



NORTH KENSINGTON PROGRAMME 2024-29 Developing a community-led recovery

Working together to decide what future health services and support should look like for those affected by the Grenfell Tower Fire



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1. Forward

On the night of Wednesday 14 June 2017 a fire occurred in Grenfell Tower in North Kensington, where 72 people lost their lives, many were injured and a whole community was significantly affected.

We would like to remember those lives lost and pay tribute to the survivors and bereaved and the North Kensington community as a whole. We would like to thank anyone affected by the fire who has already contributed their views on health concerns, issues and services. Your courage and resilience consistently leave us amazed.

Local NHS organisations began providing services in the immediate aftermath of the Grenfell Tower fire and have continued to do so.

On the 19 September 2018, Dr Fiona Wilcox, HM Senior Coroner, Inner West London **published a Regulation 28 (report to prevent future deaths)** regarding the Grenfell Tower fire. The coroner noted eight concerns within the report, requiring action to prevent future deaths. In response, the NHS Chief Executive announced that NHS England would be investing £50m to fund long-term health screening and health support for those affected by the Grenfell Tower fire over the course of five years.

This five-year period of funding is coming to an end, but community feedback and service data tells us that the health needs associated with the Grenfell Tower Fire continue.

In April 2023 NHS North West London and NHS England confirmed its ongoing commitment to making sure that the right services are in place to meet the health needs of communities in North Kensington in the long-term.



To take forward this commitment we have been gathering evidence on how health needs are changing as time goes on, and reviewing whether services are effectively meeting needs. It is clear that the upcoming milestones in the recovery process will result in new health needs, and service offers will need to adapt and change to better support people.

We now wish to work with the local community and those affected by the Grenfell Tower fire and ask them what they want health services and support to deliver in the future.

We want to make sure we are supporting a community-led recovery and working with local clinicians who are already providing care to the local community, to build a greater sense of community ownership for the services and support that are put in place. We want to help people live healthier lives and build resilience for the community as a whole. It's also important that we take further action to reduce health inequalities and social exclusion, which act as a barrier to people receiving care and support. We also need to take into account the overall **NHS NW London Health and Care Strategy** and any future service reviews and developments (such as the **adult mental health review**) that have the ability to influence how services and support are provided in North Kensington.

At this point, we want to recognise the feedback that we have sometimes received that the North Kensington Recovery Programme has not always delivered:

- The right level of communication and collaboration expected by local people and partners.
- Services and support that have successfully met all health needs.

Moving forward, we want as many voices as possible to be involved in helping us design the services and support you wish to receive in the future. We acknowledge that changes may need to be made to the existing services and support that are already in place.

Following community contributions, a plan will be drawn up outlining how changes will be made, and specifying the funding needed to deliver the future services and support that is needed.

Thank you.

North Kensington Recovery Team, NHS North West London

2. Introduction

Thank you for taking the time to read this document.

In the past year, the NHS and our partners have asked survivors, bereaved and the local community lots of questions about their current health needs and what they are worried might occur in the future. This feedback has fed into the Joint Strategic Needs Assessment (JSNA), which is soon to be published. We also received lots of feedback that people wanted more of a say and that the NHS needed to be more open about what they are doing.

In this document, we describe the overall themes of feedback we have received and set out the types of services and support that we think could be introduced or changed to deliver the help people say they want, both now and in the future. We want to see what you think about these proposals and get any other ideas you may have about how we could deliver the health services and support to meet local residents' needs.

This document is also intended to mark a shift in how we become more 'community-led' in the North Kensington Recovery Programme. This means:

- Ensuring local people of all ages and diverse cultural backgrounds in the community, including children and young people, feel that they will have better involvement in the programme in the coming years. We want to be truly inclusive so welcome the views from parents and individuals with learning or physical difficulties.
- 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.

There are some practical changes to the decision making and transparency suggested in this document.

All your views important and will be carefully listened to. None of the changes suggested here have been finalised, agreed or approved, so your contributions are vital in shaping how we work in the future.

What we would like to do, with your help

On the 07 May 2024, we will start engaging with the local community to get their feedback. You will be able to respond to the contents of the document via email, post, or by attending one of the events and workshops we will organise, working in partnership with community based organisations.

We would also like to visit as many groups as we can in the community. If you would like us to visit you to discuss the contents of this document, or to discuss how we can work together to gain people's views and feedback, please contact us by emailing **nhsnwl.nkrt@nhs.net**.

We will release a survey of key questions once we have received feedback from communities and partner organisations on what those questions should be. Additionally, we have indicated where further reading or information can be found and have also collated many of these reference documents and links on our website **www.grenfell.nhs.uk/nextsteps**. Please check the website site for new updates as we will add more information as it becomes available.

We are expecting that this phase will last until July 2024 and will inform the development of a plan for the services and support that will be put in place which will ultimately be approved by NHS NW London. We will also seek community endorsement of the plan before it is approved, as part of the commitment to build a 'community-led recovery'.

Depending on the changes proposed, there may also be a further stage of formal public consultation, but we are not at the stage yet of knowing whether this will be needed.



3. Health needs in North Kensington

Since the Grenfell Tower fire, the NHS has been working with local communities and organisations to understand what people want and expect from services.

Our Health Partners¹, and other community organisations, have collaborated tirelessly with the NHS, ensuring that commissioned health services meet the diverse needs of the culturally rich community impacted by Grenfell.

Their collaborative efforts have been instrumental in fostering a healthcare framework that is not only responsive but also culturally sensitive, reflecting a commitment to inclusivity and a deep understanding of the unique health requirements of this community. Through this ongoing partnership, the Health Partners and our other community partners continue to play a pivotal role in championing equitable healthcare access and promoting the wellbeing of the Grenfell-impacted community.

We have also carried out a number of one-off engagement process and reviews, to gather people's views on the services and support that have been put in place and these are listed in **Appendix A**.

We recognise the frustration that local people feel with the number of times you have been asked to provide information on the health impacts of the Grenfell Tower fire, and on the health needs you have. We also acknowledge that people feel unclear about how the information they have provided has been used, or that their input has not resulted in as much change to ways of working and services as expected. In this section we summarise the extensive feedback provided by communities, together with information from current services, medical advice and the requirements of the coroner's report, into some themes of current and future health needs in North Kensington.

Health and wellbeing is seen by many groups of the North Kensington community as being the single most important factor in their recovery from the Grenfell Tower fire, according to recent engagement conducted by the NHS and Royal Borough of Kensington and Chelsea (RBKC) as part of the JSNA.

The JSNA will present a detailed analysis of current and future health (and other) needs of the wider community, survivors, bereaved and children and young people, which will be shared with the community shortly. In this document, we will provide some key headlines, and focus on changes to services that you would like to see as a result of the health needs you have told us about.

3.1 Health needs associated with Grenfell are ongoing and will be changing over time as milestones in the recovery process occur

The emotional and mental health impacts continue to be felt by survivors, bereaved and the wider community living closest to Grenfell Tower. Services providing support are used by hundreds of people with a variety of enduring health needs associated with Grenfell.

We have heard how children and young people, including those born since the fire, continue to be impacted and how much the community would like us to focus on supporting them.

¹ The Health Partners Programme was set up in 2019 on the principles of an asset-based approach, working in partnership with community organisations to build resilience and enhance health outcomes for the Grenfell-impacted communities. Rooted in the belief that communities possess inherent strengths and resources, the Health Partners Programme was designed to harness these assets for effective health recovery.

We have also heard how milestones like the anniversary of the fire, the ongoing public inquiry or events such as theatre or TV productions can cause a spike in anxiety and distress. This will continue as decisions on the aforementioned public inquiry, the future of Grenfell Tower and subsequent memorial is decided and if there is any subsequent police investigation.

Physical health is also a key concern for some people, particularly those in Grenfell Tower on the night of the fire and others who were close-by on the night and in the immediate aftermath.

The monitoring of health information from local services conducted as part of the programme has not yet found clear evidence of sustained changes to physical health needs as a result of the fire at a wider community level (such as increases in the proportion of people in who have a particular condition

or disease).

However, we recognise that people remain very concerned at the impact on their future health, and are seeking much more reassurance that potential issues will be picked up as early as possible by monitoring services. People are also asking for more effective explanations of how the NHS and partners are monitoring potential health issues for the wider community, and survivors and bereaved.

3.2 People are now less likely to view any health needs associated with Grenfell as separate from other health conditions (which may have existed before the fire or being diagnosed since)

Services provided as part of the North Kensington recovery (often called Grenfellrelated or Grenfell-specific services) need to adapt to this and work with other local services (often called mainstream or core services) to provide joined-up solutions and not be provided separately.



The current range of provision is confusing to people and should be easier to access, and more co-ordinated in its delivery. The purpose of some services also need to be better explained in ways that all our diverse communities can relate to.

3.3 Access and health improvements could be made by increasing the provision of community-based services that are less medicalised and more culturally adapted

Current NHS services, including the Grenfell Health and Wellbeing Service and general practice, are generally very popular with people who use them. They have cared for and supported thousands of people with health and wellbeing issues, and are seen by the majority as an important aspect of future provision. However, local people and community and faith groups have advised us that they want health and wellbeing support to be increasingly provided in local communities by their peers and local groups. This will further develop the resilience of communities, better address inequalities in health service provision and deliver more culturally-sensitive support.

People also want to see more joint work between health, other government organisations and community groups on factors like deprivation, housing, employment opportunities that are proven to impact on people's lives and health.

3.4 The NHS must deliver on its aim to make the North Kensington programme more 'community-led'

Valuable insight has already been gathered from our previous engagement with the North Kensington community, which has resulted in a number of positive changes in our approach to service delivery. For example, we are in the process of training all GPs and practice staff in cultural competency, so they can better respond to the health needs of patients. We have also introduced a range of selfcare support provided by local organisations thorough the **Healthier Futures programme**. However, we acknowledge that there is a need to do a lot more to become a 'community led' recovery programme, and that our actions have not yet met aspirational statements.

Taking this into account we would like the community's help to monitor and improve services, as well as reach out to groups that have not often had the opportunity to have a say. Once this is achieved we would like to develop methods of explaining service offers that are easily accessible and understood by local people. If the long-term planning themes have been well understood by us, then a sense of collective ownership will hopefully make this process easier.

We also want to encourage increased community participation in decision making, transparency for communities on what Grenfell-related funding is spent on, and the impact that services are having on health outcomes. We have recently started publishing **financial** and **outcomes** data on our website as a first step, and are keen to make further improvements based on your feedback.

4. Possible future changes to services

The previous sections of this document have summarised the evidence that has been collected by engaging with communities, staff and others, and reviewing available sources of health data.

The table below explores that evidence in a bit more detail and provides some suggestions on what future services and support should aim to achieve, and the changes that will be necessary to deliver better health outcomes for North Kensington communities.

It should be noted that the findings and suggested changes listed below are not

representative of all views that have been heard. They represent an attempt by the NHS to categorise the most frequently heard views, and trends in the evidence reviewed.

No decision has been taken on the design of future services and support. We are running this design process to give you the space to challenge any of these points if you do not feel they reflect your views, or the views of community groups you associate with. We also want you to come up with your own suggestion for the services and support that could be put in place so these can also be considered.

Mental health and emotional wellbeing

- Mental and emotional health and wellbeing is one of the most important factors in the current and perceived future needs of survivors, bereaved and the community.
- Current services provided by NHS and community organisations are used by many people. A large proportion of people who have provided feedback on services are satisfied with their experiences and feel services have improved their mental health and wellbeing. A degree of service continuity would be welcomed by these people, and any changes should be managed in carefully planned way.
- The Grenfell Health and Wellbeing service, which currently receives the highest proportion of the NHS funding (around 60% each year), has changed a lot since the initial response to the fire, and the views of service users and community members have been taken into account in making those changes. For example, based on feedback, more group based therapy and support in community locations has been provided in recent times.
- However, many local people and community groups, we have engaged with, want more community-based emotional wellbeing provision to 'de-medicalise' mental health support, and increase uptake of services.
- Some staff and volunteers in community and voluntary groups feel they need more training and support to provide effective emotional support to local people. This could include:
 - Partnership agreements between NHS and voluntary sector services to increase clinical support for community workers and improve joint working with clinically-led services
 - The provision of mental health and trauma-informed training for any organisation supporting people in the local area.

Mental health and emotional wellbeing (continued)

- A general theme of feedback has been that services also need to be delivered in a more 'joined up' way, including assessment and provision that considers emotional and physical health needs together.
- Closer working between services provided as part of the North Kensington programme, and other local community services to ensure that all local services reflect and can meet Grenfell-related needs in the way they deliver support.
- Many people have fed back that they are confused or unaware of services available locally, and that more needs to be done to explain what services are available and how they can help local residents.

Physical health

- Although a number of people have suffered physical health issues as a result of the fire, it
 is not yet possible based on the data available to draw firm conclusions about the current
 scale of physical health needs directly linked to the fire, We have not been able to identify
 any long-term health conditions or trends that have worsened across the local population,
 including survivors and bereaved.
- The majority of people who have provided feedback say the current approach of monitoring and checking physical health is not providing reassurance. This is a particular concern of survivors and those living close to Grenfell Tower.
- Monitoring services are not being taken up by all those that are eligible, which also affects the ability of the NHS to monitor and detect physical health needs as required by the Coroner's recommendations. A small minority have chosen not to use services at all, and many have not engaged with services at the frequency (eg yearly) recommended by clinical experts.
- Changes are therefore needed to be made to the ongoing long-term monitoring approach and service provision to increase effectiveness, reassurance and uptake.
- More needs to be done to explain the purpose of the monitoring and to reduce the number of people not attending appointments or arranging yearly checks.
- For example, overlaps between different physical monitoring and checks are making it hard for people to understand what different services are for, and may be affecting uptake.
- The communications and engagement carried out to explain the approach and ongoing findings of monitoring services should to be more comprehensive and nuanced.
- There should be a renewed drive on encouraging the uptake of monitoring services by survivors and bereaved living outside of Kensington and Chelsea, which is low compared to those living locally.

GPs and general practice

 Enhanced primary care services for the Grenfell-affected population have been increasingly well used since the pandemic, and satisfaction rates are high amongst those who have fed back after using them.

GPs and general practice (continued)

- Some of the negative comments about enhanced services include variability of provision across GP practices, and a feeling by a small minority that tests were 'tick-box' in nature and not personalised enough.
- There are persistent difficulties reported by local people in accessing GP appointments in a timely way, which means that commissioning separate Grenfell related time and services is still an important consideration.
- It has been difficult to draw conclusions about health needs arising from enhanced services. Further clinical audits of enhanced health check appointments (EHCs) should take place, so we can use the information to influence what they cover in the future.
- NHS-wide plans to develop general practice and community services into Integrated Neighbourhood Teams (INTs) should include specific services for people affected by Grenfell.
- INTs should have differentiated services for survivors, bereaved and the wider community featuring multi-disciplinary working and co-ordination, including joint assessment and care planning across physical and mental health services.
- The good practice and learning from the North Kensington services should be taken up by other teams, ensuring all services can effectively support those with health needs associated with Grenfell.
- More community-based services should be provided, including expanding the locations used by the Community Enhanced Health Check Team.

Voluntary and community-based services

- Services and support provided by non-NHS voluntary and community-based organisations are the most highly valued and deliver good health outcomes at relatively low cost.
- Community-based provision should continue and expand, aligned to new services and support and be designed to reduce health inequalities.
- Increased investment should be provided in community-based services and support as a proportion of the NHS North Kensington Recovery Programme spend, with an emphasis on providing culturally specific services and community resilience building.
- There should also be increased alignment with other new NHS and government initiatives aiming to reduce health inequalities.
- In future, any activities and groups provided in locations close to Grenfell Tower should be prioritised for funding.
- Funding organisations should prioritise the alignment of grant award processes in the North Kensington area as there is a duplication of process across initiatives, including those funded by the NHS and the RBKC.
- Improved communication and promotion of services through a variety of channels (including through community leaders, local voluntary, community and faith organisations and social media) would result in improved uptake of services.

Children and young people's health and wellbeing

- Many of the points above are relevant to children and young people.
- Uptake of services from survivors and bereaved groups living outside Kensington and Chelsea is particularly low among children and young people.
- The overlap between long-term monitoring and enhanced health checks is also particularly apparent for children and young people, causing confusion and affecting take up.
- The NHS needs to find ways to explain the purposes of the monitoring services to improve uptake, in a way that resonates with children and young people.
- Joint working between professionals also needs to be further developed to ensure overlap between services are minimised, and support is provided in a co-ordinated way. This includes a central role for social prescribing to ensure children and young people can access community-based services and peer support.
- To reflect the additional needs of staff and pupils, we need to introduce more support is needed in the local schools neighbouring the tower site. These need to work alongside existing school-based services for children and young people provided throughout the Royal Borough of Kensington and Chelsea (RBKC).
- Services which involve the whole family are popular and have been increasingly adopted. This approach should be offered more widely. We need to better address intergenerational health issues which is where the health issues of people in a family affects the health of others.
- Children and young people have expressed a wish to be empowered to better understand services and how to access them. This also includes interest in developing peer support models in collaboration with NHS services.
- Children and young people would like to lead on the development of services and health promotion.
- As with adult services, Grenfell services should align with other 'mainstream' services to work together to reduce duplication and confusion. This includes Family Hubs, a partnership led by RBKC Children and family services which includes physical centres, a virtual information hub and a large partnership of services offering multidisciplinary support from birth to 19.

Family Hubs are well placed to offer an inclusive whole family approach to supporting families impacted by Grenfell, including increasing the uptake of enhanced health checks, mental health support, child development, family relationships, child care, youth play activity and financial wellbeing.

 All locally provided services should be trained in trauma-informed care and staff should be provided with other Grenfell-specific support and training.



Becoming community-led

- The development of shared programme outcomes should be developed jointly during the design process.
- The effectiveness of the programme and performance of services should be overseen by a community-led governance structure.
- Monitoring of NHS services should involve community leads, plus more regular publication of service data and monitoring reports to the wider community.
- Grant awarding processes should involve the delegation of decisions to community representatives.
- Opportunities to join up with 'Future Grenfell Support' programme governance, engagement and communications should be fully explored. This will help to reduce duplication between programmes and services funded, and address the confusion about services offered that has been evidence in recent feedback.

5. What this means for your services in the future

In this section, we have attempted to summarise what the suggested service and support changes might mean for you, if we have interpreted information you have provided correctly, and the changes suggested in <u>section four</u> are implemented.

We have categorised the information by survivors, bereaved and members of wider community to illustrate the different services and support that are proposed.

Survivor and bereaved of the Grenfell Tower fire

- You will be offered a multi-disciplinary assessment and review of your health needs on an annual basis. This will be done jointly between your GP and any other professionals involved in your care who you choose to be involved.
- This will include time for you to discuss any specific health concerns that you and your family have, which may or may not be related to the fire. It will also include a set of routine tests to check physical and mental health symptoms and indicators.
- Where you have symptoms or concerns, you can be referred to other NHS services, which may include but is not limited to, x-rays, blood tests, spirometry, therapeutic services, and emotional and physical wellbeing support and advice.
- Following the assessment, you and the professionals involved will agree a personalised care plan. This will include a set of goals or aims that are particular to your health needs. Depending on those needs, you will be offered a lead member of staff, if you want one, to be a single point of contact and support you and your family if appropriate, to achieve those goals. This person may be a case manager, a nurse or other clinician, a care co-ordinator or social prescribing link worker.

Survivor and bereaved of the Grenfell Tower fire (continued)

- The ongoing support you receive could involve mental health or physical health services provided by NHS or community organisations, which may also be provided in conjunction with social care and housing services.
- If you are a survivor who was in the Grenfell Tower on the night of the fire, you will also be offered an annual respiratory check led by a consultant specialising in respiratory health, including a lung-function test.
- If you opt not to have any of these services, you will be proactively contacted on an annual basis to re-check whether you would like to receive any support. This will be done once, rather than multiple times by different services.

A member of the North Kensington community

- You will be able to access a range of Grenfell related services to discuss and assess your health needs. This includes health checks at GP practices and community locations close to the Tower site and a range of NHS and community- based emotional wellbeing support.
- Where appropriate, for example, if you have long-standing or complex health needs, you will be offered a case manager or care co-ordinator who will work in partnership with your GP to support you to manage your health conditions.
- This will include options to access a range of community-based wellbeing services, which will also be offered to people who could benefit from preventative advice and support, to better manage the risks of future illness.
- This includes specific services for families, children and young people and services for people from cultural backgrounds that typically experience poorer health.

Support for clinicians and members of staff supporting the community

- If you are a clinician, or member of staff, providing services and support in the North Kensington area you will be able to receive training in trauma-informed care, cultural competency and other relevant subjects.
- Staff will also have access to their own wellbeing advice and checks, if requested.

Everyone will have access to information about the services provided locally, which will include easy to read detail on how to access those services in a range of formats, languages and locations.

Information about health monitoring service performance and outcomes will also be readily available, and you have the chance to be involved in groups or panels that will make decisions on how funds are allocated and the monitoring of services (with appropriate training and support).

6. Next Steps

This document has attempted to make proposals on the future shape and direction of health services and support. It takes into consideration a range of evidence and viewpoints on current and future health needs, professional advice on the requirements for health services of meeting the Coroner's Regulation 28 report, and the rules and processes governing the allocation of NHS funds and provision of services.

The proposals listed above are designed to generate discussion and debate on how to change or improve services. We now want to encourage people to share thoughts on any of the points raised, and welcome different ideas about the design of services and other aspects of the recovery programme. On the 07 May 2024, we will start engaging with the local community to get their feedback. You will be able to respond to the contents of the document via email, post or by one of the events we will be putting on, working in partnership with community based organisations.

Between now and then, we would like to visit as many groups as we can in the community. If you would like us to visit you, please contact us by emailing **nhsnwl.nkrt@nhs.net**.

Appendix A – List of past engagements and reviews*

- To shape the 'North Kensington Health and Wellbeing Strategy' in 2019 with input provided by 1,300 community members
- To review overall progress of the **Health and Wellbeing Strategy** in 2022/23, when 681 individual or group conversations took place.
- Review of North Kensington Recovery's asset-based approach to healthcare
- <u>Community Voices Conversations with North Kensington residents about their health</u> and wellbeing September to December 2018
- Review of North Kensington Health Partners Programme
- A range of engagement with children and young people, including
 - Young Minds reports and impact
 - Healthwatch young people's mental health and wellbeing research
 - <u>RBKC Youth review engagement findings report</u>
 - Youth Action Alliance impact reports
- Joint Strategic Needs Assessment (JSNA) 2023/2024 (to be published in May 2024)
 and 'Journey of Recovery' is the JSNA published in 2018.

*Any documents listed from external stakeholders should be viewed as reference documents only (as part of our information gathering process).

If you have any questions on anything relating to the Developing a community-led recovery, or would like to make suggestions, please get in touch with us: **<u>nhsnwl.nkrt@nhs.net</u>**