

SUMMARY OF PLANS TO UPDATE THE GRENFELL JOINT STRATEGIC NEEDS ASSESSMENT

APRIL 2023

This is a draft outline document. The focus of the next phase of the work on the JSNA (May to September) will be to work with bereaved, survivors and residents to gather additional evidence to inform the final document to be published in Autumn 2023.

1. EXECUTIVE SUMMARY

This document outlines plans to update the 2018 [Journey of Recovery](#) Joint Strategic Needs Assessment (JSNA) to build a better understanding of the ongoing impact of the Grenfell tragedy on bereaved and survivors and local residents.

An updated JSNA is needed to help us plan collectively with the community for the next phase of support, ensuring the right support is in place for those most affected by the tragedy, now and in the future.

This outline document summarises some of the evidence gathered since 2018 about the ongoing impact of the tragedy on survivors, bereaved family members and people living in the immediate local community. It sets out an initial view of what this evidence means for the longer-term needs of these specific groups, focusing particularly on the challenges ahead in the next phase (2024-28).

This document includes quantitative and qualitative evidence which the Council and the NHS have gathered through their work with communities since 14 June 2017. That we know more about the needs of the community than we did in 2018 is thanks to bereaved and survivors, local residents and grassroots organisations, their willingness to work with us and share their feedback and their support and challenge.

The document present an initial picture of the health and wellbeing needs of those most affected, now and in the longer term. The initial areas of need and key themes are set out in the table below:

Bereaved and survivors	<ul style="list-style-type: none">• The specific long-term impacts of public tragedy, including the longer-term justice process and decisions about the Tower.• The importance of considering the specific needs of different groups within the bereaved and survivor cohort.• The importance of having the appropriate ongoing mental and physical health support in place to meet identified needs.• The need to focus on enhanced support for children and young people, recognising that educational and broader opportunities for children are a key preoccupation of bereaved and survivors.• The importance of choice, flexibility and control for families in deciding what support to access, when and how, including the need for a menu of different options.• The need to continue to focus on peer support, creating opportunities for people to connect and come together to support one another.• The need to ensure bereaved and survivor voices are at the centre of plans for the future.
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<p>Immediate local community</p>	<ul style="list-style-type: none"> • The need to focus support in a more targeted way on the immediate local community living near the Tower. • The need to plan for the impact of decisions about the future of the Tower on the immediate local community. • The need for access to appropriate high quality mental and physical health services that take into the specific impact of the Grenfell tragedy on the local community and the complex and cumulative interplay of inequalities which pre-date the tragedy. • The need for an increased focus on preventive health interventions and on proactively building health and wellbeing. • Rather than a narrow focus on ‘recovery’ with a clear end point, the importance of finding long-term ways of working with the community to support them to live with the longer-term impacts of Grenfell and other events. • The need to focus specifically on the needs of children and young people, building on international best practice. • The need to support community-led recovery wherever possible in a context of low levels of trust in public authorities. • The need to ensure residents can access support in trusted, community-based settings including through local organisations. • The need to create more space for peer support approaches, building on work to date to support residents to come together. • The need to focus on cultural competency and community knowledge and expertise, ensuring that services are designed to meet the needs of the diverse communities living in the area.
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However, we are publishing this document in draft form now so that we can work with the community over the next six months to build a more comprehensive picture of community needs. We hope that the evidence presented here and the initial conclusions drawn will be discussed, debated and challenged over the next 6 months.

Residents, partners and other stakeholders are therefore invited to:

- comment on the approach to updating the JSNA;
- review and comment on the sources of evidence listed below, where possible helping to identify potential other evidence we might consult;
- review and comment on the initial areas of need identified for bereaved and survivors and the local community, suggesting changes or additional themes;
- suggest further ways we might work with the community to build a more comprehensive picture of health and wellbeing needs in the next phase.

On the basis of this work with the community, we will look to publish a final version of the updated JSNA in Autumn 2023. This will support future planning across the Council and the NHS, shaping longer-term provision for those affected and ensuring services are as joined up and aligned as possible.

Just as health and wellbeing needs of those affected have changed since 2018, so too will they continue to evolve in the future. The impact of the tragedy will be continue to be felt long into the future, especially by those most affected. While this needs assessment has a particular focus on the challenges of the next phase, it is therefore critical to acknowledge that it is not possible to put a timescale on people’s recovery journeys. As part of the final JSNA, we therefore set out plans to

continue to monitor the impact of the tragedy, refreshing the JSNA every three years, sharing data and information regularly with the community and reviewing the support that is in place.

Although the updated JSNA will focus on the specific ongoing impact of the tragedy, it is important to note that the ongoing impact of the Grenfell tragedy is experienced against the backdrop of much wider landscape of health and wellbeing needs in the local area. Targeted Grenfell provision can only ever address some of the community's health and wellbeing needs. It is therefore vital that the JSNA sits within the Council and the NHS's broader health and wellbeing plans and strategies, including those adopted by the Integrated Care Board (ICB) and the Health and Wellbeing Board (HWB), and that we consider the interplay between the specific impacts of the tragedy and wider health and wellbeing inequalities.

The document is structured as follows:

- **Section 2** sets out some background on the original 2018 JSNA and some of the progress that has been made since then.
- **Section 3** outlines the proposed approach to updating the JSNA.
- **Section 4** sets out some of the key milestones and challenges expected in the next phase, 2024-28.
- **Section 5** summarises some of the anticipated needs of bereaved and survivors, now and in the next phase, and initial considerations for effective approaches to supporting recovery.
- **Section 6** summarises some of the anticipated needs of the immediate local community, now and in the next phase, and potential approaches for supporting recovery for this group.
- **Section 7** sets out the next steps.

2. INTRODUCTION AND BACKGROUND

The events of 14 June 2017 at Grenfell Tower were a disaster on an international scale. 72 people lost their lives, including 18 children. It was the largest loss of life to fire in the United Kingdom since the Piper Alpha disaster of 1988 and the worst fire in domestic premises since the Second World War. 371 residents from the Tower and the Walk lost their homes in the fire and hundreds of others were evacuated in the immediate aftermath.

In addition to the immediate and profound impact on those most affected (including trauma, complex grief and displacement), the impact of Grenfell was felt much more widely across the local community, across London and across the country in a way that reflected the scale and complexity of the tragedy. It raised fundamental issues about the state of social housing in the United Kingdom, inequality, social injustice and the capacity of people who have power to listen to those who don't.

2018 Journey of Recovery Joint Strategic Needs Assessment

The 2018 [Journey of Recovery](#) Joint Strategic Needs Assessment, published just over a year after the fire, showed how the tragedy's 'ripple' effects were felt across many aspects of people's lives (taking into account both primary and secondary impacts) and across a wide geographical area (across Notting Dale and in other parts of North Kensington). Although it recognised the deeply personal nature of people's individual recovery journeys, the JSNA acknowledged that such ripple effects were likely to be felt for some time (see the summary, published [here](#)). It acknowledged that disasters on the scale of Grenfell 'leave an indelible mark' and that while places experience recovery, they 'never return to the way they were before'. It drew on disaster recovery research and guidance, including a version of the 'recovery graph' (Figure 1 below) which showed that long-term recovery is not a short, straightforward or linear process.

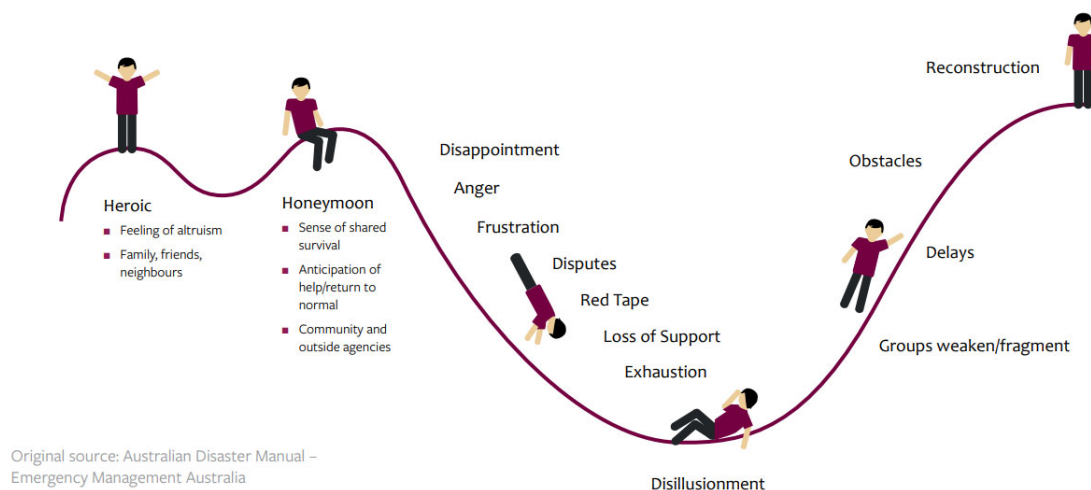


Figure 1. A version of the recovery graph featured in the New Zealand Red Cross's *Leading through Disaster Recovery: a Companion through the Chaos*.¹

The original JSNA's main objectives were:

¹ Available at: https://preparecenter.org/wp-content/sites/default/files/leading_in_disaster_recovery_a_companion_through_the_chaos.pdf.

- To give an initial picture of the impact of the fire on those affected.
- To advise the relevant public bodies (primarily the Council, the NHS and central government) on the foundations of an effective recovery.
- To inform the development of a long-term recovery strategy.
- To act as a reference point for all those wanting to assess and shape the journey of recovery, now and in the future.

The report brought together a range of evidence to give an assessment of the initial impact of the fire and make recommendations for the approach to long-term recovery:

- Evidence about the characteristics of the communities of North Kensington before the fire.
- Evidence from other disasters in the UK and across the world.
- Analysis of existing socioeconomic and health data on the impact of the disaster.
- Evidence from local communities about what matters most to those who have been affected and what their priorities for recovery are.

The 2018 JSNA made a series of eight recommendations (Figure 2 below) for public bodies to consider when thinking about long-term community-led recovery after Grenfell. However, the report also acknowledged the significant uncertainty about the nature and scale of the wider impact on the local population. This was partly a function of the relatively short period of time which had elapsed since the tragedy, the limited range of data available and the significant questions which remained unresolved (including the future of the Tower and the memorial and the outcome of legal processes, such as the Grenfell Tower Inquiry, civil claims and the criminal investigation).

While drawing heavily on learning from other disasters, it also pointed out that experience from elsewhere could not necessarily tell us exactly how people would be affected in this context. For this reason, one of the key recommendations was to continue monitoring the impact of the tragedy and adapt the approach.

1. A long-term commitment to recovery from all partners

Partners including Kensington and Chelsea Council, the NHS and Central Government, as well as local schools, housing associations, voluntary and community organisations and others at all levels need to commit to a long-term recovery.

2. A commitment to addressing long-standing needs locally

There was significant need in North Kensington but also more widely prior to the fire. Those needs have not gone away, it is vital not to underserve those whose health, social and welfare needs are ongoing.

3. Permanently rehousing survivors.

Rehousing survivors is critical to recovery including ensuring they are well supported in their new homes.

4. Ongoing monitoring of the physical health of those impacted on the night of the fire

There needs to be ongoing monitoring and support for physical health, particularly for survivors who were exposed on the night of the fire.

5. A diverse and well-resourced strategy to support mental health and wellbeing across the community

There will be significant need to support mental being delivered in ways which recognise diversity in the ways people want to be supported, which effectively reach all different parts of the population.

6. Establishing the future of Grenfell Tower and the site

The future of the Grenfell Tower and the site is critical to recovery.

7. Putting community at the heart of recovery

National and international guidance makes it clear that a successful, sustainable recovery must be community-led, with public bodies working in partnership with communities, investing in local services and community assets which allow communities to support themselves.

8. Continuing to understand emerging need and adapt the strategy with high quality data

There is a need for high quality data to understand the ongoing scale and nature of the impact and recovery and to ensure we understand how effectively peoples' needs are being met. This needs to be used to adapt the recovery strategy as new insight is gained as to the ongoing impact and what support is making a difference.



The kids club at Henry Dickens Community Centre

Figure 2. Recommendations from the Journey of Recovery Joint Strategic Needs Assessment (2018).

Work to support Grenfell Recovery since 2018

Since 2018, a wide range of support has been put in place by the Council and the NHS to respond to the recommendations of the JSNA. The Council put in place a targeted Grenfell Recovery programme in 2019 to provide dedicated support to bereaved and survivors and a wide range of community-based support to people living in North Kensington. This work is summarised in the recent annual report on the delivery, reach and impact of the programme, available [here](#). This includes details on what is being delivered through the programme, who it is reaching and what difference people feel it is making.

As set out in the report, this work has been designed and delivered in partnership with bereaved and survivors, residents and over 100 local community organisations who have worked with the Council to deliver services and initiatives.

Alongside Council-funded provision, the NHS has put in place a recovery programme comprising a range of services, some of which have been put in place in response to the HM Coroner's Regulation 28 Report recommendations. These services are summarised in the figure below.

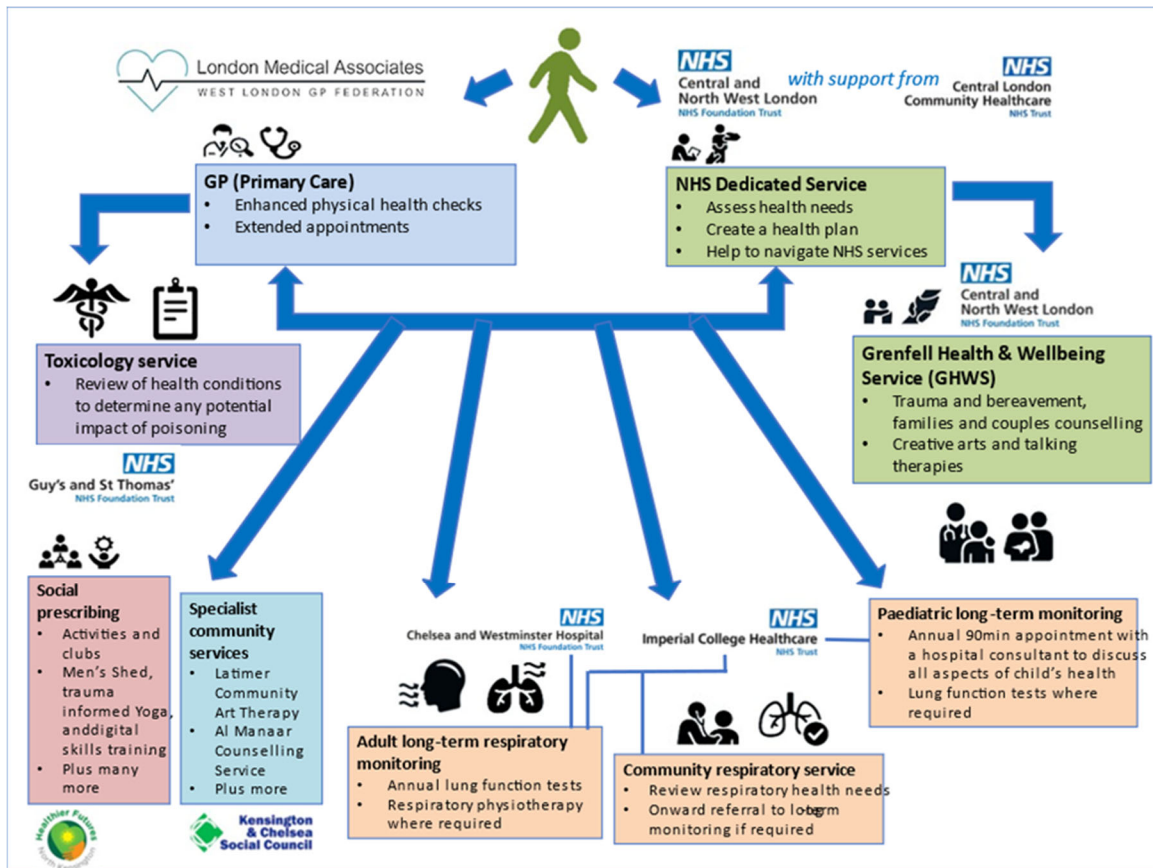


Figure 3. NHS North West London ICB North Kensington Recovery Health services.

Arrangements were also put in place to monitor the health of bereaved and survivors and the local community. In addition to the clinical monitoring overseen by the NHS and the environmental monitoring overseen by DLUHC, the Council committed to continually monitoring the health and wellbeing needs of the North Kensington population. The Grenfell Public Health programme comprises two main elements – population health monitoring (which monitors anonymous NHS patient data on health conditions, prescription medicines and use of NHS services) and an annual health and wellbeing survey (which asks residents about their health, wellbeing and recovery).

Revisiting the 2018 JSNA

Almost six years on from the Grenfell tragedy and five years from the publication of the 2018 JSNA, the ripple effects are still keenly felt by the bereaved and survivors and many residents in the immediate local community. Many people continue to experience the primary and secondary impacts of the tragedy acutely. Given the complex and highly public nature of the tragedy, those most affected are reminded daily of their trauma and loss by the Grenfell Tower Inquiry and the legal processes, by media coverage, by conversations about the future of the Tower and by their engagement with public bodies, including the Council, the Government and the NHS.

Significantly more is known about the impact of the tragedy than in 2018. Additional quantitative information has been gathered through the Grenfell Public Health programme, including through population health monitoring and the North Kensington Health and Wellbeing Survey (for a summary, see Appendix A). Information has also been collected through the Council's Grenfell Recovery programme and the NHS North Kensington Recovery Programme. This includes details of who is accessing targeted services put in place to support recovery and what difference people feel they are

making. Additionally, more information is available about the local population from the 2021 census and other sources.

We know that quantitative data and population-wide indicators don't always capture the complexity of people's experience of the ongoing impact of the tragedy. Just as important has been our work with communities to better understand their needs. Through the North Kensington Health and Wellbeing survey, for example, we have gathered qualitative information about how people *feel* and what kinds of services are most helpful to support their health and wellbeing. More broadly, there has been a strong focus on consultation and engagement, through the Grenfell Recovery programme and the NHS's development of a [Health and Wellbeing Strategy](#) for North Kensington.

Approaches have worked best where we have listened and worked in partnership, both directly with residents and with local organisations who can help us to reach people we might not otherwise reach. Using engagement and codesign approaches with bereaved and survivors through the Dedicated Service and with the local community through the wider Grenfell Recovery programme, we have built a better understanding of communities' needs, their concerns for the future and what kind of support works best for them. This has not always prevented us from making mistakes, but there are valuable lessons from approaches, both those that have worked and those that haven't, which are important to reflect on and find a way to incorporate into plans for the next phase.

There has been considerable learning from this work with communities, but there remains a lot that we still do not know at this stage. Many of the areas of significant uncertainty identified in the original JSNA remain almost five years later. The Grenfell Tower Inquiry has not yet concluded, the criminal investigation is ongoing and no decision has yet been made about the future of the Tower or the memorial (though the Grenfell Tower Memorial Commission's interim report, [Remembering Grenfell: our journey so far](#) from May 2022, outlines the ideas gathered to date for what a future memorial could look like). These issues will continue to shape people's experience of the tragedy and there will be major milestones ahead in the next period. The commemorations to mark the fifth anniversary of the tragedy in 2022 were a powerful reminder both of how much time has passed since 2017 and of the many issues people feel are still unresolved.²

We know there remains considerable uncertainty and anxiety among bereaved family members, survivors and local residents about the longer-term mental and physical health impacts of the tragedy. The response to the recent coverage about the health of Grenfell firefighters demonstrates the depth of the concern in this area. Even where there isn't evidence of specific health risks or where monitoring has not identified areas of concern (as with the recent Government-led programme of [environmental checks](#), for example), that doesn't mean that community concerns have abated. In the case of the recent environmental checks, soil tests carried out around the Grenfell tower showed no evidence of harmful contamination due to the fire, and the levels of all potential harmful chemicals in the soil were found to be within the range of typical urban areas. More work is needed to share information with communities and to work with them to understand areas of concern, especially thinking ahead to the future and decisions about Grenfell Tower.

More broadly, before, during and since the fifth anniversary, we have heard concerns from bereaved, survivors and local people about being 'forgotten' and about public authorities 'moving on' from the tragedy. There is clearly anxiety about the depth and seriousness of the collective long-term

² See, for example, <https://www.westminster-abbey.org/abbey-news/abbey-marks-anniversary-of-grenfell-tragedy> and <https://www.youtube.com/watch?v=Quypd4kwCoo>.

commitment to recovery (one of the foundational recommendations of the 2018 JSNA) and more work is needed to assure local people of this.

One reason for this is the widespread lack of trust in the Council and other public bodies, which continues to create challenges for recovery. The recent Grenfell Legacy conversation about change at the Council demonstrated the scale of the challenge we face, with 62% of the over 400 respondents telling us they do not feel the Council has changed since Grenfell or has changed for the worse. The fact that the Council is both an agency responsible for supporting recovery and an organisation that people hold responsible remains a defining feature of the Grenfell context. There are also disconnects in communities' relationships with other public bodies and this continues to have major implications for the approaches we take. Despite low levels of trust, bereaved family members, survivors and residents continue to show a humbling willingness to work *with* the Council, the NHS and other partners to improve services, even where they are not always sure of the benefits of doing so. In the next phase, we must build on this to develop genuinely community-led approaches which focus on working in partnership with residents and local organisations.

The ripple effects of the tragedy are not experienced in a vacuum but against an ever-changing backdrop of challenges, some longstanding and others more recent. Over the past nearly 6 years, there have also been other events which have had a profound impact on the health and wellbeing of local people, most obviously the COVID-19 pandemic and the rising cost of living. The Council and the NHS continued to deliver targeted support to those affected by the tragedy throughout the pandemic, but it is clear that it has had a further impact on people's health and wellbeing.

For example, in 2020 one in three respondents to the North Kensington Health and Wellbeing Survey reported they were more anxious and stressed compared to pre-pandemic and nearly half of respondents reported being made financially worse-off by the Covid-19 pandemic. Commonly reported personal impacts of the pandemic included feelings of isolation, health concerns and missing friends and family.

In 2022, 41% of survey respondents stated they were more worried about the rising cost-of-living, with those with no income, earning less than £30,000 per annum, those in part-time employment and those part of the refugee community more likely to report being somewhat to significantly worried about the rising cost-of-living. In addition, 65% of respondents reported they were struggling financially, with those living in social housing more likely to report experiencing this.

3. UPDATING THE JSNA FOR THE NEXT PHASE

As we approach the end of existing Grenfell recovery plans, including the targeted recovery programmes put in place by the Council and the NHS which are due to come to an end in 2024/25, we are beginning to work with communities and partners to plan for the next phase of support.

In line with the recommendations of the 2018 JSNA, we need to look again at what the evidence is telling us and set out a renewed understanding of the needs of those most affected, pulling all information together in one place so that it is clear what evidence is informing decision making.

The updated JSNA will set out what we know about current and anticipated future needs of the bereaved and survivors and local residents beyond the current phases of the NHS and Council programmes.

The updated JSNA will build on the 2018 document to:

- Develop a better understanding of residents' health and wellbeing needs.
- Gather and collate a single evidence base from a range of sources, shared across partners and communities.
- Share lived experiences and local voices in a co-ordinated way, recognising health, care and housing needs are connected.
- Identify best practice, strengths and gaps in local services and approaches.
- Set out progress to date against the 2018 recommendations and develop new recommendations and priority areas for action.
- Help shape future targeted Council and NHS provision for those most affected by Grenfell, including joint solutions to meeting future needs and future arrangements for monitoring health and wellbeing.

Alongside the plans for wide-ranging consultation and engagement on future service provision over the next 6-9 months, the updated JSNA will help us to shape the next phase of support, ensuring we can support people effectively to cope with the ongoing impacts of the tragedy in the next phase.

The Council and the NHS have a statutory duty to monitor the health and wellbeing of the population and JSNAs are a frequently used tool to develop a joint understanding of the needs of a particular community or area. The specific focus of this JSNA is justified by the scale and the impact of the Grenfell tragedy and the long-term commitments that public bodies, including the Council, the NHS and the Government, have made collectively to survivors (as a protected class of person) and bereaved family members and to the local community.

Although the updated JSNA will focus on the specific ongoing impact of the tragedy, it is important to note that the ongoing impact of the Grenfell tragedy is experienced against the backdrop of much wider landscape of health and wellbeing needs in the local area. Targeted Grenfell provision can only ever address some of the community's health and wellbeing needs. It is therefore vital that the JSNA sits within the Council and the NHS's broader health and wellbeing plans and strategies, including those adopted by the Integrated Care Board (ICB) and the Health and Wellbeing Board (HWB), and that we consider the interplay between the specific impacts of the tragedy and wider health and wellbeing inequalities.

Approach

Figure 4 below summarises the approach to updating the JSNA, building on the approach of the original document while also reflecting the evidence and learning we have gathered since 2018.

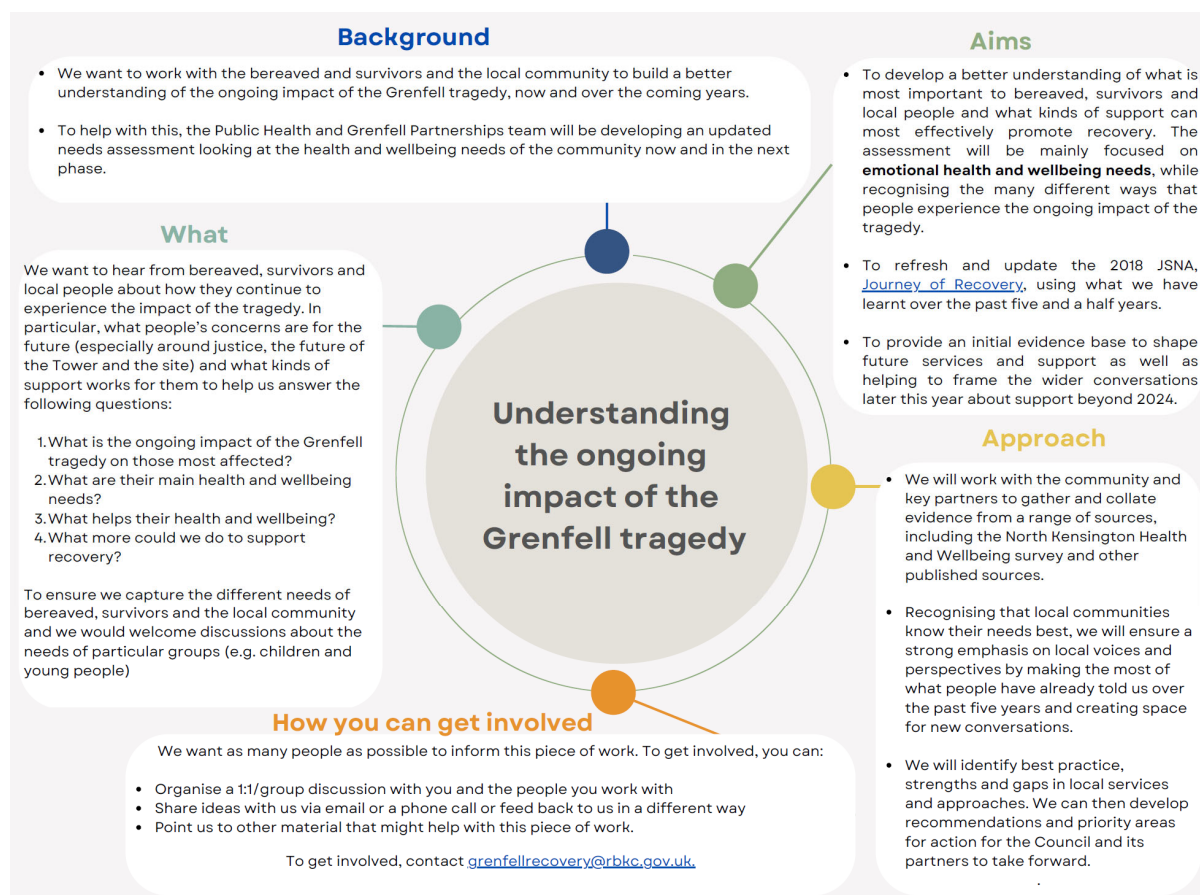


Figure 4. Summary of approach to updating the JSNA.

The updated JSNA will have a more targeted focus on the ongoing impact of the Grenfell tragedy on those most affected, including bereaved and survivors and those in the immediate local community, especially people living near the Tower. It will seek to distinguish more carefully between the different needs of people both within the bereaved and survivor cohort and within the local community, recognising the diversity of people's experiences and the different impacts on people's lives. Where at times we may have taken a broader approach, this will help to ensure a greater focus on those most affected. However, the document will also have regard for the broader context of health and wellbeing inequalities in Notting Dale and North Kensington more broadly and the complex interplay of these factors with the ongoing impact of Grenfell.

The document will explicitly consider the potential impact of some of the key milestones over the coming years, including decisions about future of the Tower and the memorial, the conclusion of the Grenfell Tower Inquiry and the criminal investigation and broader community concern about delayed or denied justice. A summary of these is set out at Section 4 below. We have some understanding of the likely impact of some of these events, but we also acknowledge the difficulties of predicting future health impacts, given the complex nature of the tragedy. It is therefore important that support in place in the next phase is sufficiently flexible to accommodate changing health needs and that we set out plans to monitor these needs in the next phase, in line with the recommendations of the 2018 JSNA.

The 2018 JSNA summarised background data and identified a range of key population-wide indicators of health and well-being, which have since been monitored through the Grenfell Public Health programme and other mechanisms. This information will be updated for the final version of the JSNA to be published later this year.

The JSNA will help to build a robust evidence base, to be used by both the Council and the NHS, for the provision of Grenfell-specific services in the next phase. Alongside the implications for the next phase of the Council’s work on Grenfell, the JSNA will also have wider implications for the work of the Council and its partners in the local area.

Just as health and wellbeing needs of those affected have changed since 2018, so too will they continue to evolve in the future. As part of the final JSNA, we will therefore set out plans to continue to monitor the impact of the tragedy, refreshing the JSNA every three years and sharing data and information regularly with the community.

Sources of evidence

The draft JSNA will draw on a wide range of quantitative and qualitative data to capture the specific impact of the tragedy in terms of both population health and broader community sentiment. The main sources of evidence are summarised in Table 1 below.

Source	Summary of data
Grenfell Public Health programme	Population health monitoring of NHS data from April 2016, and findings from the North Kensington Health Wellbeing survey 2019 to 2022 provide insight into key trends in health conditions and perceptions of the ongoing local impact of the tragedy (see Appendix A).
Data from the Council’s Grenfell Recovery programme	Quantitative and qualitative data on the reach and impact of services and qualitative data gathered through consultation and engagement over the past five years (e.g. the wide-ranging 2021 review of the Dedicated Service with bereaved and survivors). The most recent data is set out in the second annual report on the delivery, reach and impact of the Grenfell Recovery programme (available here).
NHS data	Quantitative data about the take-up, reach and impact of NHS services and qualitative information gathered through consultation and engagement on the refresh of the NHS Health and Wellbeing Strategy.
Evidence from other disaster recovery, including relevant literature and research	Review of evidence from other disaster recovery contexts, including from other mass fatality public tragedies, focusing specifically on evidence about longer-term needs of the bereaved and survivors and the likely impact of future milestones.

Conversations with specialist organisations	Conversations with national organisations specialising in supporting those with trauma, grief and bereavement (including in the context of public tragedies) to gather information about best practice in this area.
Conversations with community groups and partners	Conversations with bereaved and survivor groups, residents' groups, local organisations involved in delivering the recovery programme and local NHS and VCS partners to gather their perspectives on key needs and concerns for the next phase.
Additional qualitative research with key groups	This will help build a better picture of the ongoing impact of the tragedy, especially those identified as most affected by the Health and Wellbeing survey (particularly people living in the area immediately around the Tower).
Broader population-wide indicators and wider monitoring work	Background data on the broader social determinants of health in the local area to set the context and wider monitoring information (e.g. UKHSA air quality monitoring and the results of the Government-led programme of environmental checks).

Table 1. Key sources of evidence to inform the updated JSNA.

As set out above, much of this information is already available and conversations have begun with community groups, local partners and national organisations with expertise in this area.

Since January 2023, we have focused on:

- Starting to compile evidence from the various sources outlined above to inform the development of key themes.
- Reaching out to partners, bereaved and survivor groups, community organisations, schools, healthcare providers and local organisations to understand their perspectives on the ongoing impact of the tragedy.
- Contacting national organisations with expertise in this area to understand the medium- and longer-term impacts of public tragedy, particularly on bereaved and survivors but also on local people.
- Reviewing the broader disaster recovery literature to identify key themes and lessons and to understand the potential impact of some of the key milestones ahead.
- Using this work to develop some initial key themes, set out in Section 5 and Section 6 below, to be tested and refined over the next 6 months.

The focus of the next phase of the work on the JSNA (May to September) will be the gathering of additional quantitative and qualitative evidence to inform the final document to be published in Autumn 2023.

4. FUTURE CHALLENGES

As we look ahead to the next phase of recovery, we expect several significant milestones events which are perhaps more clearly defined than they were in 2018. The timing of these events is of course uncertain but they will include:

- A decision on the future of the Tower
- Development of plans for memorial, including agreement on a final design
- Publication of the final Grenfell Tower Inquiry report with recommendations
- Response of bereaved, survivors and residents and core participants to the Inquiry's findings and recommendations
- Implementation of a decision about the future of the Tower
- Construction of a future memorial
- Conclusion of the criminal investigation by the Metropolitan Police
- Decisions by the Crown Prosecution Service
- Prosecutions as part of the criminal investigation

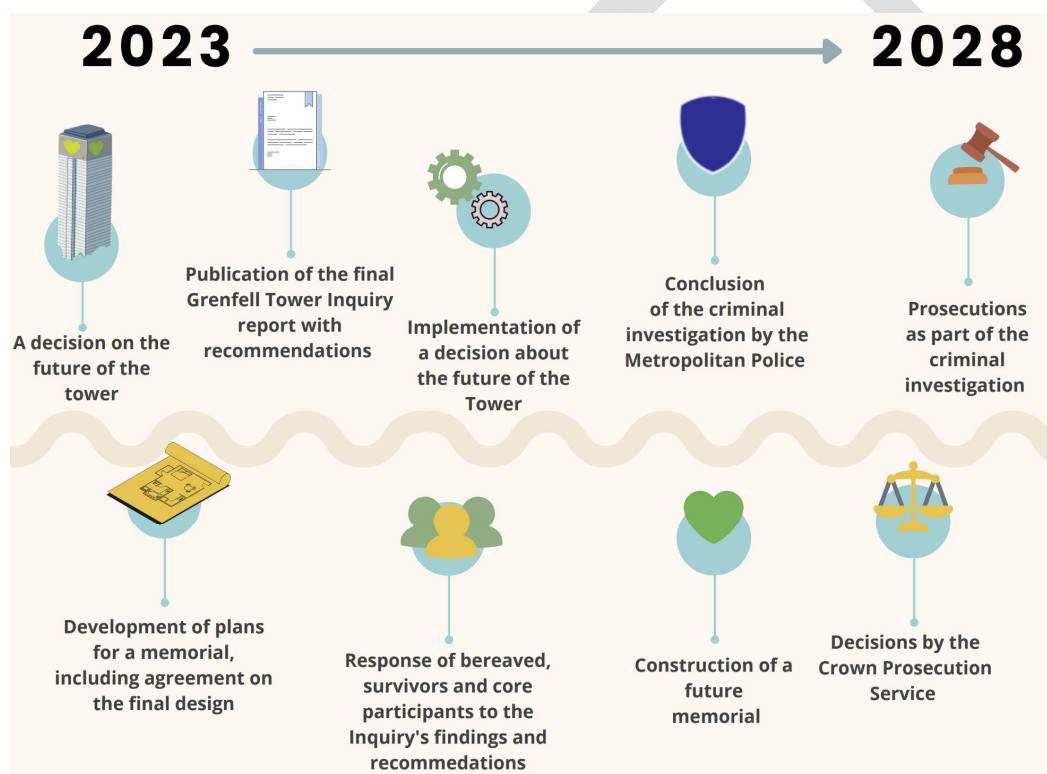


Figure 4. Summary of key milestones in the next phase (Please note: Exact dates, timings and sequencing events are unknown at this stage).

In keeping with the spirit of the original document, the sections below outline some of the expected impacts of these challenges, first for bereaved and survivors and then for the local community, and potential approaches to supporting recovery for both groups against this backdrop.

5. BEREAVED AND SURVIVORS – KEY THEMES

Understanding the needs of bereaved and survivors

The people most directly affected by the tragedy are those who lost loved ones and those who survived the fire but lost their homes and their possessions. Since 2017, the Council and the NHS have worked closely with bereaved and survivor families, providing tailored support through the Dedicated Service and a range of specialist health support.

The Council's Dedicated Service works with over 700 bereaved family members, survivors and former residents of Grenfell Walk, broken down as follows:

	Eligible (758)	Accessing (733)
Bereaved	318	303
Bereaved survivor	33	33
Survivor	331	327
Grenfell Walk	76	70

Table 2. Numbers of bereaved and survivors accessing the Council's Dedicated Service.

76% of survivors accessing the service still live within RBKC and 24% now live outside of the borough, most in neighbouring boroughs.

Of the bereaved family members accessing the service, 36% are resident in RBKC (some of whom are Council tenants) and 64% live outside the borough, mostly in London but with some further afield. This does not include bereaved family members who live permanently outside the UK. 73% of bereaved family members lost more than one relative in the tragedy.

The bereaved and survivor cohort is very diverse, reflecting the diversity of those who lived at Grenfell and those who lost their lives in the tragedy:

- 55% individuals accessing the Dedicated Service are female.
- Bereaved and survivors choose to describe their ethnic background in different ways. 39% fall under the 'Other ethnic group' category, 25% are Black, 13% are Asian, 11% are White and 10% are of 'Mixed' ethnicity.
- 50% of bereaved and survivors accessing the Dedicated Service are Muslim and 26% are Christian.
- The most common languages spoken by bereaved and survivors other than English are Arabic, Farsi, Amharic and Spanish.

The NHS also provides a Dedicated Service, designed to support and coordinate bereaved and survivor groups to access a range of emotional and physical wellbeing health services. People who take up the offer are classed as 'active'. People who are eligible but do not take up the offer, or who are not contactable, are classed as 'inactive'. All active service-users are offered a health review which is carried out by their Dedicated Service health worker. In total 96% of eligible people have been offered the service with 70% having been an active service user at some time since 2017.

The NHS Dedicated Service has collated a number of case studies detailing the impact of support offered, with approval of the relative individuals and families, and is developing an outcome tool in collaboration with service users.

Key challenges and approaches

In light of the broader challenges outlined above, the following are a number of key issues that will need to be considered in the next phase:

- The specific **long-term impacts of public tragedy**, including the profound implications for recovery of the longer-term justice process and decisions about the future of the Tower.
- The importance of considering the **specific needs of different groups** within the bereaved and survivor cohort as driven by their experiences. This includes:
 - The fundamental importance of **housing**, especially for survivors who escaped the Tower on the night and lost their homes but also for bereaved families concerned about their housing needs.
 - The need to consider the specific needs of different groups within the bereaved and survivor cohort, especially **people who lost immediate family members** who require support with bereavement and whose experience may be different from that of others.
- The importance of having the appropriate ongoing **mental and physical health support** in place to meet identified needs, including specific health needs of survivors who left the Tower on the night of the fire.
- The need to focus on enhanced support for **children and young people**, recognising that educational and broader opportunities for children are a key preoccupation of bereaved and survivors.

The sections below set out some initial considerations in each of these areas and some potential approaches, based on our work with bereaved and survivors to date and learning from other settings:

- The importance of **choice, flexibility and control for families** in deciding what support to access, when and how, including the need for a menu of different options.
- The need to continue to focus on **peer support**, creating opportunities for people to connect and come together to support one another.
- The need to ensure **bereaved and survivor voices** are at the centre of plans for the future.

The specific **long-term impacts of public tragedy**, including the profound implications for recovery of the longer-term justice process and decisions about the future of the Tower.

- National organisations and academic research remind us that public tragedies tend to complicate already difficult processes of recovery from trauma, grief and mourning, especially for survivors and bereaved family members who are directly affected.³
- The scale and complexity of the Grenfell tragedy and the range of political, cultural and psychosocial issues that it raises gives the tragedy an intensely public character, with constant coverage in the media and interest from a wide range of people and organisations.

³ See, for example, A. Eyre and P. Dix, *Collective Conviction* (Oxford: 2014) and M. Lattanzi-Licht, J. D. Gordon and K. Doka (eds.) *Living with Grief: Coping with Public Tragedy* (New York: 2003).

- For many bereaved and survivors, this focus is critical for the success of campaigns for longer-term change. However, families can sometimes feel that their trauma and loss become part of a public event, rather than a private sorrow, giving rise to a loss of control. For bereaved family members or survivors, the intensity of the public focus can lead them back repeatedly to the circumstances in which their loved ones died or force them to relive their trauma.⁴
- Where families' recovery and grief are bound up with broader national legal and political processes, bereaved and survivors may feel they have to put their trauma or grief 'on hold' while they focus on these processes. As one survivor has put it: 'It's tough for our community because, especially in this tragedy there is no conclusion'.⁵ While there is uncertainty around these issues, it may be difficult for people to move forward and, in some cases, people may not want or feel able to while these major issues are unresolved.
- When we asked bereaved and survivors accessing the Council's Dedicated Service about what was most important to them when thinking about their recovery now and in the next phase, 78% of the 130 respondents selected 'Justice, including the outcome of the Public Inquiry and the criminal investigation'.
- Similarly significant are decisions about the future of the Tower and the memorial, with 71% of respondents saying these would be important to their long-term recovery. While there is uncertainty around these issues, it may be difficult for people to move forward and, in some cases, people may not want to while these major issues are unresolved.. Progress towards a decision about the future of the Tower and the Grenfell Tower Memorial Commission's work to build consensus about a future memorial will clearly be critical and it will be important to ensure that families have access to the right support through these processes.
- These wider political and legal processes also place enormous pressure on families in the here and now. Attending the Inquiry, speaking to lawyers, participating in conversations about the future of the Tower and memorial and taking part in consultation and engagement with the Council and the NHS all place significant demand on families' time and energy. We need to recognise the different kinds of stress that these processes can have on families, including individual mental and physical health, family dynamics and relationship breakdown and conflict between individuals and groups. All of these factors can make it difficult for people to seek support.⁶
- We can expect these key milestone events to shape the recovery journeys of families profoundly over the next few years. Against this backdrop, public bodies need to clearly signal that support is in place for the long term so that people can feel more confident navigating the challenges ahead.
- It is also important to recognise the potential impact of these processes on the quality of bereaved and survivors' relationships with public authorities. Firstly, public bodies should be careful not to place additional demands on families but try to make it as easy as possible for people to focus on what is important to them. Secondly, the Council and other public bodies are core participants in the Grenfell Tower Inquiry and potential defendants in the criminal investigation, as well as agencies providing support. It is important to recognise that while some families may want a relationship with the Council (even if it is a conflictual one), others will not and will want to seek support through other channels.

⁴ See, for example, the advice and guidance from Cruse Bereavement Support available here: [Major disasters or terrorist attacks - Cruse Bereavement Support](#).

⁵ Quoted in Feruza Afewerki, *Gold and Ashes* (2022).

⁶ See [Major disasters or terrorist attacks - Cruse Bereavement Support](#).

- The separation of the Dedicated Service from the rest of the Council and the increasing emphasis on choice and control have been important for many families in this context. In 2021, over three quarters (78%) of the over 230 people who responded to the review of the Dedicated Service told us they were comfortable with the current model, but we need to recognise that this could change at any time in the future and consider whether (and when) we are best placed to provide support.

The need to consider the **specific needs of different groups** within the bereaved and survivor cohort linked to their experiences. This includes:

- The fundamental importance of **housing**, especially for survivors who lost their homes but also for bereaved families concerned about their housing needs.
 - The need to consider the specific needs of different groups within the bereaved and survivor cohort, especially **bereaved family members** who require support with bereavement and whose experience will be different from that of others.
- To date, the Council’s Dedicated Service has provided a universal service offer to bereaved family members, survivors and former residents of Grenfell Walk, albeit one that is tailored to meet families specific needs.⁷
 - Moving forward, there is a need to recognise the diversity of experience within the bereaved and survivor cohort and to tailor support more effectively to recognise the needs of different groups. In particular, it is important to consider the different impacts of experiencing the trauma of escaping the Tower on the night of the fire, the fear of losing one’s life, losing one’s home and one’s possessions and losing one’s loved ones. All of these experiences have the potential to cause considerable trauma and distress, but the remedies and solutions may be different as time moves on. Support will therefore need to be available for all groups, but it may need to be more varied than before to ensure specific needs identified can be met.
 - Conversations with national organisations suggest that it is important for public authorities not to get ‘stuck’ with their own categories. On the one hand, it is important to recognise that there is a hierarchy of impact from any tragedy (including distinctions made through legal processes), to acknowledge the different needs of families with different experiences and to avoid treating everyone in the same way. On the other, it is important (where possible) to avoid hard boundaries which might feel exclusionary and to acknowledge that distinctions created by public authorities can themselves create friction.
 - Moving forward, it is important to think more broadly about families who might have been missed. Now is a good opportunity to reach out again to people who might have been missed and to cast the net as wide as possible in the next phase, while accepting that not everyone will need or want to take up support.

Housing

- 371 residents lost their homes in the Grenfell tragedy and, as signalled in the 2018 JSNA, the main focus of the support in the emergency response phase was the permanent rehousing of survivors from Grenfell Tower and Grenfell Walk. Of the 201 households from the Tower and

⁷ For more on the support available through the Dedicated Service, see Section 8 of the second annual report on the delivery, reach and impact of the Grenfell Recovery programme (available [here](#)).

the Walk, 198 are now in permanent homes with three in high quality temporary accommodation.

- However, the initial rehousing effort was just the beginning; as recognised in the 2018 JSNA, the longer-term challenge was to support families to settle in their new homes. We have heard clearly that in a traumatic and highly pressurised environment, it was sometimes difficult to make important decisions about their housing future in the initial months after the fire. While many households are happy in their new homes, some households have subsequently found that they now cannot settle, and do not feel they can rebuild their lives in their current homes. For these families, their homes now feel like a barrier to recovery.
- In a November 2022 survey of households from Grenfell Tower and Grenfell Walk, 66% of the 36 respondents reported having settled well in their home and 78% rated the quality of their home positively. However, about 20% of respondents told us they still do not feel settled. As of February 2023, 13 of the 201 households have already moved and there are currently 39 households looking to move to a new permanent home.
- The comments from the 2022 Grenfell Housing Services (GHS) survey give an indication of the range of feelings bereaved and survivors about their new homes:

“ I am not living where I'm used to and like living, as I am used to North Kensington. The property is also not like for like from my old property ”

“ There are ongoing changes which need to happen in the property... Once these happen we will feel settled ”

Comments from respondents to the 2022 Grenfell Housing Services Annual Survey

- Many feel they have lost the community spirit they had when living in Grenfell Tower and some feel isolated where they now are. Another survivor's words capture the feeling of being out of place:

Funny how one of the labels the government/council gave us when we lost our homes was “displaced”. – because even though I am settled where I am now, a part of me still feels displaced.⁸

- More broadly, alongside specific cases where households are struggling to settle, housing concerns remain a key focus for survivors and their families. 37% of all actions identified in Council survivors' Dedicated Service support plans are linked to housing. Given their experience at Grenfell, housing issues (especially where there are safety concerns) can provoke high levels of anxiety among survivor households. Housing issues are often overrepresented in cases where bereaved and survivors feel they are making limited or no progress.
- Many bereaved family members did not live in the Tower and were not Council tenants and so have not had the same kind of housing support as survivors who lost their homes. However, they also struggle with housing issues. DS support plan data from March 2023 shows that over a quarter (27%) of bereaved families have requested support with housing in the last six months.

⁸ Quoted in Feruza Afewerki, *Gold and Ashes* (2022).

- Safe high-quality housing is foundational for people’s wellbeing more broadly, but it is especially important in the Grenfell context. Homes should be a haven for families, but issues with a property or wider anxieties about housing generated by Grenfell can often undermine the safety and security that they should feel. It is therefore vital to support survivors to settle in their homes and ensure responsive housing management services and broader support with changing housing needs.
- Beyond housing, broader practical support to navigate complex systems is often important for families impacted by public tragedy, as highlighted by the Casey Review of the needs of families bereaved by homicide. In the recent 2022 Dedicated Service survey, 69% of the 130 respondents identified their Dedicated Service Worker as important or very important to them when thinking about the future. Practical support often allows families to focus on what matters most to them and we need to consider how to adapt the support to ensure this is the case moving forward.

The specific needs of bereaved families

- Throughout the emergency response phase following the tragedy, much of the support was focused on survivors who lived in Grenfell Tower and Grenfell Walk to whom the Council had an immediate housing duty. One consequence of this was that many bereaved family members, especially immediately bereaved family members who lost close family members and often did not live in the borough, felt ‘left behind’ or ‘forgotten about’. Many did not feel able to come forward while they were still waiting for news of loved ones, struggling in the early stages of grief or trying to support their families.
- As noted in the 2011 Casey review, families who lose loved ones in traumatic circumstances have a range of specific needs.⁹ From the review’s survey of over 400 families bereaved by homicide, the vast majority (80%) reporting having suffered trauma-related symptoms and three quarters suffered depression. Families also reported other pressures, including relationship problems, additional caring responsibilities, difficulties managing their finances (especially with additional costs), alcohol and drug addiction and challenges related to employment and housing. As Casey noted, many of the challenges faced by bereaved families intensified over time:

It is perhaps not surprising that these feelings continue – their intensity may increase once the initial numbness and denial passes; grief can be stirred up again prompted by a birthday, an anniversary, or other significant event. The protracted legal process provides many triggers...¹⁰

- In this context, it is important that immediately bereaved family members receive specific support with longer-term grief and bereavement, recognising some of the specific challenges that are characteristic of bereavement through public tragedy outlined above.

⁹ <https://www.justice.gov.uk/downloads/news/press-releases/victims-com/review-needs-of-families-bereaved-by-homicide.pdf>.

¹⁰ See The Casey Review (p. 10).

The importance of having the appropriate ongoing **mental and physical health support** in place to meet identified needs, including specific health needs of survivors who left the Tower on the night of the fire.

- Conversations with national organisations have all indicated the importance of long-term mental and physical health support. Unsurprisingly, support with health needs is a key concern for bereaved and survivors. When asked in the 2022 DS review about what is most important for their recovery over the coming years, 74% of the 130 respondents identified mental and emotional health and 73% selected physical health. Health and wellbeing is an important priority area for families identified in their support plans but, like housing, it is also one where bereaved and survivors are disproportionately likely to report making limited or no progress.
- Clearly, no two recovery journeys are the same and individuals will require varying levels of support at different times. Some of the major milestone events listed above may act as triggers for bereaved and survivors, but so too may events in their own lives (e.g. marriages, births or secondary bereavement). There are likely to be people dealing with the symptoms of trauma and grief who have not yet reached out for support, for many different reasons. Some people may have been too overwhelmed in the immediate aftermath to access support and may now feel it may be too late for them to do so. There may also be some who accessed support very early on but were not ready to fully engage and have not revisited the offer.
- Against this backdrop, it is vital that future methods of support are co-designed with people to improve emotional health and wellbeing and recognises the complexity of trauma, grief and bereavement in the context of disaster recovery. Moreover, it is important not to pathologise grief and trauma, but rather to acknowledge them as a normal response to what they have experienced, and to recognise the stigma that can surround mental health.
- Research from other disasters suggests that mental health needs can be present for a very long time after a disaster. In a recent study of family members bereaved by 9/11, for example, it was found that 33% of the 454 families showed signs of meeting clinical thresholds for depression, PTSD, anxiety, or grief-related impairment 15 years after the disaster, a finding which underscores the long-term needs of families.¹¹
- It is also vital that support is sufficiently accessible and that the support is culturally appropriate (including for people who feel more comfortable expressing themselves in other languages), so that there are as few barriers as possible for people seeking support. This is especially important given the diversity of the bereaved and survivor cohort outlined above.
- We know there are also specific concerns around the longer-term physical health impacts of the fire, especially on those who escaped the Tower and had prolonged exposure to smoke. This is something that has been raised again in the context of the recent coverage about incidents of disease among firefighters. Moving forward, it is important to work with communities to ensure that services appropriately meet physical health needs, and that the health of survivors, especially those who escaped the Tower, is closely monitored in the long term.
- Currently, there are a range of services funded and provided by the NHS to support survivors and bereaved with health needs associated with the Grenfell Tower tragedy, including the monitoring of physical health conditions in view of their association with smoke or dust inhalation. These services are continually monitored and frequently reviewed and this provides insights for understanding both current and likely future needs of bereaved and survivors.

¹¹ See [Patterns of Comorbidity Among Bereaved Family Members 14 Years after the September 11th, 2001, Terrorist Attacks - PubMed \(nih.gov\)](#).

- Some headlines of this NHS provision include:
 - Respiratory health needs of adults are monitored on a yearly basis via clinics run from St. Mary’s and Chelsea and Westminster hospitals. 168 survivors (93%) have been offered the service by the NHS Dedicated Service and 61% have had a Lung Function Test.
 - Smoke inhalation-related toxicity is tested by the NHS Toxicology service, provided by the Clinical Toxicology Service at Guy’s and St Thomas’ NHS Foundation Trust. It has seen 54 survivors from inside the tower, and so far has not identified clinical indications of poor health that could be caused by poisoning amongst those who have been referred into the service.
 - ‘Enhanced health checks’ are also available in GP surgeries and trusted community locations – which give people an assessment of their current health and wellbeing, with a focus on lung function, breathing and emotional wellbeing. Since January 2019 there have been 942 enhanced health checks provided to survivors and bereaved, and many more to the wider community.
 - Extended GP Appointments: GPs in North Kensington offer longer, up to 60-minute appointments for patients affected by the Grenfell Tower Fire. The extended appointments give more time with the GP to address physical and emotional wellbeing concerns.
 - The Grenfell Health and Wellbeing service has a remit to provide resilience building support and interventions to the North Kensington community, including bereaved and survivors, and any individuals and families experiencing trauma and loss related distress as a result of the fire. There has been continuous engagement with the Grenfell community and other stakeholders to support planning the next steps in the overall community recovery journey.
 - In December 2022 there were 389 open GHWS cases; of those 129 were survivors and bereaved. Overall, 96% of survivors and bereaved have been offered the service by the NHS Dedicated Service with 71% accepting and 64% seen. The 4% that have not been offered are not contactable.
 - GHWS activity numbers fluctuate based on the needs of the community as well as external factors such as the Inquiry, Tower discussions, and other news articles.
 - Since April 2020 there have been over 1000 Adult referrals and 300 CYP referrals into the service that resulted in over 800 service users entering the service.

The need to focus on **enhanced support for children and young people**, both acknowledging the importance of health and wellbeing support and recognising that educational and broader opportunities are a key preoccupation of bereaved and survivors.

- Like adults, children and young people of all ages experience grief and trauma, though not always in the same ways. Within the current bereaved and survivor cohort supported by the Council’s Dedicated Service, there are 271 children and young people under 25, 77 of whom have been born since the fire. The age profile of these children and young people is as follows:

Under 5	65
5-10	79

11-15	54
16-17	20
16-24	53

Table 3. Age profile of bereaved and survivor children accessing the Council’s Dedicated Service.

- Guidance from national organisations suggests that:

Children find it particularly difficult to explain to others how they are feeling following trauma, with the result that parents and teachers may often not pick up what is going on for a child. Traumatic-stress reactions will also vary significantly in line with a child’s age.

It is also important to recognise that for young children trauma and grief reactions are often displayed for shorter periods than with adults. Tears turn to laughter within just a few moments, but then just as quickly back to tears again. A child’s culture, belief systems and life experiences will also shape his or her attitude to trauma, death or loss.

As a child develops, all of these concepts will take on new meaning, and he or she will process the trauma further in line with these new realisations and understanding. This means that recovery time may be extended over several years and the trauma may need to be revisited at different times.¹²

- It is important to recognise the specific impacts of trauma on those children and young people most directly affected by the fire and to acknowledge that the impact of the tragedy on children and young people will continue to manifest in different ways. As noted above, we must also recognise that the ongoing impact of the tragedy can place pressure on family relationships and dynamics, which can have a direct impact on children and young people’s relationships with their parents and their peers. There is no one-size-fits-all approach for children; instead, it is important to recognise that specific additional support is necessary which can be tailored to meet individual needs.
- In general, the long-term and sometimes delayed impacts of trauma on children are not always recognised by those responsible for their care and learning. Engaging with schools and education facilities to gauge the level of impact on the young people in a community and involving these key stakeholders in development of plans and activities ensures that young people are cared for after a disaster. It is important to note that it may take time, sometimes several years to stabilise, and that additional work with them may be necessary when they experience significant life changes, for example in adolescence.
- Children growing up in households which have experienced trauma may think of their environment as ‘normal’ and this will have an impact on the way in which they develop emotionally. As with adults, it is vital there is appropriate support in place in the long term for all bereaved and survivor children, as they can exhibit delayed symptoms of trauma.
- As with adults, it is important not to pathologise grief and trauma in children but rather to ensure that families understand that it is a natural reaction to a very difficult event. Instead, it is important to find ways to ensure they are supported by people they trust, encouraged to express their own feelings and acknowledge honestly and provide age-appropriate

¹² <https://assisttraumacare.org.uk/our-service/children-are-affected-too/>.

information about what has happened. This can then lead to a conversation with families about how the impact of the tragedy might be manifesting itself.

- Through the NHS, children and young people impacted by Grenfell are able to access the Paediatric Long Term Monitoring Service, an annual 90-minute appointment with a paediatric consultant, who undertakes comprehensive physical examination including lung and breathing functions, review of emotional health and wellbeing, how they are getting on at school, sleeping patterns, height, weight and diet, and immunisation checks. Of the 44 children who left the Tower on the night, 43 (98%) have been offered the service, 93% (41) referred, 35 seen, five decided not to take up the service and one deferred for a year. 136 bereaved and survivor children have been referred to the service in total, 67% of all child survivors and 53% of bereaved children.
- To date, children and young people's health and wellbeing services have been developed to build trust with children and families (including visiting families at home, establishing links with schools etc.) and to try a range of approaches, including art and play therapy in the right environment where children feel safe and supported. The NHS's Grenfell Health and Wellbeing Service (GHWS) offer includes comprehensive assessments, symptom management, and psychotherapeutic interventions, with services delivered flexibly as part of a family model or on an individual basis. The GHWS has also changed over the course of the recovery period to support resilience in communities, recognising the need to have more interdependence within communities. This includes collaborating with community organisations to deliver, and providing supervision, training, advice and liaison with a range of organisations, schools, and professionals.
- We know that some parents may be reluctant for their children to access Grenfell-specific support, either because they are seeking to protect their children from the impact of the tragedy or because they are concerned about them being 'labelled' or categorised as Grenfell victims. Moving forward, we need to think about ways to address this and to ensure that the support people to navigate a complex network of local services to support children and young people, which we know can be confusing and difficult to navigate for professionals and parents alike.
- As with adults, it is also vital to listen to children and young people and ensure their voices help to shape the support in place.¹³ We want to explore and address these issues with bereaved and survivors in the next phase of the JSNA process.
- Beyond health and wellbeing needs, we know that bereaved and survivors want to ensure that their children have access to the right kind of broader opportunities, including education, training and employment. Individuals have repeatedly raised the importance of educational support in schools and outside it. The Dedicated Service Steering Group has repeatedly challenged the Council's Dedicated Service to ensure high quality support is in place to support children with their education, which has led to significant adaptation of the support in place. Specific additional provision for this group of children and young people is important to ensure that this group of children and young people is adequately supported through key milestones, given the ongoing impact of the tragedy and the potential for trauma to manifest itself at different stages.¹⁴
- Moving forward, we need to focus on providing support in education, training and employment and broader opportunities for children and young people of all ages, recognising

¹³ See, for example: <https://www.lancaster.ac.uk/cuidar/en/2018/03/21/stcuk-children-voice-in-emergencies>.

¹⁴ On impact of disasters on academic performance, see L. Gibbs et al. (2019) Delayed disaster impacts on academic performance of primary school children, *Child Development*. Jul; 90(4): 1402-1412.

the complex impact of grief and trauma and the desire of families to ensure that their children are given the best possible opportunities.

The importance of **choice, flexibility and control for families** in deciding what support to access, when and how, including the need for a menu of different options which people can access at different times.

- As noted above, one feature of complicated trauma and grief is that bereaved and survivors may feel a lack of control. Without control, people can feel powerless or stuck, which makes it difficult for them to move forward.
- Through the work with bereaved and survivors through the Council's Dedicated Service, we have heard clearly that people want more control over their recovery. Bereaved and survivors have told us that families themselves know what works best for them and that what works for one family doesn't necessarily work for another.
- Following the wide-ranging review of the Dedicated Service in 2021, for example, we introduced changes to Individual Service budgets and introduced new Personal Budgets for Services to allow families to exercise greater choice and control over the support they receive. We also introduced a new process which allowed bereaved and survivors to access their funds without going through their Dedicated Service Worker, making the process quicker and less bureaucratic. Through the 2022 survey, 83% of the 130 respondents reported that the changes to the service have given them 'more choice and control over the support they receive' and 77% felt that the support was 'better targeted to meet their individual needs'.
- In the first year after they were introduced, almost all individuals have used their Personal Budgets and have accessed a wide range of services and activities, including self-care, health and fitness, and respite breaks. The 2022 DS review found that 85% feel the online solution 'gives them more flexibility and control over how they make a request' and 82% feel that it is a better process. In 2023, funding for individual services and personal commissioning budgets was increased and currently over 60% of the allocated Dedicated Service budget is controlled directly by families. When asked about what support was most important to them, moving forward, 78% of respondents identified personal budgets and individual services.
- Personal budgets are one way to help ensure families have control over their recovery, but there are other mechanisms for creating choice and flexibility. Conversations with national organisations who work in this area emphasised that it is important to ensure a broad, flexible, menu of support for people to choose from as and when they need it. This is particularly important given the constantly changing external landscape and the range of public and private challenges that people are likely to face in the coming years.
- For some, it may be enough just to know that the support is there. Families will choose to engage with different aspects of the support available at different times; what is important is that people are aware of what is available and how to access it. The Council, the NHS and other organisations need to continually offer support, while recognising that not everyone will take it up. Taking a flexible approach and ensuring people can access different services in different ways and at different times ensures there are ways for people to engage with support without coming via the Council. For some bereaved and survivors having a dialogue with the Council and getting things done can help people feel that they are moving forward; others may prefer to choose not to engage.

The need to continue to focus on creating opportunities for **peer support**, creating opportunities for people to connect and come together to support one another.

- Alongside mental and physical health support and practical support for families, research from other disaster recovery contexts suggests that peer support approaches can be valuable ways for people to come together to support one another. As Dr Anne Eyre notes, these approaches build on a recognition of the complex psychosocial dimensions of trauma and bereavement through major disaster and the importance of the ‘reconstruction of social ties and the need to connect with others as a way of processing grief, including after mass traumatic loss’. Peer support can be some of the most longstanding and self-sustaining support. For example:

In the aftermath of the Aberfan disaster (1966) in Wales in which 144 people, including 116 children, were tragically killed, a group of young mothers from the village came together to form a support group. Connected by their mutual experience and understanding of collective loss they met up a few months after the disaster to provide friendship and mutual support and continued to do so; their weekly tea-and-chat gatherings continuing to this day.¹⁵

- Peer support approaches can take many different forms, from more formal facilitated talking groups to groups focused on campaigning to activity-based groups which connect people in more informal ways. Many national charities and organisations, such as Support After Murder and Manslaughter (SAMB), began as peer support groups and have evolved to offer a wide range of different kinds of peer support.¹⁶
- Within the Dedicated Service, we have worked with bereaved and survivors to establish a number of small peer support groups which offer people a chance to come together. Feedback from these groups, mostly attended by small numbers of individuals, offers a glimpse of some of the benefits that peer support can provide:

“ Its so good to see so many people I knew from the tower this is the first time for me and it just feels like we never left each other ”

Bereaved and survivor feedback about the ‘Walk and Talk’ group

“ I lost all of my photos in the fire, all of the important pictures of family weddings, and the children growing up, its important to make new memories ”

Bereaved and survivor feedback about the Photography group

- Moving forward, we can do more to create opportunities for people to come together and to connect people with other local and national organisations. In particular, we need to continue to focus on those who might particularly benefit from peer support, including those who might be lonely or isolated. We need to recognise that some people will want to connect with others within the community, whereas others might benefit from seeking new communities,

¹⁵ See Dr Anne Eyre (2019). ‘The value of peer support groups following disaster: From Aberfan to Manchester’, *Bereavement Care*, 38:2-3, 115-121.

¹⁶ See, for example: <https://samm.org.uk/support-information/>.

including ones brought together by local and national organisations. We should also explore the full range of forms that peer support can take, from more structured facilitated talking groups to less formal, activity-based groups.

- We should recognise that public authorities aren't always the right agencies to run peer support groups, but that they can provide help and assistance to groups who are trying to get started. Small organisations often prove better at bringing people together than the Council or NHS and it may be worth considering letting go of some work and handing it over to community partners in the future. As part of this, it is important to be conscious that new groups may emerge at any time. The key is having flexibility, choice and control and creating space for families to come forward whenever they are ready, ensuring there are as few barriers as possible in between them and coming together to support one another.
- Memorialisation can be a powerful way for people to come together and support each other. The anniversary of the tragedy and the silent walk have been significant for both bereaved and survivors and the wider community in the years following the tragedy. Alongside big public events and forms of memorialisation/commemoration, it is important that there are opportunities for people to come together in smaller ways that feel more comfortable for them. Specific consideration should therefore be given to facilitating peer support around anniversaries and at other times when people may want to come together.

The need to ensure **bereaved and survivor voices** are at the centre of plans for the future.

- For many bereaved and survivors, Grenfell happened because of a failure to listen. Since the tragedy, many have found powerful public voices through campaigning and other activism. However, others still do not feel heard. In line with the emphasis on choice and control, it is particularly important that people feel listened to (and heard) in the next phase.
- Conversations with national organisations emphasise that open, ongoing engagement is crucial to building trust, especially in a context where levels of trust are extremely low. It is important to recognise that there will always be different perspectives and that there is always a danger of listening too much to some and not enough to others, including privileging loud voices who don't necessarily speak for the whole community and missing valuable feedback that might come from 'quieter' voices. This means that public authorities must continue to talk to all parties, recognising that some people will step back and others will step forward at different times, and ensuring and to be transparent about how people can influence decisions.
- We have developed different approaches to communication and engagement with bereaved and survivors over the past six years, including regular conversations with key stakeholder groups and a Dedicated Service Steering Group, which acts as a mechanism to ensure that bereaved and survivor voices are always at the heart of decisions about the service. As one member of the Steering Group described their involvement in the group:

'It is a privilege to have been part of the Steering Group and I'm glad to have had the opportunity. We have tried hard to make a change for the better and bring issues to light and we have challenged the management team when we thought things weren't good enough or needed improving. Whether we have made a difference is up to other bereaved and survivors to decide but we have tried!'

- In the next phase, it is vital to ensure that public authorities are finding ways to listen to what bereaved and survivors are telling them, both individually and collectively, and use what we are hearing to shape the design and delivery of services.

- At the same time as embedding a meaningful approach to engagement, we must also recognise the demands that engagement can place on bereaved and survivors. There is a real danger of 'consultation fatigue' and public authorities need to ensure that they are not placing unnecessary burdens on families at what is already a difficult time.

6. NEEDS OF THE LOCAL COMMUNITY

Understanding the needs of the local community

As set out in the 2018 JSNA, the ripple effects of the tragedy are felt not just within the bereaved and survivor community but also among people in the local area.

The following section summarises some of the key sociodemographic characteristics of and health outcomes for Notting Dale ward, which corresponds broadly to the area within 500m of Grenfell Tower. This is the background against which the specific ongoing impact of the tragedy should be considered.

Sociodemographic characteristics of Notting Dale

- The 2021 Census records the population of Notting Dale ward as 9,143.
- Notting Dale is the second most deprived ward in RBKC and the ninth most deprived in London.
- 56% of resident are from a black or minority ethnic background compared to 36% of Kensington and Chelsea residents, 46% in London and 19% nationally.
- 67% of residents in Notting Dale live in social rented housing compared to 23% in London, and 17% in England.
- 17% of households are overcrowded, compared to 8% in Kensington and Chelsea, 11% in London and 4% in England.
- Notting Dale has the second highest rate of unemployment of wards in Kensington and Chelsea, with 9.5% of working age adults claiming out of work benefits. This is above the borough rate of 4.8%, the London rate of 5.6% and the national rate of 5%.
- The long-term unemployment rate in Notting Dale is 2.2 per 1,000, but given the relatively small size of the population, the difference between this rate and borough and national averages (1.4 per 1,000 and 1.9 per 1,000, respectively) is unlikely to be statistically significant'.

Health Outcomes

Note: Published data on death rates from all causes and data on premature deaths (those occurring under the age of 75 years) include the deaths that occurred at Grenfell Tower and may also include some deaths occurring early in the Covid-19 pandemic (2016-2020 pooled data). Life expectancy estimates for Notting Dale ward and Kensington and Chelsea are therefore impacted by the loss of life in the tragedy. Published data on emergency hospital admission ratios may also be impacted by the tragedy and the Covid-19 pandemic, as data on this activity is taken from the period 2016/17-2020/21.

Life expectancy

- Life expectancy at birth in Notting Dale ward for both males and females is the lowest in Kensington and Chelsea at 73.4 years for males and 75.7 years for female. Furthermore, within Kensington and Chelsea, the life-expectancy of males living in Notting Dale is estimated to be 17 years lower than males living in Queen's Gate (the ward with the highest male life-expectancy in

the borough) and of females, 17.9 years lower than females living in Holland ward (the ward with the highest female life-expectancy in the borough).

- The life-expectancy gap between the poorest areas of Kensington and Chelsea (including Notting Dale) and the most affluent areas has widened in recent years. This is in part due to the Grenfell Tower tragedy where 72 people lost their lives and also due to the impact of the Covid-19 pandemic which is known to have disproportionately affected poorer populations, those from a BAME background, and those with particular chronic health conditions, such as diabetes – as we know are experienced more in Notting Dale ward. Further published data are required to fully understand the impact of the pandemic.

Death rates

- The rate of deaths (all causes), of premature deaths (deaths under the age of 75 years) and preventable death rates for Notting Dale ward are the highest of Kensington and Chelsea wards and statistically above the England average. However, rates of death from all cancers, all circulatory diseases, and coronary heart disease (all age and under 75 years) and age Stroke and Respiratory diseases (all age) are not statistically different to the England average.

Emergency admissions

- Data published by the Office for Health Improvement and Disparities (OHID) on emergency hospital admissions rates occurring 2016/17 to 2020/21 show, compared to other Kensington and Chelsea ward rates (total 18 wards), residents of Notting Dale ward have the highest rate of adult emergency admissions and the highest rate of emergency admissions for heart attack.

Long-term conditions

- Data from the Whole Systems Integrated Care database shows Notting Dale ward to have higher rates of long-term conditions than most other wards in Kensington and Chelsea. For example, Notting Dale ward (in comparison to Kensington and Chelsea averages) has the highest rates of chronic obstructive pulmonary disease (COPD) – 2.7% compared to 1.2%. It also has the highest rates of diabetes - 8.4% compared to 3.9% respectively. (WSIC DID June 2022)
- Unfortunately, there is currently limited published NHS data on the health outcomes for residents of Notting Dale and North Kensington. What is available does not provide data in the same format prior to Grenfell Tower tragedy. This means we cannot assess how resident health outcomes in Notting Dale have changed over time compared to areas of similar socio-demographics, London or England.
- We are, however, able to analyse local NHS data from 2016 and local deaths data from 2014 to monitor over time and identify any changes in health since the tragedy in Notting Dale and North Kensington. Outcomes can be compared to averages for RBKC and WCC and to outcomes for residents of Queen's Park ward in WCC - an area with similar social and health challenges to Notting Dale prior to the tragedy.
- It is recognised that it is still too soon to assess all the long-term health impacts however there is an agreed alert process in place between the NHS and Public Health, and intensive clinical follow-up of people exposed.

Long-term Limiting Illness and Disability

- Data from the 2021 Census show that compared England (17.5%), and Kensington and Chelsea (12.8%), Notting Dale ward residents have higher rates of long-term limiting illness and disability (19.6%), which is the second highest rate of the 18 Kensington and Chelsea wards.

Key challenges and approaches

It is important to consider the broader health and wellbeing inequalities set out above when thinking about the impacts of the Grenfell tragedy. These provide the context in which the immediate local community continues to experience the specific impact of the fire.

The final JSNA will need to include discussion of these wider health and wellbeing inequalities, which must be at the heart of the broader plans and strategies put in place by the Council, the NHS and our partners. However, there are clearly a number of key issues which are specific to the Grenfell tragedy that will need to be considered in the next phase:

- The need to focus support in a more targeted way on the **immediate local community** living near the Tower, as evidenced by the North Kensington Health and Wellbeing survey.
- The need to plan support for this group and to take into account the impact of **decisions about the future of the Tower** on the immediate local community, including impact on mental health and renewed concerns about physical health.
- The need for access to appropriate **high quality mental and physical health services**. These need to take into account the specific impact of the Grenfell tragedy on the local community and the complex and cumulative interplay of inequalities which pre-date the tragedy (such as deprivation and racial inequality), as well as the more recent impact of the pandemic and the rising cost-of-living. Support needs to be available through key milestones and trigger points.
- The need for an increased focus on **preventive health interventions** (such as routine immunisations, cancer screening and NHS Health Checks for healthy hearts) **and proactively building health and wellbeing**. This includes empowering the community with both the information and the means to look after their health and keep well.
- Rather than a narrow focus on 'recovery' with a clear end point, the importance of finding long-term ways of working with the community to support them to **live with** the longer-term impacts of Grenfell, COVID-19 and other events (including supporting people to access key opportunities in areas such as employment, education and training).
- The need to focus specifically on **the needs of children and young people**, building on international best practice which shows the importance of hearing and amplifying children's voices and perspectives.

The sections below set out some initial considerations in each of these areas and some potential approaches, based on our work with bereaved and survivors to date and learning from other settings:

- The need to support **community-led recovery** wherever possible in a context of low levels of trust in public authorities, focusing on involving residents in the design and delivery of services and amplifying residents' voices.
- Ensuring residents are able to access **support in trusted, community-based settings** including through local organisations which reach people that public bodies don't, alongside mainstream Council and NHS services.
- Creating more space for **peer support approaches**, building on work to date to create opportunities for residents to come together to lead their own recovery and support one another in settings where they feel comfortable.
- The need to focus on **cultural competency and community knowledge and expertise**, ensuring that services are designed to meet the needs of the diverse communities living in the area around the Tower and creating a menu of different types of support.

The need to focus support in a more targeted way on the **immediate local community** living near the Tower, as evidenced by the North Kensington Health and Wellbeing survey.

The need to plan support for this group to take into account the impact of **decisions about the future of the Tower** on the immediate local community, including impact on mental health and renewed concerns about physical health.

- Although many people across the borough, London and the country were affected by the Grenfell tragedy, available evidence suggests that the ongoing impact for the local community is most acute in the immediate area around the Tower. Data from the North Kensington Health and Wellbeing survey has shown that the closer respondents live to the Tower, the more likely they are to report being affected by the Grenfell tragedy and to experience an enduring negative impact.
- This association has strengthened during the last four years the survey has been being carried out. In 2022, 1 in 2 respondents living within 200m of Grenfell Tower reported being affected by Grenfell, compared to an average of 1 in 3 for those living 201m or further from the tower and 1 in 5 among respondents living furthest away from the tower (1000m or further). Over the four years of the survey, the percentage of respondents still affected 'a lot' has become more concentrated closer to the Tower, with the percentage of all respondents still feeling affected 'a lot' who live within 200m rising from 30% in year one to 73% in year four.
- In years one to three of the survey (2019 to 2021), 11% of respondents reported still feeling specific impacts of the tragedy 'a lot', circa 200 respondents each year. Specific impacts include an 'unwillingness to socialise', 'dealing with frightened upset or unsettled children', 'anxiety or distress due to Grenfell' or 'relationship problems'. In the same period 24% of respondents reported still feeling these specific negative impacts 'a bit' (c. 400 residents). In year four, the number of respondents still reporting feeling an enduring negative impact 'a lot' fell for the first time, to 1% (11 respondents) and still feeling the impact 'a bit' to 11% (176 respondents).
- The North Kensington Health and Wellbeing survey data for years 1 to 3 indicate low wellbeing scores (and high anxiety scores) were not found to be related to reporting being affected by the Grenfell tragedy or living close to Grenfell Tower. By contrast, being in fair to poor health was consistently associated with low wellbeing and high anxiety. In year four, in addition to fair to poor health, living close to Grenfell Tower was found to be associated with respondents giving a high anxiety score.
- The Tower was also frequently mentioned in free text responses on the negative health and wellbeing impact of the Grenfell tragedy (see Figure 5 below). These included mention of the negative impact of seeing the Tower every day and calls from some for the building to be taken down.

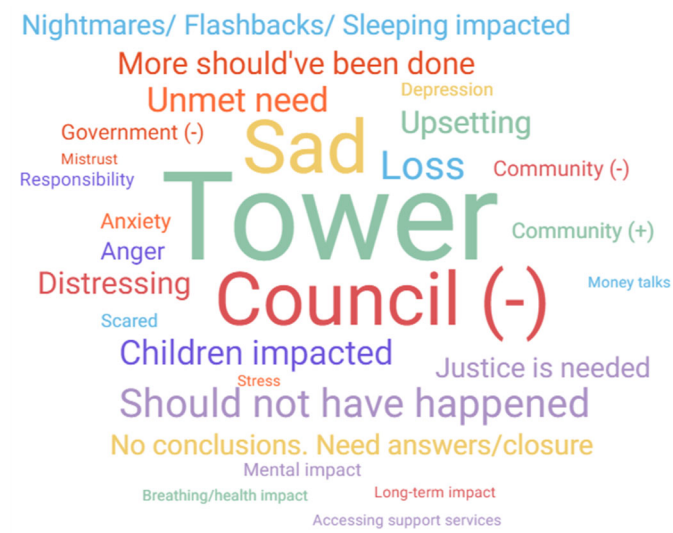


Figure 5. Themes captured in the North Kensington Health and Wellbeing Survey years One to Three (2019-2021). Too few free text responses were provided in Year 4 to include.

- We recognise that local people were impacted in different ways and that even within the area immediately around the Tower, there are different experiences and levels of impact which depend on a range of circumstances (including proximity to the Tower, experience of the tragedy and personal circumstances). Moving forward, it will be important to target support more effectively to those in the immediate area, while taking into account these differences.
- A recent study has suggested that ‘relatively high prevalence of PTSD among populations close to the epicentre of a natural disaster supports the importance of geographical proximity as a contributing factor for the development of PTSD in community residents’.¹⁷ Another study, following the Fukushima nuclear disaster suggested that residents in the affected area continued to experience psychological distress, post-traumatic stress and health anxiety (specifically around radiation) after the area had been permanently rebuilt, suggesting the need for long term mental and physical health support.¹⁸
- However, the relationship with geography can be complex and, in some cases, psychological proximity may be more important than geographical proximity. The impact of the site’s ongoing presence may be felt more intensely by the bereaved. After the Sewol ferry disaster in Korea, the residents of Ansan, where most of the victims lived, were more severely affected by the disaster than residents of Jindo who lived nearer the disaster site. This indicates that the meaning of a traumatic event, including having a personal connection to relatives of victims and worrying about the safety of someone close, is significantly associated with the development of PTSD.¹⁹
- The Department of Health and Social Care’s National Institute for Health Research (NIHR) commissioned a literature review on behalf of the Government from the Health Protection Research Unit (HPRU) in Emergency Preparedness and Response at King’s College London on international disasters and the psychological impact of living near a disaster site. The review, published [here](#), did not find any evidence internationally on the long-term impacts of living

¹⁷ See [The Impact of Community Disaster Trauma: A Focus on Emerging Research of PTSD and Other Mental Health Outcomes - PMC \(nih.gov\)](#).

¹⁸ See [Current Psychological Distress, Post-traumatic Stress, and Radiation Health Anxiety Remain High for Those Who Have Rebuilt Permanent Homes Following the Fukushima Nuclear Disaster - PMC \(nih.gov\)](#).

¹⁹ See [The Impact of Community Disaster Trauma: A Focus on Emerging Research of PTSD and Other Mental Health Outcomes - PMC \(nih.gov\)](#).

near to a disaster site. However, it did note that more research was needed in this area and highlighted that lessons from other disasters suggesting that ensuring a community is involved in discussions about the future of a site is likely to be beneficial.

- Whatever the longer-term impacts of living near a disaster site, it seems likely that the ongoing presence of the Tower and decisions about its future will have a significant effect on those living in the immediate local area. Any changes to the Tower site may cause psychological distress but also give rise to renewed concerns about physical health. It is therefore vital that the right mental and physical health support is in place to support the immediate community through the next phase.
- It is important that we clearly explain the rationale for targeting support to the local area and ensure that in doing so we do not inadvertently exclude people who were affected by the tragedy, thereby preventing them from seeking support. We also recognise that the community expect to see clear evidence of how the support is being targeted to those who need it most and what impact it is having.

The need for **access to appropriate high quality mental and physical health services**. These need to take into account the specific impact of the Grenfell tragedy on the local community and the complex and cumulative interplay of inequalities which pre-date the tragedy (such as deprivation and racial inequality), as well as the more recent impact of the pandemic and the rising cost-of-living. Support needs to be available through key milestones and trigger points.

The need for an increased focus on **preventive health interventions and proactively building health resilience**, empowering the local community to optimise their health and supporting them to counter negative health risks.

Rather than a narrow focus on 'recovery' with a clear end point, the importance of finding long-term ways of working with the community to support them to **live with** the longer-term impacts of Grenfell, COVID-19 and other events (including supporting people to access key opportunities in areas such as employment, education and training).

- In addition to the broader population-wide health outcomes reported above, the Public Health Population Health Monitoring programme monitors key health trends in the area based on anonymous data. Some of the key findings to date are described below.

Cancer: The Public Health Population Health Monitoring programme *has not detected any increased incidence* of cancer in the Notting Dale population or within the Wider North Kensington Area.

Respiratory conditions: The Population Health Monitoring programme monitors, the incidence of all respiratory conditions and in particular, Asthma, COPD, Upper and Lower respiratory infections, as well as respiratory prescribing rates in adults and children and lung cancers. To date, there have not been increases in the incidence of respiratory conditions in Notting Dale or the North Kensington Area other than for seasonal influenza or due to the Covid-19 pandemic, findings also made in wider-RBKC, WCC and Queen's Park ward. The process did also flag an increase in GP events for asthma in adults, however investigation established the increase as a provider data coding anomaly and not due to an increase in the diagnosis of asthma.

Mental health prescribing (Adults): *Increasing trend* in adults in Notting Dale: agreed findings are in line with longer term increasing trend observed in all areas.

Mental Health prescribing Children: *No clinically significant increase* in mental health prescribing in children has been seen.

Self-harm: The Public Health Population Health Monitoring programme has *not detected any increased incidence* of self-harm.²⁰

Sleep disorders: - there was noted an increase in the incidence of sleep disorders in adults, however due to the timing of this finding (22 months later) it *may not be related* to the Grenfell Tower fire.

- The North Kensington Health and Wellbeing Survey includes information about people's perception of their health. Respondents living closest to Grenfell Tower are indicated to have poorer health than those living further away, with 17% reporting their health as poor compared to 6%. This was not found to be linked to being affected by the tragedy but demonstrates the poorer health outcomes for this population linked to other factors.
- Respondents have also told us what is most important for them in meeting their current health and wellbeing needs. Access to Mental Health services and GP access were the most commonly reported, followed by access to sport and exercise facilities and the availability of more community groups, activities and centres.
- Many of the NHS services offered to the survivors and bereaved, as described previously, are also available to the wider North Kensington community. This includes the GHWS, primary care service offers, and other community-based services:
 - Since January 2019 there have been 3,748 Enhanced Health Checks have been taken up by the wider community.
 - A case management service is available for the wider community who have been impacted by the fire.
 - The community respiratory service provides a multidisciplinary, hub -based clinical service that supports the early identification of possible respiratory conditions via assessment and diagnosis, with onward management and support.
 - 'Healthier Futures' self-care services, which provide a range of community-based health and wellbeing services providing peer support, healthy living advice and a range of other services, plus support for organisations from Kensington and Chelsea Social Council to establish and grow support groups and networks. This service is open to anyone who has been affected by the fire and over 3000 individuals have accessed the services to date.
- Moving forward, it is important that approaches to mental health are non-stigmatizing, non-pathologizing and tailored to meet that the diverse needs of the community.²¹ We need to ensure that people who need support do not feel excluded or left out and that we consider the language we use to describe services and support, mindful of the dangers of creating boundaries and the stigma that can be attached to 'mental health'. More broadly, it is vital that services are culturally appropriate and that alongside specialist clinical services there are community-based services in settings where people feel comfortable.

²⁰ Professor Louis Appleby's 2020 report on suicides in North Kensington concluded that whilst suicide rates had not increased following the Grenfell tragedy, there was a community concern that required response (see [here](#)). In response, the recommendation to developing a 'suicide safe' approach.

²¹ <https://thekandcfoundation.com/insights/understanding-inequalities-borough-extremes>.

- In line with the recommendations of the original JSNA, it is important that we also consider the broader health and wellbeing inequalities as well as the specific impact of the tragedy and look closely at the wider determinants of health, including housing and education, employment and training and explore ways to connect local people to opportunities in these areas.
- As noted above, there have been changes in the health of the local population, including as a result of COVID-19. But it is also vital to acknowledge that even where data does not suggest increases in incidence of health conditions, there may be significant community anxiety, for example about the long-term physical impacts of the tragedy, which needs to be addressed when thinking about the provision of future services. Moreover, more needs to be done to share and interrogate this information with residents.
- Moving forward, ongoing monitoring in this area will be important for identifying health and wellbeing trends, even where they are not specifically related to the impact of the tragedy, and the Council and the NHS will commit to regularly sharing information about these trends with the local community.

The need to focus specifically on **the needs of children and young people**, building on international best practice which shows the importance of hearing and amplifying children’s voices and perspectives.

- We know that the health and wellbeing of children and young people is particularly important after a disaster. As with bereaved and survivors, the impact of the tragedy on children living in the local community may be felt at different times and in different ways and may be compounded by existing or subsequent trauma.
- In the North Kensington Health and Wellbeing Survey, residents that stated they were affected by the tragedy were asked if and to what extent they experienced *dealing with frightened, upset or unsettled children*. In Years one to three of the survey (2019 -2022), a median of 10% of respondents reported having experienced this impact, but not now, and 16 to 19% of respondents reported still feeling this impact ‘a bit’ or ‘a lot’. In 2022, the percentage of respondents who felt this impact, but did not now, rose to 20%, while the percentage of respondents reporting still dealing with frightened, upset or unsettled children ‘a bit’ or ‘a lot’ fell to 2% of the survey population.
- Survey data from Years one to three indicate the enduring impact of still dealing with frightened, upset and unsettled children ‘a bit’ or ‘a lot’ has become more concentrated among residents living closest to Grenfell Tower over time. In 2021, 32% of respondents living within 200m and 29% of respondents living within 400m of the Grenfell Tower reported still dealing with frightened, upset and unsettled children ‘a bit’ or ‘a lot’. In Year four (2022) too few respondents reported this impact to analyse by proximity.
- Some of the free text comments also refer specifically to concerns about the impact of the tragedy on children and young people:

“The kids I feel sorry at the local school having to see the tower still there knowing some of their friends died in the fire.” – North Kensington Resident (2019)

“My daughter lost her school friend and it is still having major effects.” – North Kensington Resident (2019)

“My grandchildren were distressed. Thankfully I had neighbours around me helping when it happened.” – North Kensington Resident (2019)

- Ensuring trauma-informed support in families, schools and community-based settings is particularly important and recognising the need for different approaches, including art and play therapies alongside specialist clinical services is important. Children and young people accessing existing services in schools and community-based settings report a range of outcomes, including increased confidence and self-esteem, improved relationships with their family and friends and feeling more optimistic about their future.
- More broadly, parents want to see a positive legacy for local children and young people and activities and spaces where they can connect with one another. Alongside ensuring the right mental and physical health services are in place for children and young people, it is also important to take a broader focus on educational and other opportunities for children and young people.
- Just as community-led approaches are vital for all disaster recovery efforts, disaster recovery research suggests that it is important to ensure that children and young people's voices are championed and promoted.²² Recent work through the Grenfell Recovery programme has shown how young people can be actively involved in shaping the provision (as illustrated by the case study from Baraka below) and, moving forward, there are opportunities to build further on this type of approach.

Baraka: reflections on hearing young people's voices (Summer 2022)

Children and young people deserve a place at the table with the grown-ups. They deserve to be heard, and not only that but us grown-ups might find that we learn a thing or two when we take the time to stop and listen!

Children and young people are involved and contribute to the planning, delivery and monitoring of Baraka's services. 12 of them participate in the Youth Forum that meets quarterly and allows them to discuss what is working well and have a say in the new activities they would like to see delivered. Recently the Youth Forum contributed to shape Baraka's recent residential trip by suggesting activity types, and distributing and collecting monitoring forms.

There are also plans to enable Children and young people to attend future Trustee meetings and represent children and young people's needs and wishes.

Additionally, a number of Youth Forum members who have been with Baraka for several years have completed their compulsory education and now volunteer at different Girls and Boys youth sessions.

The need to support **community-led recovery** wherever possible in a context of low levels of trust in public authorities, focusing on involving residents in the design and delivery of services and amplifying residents' voices.

- Disaster recovery research and guidance identifies community-led recovery as a crucial feature of all successful recovery efforts and 'putting the community at the heart of recovery' was a key recommendation of the 2018 JSNA. As set out in the UK Cabinet Office guidance which accompanies the Civil Contingencies Act:

The management of recovery is best approached from a community development perspective. It is most effective when conducted at the local level with the active

²² <https://www.lancaster.ac.uk/cuidar/en/2018/03/21/stcuk-children-voice-in-emergencies>.

participation of the affected community and a strong reliance on local capacities and expertise. Recovery is not just a matter for the statutory agencies – the private sector, the voluntary sector and the wider community will play a crucial role.²³

- However, community-led recovery is particularly important where there are low levels of trust in public authorities. The free text comments from the North Kensington Health and Wellbeing Survey (see Figure 5 above) shows the importance of negative perceptions of the Council and its role in the tragedy. The 2022 Grenfell Legacy conversation about change at the Council has further shown the scale of this challenge. A majority of respondents said they felt that the Council had not changed since Grenfell or had got worse, with bereaved and survivors and residents of North Kensington more likely to report a lack of change. Residents told us clearly that the Council needs to do more to listen to its residents and act on what they say.
- This disconnect has been a longstanding feature of the local area but has deepened because of Grenfell. It is not unique to the Council. As one local observer has put it in evidence to a recent review into social prescribing:

I have always been aware of the gap between local health professionals and local authorities and the local population – which has been indifference and sometimes almost contempt. Nobody wanted to connect too closely...²⁴

- Community-led recovery is essential for closing this gap. It means meaningfully involving residents in the design and delivery of services and amplifying residents' voices to ensure that their needs and concerns are heard and addressed. One of the key benefits of community-led recovery is that it helps to build trust and foster a sense of ownership of and investment in the recovery process.
- To effectively support community-led recovery, it is important to support resident-led organizations, faith groups and other networks.²⁵ This may involve providing funding, training, and technical assistance to help build organizational capacity and ensure that these organizations have the resources they need to effectively advocate on behalf of the community. Crucially, community-led recovery means connecting with and building on community expertise. As one local organisation told us:

Our communities, local residents and parents have the expertise – make them the leaders of our services. [We] already have a model for this and people feel the Council should support and build on this.

- Since the start of the Grenfell Recovery programme in April 2019, the Council and NHS have worked with over 100 local voluntary and community organisations to deliver services and initiatives for bereaved, survivors and the wider community. We have also found different ways to involve local people in the design and delivery of services, including traditional consultation and engagement, resident-led groups and resident decision-making processes.²⁶ We know that people feeling that their voice is heard and that they have control over priorities and decisions are critical elements of recovery and that projects are most successful when they make use of local residents' knowledge about what the community needs.

²³ [Emergency Response and Recovery 5th edition October 2013.pdf \(publishing.service.gov.uk\)](#), p. 85.

²⁴ See [lsbu asset-based health inquiry.pdf](#) (p.14)

²⁵ See A. Gilchrist. *The Well-Connected Community. A Networking Approach to Community Development* (Policy Press: 2019).

²⁶ For more on learning from these approaches, see Section 7 of the second annual report on the delivery, reach and impact of the Grenfell Recovery programme (available [here](#)).

- More generally, as with bereaved and survivors, we need to continue to focus on meaningful engagement. The recent King’s Fund project on ‘Learning the lessons from Grenfell’ demonstrates the need for a different approach to engagement in this context, which focuses on making it everyone’s business to connect to the communities they serve.²⁷

Ensuring residents are able to access **support in trusted, community-based settings** including through local organisations which reach people that public bodies don’t, alongside mainstream Council and NHS services.

The need to focus on **cultural competency and community knowledge and expertise**, ensuring that services are designed to meet the needs of the diverse communities living in the area around the Tower and creating a menu of different types of support.

- From the experience of the Grenfell Recovery programme, we know that community-based support delivered in partnership with local organisations is vital for ensuring that services reach local people and make a difference to them. We have worked with local organisations to provide support in settings where they need comfortable. This can not only help individuals cope with the trauma and stress of past events but also foster a sense of community and social connectedness, which can contribute to long-term resilience and recovery.
- London South Bank University’s recent (2019) Social Prescribing review, which includes evidence from North Kensington, suggests that it is vital to look at approaches which link residents to support within the community and promote self-care.²⁸
- The NHS’s North Kensington Health and Wellbeing Strategy emphasises the importance of ensuring that the needs of the diverse community are reflected in local services and promoting and enabling self-care and community resilience through information and support.
- Furthermore, evaluation of the NHS-commissioned ‘Healthier Futures’ self-care service, provided by a range of local community organisations provides evidence of the health and wellbeing benefits of community activities and preventative health and wellbeing initiatives, with over 96% of 335 users finding the services beneficial. Across all services, average wellbeing outcomes improved as a result of the service. The North Kensington Health and Wellbeing Survey findings show the increasing importance of use of gyms and physical exercise to support health and wellbeing and shift towards self-care/hobbies. While we know that physical activity, hobbies and other forms of self-care can be important for people in recovery, it is important that this does not mask difficulties accessing other services (such as primary care or mental health care). Community centres remain in the top 10 services residents use to aid their health and wellbeing and the satisfaction with these has increased over time.
- Delivering culturally competent services is a key factor in meeting resident’s diverse needs. Cultural competency means recognising that we should empower services to provide equal and meaningful care to all, including in community languages and with approaches that recognise the importance of people’s faith and culture. Empowering people to have a meaningful voice in shaping their local services will mean services are more likely to have buy in and engagement from the people whose wellbeing they are looking to support.

²⁷ [Learning the lessons from Grenfell | The King's Fund \(kingsfund.org.uk\)](https://www.kingsfund.org.uk/projects/learning-the-lessons-from-grenfell).

²⁸ [lsbu asset-based health inquiry.pdf](#). See also Kimberlee, R. H. Developing a Social Prescribing Approach for Bristol. University of the West of England (2013), p.14.

- The NHS North Kensington Recovery engagement team worked in partnership with the North Kensington community to develop a whole systems approach that seeks to link together many of the influencing factors that lead to culturally appropriate services. This led to the development of a training module on Developing a Culturally Competent General Practice. This module has been successfully piloted and has received CPD-accreditation from the Royal College of GPs (RCGPs).
- Given low levels of trust in public authorities, work with local organisations and networks is vital for connecting with local people, especially with specific cultural or language needs. It is particularly important to think about those from specific groups who might be affected by the tragedy. Responses to the North Kensington Health and Wellbeing survey indicates that women and residents from non-white ethnic groups are more likely to report still being affected by the Grenfell tragedy. On the other hand, women are more likely to access emotional health and wellbeing services through the Grenfell Recovery programme and recent efforts have focused on finding ways to make sure men feel comfortable seeking support.
- Within the Grenfell Recovery programme, service users have reported benefitting from accessing services which are culturally appropriate. As one resident put it:

“I find it comfortable attending Midaye’s activities – they provide the kind of support we need. They also provide different community language support Arabic, Somali Tigre etc. It’s so helpful and they understand people’s needs and I hope they continue to deliver what they’re so good at delivering.

- Others have spoken about the significant trust and community networks that commissioned providers held with Somali and Arabic communities “as a bridge” to the Council, providing a “safe space” .²⁹
- This is particularly important given different perceptions of mental health and concerns about the potential stigma that can be attached to accessing mental health services. There is an ongoing need for more awareness and information about mental illness and mental health, the option for people to connect to services in ways that are non-stigmatizing and a recognition that services need to be tailored to the needs of specific.
- The following testimony from a patient access the Arabic language counselling service at Al Manaar Muslim Cultural Heritage Centre demonstrates the value that community-based support in a person’s mother tongue can provide.
- While we recognise the importance of trusted, local organisations in reaching people, it is important that we continue to focus on the needs of those residents who have been most affected and carefully consider which organisations are best placed to meet these needs. Moving forward, it will therefore be important to focus on ensuring a sufficiently broad range of culturally appropriate support and to ensure that it is targeted at those most affected.

²⁹ [RBKC Adults Emotional Health and Wellbeing Services, Analysis of stakeholder consultation.](#)

Al Manaar – Testimonial from a resident who finished long-term therapy (2021/22)

“I was very grateful for the opportunity to access free counselling at al Manaar. Here I found a place to talk about my own trauma and struggles following the Grenfell fire. I had tried to look after others, the whole community, and carried a huge burden on my shoulders. With my counsellor’s help, I was able to re-focus on myself and address the trauma I had lived with since the fire and from other incidents in my life. It was not easy to look at my trauma, pain and shame, but my counsellor was a constant ally who related to me positively and compassionately.

It was important that my counsellor was somebody who understood North Kensington and the level of trauma suffered by local people. My counsellor and the staff at the mosque always made me feel welcome and valued and I would recommend the service to anybody”.

Creating more space for **peer support approaches**, building on work to date to create opportunities for residents to come together to lead their own recovery and support one another in settings where they feel comfortable.

- As set out in Section 5 above, peer support approaches are a vital component of long-term recovery, not just for bereaved and survivors but also for people living in the local community. This had been a gap in the Council’s provision for the local community, which we began to fill with the launch of the adults peer support programme in early 2022.
- This programme has seen the establishment of a range of new initiatives for adults run by established local providers and community groups, some of which existed before the tragedy and others which were established in the aftermath to support those affected. They are offering a range of activities, but all with a focus on peer-led, trauma-informed and recovery-focused approaches. The provision has been very successful in reaching local people with relatively small amounts of funding, with over 560 adults participating since the projects launched in January/February of this year. This far exceeds the original target of 150 people and has more than doubled the reach of our offer for adults in the community.
- This provision has not only supported a significant number of local residents, it has also helped bring together local organisations and created opportunities for them to share expertise and learning, building a network of organisations through the two provider forums. Local providers have been able to access a range of training and resources from local resources like the Council’s Learning and Development offer, KCSC and North Kensington Recovery College.
- Additional support was provided by Disaster Action to help ensure the support was shaped by best practice in disaster recovery, and a series of three bespoke Trauma Awareness and Trauma Informed workshops was organised for providers, based on what we had heard from them about where they wanted to build knowledge and expertise. By connecting providers to other resources and creating opportunities for us to learn from each other, we hope we are contributing to stronger relationships and better mutual understanding across the partnership.
- We have recently launched the latest round of the peer support programme, and moving forward, we want to find ways to build on the successes of some of these projects, while also findings ways to encourage new groups to come forward with ideas for projects and, in particular, to look at how we might encourage more men to come together to support one another.

- It is clear that investment in peer support will be an important feature of the next phase and that we can do more across the partnership to facilitate people coming together to provide support to one another.

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7. NEXT STEPS

Between now and the Summer, we will be developing the themes and evidence base to build a clearer picture of the ongoing health needs of the local community.

We will do this by:

- Reviewing and sharing existing population-wide data and information from the delivery of Council and NHS services to build a better understanding of local needs.
- Gathering additional qualitative data and understanding of what is important to people through conversations with bereaved and survivors, local residents living in the area, partners and other stakeholders and qualitative research with key groups.
- Reviewing additional evidence, research and best practice from other disaster recovery contexts.

We will be actively seeking discussions with residents, partners and other stakeholders to inform the development of the final document, including through the wide-ranging consultations on future service provision between now and the autumn.

To get in touch or to find out more about updating the Joint Strategic Needs Assessment, email grenfellrecovery@rbkc.gov.uk.