses identified concerns around the cost of living, housing related issues, the overall state of the NHS and public services. Anxiety was linked to these issues alongside a recognition of the impact experienced of previous trauma. Dissatisfaction was expressed around the ICB and the systems in place to support people, resulting in low trust. Insufficiently transparent allocation of resources was a specific cause identified here.

In terms of more general support, insights demonstrate a strong preference for personalised, responsive, and culturally aware support that allows for individual choice and flexibility, while also ensuring that long-term health and well-being are proactively managed. Housing was identified as a significant determinant of health and wellbeing. Overall analysis points to more accessible and practical support, a responsiveness to people's physical and mental health needs, and an understanding of individual spiritual, emotional and cultural needs.

**141 Residents** responded on whether their Grenfell affected health needs were being met, with 46% stating yes and the majority of 54% stating no. Stated health needs included worries about longer term impacts on health from pollution, toxins and air quality near the tower site, linked to concerns around respiratory issues. Several responses highlighted the importance of monitoring health conditions including accessible screening, along with frustration with access to primary care and long waiting times for other health appointments, and difficulty with timely access to specialists via NHS referrals. Inadequate and poor quality housing was identified as







impactful on health, and exacerbating of health conditions alongside poverty, cost of living challenges and employment difficulties.

Further insights around general health now and in future gave a mixed picture of how people felt around their own health. Some described their health as good and stated a degree of optimism. Others described worsening health, particularly around long term conditions, increasing frailty, and anxiety and depression that have an impact on overall quality of life. A number of respondents indicated health concerns that linked to Grenfell and the subsequent impact on their own lives- specifically around concerns for future respiratory health and cancer risk, as well as psychological impacts and poor mental health experienced as a result. Concerns around the ability of the NHS to meet future health neds was also raised.

A further follow up question was asked: 'As we look forward to the next few years, what support would you find helpful? And why?'. Mental health support was reflected as a priority, with responses covering trauma and psychological strain experienced and the need for consistent mental health support, including talking therapies and community led mental wellness initiatives. Long term monitoring was the second Grenfell affected health need to be prioritised. Other responses showed importance placed on wider issues of access to health care and the timeliness of diagnostics, treatment and care. Community led and social support emphasised the need to reduce isolation and improve wellbeing, and there was consideration given to affordability and safety of housing, alongside support with cost of living challenges.

