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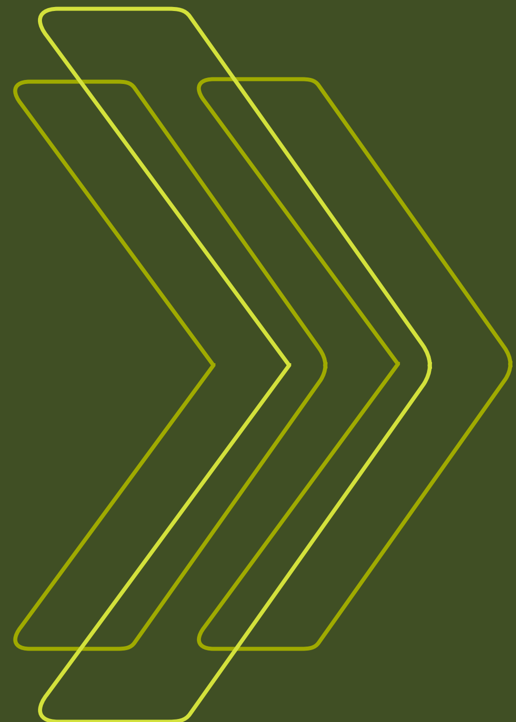
People power

Lessons from the health care response to the Grenfell Tower fire



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Foreword

The fire in Grenfell Tower was a truly shocking disaster. The care and support for the survivors and bereaved and the local community, both in the immediate term and over subsequent months and years, was of utmost importance, and this report explores what the wider health and care system should learn from the response to the fire.

But first and foremost, we should remember the 72 people who died in the fire and recognise those whose lives have been impacted by the tragedy. Seven years on, the grief for those who lost their lives, the terror of the fire, and the anger that it even happened, are all still present. We at The King's Fund acknowledge what people have been through and pay our respects to those who died, those who were bereaved, and those for whom memory of the fire is still all too real.

At its heart, this report is about health and care services learning to listen to the communities they serve, becoming more open to acting on what they hear, and building trust. As such, it is directly relevant to all local health and care systems. Now that structural changes have been put in place to join up services around the people who use them, changing the relationship with those people – so that they participate in, rather than fit in with, decisions that affect them – is surely the next stage for developing integrated care. I challenge any leaders in the health and care system who claim the issues described in this report do not apply to them, or that they already listen enough to their communities.

Learning to listen is far harder than it sounds. It can expose where services do not properly meet people's needs, where structural racism exists, and where ways of working leave some groups systematically disadvantaged. We all know those issues are real, but hearing it in your own service and, above all, working out how to address it, is a massive challenge for NHS leaders. This report offers insights into that challenge, and also some optimism that it is possible to move towards a more responsive, fairer NHS.

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About this report

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Key messages

Our voices are never heard because Grenfell was social housing… the residents were not listened to before the fire. These are working class people of colour, and racism is one of the things which we still say you [the authorities] will not acknowledge.
Community interview participant

- The Grenfell Tower fire was a preventable tragedy. Residents had repeatedly raised concerns about health and safety, and had warned about risks in the refurbishment of the tower. They were not listened to, and opportunities to prevent the tragedy were missed, leading to the fire that resulted in the deaths of 72 people.
- Before the fire, trust between the community and statutory services had broken down. We found evidence of structural racism and discriminatory attitudes towards residents.
- The initial response to the fire was experienced as chaotic and fragmented. It was the community, voluntary sector organisations and faith groups that stepped in and delivered much of what was needed.
- When it became clear that the subsequent health care response was falling short of what was needed, there had to be a recognition that a different approach was required – one that moved away from 'one-size-fits-all' solutions driven by what those working in the system thought would be best, towards one driven instead by what people in the community needed. Two main factors drove this change in approach:
    - The survivors and bereaved of the Grenfell Tower fire, and the wider community, organised themselves so that they could engage with the statutory organisations and their voices had to be heard. They refused to be silenced again and consistently made the case that the health and care response to the fire should be community led.
    - A few key individuals in leadership positions within statutory organisations recognised that they needed to work differently, and so advocated for and modelled new ways of working. They emphasised listening to the community and acting on their priorities, working as partners rather than a hierarchy, and rebuilding trust.

- Seven years on from the fire, working this way is still work in progress and there is still a risk that the system sees it as time-limited and a particular response to the Grenfell Tower fire rather than understanding its wider application.
- It would be a mistake to see Grenfell and the subsequent health and care response as unique. There are clear lessons for the wider health and care system, and for individuals (especially leaders) working in it. We identify five key insights for the wider health and care system:
  - **If you are going to listen, you have to be prepared to act.** Listening is not enough. Services need to be willing to make change informed by what they learn from communities. That means being prepared to work differently and giving permission for staff to do so.
  - **Engagement is not a separate activity, it needs to be core business for all.** Community engagement should not be the preserve of dedicated engagement teams, or a separate activity undertaken by other people. Instead, staff need to understand and work with the local community if they want to deliver services that are effective.
  - **You cannot engage people in silos and should instead take a system-wide approach.** People's experiences of public services are interlinked. Rather than asking people's views on individual services, organisations need to take a more co-ordinated approach to listening to and learning from people and communities across the local system as a whole.
  - **Identify and address the issue of structural racism.** If health and care systems want to build genuine partnerships with local communities, they need to build trust. People will only trust those systems if they feel that services are on the same side as them – not part of, or a cause of, the structural disadvantages that they face.
  - **Making partnership working with local communities a reality is the biggest challenge – but also the greatest opportunity – for system leaders.** Sharing power with communities involves changing organisational cultures; there is no roadmap for how to do it, and it can never be ticked off as 'done'. But it is key to delivering health and care services that reflect what people, rather than organisations, need.

1 Introduction

Grenfell Tower was a tower block of 129 flats owned by the Royal Borough of Kensington and Chelsea (RBKC) in London. Most of the flats could be described as social housing. On the night of 14 June 2017, a fire broke out in Grenfell Tower, resulting in the loss of 72 lives.

This report outlines a study of the health care response to the fire and how the local community (the survivors and bereaved, and people living in the areas surrounding the tower) brought their voices to influence how services were designed and delivered. This is not an evaluation of the impact or outcomes of the health care services put in place following the tragedy. Instead, we have provided an independent review, focusing primarily on people's experiences and their perceptions of what worked well and what could have been done differently. We have taken the approach of listening to people, being led by what they told us, and drawing out the learning about listening to communities that is relevant to all health and care systems.

Aim and objectives of the study

The overarching aim of this study was to draw out the lessons from the Grenfell health care response that can be applied to the wider health and care system around involving people and communities. The objectives of the study were:

- to tell the story of how the Grenfell community brought their voices to the aftermath of the tragedy and the subsequent public service response
- to understand what this meant for how health and care services worked with the Grenfell community and how this developed over time
- to understand the lessons that Grenfell offers for how the wider health and care system can work with people and communities to tackle health inequalities
- to explore the barriers and enablers to taking an asset-based approach to working with people and communities, and understand what it requires both of the system and communities themselves
- to connect this work to wider efforts across health and care services to ensure that people and communities are listened to.

Methods

Our methodology included a non-systematic literature review that spanned key publications, grey literature and the National Theatre verbatim play 'Grenfell: in the words of survivors', which uses interviews with survivors of the fire to tell the story of events that led up to the disaster and how the tragedy unfolded that night. We refer to key sources from the literature review throughout the report.

We also undertook in-depth interviews with 30 people between May and November 2023. Different interview guides were created for the different categories of participants. Information sheets and consent forms were provided for all participants. To preserve the anonymity of interview participants (many of whom have ongoing working relationships with each other), we have broadly categorised them as follows:

- Community – including the survivors and bereaved of Grenfell, people who work in local voluntary, community, faith and social enterprise (VCFSE) organisations, a residents' association, and individuals who are employed by the Grenfell Health and Wellbeing Service (GHWS) in community roles – that is, connectors and champions.
- System stakeholders – including people employed by the NHS locally (including health care professionals, commissioners and senior leaders) and the local authority (RBKC).

Through purposive sampling, we aimed to capture a wide range of views and experiences, particularly focusing on members of the community, local health care services and VCFSE organisations. We were reliant on key individuals at GHWS for access to both community and system stakeholder interview participants. We acknowledge this means that there were some limitations to building a comprehensive picture of what happened, and that others whom we did not speak to may have different views and experiences. The slightly higher number of system stakeholder interview participants reflects the number of individuals involved in the health care response and the number of interviews needed to piece together the overall picture of what happened.

Table 1 Interview sample

Interview category	Number of participants
Community	14
System stakeholder	16

Following an inductive approach, we generated high-level themes under each interview category from interview recordings and transcripts, which we have reflected in this report.

We convened a workshop in November 2023, bringing together local and national stakeholders to share emerging findings and discuss the implications for policy and practice.

Background

The various circumstances leading up to the fire at Grenfell Tower, the poor state of the previous relationship between residents and the local authority and tenant management organisation (TMO), and the response of different services since the fire have all contributed to a sense within the local community that people have been severely ill-treated by various public authorities.

The tragedy was a very high-profile event that drew significant political attention, locally and nationally. In the aftermath, a group of survivors and bereaved formed the Grenfell United collective, which became a powerful voice demanding justice and advocating for the health and wellbeing of the people affected by the fire.

The event had a devastating impact not only in terms of the number of deaths, but also the trauma and displacement that former residents of the tower and surrounding area have experienced since the fire.

The joint strategic needs assessment (JSNA) for North Kensington (where Grenfell Tower is located) conducted in 2018 (Strelitz *et al* 2018) identified different types

of impact of the fire that highlight the very broad and complex ways that public services needed to support the people affected:

- primary impacts – for example, loss of housing, psychological trauma, physical health, 'collapse of trust in public authorities' (Strelitz *et al* 2018, p 10).
- secondary impacts – for example, mental and physical health, supporting the key foundations of people's wellbeing, such as housing, family relationships and employment (Strelitz *et al* 2018, p 11).

In September 2018, in direct response to the strong advocacy of members of Grenfell United, the Senior Coroner issued a Regulation 28 report to prevent future deaths addressed to the then chief executive of NHS England, which highlighted several concerns about the physical and mental health of the survivors and bereaved (Wilcox 2018). In October 2018, it was announced that the NHS would provide up to £50 million over a five-year period to fund long-term screening and treatment for those affected by the fire (NHS England 2018). In 2019, the RBKC committed to providing £50 million over a five-year period to support the Grenfell Recovery Strategy (The Royal Borough of Kensington and Chelsea 2019).

There has been a large-scale response to the fire at Grenfell Tower, including local and central government, the NHS, the local grassroots VCFSE sector and – most significantly – the community itself. Those who were closely involved in part of the recovery work have described how lessons need to be learnt from the initial public service response.

> *Grenfell demonstrated that the systems around us were failing. Public service organisations were not speaking to each other and were not connecting to their real purpose – serving their communities. The local authority may have borne the brunt of public anger, but the lessons are there for everyone to learn from.*
> (Elguenuni *et al* 2020)

Furthermore, what happened in the aftermath of the fire has highlighted the crucial importance of health and care services listening to and learning from the communities they are meant to serve, as identified in previous research by The King's Fund about the Wigan Deal (Naylor and Wellings 2019). More specifically: if services are to meet people's needs, then the first step has to be understanding what will make a difference to people's lives by working with them and listening to them.

Terminology used in this report

Throughout this report, we refer to the ‘community’ numerous times. We understand that this is a broad term and that it is important to distinguish between people who were directly impacted by the fire (the survivors and bereaved) who were the primary intended recipients of the health care services funded by NHS England (and the RBKC), and people who live in the surrounding area who were impacted and involved in other ways. Where this was made clear to us in interviews, we have specified where actions can be attributed to the survivors and bereaved of the fire (or Grenfell United acting on their behalf), or to people living near Grenfell.

Similarly, we refer to the ‘system’ and ‘statutory’ organisations throughout the report. In order to understand what happened, we spoke to various NHS providers and commissioners in the local health care system. We also found that local VCFSE organisations played a key part in the response to the fire, and they were perceived by interview participants as forming part of the community response, as opposed to statutory organisations, such as the NHS or the RBKC.

Furthermore, it became clear to us during interviews that the survivors and bereaved held a strong belief that the system and statutory organisations such as the NHS, the RBKC and the TMO represent institutions of power. In participants’ lived experiences, such institutions have previously not listened to them when they have spoken up or challenged hierarchical decisions, often leading to tragic consequences (which we describe below).

We begin our report by familiarising readers with the local area and the people who lived in Grenfell Tower, and setting the context in terms of what happened in the immediate aftermath of the fire. We go on to describe how the health care response took shape, and what that meant in terms of working differently. We discuss the challenges and barriers experienced by services and people in trying to deliver health care that was community focused. We reflect on what worked well and what challenges remain to be addressed. Finally, we discuss the implications of the Grenfell health care response for the wider health and care system.

2 Context: the Grenfell area and the community

The story of the Grenfell health care response could very quickly become one that is centred on services like the NHS. However, that version would overlook the key role of the strongest asset in the community and the backbone of the recovery from the disaster – the people themselves. Therefore, it is important to understand who the people are and what they experienced, before and after the fire.

The residents of Grenfell Tower and the areas in the immediate surrounding neighbourhood were and are socially and ethnically diverse. This is in stark contrast to the profile of people living in other parts of the Royal Borough of Kensington and Chelsea (RBKC). For example, the 2018 joint strategic needs assessment (JSNA) noted that 59% of people from Grenfell Tower, Grenfell Walk and the local neighbourhood were from ethnic minority backgrounds compared with the RBKC average (29%) (Strelitz *et al* 2018). Furthermore, 48% of people from Grenfell Tower, Grenfell Walk and the local neighbourhood were living in deprived circumstances compared with the RBKC average of 22%. The JSNA also highlights the 'significant differences' in income, education and employment, stating that the area has 'higher numbers of people on low incomes or with no qualifications than the rest of the borough' (Strelitz *et al* 2018, p 9). In a paper in *The Lancet* journal, highlighting the 'slow burn of inequality', Professor Sir Michael Marmot points out that the mean salary in the RBKC in 2017 was £123,000, whereas the median of the salaries in the area was £32,000, reflecting a 'huge contrast between high and low earners'. In addition, life expectancy for men living in Golborne Ward (adjacent to Grenfell Tower) was 22 years lower than that for men in the richest part of the borough (Marmot 2020: 1413).

At face value, this could give the impression of a population in deficit. It is true that the residents of Grenfell Tower and the surrounding areas were and are at a relative socio-economic disadvantage and have faced significant hardship in life – not least, being more likely to live in social housing (including in Grenfell Tower). However, the area has a strong sense of identity that is shaped by the rich diversity of the people who live there. The North Kensington area also has a vibrant and strong

history of activism and resilience in the face of a historically strained relationship with the local authority and its various services, such as housing, social care and education (Prescod 2017; Walker 2017). Furthermore, interview participants told us there was a prevailing narrative about people living in the North Kensington area being deprived, which contrasted with how they saw themselves.

> *…if you think about the narrative that was set around North Kensington, [as the] most deprived borough in the country… Now I will be honest, me and him [points to other interviewee], we lived in a tower block… I look at him and say, 'do you think you are poor, bro?' He's got a catering business, I was working for [name of department store]… I didn't see myself as poor.*
>
> Community interview participant

Before the fire: how people were not heard

In 2017, the then Prime Minister Theresa May ordered a public inquiry to look into the circumstances leading up to and surrounding the fire at Grenfell Tower. The inquiry took place in two phases (*see* the Grenfell Tower Inquiry website, www.grenfelltowerinquiry.org.uk). The findings of the first phase show a history of a very strained relationship between residents and authorities such as the tenant management organisation (TMO) and the RBKC. For example, during the refurbishment of Grenfell Tower between 2014 and 2016, the residents repeatedly raised health and safety concerns and complaints with both RBKC and the TMO. Some of their concerns about the dangerous living conditions in the tower included residents having only one staircase in the entire tower, with lifts that often did not work, a lack of communal fire alarm, and fire doors that were known to be defective. Whenever Grenfell Tower residents presented evidence of safety concerns and areas that the TMO needed to address, they were repeatedly ignored and undermined (Apps 2022; Grenfell Tower Inquiry 2019; Hodkinson 2018).

The lack of response from the TMO and RBKC led residents to create the Grenfell Action Group to campaign on their behalf. Members of the action group blogged about the safety issues prior to the fire and in one of their blogs (co-written by 16th-floor resident Edward Daffarn, in November 2016), they had warned:

> *Only an incident that results in serious loss of [Kensington and Chelsea] TMO residents will allow the external scrutiny to occur that will shine a light on practices that characterise the malign governance of this non-functioning organisation.*
>
> (Grenfell Action Group 2016)

When the Action Group spoke out publicly in this way, they were threatened with legal action by RBKC for talking about the issues publicly. The TMO blocked its staff from accessing the blog (Roberts 2017). By blocking access on its servers to staff working on the refurbishment project, the TMO was effectively silencing community voices.

Tragically, those very health and safety concerns became significant impediments to rescue efforts on the night of the fire. The cladding was also responsible for toxic smoke, which had detrimental effects on residents and emergency personnel involved in helping people during the fire, such as the 'Grenfell cough' (Apps 2022). It is due to factors such as these that the survivors and bereaved and people living in the wider community hold the RBKC and the TMO responsible for the fire and the deaths of 72 people.

> *I'm talking about the local authority, government – like, wait, they burned me out of my house, why can't I talk back to them? Why can't I say to them that you lot have failed? Why can't I say that you lot nearly killed us?*
> Community interview participant

Our interview participants (both community and system stakeholder interview participants) were convinced that the actions of RBKC and TMO staff were a result of discriminatory attitudes towards tower residents. For example, a former resident told us:

> *The system sees this community as the media made out this community to be in 2017 – a bunch of illiterate people that don't know what's right for themselves. And I think that is how the system is designed to be built... We're uneducated, we almost see ourselves as a community that are on the floor because we know that's how we're perceived... We don't have a [university] degree, we've got a degree in life... We have that element of common sense and we [know] what needs to be right for us as a community. But you're constantly being told, 'no, you don't really know what you're talking about, we're the experts', and the system is designed to continue being the expert.*
> Community interview participant

A significant proportion of Grenfell Tower residents were from ethnic minority backgrounds, on lower incomes (relative to the rest of the population in North

Kensington) and with a range of religious beliefs and immigration statuses (Strelitz *et al* 2018). Most of the people who died in the fire were Muslim and people of colour. Structural racism and experiences of discrimination were called out by legal representatives of the survivors and bereaved at the public inquiry hearings.

This experience of discrimination was captured by a resident who told us:

> *Our voices are never heard because Grenfell was social housing… The residents were not listened to before the fire… These are working-class people of colour, and racism is one of the things which we still say you [public services] will not acknowledge…*
> Community interview participant

It is important to note that the difficult relationship between the residents and those in power was a longstanding issue that pre-dated the fire. Interviewees shared examples of planning and regeneration decisions made by the RBKC which they felt did not reflect what they wanted – for example, the Citizens Advice Bureau and the community engagement team buildings were turned into a Pret A Manger coffee shop and Sainsbury's. Changes such as these contributed to a sense of being 'done to' and fed into the mistrust of authorities felt by residents and people in the wider community.

> *We could just see it before our very eyes that as a community, as working-class people of colour, we were losing our [community] assets, that actually the gentrification was starting to strangle us and we were being socially cleansed, effectively.*
> Community interview participant

It was clear from the people we spoke to that the fire was a culmination of community experiences and voices being ignored and effectively silenced by the RBKC and the TMO. A system stakeholder told us that the fire was 'a result of what happens when you don't listen to communities and especially to minoritised communities'.

Similar views about what happens when communities are ignored, and the consequences, were found in research by Snoussi and Mompelat (2019) for Runnymede Trust, based on interviews with 78 Grenfell residents. The purpose of the project was to explore how residents' background impacted their everyday lives. The research found that for some participants, their ethnicity and class

negatively impacted their interactions with public services. It found that these were not isolated incidents, but were instead 'routine instances of indignity, disempowerment and indifference which culminated – in the worst cases – in disasters like the Grenfell tower fire' (Snoussi and Mompelat 2019, p 22).

Edward Daffarn (author of the Grenfell Action Group blog mentioned earlier) was interviewed for the play, *Grenfell: in the words of survivors* (Slovo 2023). Excerpts from his transcript are used in the play:

> *We said at the time it's gonna take catastrophe here before the council wakes up to what's really going on… People talk about the Grenfell Action Group being prophets of the fire. We weren't prophets. The fire was a logical conclusion of a borough council, Royal Borough of Kensington and Chelsea, that was failing to scrutinise a landlord that was failing to implement health and safety. Even when the Fire Brigade were getting involved, the tenant management organisation weren't responding in time to these orders. So yeah, although the horror of what happened could never be imagined, it was simply unimaginable, it was like, it was a prediction rather than a prophecy. To predict something is going to happen and have it happen and not be able to stop it – there's no words for that.*
> (Slovo 2023, p 43)

Although the main focus of this report is on the subsequent health and care response to the tragedy and its after-effects, it is critical to understand the context and background. Trust in statutory services had been broken, people were angry that their voices and concerns were being ignored, and the communities affected were not going to be ignored or silenced again.

In the immediate aftermath of the fire

According to the literature about recovery, when disasters occur it is the norm for emergency plans to be enacted quickly and for a command-and-control structure to be implemented (Cream *et al* 2021). However, what we heard during interviews and what we found in publications about the Grenfell fire suggest that the initial response by the authorities left the survivors and bereaved and people in the wider community feeling angry and badly let down. Our research shows that a range of emotional responses (highs and lows) are common during different phases of a disaster (Cream *et al* 2021).

The book *Show me the bodies: how we let Grenfell happen* (Apps 2022) draws heavily on testimonies given at the public inquiry and describes key services working in a haphazard and unco-ordinated way in the days and weeks after the fire. Having escaped the fire, survivors were met with chaotic scenes. The RBKC emergency response team could not find the keys to open the doors to the major incident room. No one from the TMO was visible, and it was not clear where to go for assistance. RBKC did not collate a central list of people who had escaped the fire (Apps 2022). Eventually, a local centre called the Curve was set up by RBKC to provide emergency assistance. In some ways, the lack of co-ordination in the immediate period after the fire reflected the fractured nature of the relationship between residents, the community and the authorities.

On the other hand, local people and organisations from the voluntary, community, faith and social enterprise (VCFSE) sector reacted at pace (**Muslim Aid 2018**; **Plender 2018**). One of our interview participants who is both a system stakeholder and a volunteer said:

> *I helped set up one of the community centres about 11 o'clock in the morning and I met someone from the council in the building and I said, 'look, you're the council, what should we be doing?' She said, 'I don't know'. F***ing useless. So, we just carried on doing what we were going to do. Anyone that had the key to a building opened the building. They started setting up beds, everything, just in case, and the donations were coming in. So, the rugby club [Rugby Potobello Trust] got full very quickly.*

A number of local community centres, churches and mosques opened their doors to provide shelter and support. A local youth club became a focal point for the survivors and bereaved, stepping in to provide shelter and practical support (such as organising transport or cash) to those who had lost their possessions in the fire. According to Apps: 'Where the state utterly failed, these community organisations provided dignity and respect' (Apps 2022, p 278). The British Red Cross mobilised quickly after the fire and was involved in providing support in the immediate aftermath, although it acknowledges that large voluntary organisations can struggle to meet diverse and wide-ranging needs of people in emergency situations (**British Red Cross 2019**). The following quote is from someone who lived very close to the tower:

> *Let's be honest, the authorities were very thin on the ground. The council were nowhere to be seen. In fact, on the day of the fire, I can tell you that we had no*

idea what was going on, those of us living... I'm talking directly around the tower... I mean, obviously the emergency services were trying to do what they were doing... By six o'clock that evening, I remember that there was fire coming from the top of the tower. I'm not the only one who was thinking, 'is that tower going to collapse?' But we were completely left. The locals... will tell you, the ordinary people of Kensington, North Kensington and other people were coming in with the food, with the blankets. It was ordinary people power that day, because nobody else was to be seen, apart obviously from the emergency and the police... We were just left.
Community interview participant

Following the very turbulent initial period after the fire, an independent government taskforce was established in July 2017 to support RBKC with long-term recovery (focusing on issues of rehousing, community engagement and holistic support) and provide assurance to the then Secretary of State for Housing, Communities and Local Government (Sajid Javid) that the council could deliver an effective long-term recovery plan (**Ministry of Housing, Communities & Local Government 2017**). The first report of the taskforce stated that 'RBKC failed its community on the night of 14 June and in the weeks following' (**Independent Grenfell Recovery Taskforce 2017**, p 1).

There was also very understandable anger among the survivors and bereaved and local people about their portrayal in the media. As one interview participant (a system stakeholder) recalled, the Grenfell community was being portrayed as a 'neighbourhood of illegal immigrants and benefits scroungers' with no basis in truth. The implication of this was creating doubt about deserving and undeserving victims of the fire. Lucy Easthope – an expert in disaster recovery – has also commented publicly on the stigmatisation and othering of tower residents (Easthope 2022). Our interviews were often emotionally charged, and the anger and frustration felt by community members (and some stakeholders) about how unfairly they had been treated was palpable. That is the context within which, after the fire, the community was no longer going to be ignored. In the following sections, we discuss how the community called for better inclusion in and transparency about the design and delivery of health care services – as one aspect of a broader effort to address how systems should work with communities.

3 The health care response to the Grenfell Tower fire

In this section, we outline how the health care response has evolved since the day of the Grenfell Tower fire up until now, and what types of services are available to the survivors and bereaved today. For clarity, by 'health care' we are referring to both physical and mental health services that were put in place to support the survivors and bereaved. It is also important to note that we are not referring to urgent treatment provided to people who were in the tower at the time of the fire, or other aspects of how the emergency was managed.

'All hands to the pump': how the health care response was first set up

In terms of the health care response, one interview participant (a commissioner) said there was no formal set of responsibilities agreed for the then clinical commissioning group (CCG) in the immediate aftermath of the fire. Instead, he described the health response as 'all hands to the pump', with no specific plan – other than what was known to have worked well in previous traumatic events. Interview participants who were employed by Central North West London (CNWL) NHS Foundation Trust (the local mental health and community health care provider) recall staff 'jumping in… to deliver things'.

The fire prompted many non-NHS organisations to put forward different forms of support, including offers that may have been well-intentioned but not necessarily what the survivors and bereaved most urgently needed (for example, ear acupuncture). This meant that the initial health and wellbeing response felt disorganised and confusing, for the survivors and bereaved and for NHS staff.

> *…there were lots of other agencies that seemed to be around. There were people from all over the world that kind of come into the community when a disaster like this happens… I think they're called trauma tourists… they come from all over the world… And, you know, offer all kinds of things, some helpful, some not helpful to the community.*
>
> System stakeholder

Within this chaotic environment, it was notable that some individuals working in local NHS organisations demonstrated much-needed leadership by listening to people's needs and taking a practical approach. It was clear to them that the fire had taken trust and faith in statutory services (and particularly the local authority) to an all-time low, and that people were traumatised and in urgent need of a wide range of support. As one system stakeholder based in CNWL described it, 'We didn't have any funding for anything… We hadn't done a business case, or any of that, but we just needed to get on and deliver. We're one of the statutory services that had a moral obligation to deliver.' This began with using connections and influence with local stakeholders to ensure that people's very practical and basic needs were met.

> *…there [were] practical things. So… again, it was listening to the community. It was something about, you know, it's kind of Maslow's hierarchy of need [physiological, safety, love and belonging, esteem and self-actualisation], isn't it? A practical thing… is that there were people who were camping under the Westway [a flyover] because they weren't leaving… members of the community who just felt they needed to be there. It was like a vigil, and they weren't going anywhere. And they needed some toilets… So I remember working with one of the guys in the local authority and just saying, 'Can we get them some toilets?'… You know, it's not really my job to get toilets for people, but it doesn't matter. It's what they needed. So I guess it was about listening to people and getting a real sense of actually… what needs to be done and what needs to be done right now… People just needed to feel that people were around.*
>
> System stakeholder

The first year after the fire

There was no specific health care plan immediately after the Grenfell Tower fire; although as we describe below, a plan took shape over the course of the next 12 months. It is important to note that there was no designated funding for NHS services for several months after the fire according to a system stakeholder. We heard that NHS services pressed on with their support of the survivors and bereaved and people in the wider community without specific funding for several months (we note that CNWL released backdated emergency funding in April 2019).

According to interview participants from CNWL, the trust scrambled to boost its capacity to provide mental health support available within its existing services such as a telephone helpline and Improving Access to Psychological Therapies (IAPT).

Initially, a high number of therapists and other staff were 'borrowed' from other London trusts and the trust found that a number of therapists volunteered their help too. The Chief Operating Officer knew this was not a sustainable solution and, at some point, it was going to be necessary to engage NHS England to discuss long-term options for mental health care for the survivors and bereaved of Grenfell.

The trust set up some services that were more targeted to a community that had experienced the shock and trauma of the fire – specifically types of outreach, informed by learning from other disasters about what is important (Cream *et al* 2021). One aspect of the outreach was aimed at children, parents and teachers who were affected by the fire – most likely exacerbated by the tower casting a literal and metaphorical shadow over schools in the vicinity. A multidisciplinary team was also convened, involving mental and physical health care services and the voluntary, community, faith and social enterprise (VCFSE) sector, to reach out to people in the community (survivors and bereaved, witnesses and residents in the area), to screen them for signs of post-traumatic stress disorder, and to provide information – referred to by many of our interview participants as 'screen and treat'. However, screen and treat was not introduced as a long-term intervention, and mental health service provision for the survivors and bereaved has since evolved into something else, which we describe later in this report, reflecting how the community has brought its voices to the health care response and different ways of working.

From 2018 to the present day

Grenfell United played a key role in advocating on behalf of the survivors and bereaved, and its representatives met with the Senior Coroner to emphasise the need to recognise and address the long-term physical and mental health impact of the fire. That advocacy led to the Senior Coroner's Regulation 28 report, which states that 'the potential impact of this disaster is very wide ranging' and outlines several specific concerns regarding serious health conditions that could arise due to smoke and dust inhalation and potential exposure to asbestos. It also identified the need for the NHS to 'oversee and co-ordinate and provide appropriate mental health support for all those affected by their involvement in the incident' (Wilcox 2018, p 4).

In response, NHS England announced that it would provide up to £50 million to fund long-term screening and treatment over five years for those affected by the Grenfell Tower fire. The Senior Coroner's report, the joint strategic needs

assessment (JSNA) and the allocation of funding prompted a gear-change in terms of the health and wellbeing services provided for people affected by the fire.

The funding allocated by NHS England went to the CCG in West London (now the North West London Integrated Care Board) as the local commissioner of health care services. Local NHS health care providers (spanning primary care, acute care, mental health care and community care) would need to put forward business cases annually to the CCG. The CCG commissioned the following services, which are still providing health care for people affected by the Grenfell Tower fire:

- Local GPs to provide 'enhanced services' to survivors and bereaved (essentially extended appointments to review physical and mental health).
- 'Specialist care' for respiratory health, toxicology monitoring and paediatric long-term monitoring.
- The Grenfell Health and Wellbeing Service (GHWS) – *see* Box 1 on page 22.
- Social prescribing – that is, non-medical activities and services available in the community.

(NHS West London CCG 2019. *See* also www.grenfell.nhs.uk/nhs-services)

It is important to note that the health care response did not stand in isolation and the local authority also put significant time and resources into supporting the health and wellbeing of the survivors and bereaved. For example, the Royal Borough of Kensington and Chelsea (RBKC) funds a programme called Together for Grenfell, which brings together three local voluntary organisations who partner with GHWS to offer culturally sensitive mental health and wellbeing support to Arabic and Somali-speaking people who have been impacted by the disaster. Also, the survivors and bereaved could access support via a key worker or mental health care professionals based at a community centre called the Curve. However, the RBKC has struggled to build trust within the local community since the fire, and that is probably reflected in the lukewarm way in which our interviewees spoke about its role in the recovery.

> *There was the Curve that was created, I think it was a lot of money that was wasted… But I did like the fact that they put counsellors in there… because sometimes people don't like hospitals… The Curve was good, I just think it lost its way with what it was supposed to be there for and what the need was for.*
> Community interview participant

Box 1 Grenfell Health and Wellbeing Service

The allocation of additional funding enabled the then West London Clinical Commissioning Group to commission a bespoke service from Central North West London NHS Foundation Trust. The bespoke Grenfell Health and Wellbeing Service (GHWS) provides a wide range of psychological therapies for trauma on the basis that there is no 'one-size-fits-all' approach. GHWS aims to work with children and young people, adults and families to find therapy that is best suited to individual needs. There is a very strong emphasis on providing support that is culturally adapted – for example, being offered therapy in someone's native language that takes into account the person's faith or cultural background and/or working with a therapist or support worker from a similar background.

Through its Grenfell Recovery College programme, GHWS offers free wellbeing workshops to anyone living in the Kensington and Chelsea area or anyone affected by the fire at Grenfell Tower.

GHWS values a co-production approach and has formed a 'service user involvement team' consisting of young and adult service users. Consultants within the team play an active role in staff recruitment, training events and designing therapy materials.

The NHS Dedicated Service was designed with the survivors and bereaved to look after the long-term health needs of the group. The service sits within GHWS and supports and co-ordinates access to the various emotional wellbeing and physical health care services.

Source: https://grenfellwellbeing.cnwl.nhs.uk/

The RBKC agreed its Grenfell Recovery Strategy in January 2019 and set out plans for a community-led recovery (The Royal Borough of Kensington and Chelsea 2019). The core elements of the strategy included the following:

- A dedicated service for survivors and the bereaved, which is separate to the NHS Dedicated Service based in GHWS (described in Box 1 above). We discuss the implications of these two similar services in section 6 (Box 4).
- Ongoing support and a community programme for the local area (some of which was to be delivered alongside the NHS services mentioned above). This includes supporting people who had accessed the key worker service or commissioned services during the earlier stage of the recovery.

- Emotional health and wellbeing support. In addition to the services described above for adults, the RBKC funds a range of providers who work across local schools and community centres.

The public health service within the RBKC also partners with the local NHS to monitor the health and wellbeing needs of people directly impacted by the fire, as well as people living in the wider North Kensington area.

It is notable, however, that the council's support for mental health and wellbeing services was not widely publicised due to high levels of 'distrust and anger' within the community (**The Royal Borough of Kensington and Chelsea 2019**, p 4). We return to issues of trust (and building trust) later in the report, as well as giving our reflections on the extent to which the survivors and bereaved (and people in the wider community) feel that the health care response has been helpful (*see* section 7).

4 'They weren't going to be silenced and pacified': how the survivors and bereaved brought their voices to the response

As discussed in the previous sections, the initial response of different services and organisations to the Grenfell Tower fire was described as chaotic and 'scattergun'. Essentially, there were multiple organisations – probably with the best of intentions – trying to help a population they did not understand sufficiently, with methods they believed were tried and tested; it took time to establish an 'offer' that was more tailored to the needs of a diverse group of people, such as the Grenfell Health and Wellbeing Service (GHWS). In this section, we outline how the survivors and bereaved and people in the wider community brought their voices to the health care response to the fire.

An organised community

As outlined in section 2, the residents of Grenfell Tower and others in the wider community have a strong history of activism and organising to challenge organisations and people in power, and fight for better living conditions. The survivors and bereaved were by no means passive bystanders in the aftermath of the fire. Some of those who escaped the fire formed a WhatsApp group, which was a key method of communication given the lack of information about where people had gone when they were displaced. The WhatsApp group evolved into the Grenfell United collective of survivors and bereaved. To this day, Grenfell United has been campaigning for justice, safety, and the health and wellbeing of the survivors and bereaved. Grenfell United and other Grenfell community-led groups have organised

themselves to advocate for the needs of people who survived the fire or were affected by it.

> *We decided as survivors and bereaved as a whole… Actually, we have a voice, right? We may not be as qualified as other people, but we know what we need, and we know what we want… We have a voice.*
> Community interview participant

As outlined in section 3, Grenfell United directly influenced the Senior Coroner's report. Members of Grenfell United used the report to influence discussions they had with the then Prime Minister and senior leaders within the NHS. There were also connections made between members of Grenfell United and people across the country (and around the world) who had been affected by other traumatic events – for example, the bombing in Manchester Arena. This network meant that people could support each other based on a common understanding and experience of a traumatic event.

As time went on, the survivors and bereaved and people in the wider community continued to express their concerns and challenge the 'business as usual' approach of people working in the local health care system. They pushed them to be more open about the decisions they were taking and to listen to their needs. Sometimes this was done through formal meetings and sometimes this happened more opportunistically and informally – which made community engagement challenging to do comprehensively.

Alongside this, people who live in the area mobilised and created other campaigning groups such as Justice for Grenfell, with the aim of keeping media and political attention focused on the injustice of the fire. People were angry; they wanted to be heard and they wanted answers about why people were killed in the fire (some say they were murdered). At times, the different community-led groups have disagreed between them about the way forward, but there has largely been a consensus about having to fight against powerful organisations and institutions just to be treated fairly.

> *I will say this with absolutely no regret, I was white with rage. Steel white with rage. I thought, 'how dare you do this to our community, how dare you?' I organised protests… 'Let's take it to parliament', I said. We cannot have shouting and*

screaming in our community at the moment [in the initial period after the fire]. So Justice for Grenfell organised the first silent walk… I did a lot… in all sorts of different ways. I've sat in parliament, I've talked in parliament, I've been all around the country, Ireland, Scotland, Liverpool, Manchester, everywhere talking about Grenfell to a range of people from workers, trade unionists, campaign groups.
Community interview participant

One size does *not* fit all: community voice in commissioning and service design

Mental health support services were given as a key example of a disconnect between services and the communities they serve. Central North West London (CNWL) (the mental health care trust) undertook the 'screen and treat' programme. This was based on learning from previous disasters, such as the terrorist attacks in Paris and in Sousse (Tunisia) (Cyhlarova and Knapp 2018) – as opposed to what the Grenfell Tower survivors and bereaved had necessarily asked for.

In North Kensington, screen and treat involved knocking on thousands of doors in the local area, which we heard led to some mixed reactions. For some people, services reaching out in this way meant they could talk about their trauma and get referred to therapy (NHS Confederation 2018). However, for others, the screen and treat approach did not feel appropriate to the survivors and bereaved; the approach was felt to have cast the net too widely, leaving the survivors and bereaved feeling that their unique traumatic experiences and subsequent needs were being overlooked or diluted.

The screen and treat programme used questionnaires administered by consultants and community outreach workers either face-to-face or over the phone. The questionnaire asked many questions, including whether people were having thoughts of suicide. The survivors and bereaved found such questions difficult and emotionally triggering.

People did not know how to talk about loved ones dying because they were still looking for the bodies.
System stakeholder

We interviewed two representatives from Grenfell United (both residents of the tower) and they described their perceptions of screen and treat, and conveying their feedback to the trust's Chief Operating Officer.

> *...we were told that people were out door-knocking 11,000 doors in North Kensington, but they never knocked [on] mine... So, a net was spread... but they were working outwards in, so the people that were actually affected were the ones that were being forgotten about, so it was about changing that. We need to work with the people that were most affected and work our way out... It was a case of coming and talking to the relevant people [such as the Chief Operating Officer], and saying, 'If you're out there door-knocking 11,000 people in North Kensington but you haven't door-knocked the 274 survivors or the 200 bereaved... then you haven't got the people that probably should have been focused on'... And it was just the approach around how things have always been, so it was very much tick-box, textbook, 'this is how we approach mental health', and it took for... CNWL, [the Chief Operating Officer] at the time, to say, 'here's the textbook, let's throw it out the window, we're going to start again, how do we get this right?'*

Initially, CNWL relied on its existing services such as Improving Access to Psychological Therapies (IAPT) and the Time to Talk telephone helpline to treat people affected by the fire. On reflection, the Chief Operating Officer said those types of services were not meeting the needs of people affected by the fire because 'IAPT is pretty formulaic'. One of the Grenfell United representatives explained how she felt the approach of the helpline was not appropriate:

> *Time to Talk, that's it, and that was the number that you had to call as a survivor. So I called up, they called me back, and they went through a kind of tick-box exercise, and one of the questions to me was, do I feel suicidal? And instantly in my head I was thinking about the community and how that would be perceived to someone where English isn't their first language and understanding the cultural differences around what suicide means in certain communities. I had a conversation with [other Grenfell United representative] and I said, 'you know, they just asked me do I feel suicidal and how do I feel about that?' I've just come out of a fire that's probably... you know, I nearly died, so why am I being asked that?*

Grenfell United representatives told us the mental health of the survivors and bereaved was a key priority, as people were dealing with bereavement, losing their

homes and had not had time to address their trauma. Some people found the screen and treat and Time to Talk programmes inappropriate and insensitive, being based on Eurocentric ways of thinking and working, whereas the majority of survivors and bereaved were from ethnic minority groups and for some English was not their first language. This lack of cultural competency in supporting people from ethnically diverse backgrounds and with different religious beliefs compounded the trauma people had experienced. This disconnect between the standard services for mental health and what the community needed was reflected in the initial low levels of service take-up.

As one of the Grenfell United representatives told us, the standard solutions offered by the NHS were not working for this community:

> *...we did have a lot of complaints coming in from the survivors and bereaved, especially the bereaved, at the time, because it was still early days and where people are just going through bereavement and they haven't even buried their loved ones and they're given three appointments upstairs in Time to Talk and saying, 'oh, well, it's done now'. What do you mean, it's done? Am I better? I haven't even started to speak, right?*

Grenfell United representatives and others in the community would frequently challenge CNWL about the mental health support for the survivors and bereaved. There was a lot of frustration about the NHS's perceived lack of empathy and lack of consideration of the diverse needs of the people affected by the fire. It was clear to the Grenfell United representatives and to the Chief Operating Officer that the mental health 'offer' would need more flexibility to meet people's wide-ranging needs – and would need an experienced team who could work differently. Around this time, the trust brought in a semi-retired mental health practitioner with a strong connection to the local area. It was their role to change minds about how to respond to people's trauma, how to meet people where they were – particularly those from different cultural backgrounds who did not or could not engage with the traditional NHS model of mental health care.

One Grenfell United representative described how they challenged CNWL and pushed for a different model of mental health care support:

> *...it's quite difficult to understand how we created this [GHWS], but it was very much, I think the bit that works so well here is unlike any other therapy, which we*

understand has to have a kind of… timescale, but unlike that, it was very much 'come in and let's have a conversation like we're having, let me build the trust with you'. That was what we needed from this service, and we explained that. Don't make it, 'come in, let me have a list of questions and we're going to go through them and then I'm going to work out what is needed'. [Instead, it should be] 'Let me find out a bit about you'.

Another representative recalled telling the trust and GHWS that its initial approach was off-putting to some, and people were seeking something more humane and relatable from mental health care services. The representative told us that the flexibility and listening approaches of NHS managers was helpful to develop the mental health offer and make it more personalised. The following quote refers to cognitive behavioural therapy (CBT) and eye movement desensitisation and reprocessing (EMDR) (a method based on eye movement as a way to process traumatic memories):

…it's the flexibility, right? It's the flexibility of the service, the flexibility from the head [of service] downwards to say, well, actually, 'what works for you?' And it's had its challenges throughout. What you've had is, you've had this very heavy… I'm not a therapy fan, believe it or not, I was never a therapy fan anyway. I advocated for it for my family, for my kids, I think they need it, but personally, I don't necessarily think it's helpful. But there was this heavy kind of psychological, CBT, EMDR and all this kind of… they'll come in and it's almost like you're talking to someone and you're saying to someone, like, you're really talking and in other words you're saying 'I need a hug', right? And they're sitting there, going, 'hmm, interesting, look at my finger, look at my finger'… Brother, all I need is a hug, right… Not everyone needs treatment. You don't need to over-analyse someone. Just be human.

Another example of the influence of the survivors and bereaved is the paediatric long-term monitoring service established as part of the suite of health screening and monitoring put in place after the fire. The lead paediatrician had conversations with Grenfell United representatives and other members of the local community to scope what people wanted from the appointments. Children and young people have also been involved in setting outcome measures.

Community voice in holding the health care system and local authority to account

During our interviews, the anger people felt about how they had been failed came across loud and clear, as did their frustrations about how the solutions on offer were not meeting expectations or matching needs. For instance, representatives of Grenfell United were critical of individuals or organisations who had co-opted the NHS logo on their signboards and were offering ear acupuncture to the survivors and bereaved in the help centres. They wanted to know how such things had been decided and sanctioned, without first hearing from the survivors and bereaved about what they needed from the NHS.

We also heard that people wanted clarity about how the funding committed by the NHS and the Royal Borough of Kensington and Chelsea (RBKC) was being used – especially as they had mixed experiences of NHS screening and monitoring and services provided by the local authority (*see* section 7).

> *…there's no way that £50 million is going to come into our community and it's just going to disappear, it's going to be misspent, and no one's going to be held accountable for it. Of course there [has to be] accountability, that's a lot of money, right?*
> Community interview participant

A therapist who works with the survivors and bereaved told us he was acutely aware of people's questions, suspicions and misgivings about how statutory organisations were using the funding:

> *I know that there's a [feeling], like, 'there's all this money being spent, how are you helping us?' And I suppose the community… this is talked about widely… hold us to account.*

According to another interview participant, it was clear that people had had enough of being ignored and excluded from decision-making:

> *I guess because of what had happened, people just weren't taking any nonsense. You know, they weren't going to be treated… although in truth they have been to some extent by statutory services… but they were very clear that they weren't going to be treated in the way that they have been ignored leading up to the fire and arguably that was part of the cause of what happened to them. So they*

weren't going to be silenced and pacified, they wanted to be actively involved in determining what they considered, particularly in the NHS, the money they've got for this service was and how that was going to be deployed.
System stakeholder

Both the NHS and the RBKC have tried to be clear about what they have done with the funding and the impact on the community. Our interview participants described numerous engagement exercises carried out by NHS commissioners and RBKC and there are numerous reports on the RBKC's website following overview and scrutiny meetings. We also heard about multiple steering groups and forums for the survivors and bereaved to be involved in shaping recovery and support activities. To a degree, these groups have provided a level of insight and scrutiny; however, people's concerns and frustrations were still evident, particularly about the difficulty in getting information and seeing tangible benefits from the funding (from either the NHS or the local authority).

So people used to shout and scream, but because there were hardly any resources round here, they didn't get anything anyway, they just shouted. Whereas now, people were shouting if there was a big pot of money, because they knew that's what they were going to get.
Community interview participant

...money is a major issue. It causes enormous distress. We all know historically if you give [money to] communities that are not used to having any money, it creates enormous divisions, it can create organisations talking about only certain voices being heard or favouritism, etc. Now, some people have relationships with the council that are more vociferous and they perhaps sometimes fall out of favour with the council, and others know how to schmooze the council with the councillors who sometimes hold the purse of the money.
Community interview participant

In an attempt to be more open and transparent, the RBKC has involved members of the local community in the commissioning of community support services to give them a better overview and a say in how resources are allocated. This was referred to by some interview participants as 'community commissioning'.

What has happened since the Grenfell Tower fire shows that there is potential for change, in terms of people and communities being able to exert more influence over the decisions made by statutory services – and for statutory services to listen and adapt their processes. This does, however, require a lot of time, commitment, and constant attention from all parties.

In the next section, we look at how challenge and feedback from the survivors and bereaved and people in the wider community prompted services to adapt and change their ways of working.

5 'It's the idea that you understand who you are there to serve': a different way of working

As detailed in section 2, the initial response had been chaotic, fragmented and ill-informed and those working in the area 'could not respond in the human way that they wanted to'.

> *The response was system-led, it was anxious, it was prescribed, it lacked compassion and humility.*
> System stakeholder

As the community increasingly brought their voices to the response and made clear what was not working, there was a growing recognition across the health system that services would need to work in different ways. They needed to be more responsive to what the community was telling them and move away from a 'one-size-fits-all' approach towards a more human approach that would be tailored to what the community and individuals needed. Rather than 'doing to', there was a need to shift to 'working with', building relationships with communities and working in partnership. Moreover, there was an increasing recognition of what communities themselves were bringing to the response and the assets that were already in place in the area. Statutory services could see the role that local, well-established and trusted voluntary sector organisations like the Rugby Portobello Trust and the Harrow Club had taken in the immediate aftermath and were continuing to take in supporting the local community.

What statutory organisations heard from the survivors and bereaved forced them to acknowledge that their own structures and processes were creating barriers to addressing the needs of the communities they served. These barriers were in

turn fuelling a sense of 'us and them' between the community and statutory services. The community was asking for a different style of working – connecting in a human, relational way and being held to account by communities. This has taken time and has often felt uncomfortable to services that have traditionally adopted top-down models. However, clear progress has been made across the system, caveated with the view that far more could be done and that not all partners in the system have found it easy to work in this way.

The importance of a different model of leadership

If services were to work differently, then there needed to be a different style of leadership in place, one that was less top-down and instead allowed staff to work flexibly, giving them permission to act on what they were hearing from the people they serve.

Many of the early meetings between services and communities were characterised by mistrust and rage at the very same public authorities that people held responsible for the deaths of the 72 people:

> *So, if you look at those videos, if you go back on YouTube and you can watch all the videos, just after the fire, that is what the health service, the police, well, all the emergency services thought was engagement, but it didn't work. After a while, then, it was just anger, disgust, we weren't going anywhere, but then you realise that if, for instance, they'd have come in and more or less allowed them to channel the energy somewhere, you would have gotten more from them and we could have made more changes in the community shortly after the fire, not six or seven years after the fire.*
>
> Community interview participant

At these meetings held in the aftermath of the fire, leaders from different public services sat up on stages and talked from podiums, while the survivors and bereaved and the wider community sat in the halls or meeting rooms. Thus, the authorities were elevated and removed from the people who were grieving and impacted by the fire. This was seen by the community as those in power talking down to people, reinforcing the widely held view that statutory services saw themselves above the communities they were there to serve. They were seen as public services broadcasting *to*, rather than sitting *with*, the community – particularly at a time when

people needed to feel compassion and empathy. These hierarchical dynamics were reflected in how health services and the local authority were treating people – that is, the professionals were experts holding the knowledge while the people using their services were expected to be passive recipients.

If this was to change, there had to be conversations to address the nature of the engagement and the hierarchical dynamics of many of the relationships. This is where the importance of having people rooted both in the community and in statutory services became clear. It needed individuals to bridge the gap between services and communities and to broker relationships if things were to change. Working with community leaders (who were speaking on behalf of different community groups), there were honest conversations about how the relationship needed to be reset on a more equal footing:

> *In the context of people feeling othered, people feeling they do not belong, that nobody likes them, that authorities think they know best and sitting among the other removes the element of othering people, that removes that little barrier… It is acting on your instinct as a human being.*
> System stakeholder

Community leaders had insights into both the communities within which they lived and the services with which they had relationships. In their conversations with community leaders, NHS and the council leaders at the Royal Borough of Kensington and Chelsea (RBKC) had to acknowledge the hierarchical nature of these meetings and to understand the power dynamic they represented. This had to be acknowledged and a different relationship forged, one that was based on partnership working and shared power. Participants interviewed for this work used the example of the Chief Operating Officer at Central North West London (CNWL) NHS Foundation Trust as someone who grasped this early on.

> *She went out to the community, she had the conversation, she took the flak, she built relationships, and I think she also gave us permission and an example about how to do that… leading by example.*
> System stakeholder

The Chief Operating Officer listened to community leaders who advised her on the best way to approach and engage with the bereaved, the survivors and people in

the wider community. There had to be a conversation as equals, and community leaders in turn also had to reflect on how they approached these meetings:

> *They [community leaders] understood that if they do not have conversations, if they just rant and rave, they shouted and they were angry, and rightfully so, but I said if you don't talk to the system you will not get anywhere – if you don't make them change it will always be and they will other you – they will say 'we can't even talk to you without you ranting and raving at us'. It was helping them to come into a room and not lose it.*
>
> System stakeholder

Over time, the survivors, the bereaved and people in the wider community had some success in influencing how services were delivered. As the Grenfell Health and Wellbeing Service (GHWS) was set up, there was an increasing shift away from rigid adherence to guidelines to working in a more person-centred way based on what would work for each individual taking into account their background and context. This required leaders to work in ways that cut through existing administrative processes and have more appetite for risk by trying things that the community was asking for. It was also about removing barriers and resistance within health care organisations and changing cultures of 'we know best'.

There are examples elsewhere on the benefits of models of leadership that empower staff to work flexibly, and work as equals with local people (Naylor and Wellings 2019). The tensions inherent in adopting this approach are encapsulated in the story of residents asking to go back into the tower (*see* Box 2 on page 37).

Box 2 The story of revisiting the tower

Interview participants described what happened when residents wanted to go back up the tower several months after the fire – for different reasons, including having the chance to say goodbye and begin to process what had happened. However, officials had significant concerns about the physical and emotional safety of the survivors and bereaved going back into the gutted building.

> *There was one particular situation where the survivors and bereaved wanted to go up the tower to say goodbye to their loved ones and so they had many meetings and the whole system just felt they can't do this. So, you have got the police saying, 'it's a crime scene', you have got the NHS saying, 'well clinical guidelines say it will retraumatise people'... and the survivors and bereaved said, 'you find a way, because we need to get up there'. And it was probably about nearly a year in that systems came together, and they did make that possible, they made it happen. And all of a sudden you saw a shift in that, 'okay, you can work together to make that happen'. (A) They listened; and (B) they said, 'okay, it's going to be hard, but [let's] try' and yeah, they did try. It is the idea that people come together to support a particular person.*
>
> System stakeholder

A small number of former residents were escorted back into the tower by the police, mental health professionals and others. For some, revisiting the tower was predictably difficult and a painful experience. However, overall, people felt that they had been given a choice, that their decision had been respected, and that services were expressing their solidarity and support by accompanying them. For many, this was seen as a turning point in working differently.

Listening and acting

When concerns about how mental health services were not meeting expectations or needs were fed back to CNWL, it was important that services listened and acted on those concerns rather than reacting defensively. During our interviews, leaders of a community-led organisation described a meeting where they fed concerns about screen and treat back to the mental health service and described it as a 'watershed moment', because health care leaders took on board that the standard offer was not working. Their reaction to the criticism was felt to be positive and showed a willingness to listen, to be flexible, and to change despite finding it difficult

to feel like they were doing the right thing only to be told it was not working. The relationship started to change, with mental health services now asking the community and people using services, 'what will work for you?' People working in public services needed to connect with the communities in a human way rather than one based on guidelines and practice that did not take into account context and history. The approach that was required from services was described by a leader from the voluntary, community, faith and social enterprise (VCFSE) sector as follows:

> *You don't have to be from the area, I think you've just got to have empathy, you've got to understand a community and be able to listen and hear a community. You've got to want to build a community, and you have also got to want to have that heartbeat within the community and have good intentions.*

Listening to staff

The need for leaders to listen was not limited to the community. Equally important was health care leaders listening to the staff who were delivering services, and ensuring that their voices were heard during discussions on what was working and what needed to change. Those staff who were working closely with the community were hearing first-hand what was working and what needed to improve.

GHWS was set up in response to the fire and had grown organically and rapidly over time, having to constantly adapt to the changing needs of those affected. One of the ways that GHWS engaged with staff and listened to their views was through staff listening exercises. A staff engagement exercise was carried out to understand the staff perspective on the first year of the GHWS, with an emphasis on outreach, adults, and children and young people services (Central and North West London NHS Foundation Trust 2021).

Thirty-three staff members from the service were interviewed across all pay grades and the three main elements of the service. The key themes of the exercise were around the challenges in the early stages of the work. There were difficulties around recruitment, with lots of new starters coming on board, and a lack of clarity around roles or boundaries between teams, with little time or capacity to provide inductions. There was pressure to meet the estimated screen and treat target (c. 11,000), when the numbers seemed unrealistic to staff, as did the time frame in which to

deliver them. The 'one-size-fits-all' approach was causing damage to relationships with people, and there was a need to move back to basics and sit and listen, as gaining trust was key to being able to help people. One interviewee recalled hearing from a colleague about what the implications of the initial ways of working were for practitioners:

> *It is heartbreaking for me to see this community suffer and we can't do anything because our hands are tied behind our backs.*
> Community interview participant

The basic needs of the community had to be met before considering any therapeutic interventions and measures. Staff recognised the importance of taking the time to understand the community and learn what different groups and individuals needed, and yet equally there were challenges in working with the community.

> *(We) felt we had done so much for the community but were still not getting it right.*
> System stakeholder

Forging connections with existing organisations within the community was important to GHWS staff.

Initially, staff did not feel they had the freedom and trust of the management to treat clients as they saw fit, although this improved over time. Management, once established, was felt to be good at finding new ways to engage with the community, which was important when the teams had to be adaptable and flexible, although more work needed to be done on staff wellbeing. One key theme from this exercise was the need for greater integration and communication between and across teams. Moreover, the workforce initially did not represent the demographic profile of the community they were serving, particularly in terms of ethnic diversity.

This feedback, and ongoing conversations with the community, led to GHWS putting in place a service transformation in 2021, with the following changes:

- Bringing the three separate teams together (children and young people, adults, and outreach) into neighbourhood teams to be tailored to reflect the needs of the community.

- Diversifying the staff complement, bringing in new roles, such as community connectors. The Grenfell community connectors programme preceded the national Core20PLUS5 community connectors programme (**NHS England undated**). It was a programme developed in response to feedback from the survivors, the bereaved and people in the wider community, and some of the connectors are themselves survivors and bereaved. Aligning the programme with the NHS Long Term Plan enabled the service to demonstrate the benefits of the programme to the rest of the system within CNWL and the clinical commissioning group (CCG) (now the integrated care board, ICB). It also allowed them to make the changes they needed to improve the service and ways of working. Community connectors are defined by the NHS as 'those with influence in their community who can help engage local people with health services. Offering unique insight into the barriers people living in their communities face, connectors are ideally placed to advise local NHS services on how these can be overcome and what makes a good service' (**NHS England undated**).
- Bolstering the 'front door' to the service and creating a single point of entry to the service.

These service changes aimed to ensure that the service was better able to tailor its offer to reflect the needs of the local community and to cater for a diverse population. Moreover, it was attempting to address the fragmented and siloed working that was too often proving a barrier for people to access the care and support they needed.

Alongside the formal nature of a service change, there were other initiatives to break down the barriers between the community and statutory services. One initiative that was key to this was Lucy's walk (*see* Box 3 on page 41).

Box 3 Lucy's walk

> *Another thing that people don't understand, that Ladbroke Grove has a history and if you don't understand the history of Ladbroke Grove, then the service you're delivering to the people will be an issue.*
>
> Community interview participant

Central North West London (CNWL) NHS Foundation Trust has a requirement for new staff at the Grenfell Health and Wellbeing Service (GHWS): they have to do Lucy's walk. The walk is also offered to visitors who need to understand the locality.

Lucy is a community liaison manager in GHWS and has lived in the local community her whole life. After the fire and in the earliest days of GHWS, many people visited the service who did not know the area well. Lucy developed a guided walking tour of the area to help people begin to understand and connect with the community. The walk offers an experiential sense of the area and Lucy talks about the impact of changes that are under way in it.

The walk helps to break down misconceptions about the area being deprived. When taking staff from The King's Fund on the walk, Lucy told us about how sections of the media had demonised the community. The walk was designed to counter this narrative and show the strength of the community in the area, break down assumptions, and demonstrate what the area has in terms of assets rather than focusing on what it does not have. As one community interview participant put it:

> *Just because we live in a building block and we're from different backgrounds does not mean we are stupid or poor. Some of us are poor but we are not poor in resource.*

On page 42 is a set of photographs taken by The King's Fund team of areas surrounding Grenfell Tower, the A40 underpass and the garden at GHWS in May 2023.

IT SHOULDN'T HAVE HAPPENED TO THEM.
MAKE SURE IT DOESN'T HAPPEN TO ANYONE ELSE.
Rest in eternal peace ♡

POEM
NEVER FORGET...
I WILL NEVER FORGET THE SIRENS
I WILL NEVER FORGET HOW SCARY THE FIRE WAS
I WILL NEVER FORGET HOW WORRYING THE FIRE WAS
I WILL NEVER FORGET THAT I SURVIVED
I WILL NEVER FORGET MY FRIENDS AND NEIGHBOURS WHO DIDNT SURVIVE
WE CANT CHANGE THE PAST — BUT WE CAN CHANGE THE FUTURE
— WE WILL STAY STRONG —
WE WILL RISE UP AS A COMMUNITY
WE WILL FIGHT FOR JUSTICE TOGETHER
WE WILL ALWAYS REMEMBER OUR FRIENDS AND OUR NEIGHBOURS
WE WILL ALWAYS REMEMBER OUR HOMES
WE CAN'T CHANGE THE PAST BUT WE CAN CHANGE THE FUTURE...
...NEVER FORGET

Cultural competencies

One of the main themes that came up time and again during our interviews was the need to deliver culturally appropriate services – that is, services that recognise the diversity and differences within the local population – and ensure that the services offered are designed and delivered in ways that meet people's diverse needs. In essence, it is about staff awareness, knowledge, skills and behaviours that are integrated into a service to create conditions for people from diverse backgrounds to flourish – both the staff providing the service and the people using the service (**Ridley *et al* 2001**; **Sue 2001**).

As outlined previously, the population in the Grenfell area is diverse in terms of ethnicities, languages spoken and religious beliefs/faiths, and yet the initial response was widely felt to not take this into account. That led to the provision of services that did not meet people's needs.

> *The health service has an issue reaching the Afro-Caribbean community and the Moroccan community and we always asked ourselves why this is a cultural issue there? And if you don't understand that, then you would not be serving the majority of this community.*
>
> Community interview participant

System stakeholders made the point that they knew they were not reaching certain communities *before* the fire and should have known this when thinking about how to respond. Leaders from a community-led organisation gave examples of how a lack of cultural understanding was stopping services meeting people's needs. People were being asked questions about forced marriage as part of mental health assessments, leading to disengagement (people feeling they were being profiled based on stereotypes). Services were making assumptions that all communities would be affected by certain cultural practices when this was not actually the case. There was also a lack of understanding of how death and grief were experienced by people of faith:

> *There's no Muslim man going to come and tell you I'm hurting. I'm pained because I lost five of my family members.*
>
> Community interview participant

An early issue identified by people using the mental health service was that it predominantly comprised white female therapists. A lot of people who should have been accessing services were showing up for one or two appointments but were then disengaging. An internal report in 2019 by GHWS staff showed marked differences in engagement between people of different ethnic groups who were accessing the service. GHWS commissioned a study to understand the psychological wellbeing of Black Africans using mental health services in North Kensington and their reasons for disengagement (Osmany *et al* 2020). The study found that those they spoke to were reluctant to engage with mental health services for fear of being stigmatised – as well as having a mistrust of mental health services based on historic mistreatment of Black people. The report further added that the mistrust and fear were a result of 'myths or truth' that Black people were more likely to be prescribed high doses of antidepressants, misdiagnosed by mental health practitioners, and be sectioned under the Mental Health Act (Osmany *et al* 2020, p 31). This is further highlighted by one of the community participant interviewees:

> *This community has always been apprehensive about mental health and from the [Black, Asian and minority ethnic] community, it's a bit of a taboo subject. So you talk about mental health, and I know obviously we now talk about it really openly everywhere, but back then, six years ago, it was… if you said you felt that your mental health was… you're instantly thinking you're being sectioned into St Charles [the local hospital for mental health care], that's how this community thought.*

The study concluded that practitioners and therapists in mental health services were not trained or equipped to fully understand the needs of Black people, or how to engage with the Black community. This lack of understanding often led to treatments that were unsuitable or not culturally appropriate, leading people to discontinue treatment and view the service as racially discriminatory/prejudicial. Consequently, a barrier is created between the community and the mental health service provider, creating a further cycle of disengagement at community level. The report made a series of recommendations, including: recruiting more people from ethnic minority backgrounds; co-producing with the community culturally sensitive interventions and activities; mandatory training for staff on cultural competency, systemic racism and unconscious bias; and inducting staff to develop understanding of the Grenfell Tower disaster and the local context and history (Osmany *et al* 2020, pp 33–4).

As a result of these recommendations and ongoing feedback, the service had to adapt and look at its staffing and put in place initiatives to make therapists and others working at all levels more culturally aware, and for the service to be more accessible to different groups in the community. A cultural competency framework is core to the training and delivery of services at GHWS. There is regular training of GHWS staff around cultural competencies, some of which has been provided by local voluntary sector organisations in the area. Apart from internal regular cultural competency training for staff and partners, GHWS also works with local services that provide counselling to people from diverse ethnic and religious groups at Grenfell. For example, GHWS provides training and supervision support to some of the Almanaar Muslim Cultural Heritage Centre counsellors, who aim to provide culturally appropriate services:

> *Another key element in the trust for the children's services has been using Muslim heritage therapists, because there's something about… I think because of the socio-political narrative of the last 20 years or so, combined with for many people experience of racism, and anti-Muslim experiences that they just have on a daily basis in communities, it was an added barrier to approaching mental health services, like CAMHS [Child and Adolescent Mental Health Services]. So I mean, I worked in CAMHS for many years. I know we think we're accessible but actually I think maybe we underestimate what some of those barriers are.*
>
> Community interview participant

Relationships with local VCFSE organisations like Almanaar enable GHWS staff to build networks and get a better understanding of the local population. Several interviewees spoke of the changes they have seen as a result of the work undertaken to train staff and create a service that is appropriate for the diverse communities. One of the key reflections was that this work takes time and needs people to engage with it, and for them to see the benefits in their practice:

> *Some colleagues go on about white fragility. I don't particularly like that term. I just think that it's not like, 'oh I've just gone to this unconscious bias training and now I've seen the light'. It doesn't work like that. You aim to do it very consistently and in a way that doesn't make people feel guilty.*
>
> Community interview participant

New roles at GHWS

Key to making GHWS more culturally appropriate and competent has been bringing in members of the community to work within the service. Service user consultant roles were set up to bring community voices to how services were set up. The Service User Involvement Team (SUITs) was formed in 2018 and is made up of adult service user consultants, young people service representatives, and clinicians who 'are engaged in a process of coproduction in the design and delivery of GHWS' (NHS Grenfell Health and Wellbeing Service 2022). Community interview participants highlighted the benefits they saw from working as user consultants, and how the service created an environment in which they felt listened to and worked with staff as equals.

> *Because the service felt that even though they had the technical knowledge, they didn't have the lived experience side. So, they really needed those of us who had the lived experience to come on board.*
> Community interview participant

> *I absolutely loved being a service user consultant. I definitely was listened to… I felt listened to, I could give ideas. I could do all of that and I tried to fully engage as well, because I thought it was really important to try and help the community and this was a way of doing it. But I absolutely loved my time as a service user consultant, but it was that value that the service put on you. They looked on you as an equal.*
> Community interview participant

> *They [CNWL] have done a good job of placing that [community] at the front and centre of their transformation approach and… they've emphasised hiring people from the local community.*
> System stakeholder

Service user consultants would work on specific projects or initiatives that GHWS was working on, such as a digital marketing project or how patient experience questionnaires were designed. Both the adult and young people's teams have also been involved in the recruitment of staff, designing training, supporting events in the community, and quality improvements projects (including seeking feedback from the people who use services).

Recognising the need for GHWS to go out into the community rather than expecting people to come to it, four community connector roles (described earlier) were put in place. The community connector role is there to act as a bridge between the service and the community. Part of the role involves spending time in the community at events, understanding needs, and referring people to the service.

> *I love going out. That's my main job, going out and doing these projects on the ground. There's no point sitting in the office – you've got to go out on the ground and talk to people.*
> Community interview participant

There was recognition that the role of community connectors was not one that the NHS is always comfortable with resourcing:

> *I think there has been a struggle for the NHS to recognise this as a valid role that could improve the health of the community, because I'm not a clinician.*
> Community interview participant

This section has explored the different ways that CNWL worked to try and adapt its approach to what it was hearing from the communities it serves. The next section explores how co-ordinated the response was across a wider range of services.

6 Working together: a co-ordinated response?

> *The statutory services need to be talking to each other… They're not really talking to each other. They're used to working in silos.*
> Community interview participant

One of the key themes highlighted in the interviews was the lack of co-ordination between health service commissioners, providers, the council and the voluntary sector within the area. This resulted in services often working in a fragmented way – sometimes duplicating each other's efforts – and not coming together as one system to meet the community's needs. Moreover, there is a question over how well statutory services have worked with the voluntary, community, faith and social enterprise (VCFSE) sector, leading to questions over duplication and efficiency.

Listening in silos

In the immediate aftermath of the Grenfell tragedy, there was what one interviewee called a 'scattergun' approach to engaging and collaborating with local people, which led to confusion at times over who had said what to whom. Over time, this activity has become more organised but has lacked co-ordination across the different organisations working in the area.

Most of the subsequent engagement has been at the level of individual services rather than services and commissioners coming together as partners to work with the communities. This has meant the same individuals and groups from the community have been working with the different services across the area. This has led to confusion and frustration within the community (with people having to recount the same experiences many times over) and challenges for services (in trying to understand and track who has agreed what, and with whom).

This 'industry' around engagement has led to difficulties in services prioritising what was most important to listen to and act upon. It has also been frustrating for people

in the community, who felt they were continuously being asked for their views but were often not seeing any change as a result:

> *I've lost count of the number of people that I've spoken to who have been engaged in some kind of survey work or insight work or research in the area, and most of it is not meaningful for the population and is enraging for the population because what we have here is... a wealth of surveying but with very little action that moves the statutory agencies in particular beyond their comfort zone.*
> Community interview participant

One of the examples given was that the community has repeatedly made clear (in these surveys and through other routes) that social housing is their top priority, and yet they have not seen this translated into action. Those we spoke to clearly made the link between housing and mental health, and found it frustrating that the two were not joined up. They talked to NHS services about mental health and talked to the council about housing.

> *So, if we haven't seen that, and yet the population has said overwhelmingly time and time and time again that [housing] is their priority, what does that tell us about community-led recovery?*
> Community interview participant

Moreover, this focus on engaging at the level of individual services has meant that most attention has been paid to whether existing services are working and how they could be improved, rather than working with the communities on what services there should be in the first place. The implication of this is that decisions have already been taken without the involvement of the community. This has led some in the community to question whether the health and care system sees them as equal partners:

> *The distinction I'm making is co-production as equal partners, that the community we're working with shape it and have equal power to shape it. They don't get a menu and [they're told] 'choose just from this menu but we've decided the menu'.*
> Community interview participant

Effective delivery of services starts with placing the needs of communities at the heart of decision-making. This includes being able to communicate with people

and understand what they need, and then working with them to design and deliver the service. If services are to shift to community-led approaches, then they must consider how they co-ordinate their efforts and engage with local people in ways that demonstrate their willingness to listen and effect change. For many in the community, despite some progress being made on listening to what the community needs, this has still not happened:

> *The concept of community-led recovery, apart from where it pertains to the survivors and bereaved directly, has also been largely ignored. So, community-led recovery has not been a key criterion for decision-making when it comes to resource allocation.*
>
> Community interview participant

This issue is challenging for those working in the North West London Integrated Care Board (ICB), who are also engaging with communities and recognise that multiple players are doing the same thing.

> *As partners across the system I still think there's quite a long way to go in terms of… maybe from the NHS's side as a single team that does all that kind of collaboration at a systems level rather than organisationally driven engagement and communications around what should our service do? And I think that has led to… a bit of kind of survey engagement, consultation fatigue in the community… Where I'd like to get to is a more co-ordinated set of kind of collaboration… activities and aims across partners.*
>
> System stakeholder

The weight and volume of feedback and consultation carried out at different times by different service providers has, at times, meant that the ICB was unable to focus on key issues, and has instead led to a more reactive culture of using feedback. Rather than partners across the system coming together and focusing on two or three key issues together, there has been a lack of prioritisation:

> *And so a lot of people in the community were so open to be like, 'okay, you're going to answer my question, let me tell you my view'. And there were like 150 views, but really you should take those 150 and be like, 'here are our top three, we're going to hit the top three, let's do the top three really well, and then we can get on to four, five and six'. But what they sometimes do is, 'oh my god, they've given us 100 things*

to think about, let's do 94, 52, which is maybe the easiest, but we're not going to do them very well'.
Community interview participant

Co-ordination of services

I'm not sure we really got together in the way that you could have done and actually formulated a plan that would enable us all to understand what our individual remits were, what we would and couldn't do and what might really be beneficial… I mean we had individual relationships [with] each other, but we didn't really come together and say with the community… how are we going to do this together?
System stakeholder

The lack of co-ordination around engaging communities is replicated in service provision, which has often felt fragmented, resulting in a lack of continuity of care. Trying to make sense of the system has proved a challenge at times, both for people in the community and those representing them.

A number of different services have been set up in response to the health needs of the people affected by the fire (these are listed in section 3) following on from the Senior Coroner's report and the NHS's £50 million that followed. However, many of the people we spoke to questioned how well these services were co-ordinated and how well they were working together effectively around what the community needed.

I think it has been really hard for us to navigate the different components of the response from health and care services… Things popped up that were there short term… There were different professionals, a new Dedicated Service from NHS and from the local authority, trying to work out what resources were out there and how best to signpost families was quite tricky. Voluntary sector vs commissioned services. It's a really messy environment and I think that mental health plays into the messiness.
System stakeholder

The NHS Dedicated Service that was put in place has gone some way to helping the survivors and bereaved to navigate services, but not all aspects of it are working well – particularly around people's physical health needs. One of the obstacles to joint working has been issues around data-sharing across services. The inability

to share data between general practice and mental health services has proved a barrier to co-ordination. Many people in the community were reluctant to allow their data to be shared because of a lack of trust. This has made it difficult for the mental health service and primary care to work in a joined-up way around what that person needs, and can leave people using the services questioning why the NHS is not working as one.

One question raised by Grenfell United was about how different groups in the community were segmented and how service provision was decided based on that segmentation. This came up in an interview with a commissioner about multiple discussions he had had with the survivors and bereaved. There was a challenge around whether the NHS Dedicated Service was for the survivors and bereaved, or for the wider community. If someone was a survivor from the tower fire, they were eligible for the adult respiratory long-term monitoring. If someone lived nearby but had not been in the tower, they would be directed to the community respiratory service for a one-off check with onward referral as indicated. The different eligibility criteria for different groups led to some people being unhappy, and created a sense of division among the survivors, the bereaved and the wider community.

Box 4 Services not working together: a tale of two dedicated services

At the time of our research two dedicated services had been set up to provide points of contact: one by the NHS and one by the council to allow the survivors and bereaved point of access to a range of services provided by the respective organisations. The NHS website describes the NHS Dedicated Service as follows:

> *The NHS Dedicated Service was designed with the survivors and bereaved of the Grenfell Tower fire and Grenfell Walk to look after the long-term health needs of these groups. The Service supports and co-ordinates bereaved and survivor access to a range of emotional and physical wellbeing health services.*

The council also has a separate dedicated service, again offering a first point of contact for key concerns and support from partners (including education, housing and health). These were both put in place to address concerns from the survivors and bereaved that they had many points of contact with a range of different services that were proving difficult to navigate.

continued on next page

Box 4 *continued*

However, one story we heard very clearly illustrated the challenge around having two dedicated services, one embedded in the NHS and another in the council, and the resultant challenges facing the people using those services.

One survivor was rehoused after the disaster. This person went away for a period of time and when they returned, their basement flat was flooded, destroying their belongings. They went to the dedicated service at the council to deal with this housing issue. However, it was not solved for four years after the fire. The impact on the individual's mental health was significant.

The NHS Dedicated Service (based in the Grenfell Health and Wellbeing Service) had to manage this person's mental and physical health problems, which were largely being caused by housing issues. Both services were working closely with this person but were not working closely with each other.

> *If somebody's having housing issues, it's going to impact on their mental health. I don't think they talk to each other because if they did, mental health services would be saying to them 'what the hell are you doing?'*
> Community interview participant

Despite good intentions, having two dedicated services only served to perpetuate the lack of co-ordination across services.

Primary care services

Part of the £50 million funding allocation from NHS England was to enable the survivors and bereaved to access enhanced health checks in primary care. The NHS Dedicated Service (based in the Grenfell Health and Wellbeing Service, GHWS) was meant to fast-track people impacted by the fire for the enhanced health checks. There was also an agreement between the clinical commissioning group (CCG) and GPs that they would flag patients on their records who were former residents of the tower, thus signalling they were a priority for different health care services. The survivors and bereaved were seeking a co-ordinated and holistic approach to their health care. However, some participants told us that they found it very challenging to access the enhanced health checks – either due to the long-standing issues with access to GP appointments exacerbated by Covid-19, or because some local GPs

seemed unaware they were meant to be providing enhanced health checks. One community interview participant told us:

> *I tested it. I don't mess around. I phoned my GP, I'm coming for an enhanced health check. They said, 'what's that?' I said, 'sorry, have you not been informed? It's been instituted a month ago… it's for Grenfell impacted.' She went, 'oh, give me a minute. Oh yes.' Off I go. So that was the issue.*

Another community interview participant shared that:

> *They gave us the enhanced health check… you go in and you get your blood pressure and cough into the thingy and they check your lung functioning and a lot of the GPs didn't even know about it.*
> Community interview participant

Thus, from the point of view of the survivors and bereaved and others in the wider community, primary care was not delivering what was expected. This has left some people feeling that the impact of the fire on their physical health has been downplayed or not given due consideration. Also, it was clear from the interviews that they still do not think that the CCG (now ICB) listened to people or worked with them as equal partners – requiring groups such as Grenfell United to keep pushing for information and action.

> *…there's a physical health element to this… and that's been the biggest challenge that we've had but we're still persevering with it… The physical health is an absolute let-down, safe to say, right?*
> Community interview participant

We interviewed people working in the ICB who acknowledged the challenge for people in accessing enhanced health checks. A commissioner told us the ICB (as part of the North Kensington recovery programme) has worked towards increasing capacity, including commissioning the GP Federation to provide enhanced health checks. The ICB has also worked with the Royal Borough of Kensington and Chelsea (RBKC) to implement a programme for digital literacy to help people to navigate access to appointments. However, the strength of feeling in interviews shows that the survivors and the bereaved feel that the physical health 'offer' has

been a let-down, particularly in primary care, but interviews suggest people have also not been able to access the screening and monitoring they expected to.

We interviewed a local GP who expressed deep empathy for people who had survived the fire and acknowledged that the community was not getting the care and attention they were asking for regarding their health and wellbeing:

> *…there's very strong emotions that can transfer across when I'm in, you know, my GP consultation, very powerful emotions and… I really try and empathise [with] that… Although it has been six years on [since the fire], it still, you know, feels like as though it just happened yesterday… It's until there's justice for this community… they're not going to let this go… There was something called [the] enhanced health check and that… looks at both physical and psychological health needs… However, it's not meeting the needs of what the community have been… asking for.*
> System stakeholder

The VCFSE sector

A large number of VCFSE organisations stepped up in the aftermath of the fire (British Red Cross 2019; Plender 2018). Their significant contribution was widely acknowledged throughout the interviews. Lucy's walk (*see* Box 3, p 41) was in part set up to demonstrate to people coming to work in the area how many organisations there are and what an important role they played in the aftermath of the fire – and have continued to play. Their immediate presence on the day of the fire was recognised and contrasted with the absence of the local authority's response. Many of these organisations are long-standing and have very clear and trusted links into the community. They have also supported how NHS services work with ethnically diverse communities, providing training for statutory services to recognise and adapt what they provide to be more culturally appropriate. The services they provided and how they worked with the community was often a model for working alongside the community rather than imposing top-down solutions, and yet many of the community interview participants felt that this contribution had not been sufficiently recognised by statutory services.

Two questions that were raised in our study were how well statutory services were working with the VCFSE sector, and how well the different VCFSE sector organisations were working with each other.

During the interviews, we heard examples of voluntary sector organisations that were providing very similar or complementary services to the NHS to treat mental health and wellbeing issues. However, when voluntary sector leaders raised questions about who was best placed to deliver these and explored the possibility of the NHS funding the VCFSE services directly, they found it challenging to be heard by the NHS. There had been a missed opportunity to come together to decide who was best placed to deliver what type of service, and instead there was duplication of services, raising questions of efficiency.

Another issue that was raised was competition between voluntary sector organisations:

> *Because following the fire, organisations sprung up because of need and they continued to work in the way they did and they were funded according to how well the lead person could advocate for funds. You had these silos of organisations almost in competition.*
>
> Community interview participant

The money that came into the area in response to the fire inevitably meant that there were many organisations seeking funding for a range of different services and support. However, questions were raised about how well the provision of funding was co-ordinated, and whether it took into account what was needed in the round rather than going to those whose voices were loudest:

> *And then somebody starts shouting over here, because a lot of people start shouting in meetings, which pees me off, and then they get what they want, and especially for Grenfell. They're like, 'oh, let's deal with that person who's the loudest'. But then the quietest person could be sitting there going through trauma and not getting what they need or not being heard. Those who shouted loudest benefited from getting funding.*
>
> Community interview participant

A common theme across the interviews was that there had been missed opportunities for statutory services to work more effectively with VCFSE organisations in the area in a more co-ordinated way.

7 Reflections: what has changed in Grenfell and what challenges remain?

> *We didn't sacrifice six years of hard work for personal gain, right? We could have got the best service for ourselves on the individual level with minimal work, just being go there and put pressure and get our kids sorted and that's it, we're done. But we didn't, we helped create this service and we helped think outside the box. We tried to change the service over the last five years and it's worked, and the evidence here where we're sitting today, it shows that it's worked. There's elements of it, the fundamentals of it have worked, right?*
>
> Community interview participant

If you were to ask people in the Grenfell area whether partnership working with the community has been established as the norm, you are likely to get very different responses depending on who you ask and when. Indeed, the strength of the relationships and the level of trust between the health and care system and the community is not uniform or consistent, and at times can still feel very fragile.

In this section, we take stock of where health and care services are now and the challenges they still face. Clearly, there has been progress in many areas, and we have described earlier in the report how key agencies have learnt to listen better and to let go of power. But people expressed concern that this shift towards genuinely working with the community was at risk – particularly at a time when health and care leaders are under acute financial and operational pressures to deliver substantial improvements at pace.

What was achieved and what has changed

There are several parts of the story that indicate some significant steps being taken in the right direction – towards a health care response that placed the survivors and bereaved at the centre of its approach. That began with members of Grenfell United raising their concerns to the Senior Coroner and being heard about the need to look after the long-term health and wellbeing of the people directly impacted by the fire. That dialogue was crucial in securing a commitment from NHS England to fund health and wellbeing services over a five-year period.

The NHS's first instincts were to spend the additional funding on more clinical interventions from their professional staff. It is a testament to the ability of the community leaders to get their voice heard, and of senior leaders within Central North West London (CNWL) and other health care organisations to listen to what the community was saying and then act differently. Listening and letting go of power was the biggest enabler of trust that we heard about. It also allowed different services and approaches to be put in place.

This openness and willingness set the conditions to introduce the Grenfell Health and Wellbeing Service (GHWS), which formed a core part of the health care response to the fire. The service has been designed to provide holistic, inclusive and tailored support, and to enable individuals to better engage with mental health care – something that is particularly important given the issues with access and outcomes for people from ethnic minority groups.

Doing things differently is hard work – and GHWS shows that it is possible to introduce new approaches and move towards a community-driven system in spite of unfavourable conditions. As we said earlier in this report, the relationship between the local authority and the former residents of the tower was in an extremely poor state. Although it will be a significant challenge for the Royal Borough of Kensington and Chelsea (RBKC) to make amends, it clearly matters that the local authority has stepped in for the community since the fire and is starting to try to tackle the root causes of health inequalities in the area.

> *So when we [the local authority] talk about rebuilding trust, it's the process of trying to have more of a presence, fronting up some of the difficult conversations so people have the ability to say their truth… and to try and rebuild and re-show the*

sense that this council is here for people who live in social housing, who come from diverse backgrounds and who live in the north of the borough as well as everywhere else.

System stakeholder

Also, we can see in the example of GHWS that at least a part of the health care 'offer' was shaped in response to what people said they needed. Our research suggests that the health and care system has made shifts towards being more community focused, but still has some distance to travel before the health care response to the Grenfell Tower fire could be described as community *led*.

Three challenges for Grenfell

We explore below three issues that threaten to derail the very real progress that has been made towards designing and delivering health and care services that meet the needs of the community. These issues particularly relate to where there is a need to go further in developing trust, strengthening relationships and shifting mindset.

1. Decision-making on how money is spent

As a direct result of Grenfell United's advocacy, up to £50 million from the NHS and a further £50 million from the RBKC was allocated for support to those affected by the fire over a five-year period. This has created a highly unusual situation, both in terms of the amount of money allocated, and the sense of ownership over it.

It's taxpayers' money that's dedicated to us and our recovery so you need to pay us the respect to tell us how you're spending it or you need to ask us how it should be spent, and that's still not really happening and people get resentful.

Community interview participant

How this money is spent, and who gets to decide that, continue to be a source of tension and distrust that threatens relationships between the statutory health and care organisations and the community. Resolving this will require the statutory organisations to have more confidence in sharing information and decision-making with the community and greater openness to shifting where resources are spent.

This research has offered a glimpse of how communities could be involved in deciding where money is spent. GHWS illustrated how it wanted a broader focus on health and wellbeing and not just clinical treatment. If local communities want GHWS to go further with this approach, which would mean more efforts to create health in communities through prevention, would the statutory bodies be open to that change in funding priorities, or would they just defend funding of existing services?

2. Transparency and accountability

We heard that the survivors and bereaved have faced challenges in getting information about how the £50 million committed by NHS England has been spent. This has been a particular point of contention between Grenfell United (and others representing the survivors and bereaved) and the commissioner (the CCG up until 2022, and now the ICB). In general, it has been an uphill challenge for community organisations and individuals to navigate the complex NHS and local authority landscape – its design is far from user-friendly for outsiders – and Grenfell United representatives particularly described the CCG/ICB as gatekeeping information about funding so that there was no way to hold it to account. This lack of transparency has been damaging to already fractured relationships and levels of trust and mistrust among the survivors and bereaved.

> *Transparency is a myth. Accountability is non-existent. Misspend is ridiculous and the power dynamics are unbalanced… They [the ICB] own the NHS, GPs, no one can tell them anything. They have the ultimate power within the system. They are untouchable. They do what they want, when they want, and no one can question them, although you're [the taxpayer] funding them… So what we're pushing for now, and this is very personal to me, is accountability… I will push for… accountability for the mistakes and the blunders that they've done by misdiagnosing my family, by putting people's lives at risk because of agendas, because of politics. That I can't forgive. I cannot forgive.*
> Community interview participant

We heard repeatedly that people felt the dedicated funding streams were not being spent appropriately – most notably the funds allocated for enhanced health checks from GPs, which many said they were not receiving. They explained that

although there might be accountability to internal governance systems, they did not experience a mindset of accountability to the community that the services are meant to serve.

> *I have a very close colleague who has lost his family in the fire... If he goes to the GP asking for something for him or his family, it's like, 'we're doing you a favour'. It's really frustrating and not up to the responsibility that they have to show.*
> Community interview participant

3. 'Organisation-focused' rather than 'system-focused' behaviours

We heard how organisational boundaries, and organisations defending their existing services rather than focusing on what people and communities need, have thwarted efforts to allocate resources effectively. For example, those working in the RBKC have found it challenging that the NHS was effectively duplicating some of their efforts, and were reluctant to refocus investment from their existing services (based in NHS buildings) towards services based in the community that local people were asking for.

> *We [the council] funded a collection of culturally appropriate therapeutic interventions... Some of it's based at the mosque, some of it's based at the Somali centre... [Something] we've never managed to do is get the NHS to spend any money on some of this community provision... The NHS still spends the [£50 million on services] they always spend on. They spent... their £50 million on GP surgeries, enhanced health checks. They spend it on the mental health trust that – don't get me wrong, has done some good work to evolve their formal mental health practice. But there is a complete dearth of spend in the community and on the community. And therefore there's a lack of sharing, of power and sharing of accountability that I think has hindered some of their programmes... They know this. I say this, I say this in their meetings all the time, so this shouldn't come as a surprise.*
> System stakeholder

There have been missed opportunities to avoid duplication of services between the NHS, the council and the voluntary, community, faith and social enterprise (VCFSE) sector, and some services were described as fragmented, with providers working in siloed ways resulting in a lack of continuity of care. The dedicated services that

were set up have gone some way to addressing this, but we heard that some aspects – particularly the physical health checks – were not delivering what people needed. There have also been missed opportunities to address the complex drivers of health inequality and poor health outcomes by working as one system.

Where next for Grenfell?

Given the lack of trust and transparency that remains, there is a question hanging over what will happen in the future beyond the five-year funding period. Can commissioners and service providers, the survivors and bereaved, and the wider community take advantage of the new integrated care systems (ICSs) and use the associated infrastructure and ambition to their advantage?

ICSs and their place-based partnerships provide ready-made structures (which community leaders need to be part of) through which local authorities, the NHS and the wider community (including the VCFSE sector) can work on jointly agreed priorities. This could start to shift the emphasis to focusing on ingrained issues (such as the social determinants of health) and the health inequalities that characterise the area (NHS West London CCG 2019; Watt 2017). Furthermore, it could address the community's significant concerns about the physical health offer and long-term monitoring of the effects of the toxic smoke and trauma.

There is a window for the ICB, the council, and all those working on behalf of the community to learn from the events of the past few years and look for opportunities to embed the ways of working that have started to develop into 'business as usual', and to build on what has been learnt. But there is a significant risk that this potential may not be realised, if the ICB and its partners see this community-focused approach as an exception to how people work (rather than the rule), and as a time-limited approach while there is extra funding. To revert to top-down ways of working would be a backward step. It would be damaging to the relationship with the community and an insult to those who have invested time and effort in bringing about change. The refreshed Joint Strategic Needs Assessment published in May 2024 states:

> *The 2018 JSNA emphasised the importance of putting the community at the heart of recovery. Despite this recommendation, there remains a disconnect between some of the organisations providing services and the people affected*

> *by the Tragedy. This refreshed needs assessment clearly reaffirms the need for all organisations to put the community at the heart of ongoing and future recovery efforts.*
>
> (Royal Borough of Kensington and Chelsea 2024, p 75)

There is also an opportunity to reflect on how working without trust and transparency can impact individuals. It was the community and local VCFSE sector that stepped up in the immediate aftermath of the fire to provide food, shelter and comfort to those affected. They have provided support for the survivors and the bereaved throughout their recovery. Asking, and advocating on their behalf, for partnership and involvement as equal partners should not feel like a battle. Yet we heard people describe this work as a fight that was often distressing and exhausting.

8 Discussion: learning for other health and care systems

It would be a mistake to think that lessons from the health and care response to the Grenfell Tower fire are only relevant for those supporting a community after a disaster, or those living in urban areas with high levels of deprivation.

In this section, we discuss what other health and care systems can learn from the Grenfell response. First, we explain that they need to recognise how the same challenges also play out in their own local health and care systems. We then offer five insights into what is involved in addressing those challenges.

Grenfell is not unique: the same challenges exist in other local health and care systems

> *I don't think Grenfell is unique… There is a Grenfell that happens in every deprived neighbourhood across the country every single day but we don't look at it that way, because it's not – you know, for want of a better word, it is not kind of, in a crude way – sexy to look at health inequalities, to look at people dying younger, to look at all of those things. It is not. The story of Grenfell needs to be told not in the context of 'there's a fire in a unique situation'. The only unique thing about it is the fire. Everything else is not unique. Everything else happens every day in every community. We saw with Covid and the effect on Church End [a neighbourhood in the London Borough of Brent] – we saw the disproportionate effect on those communities.*
> System stakeholder

Many of the issues that we heard about in this work are not particular to services and people's experiences in the Grenfell Tower area. Failing to value community voices (Snoussi and Mompelat 2019), not working effectively in partnership with the voluntary, community, faith and social enterprise (VCFSE) sector, structurally racist policies and practices (Danso and Danso 2021; Hui *et al* 2020), and a lack of co-ordination across providers and commissioners of services are all well-documented and long-standing

challenges that can be found across the health and care system (House of Lords Integration of Primary and Community Care Committee 2023).

Grenfell represents another example in a long and shameful history of people raising significant concerns about public services but being ignored or undermined when they do so. From the tragic events at Mid Staffordshire NHS Foundation Trust in the 2000s to the recent case that led to Martha's Rule, not listening to patients and the people who use services has too often led directly to the loss of life (Wellings 2023). In the case of Grenfell, not listening led to the loss of 72 lives.

Grenfell shows in sharp relief what happens when minoritised voices are not heard by statutory services. It also shows a possible way forward. This research acknowledges what went wrong, but it also shows what can happen when services are willing to engage differently – and find a way to have honest, often uncomfortable and deeply challenging conversations about power, inequality and racism.

Health and care systems need to learn how to listen better, learn from communities, tackle inequalities and work in partnership. These are all aspirations that few would disagree with, yet they are far from being achieved. The first step is to acknowledge that these challenges are not unique to Grenfell but exist in other local systems too, and then to be open to addressing them and build partnerships for doing so.

Five insights for local health and care systems

The health and care response to the Grenfell Tower fire shows that it is possible to shift from a place where trust is in short supply, patience worn thin and decision-making opaque, towards a space in which people feel that they are heard and are able to work in partnership to try out new approaches. There is still a long way to go in this journey, however, and progress has been variable and sometimes fragile.

Many other local health and care systems similarly have a long way to go before they can claim to be truly working in partnership with the people and communities they serve (Wellings and Ansari 2023), despite a wealth and long history of evidence of the benefits (eg, South *et al* 2019; South 2015).

With that in mind, we highlight five insights that other health and care systems should consider.

1. If you are going to listen, you have to be prepared to act

If you are going to listen to and work with people and communities, you need to be prepared to work differently and give staff permission to do the same.

Leaders are critical in creating a context in which systems can change and improve. In Grenfell, the NHS and the council began to adopt a different model of leadership. Their actions – such as coming down from podiums to sit alongside the community and making decisions in the open rather than behind closed doors – sent very clear signals that the leadership style had changed.

Leaders also recognised the need to build trust with the community. This required a leadership approach that places community voices on an equal footing with other insights about what is working and what is not. It involved spending time with people who were angry and wanted action, listening to them and, above all, responding to their needs. Moreover, it required a different approach to risk – one that was willing to try new approaches based on what communities themselves say is needed to make a difference.

Leaders also had to trust their staff and tackle entrenched blame cultures that inhibited the ability to change. They provided 'air cover' and protected staff from the fear of failure, and gave backing to doing things differently. This model of leadership recognises that top-down solutions often do not take into account local context and are not tailored to what is needed. Working this way requires leaders to have courage and to let go of power rather than grip tighter.

What is clear is that this way of working takes time to put in place. Moreover, it requires systems to place more control in the hands of those they are there to serve. This shift from 'power over' to 'power with' communities involves leaders reflecting on and challenging their own positions of power, to shift towards collective action, mutual support and collaboration, including for communities who are often marginalised (Fenney *et al* 2023).

Much of this is challenging for statutory services that tend to be organised as hierarchies within a hierarchical system, which normalises decisions being handed

down from those higher up. If you are going to listen to and work with people and communities, you need to be prepared to stand up and actively change those ways of working and counter the fear of blame that inhibits change. This is fundamental to this way of working and its importance cannot be overstated.

2. To provide effective services, all staff need to understand their communities

Grenfell Health and Wellbeing Service (GHWS) has adopted a position that community engagement is not the preserve of dedicated engagement teams or a separate activity undertaken by other people. Instead, it regards it as a fundamental principle: that staff need to understand the local community if they want to deliver services that are effective. This requires staff to develop the ability to listen well and be engaged. It has been key to establishing trust between public services and the community.

Connecting or reconnecting with the community needs to be a fundamental part of how people work rather than something separate to core business. For example, GHWS included community connectors as a central feature of the service – an approach that subsequently developed significantly during the Covid-19 pandemic (Gilburt *et al* 2024). It has also now been incorporated in the national Core20PLUS5 policy as one of the ways to improve health and tackle inequalities, and involved local people in its management team.

> *A common thread throughout all of our stories so far, is the need to rethink what is meant by 'engagement'. We've seen in our discussions with public services that engagement can be a double-edged sword, because while it does involve gathering important information to shape services, it often over-promises and under-delivers. Rather than creating a bridge between services and the communities they serve, the engagement function can act as a buffer between them instead.*
> (Elguenuni *et al* 2020)

Lucy's walk (*see* Box 3, page 41) is another initiative designed to foster stronger connections for staff, many of whom were not familiar with the local area at Grenfell.

This approach is similar to the one taken by Wigan Council in its work around developing a citizen-led approach to health and care (Naylor and Wellings 2019). Everyone who worked at Wigan Council underwent training on connecting with the

communities they served. Developed by anthropologists as a means to observe and understand other cultures, these techniques emphasised the importance of setting aside one's assumptions and preconceptions, and taking time to listen, to observe, and to explore the world through the eyes of the person or people being studied. The aspect of the training that turned out to be key was practising having 'different conversations' with the people using services – conversations that are more open and exploratory, and which encompass a person's strengths and interests as well as their needs.

The point of both these initiatives has been to re-establish a connection with people, to allow staff to recognise what assets already exist within communities, and to understand better what would make a difference to the lives of those they serve. Other health and care systems need to decide how they can enable staff to reconnect with the communities they serve – for example, as part of induction or regular training opportunities – and establish it as the normal way of working.

3. You cannot engage people in silos – take a system-wide approach

The health and care services set up in response to the fire are now formally part of an integrated care system (ICS), and there is an expectation that partners will collaborate to improve outcomes for the local population. The King's Fund has argued that a similar collaborative approach should also be taken to engagement. If care is to be co-ordinated to meet people's needs, then all partners in a system need to work together to understand how people experience care and support (Thorstensen-Woll *et al* 2021).

All too often, people get asked for their views on an individual service. This approach fails to recognise that people's experience of housing, health, social care, employment and education services is interlinked and their use of services does not happen in silos. Individual services and organisations need to take a more co-ordinated, community-centred approach to engagement across the local system as a whole if they want to understand the improvements that will genuinely make a difference to people's lives. It is worth noting that underpinning this approach, there needs to be an acceptance that the outcome might not involve the services currently provided.

We heard that NHS organisations and the council, once they had recognised that they had to work in partnership with the Grenfell community, put a great deal

of energy into engagement. Arguably, however, there has not been enough co-ordination of effort and, instead, much of the listening and learning has been siloed rather than a process of partners coming together around what they are hearing.

The other challenge with the 'industry' of engagement that has developed has been that services have felt overwhelmed by the volume of feedback. If a system is constantly engaging with people in different settings and asking them what they need, it can become overwhelmed by the sheer range of wants asked for by different people at different times. Some of those we spoke to who were working in the system had felt this keenly – that by repeatedly having engagement and feedback exercises, it stopped them developing a clear way forward as they were constantly being buffeted by the next round of feedback. It also had a draining effect on the community, which was constantly being asked for its views by different service providers. It was both time-consuming and exhausting. This requires system leadership skills to ensure that there is strategic oversight, both about where the focus needs to be as well as collective oversight of what the feedback is telling you.

4. Identify and address the issue of structural racism

What has been clear throughout this work is that people living in that area have faced racism and discrimination for decades. From how the community was portrayed in the media in the aftermath of the fire, to how services were set up not taking into account socio-cultural, religious and other demographic factors, racism has been an ever-present theme.

Efforts have been made to address this, including training staff in cultural competency, ensuring that the workforce better represents the diverse communities, and openly acknowledging the role that structural racism has played, both in the circumstances leading up to the fire and in the response to it. We heard from staff working at the front line who have developed their own understanding about what role structural racism has played in how services are delivered. This has been uncomfortable for them at times, but this understanding has also allowed them to provide care that is more effective at engaging people because it is based on what will make a difference from the perspective of the person in front of them.

It has also been clear that although efforts to address structural racism can make a difference, they require time and constancy of purpose. If health and care systems want to build genuine partnerships with local communities, they need to build trust, and people will only trust them if they feel that services are on their side – not part of, or a cause of, the structural disadvantage they face.

5. Making partnership working with local communities a reality is the biggest challenge – and the greatest opportunity – for system leaders

Our findings illustrate how hard it is to share power and for people to make fundamental shifts in how they behave with each other. Individual leaders (both in the community and in the health and care system) have played critical roles in shifting the balance of power and modelling behaviours that support genuine partnership working. The approach has endured, even through tense and sometimes hostile situations. However, these shifts feel fragile rather than accepted as the way things are routinely done and embedded in system-working.

Over time, this way of working needs to deepen and be built into the systems and processes that drive how health and care services develop – bringing partnership approaches into planning, monitoring, decision-making, funding and so on. There is no pre-existing model of what that looks like, and no roadmap for how to get there, and it will need constant attention rather than ever being considered 'done'. But there are some resources that may help local systems in exploring approaches and actions that support it, for example:

- Naylor *et al* (2024) identified four 'enabling actions' for ICSs to strengthen collaboration and share power – including with the community
- Thorstensen-Woll *et al* (2021) set out practical approaches to engaging people, including diverse communities
- Fenney *et al* (2023) explored what local systems can do to address power imbalances
- Felter and Chauhan (2024) recognised the anxiety that letting go of power and sharing control causes in organisations, and interventions that can help leaders to contain and manage it.

9 What does all this mean for national bodies and health and care leaders?

National bodies

There has been clear evidence for many years about the benefits of working with people and communities and yet, despite all this evidence, things largely have not changed.

National bodies such as NHS England and the Department of Health and Social Care have key roles to play in unblocking this impasse. They can set the strategic direction, expectations and culture that support systems, places and neighbourhoods to adopt approaches we have started to see in Grenfell and to become community centred.

A major drive is needed to ensure that the health and care system is focused on people and communities. National bodies need to be clear and sustained in setting expectations for this. But it will not be enough to issue guidance documents and toolkits. We invite national bodies to think through three questions to achieve what is needed.

1. **How will national bodies balance their overall accountability with allowing local delegation?** This approach involves a journey of learning and experimentation (not all of which will work), and letting people identify priorities, which will result in local variation and is a cultural shift from top-down one-size-fits-all approaches that are more familiar in the NHS. But clearly, national bodies still also need to ensure as rapid as possible progress on national priorities in every area of the country. Setting frameworks for assurance which focus on the outcomes that are needed but allow for local solutions will be key to achieving this balance.

2. **What will setting this strategic direction require of national system leaders' behaviours and leadership style?** National leadership may well require a strong narrative, but that needs to be balanced with allowing space for local areas to develop. Without that balance, when national bodies insist that plans are on track, or when they sign off apparently balanced budgets when staff and patients know these do not match reality, it can help build a culture of denial. That culture makes it harder for local leaders to stand up for change and to admit their inability to achieve goals without the support of their partners and communities. National leaders should consider how the behaviours and competencies we identified for local leadership of community-centred ways of working can also apply at a national level.
3. **How will national bodies sustain a long-term approach?** The shifts described in this report are inherently long term, but the NHS has a history of reorganisations, new policies, interventions and initiatives constantly cascading from above. It also has a history of reverting to top-down direction at times of pressure. A key task for national leaders – which has not been achieved in the past – will be to ensure that this long-term agenda is not squeezed out by relatively short-term priorities.

Health and care leaders

If you work in the health and care sector in a leadership role, at any level, there are also lessons from Grenfell for you to consider personally.

None of the challenges we have described in this report – failing to listen to and work with communities, working in silos, structural racism, and health inequalities – are unique to the Grenfell area, and none of them are new. But what this research shows is that change is possible.

There is no single recommendation from this research or from a national policy document that will deliver the change needed. And that is the point: the change is not a standardised one but is rather about a way of working and a cultural approach that will reflect differences from one place to the next. Leaders have a key role in shaping and nurturing that approach to fit their local context.

Doing so will involve releasing grip, not attempting to control or decide everything on your own, and living with the uncertainty that it causes. It will be hard work and it will take time. It will require faith that communities and partner organisations bring assets that are part of the solution and make the investment in building partnerships worthwhile. And it is sophisticated work, which will stretch your skills in listening, understanding and bringing people together.

In the box below, we present four questions that should help you reflect, with your partners, staff and the people you serve, on whether you are on the right path to the kind of change needed.

Box 5 Four questions for health and care leaders

How well connected are you to the communities you serve?

- Ask questions about whether your workforce reflects the community you serve. Who is there to advocate for different groups?
- Ensure that inductions and ongoing training reconnects all staff with local people, taking inspiration from Lucy's walk (*see* Box 3, p 41).
- Learn from the work of community champions and community connectors and how they build trust, bring insight and support the development of community-based approaches by increasing capacity and capability within the community.

How well are you listening to your local communities?

- Do not engage because you think you have to but do it because you want to deliver services that will be better because they are based on what is going to work from the perspective of people rather than organisations.
- Create spaces for genuine dialogue that allow you to hear what people want to tell you rather than statutory organisations defining the terms and content of any engagement. Listen together as a system: people do not live their lives in silos, so bring partners in your system together to listen as one.

continued on next page

Box 5 *continued*

- Do not just listen; be prepared to act on what you hear, recognising how you might need to shift the provision of services to reflect what you hear.
- Be prepared that if you are to act on what people say is important to them, then services will likely need to come together around prevention, health inequalities and the social determinants of health rather than just treatment and care.
- Ensure you have the right measures and outcomes in place that reflect this way of working and capture the change you are trying to achieve

What are you doing to tackle racism?

- Start by recognising the role structural racism plays in how services are delivered.
- Build commitment to ensuring that all voices are heard, even if this is at times challenging or uncomfortable.
- Develop staff understanding of how people's backgrounds, including culture, religion and ethnicity, affect their experiences of health and care services.

How are you modelling this way of working?

- Recognise the importance of leading by example and demonstrating how you are sharing power with the communities you serve.
- Spend time personally directly working with the community, listening to people and ensuring action in response.
- Allow staff permission to try different approaches based on what they are hearing from the community.
- Recognise that this approach takes time and will mean trying new approaches. Not all of them will work but they can all be learnt from.

References

Apps P (2022). *Show me the bodies: how we let Grenfell happen*. London: Oneworld Publications.

British Red Cross (2019). *People power in emergencies: an assessment of voluntary and community sector engagement and human-centred approaches to emergency planning*. London: British Red Cross. Available at: www.redcross.org.uk/-/media/documents/about-us/research-publications/emergency-response/people-power-in-emergencies.pdf (accessed on 3 April 2024).

Central and North West London NHS Foundation Trust (2021). 'Grenfell Health & Wellbeing Service change paper outlining transformation of the Grenfell Health & Wellbeing Service. A community driven change…' (unpublished).

Cream J, Baylis A, Jabbal J, Babalola G, Anandaciva S (2021). *Covid-19 recovery and resilience: what can health and care learn from other disasters?* London: The King's Fund. Available at: www.kingsfund.org.uk/insight-and-analysis/long-reads/covid-19-recovery-resilience-health-and-care (accessed on 4 April 2024).

Cyhlarova E, Knapp M (2018). *Evaluation of the Screen and Treat Programme offered to people affected by the terrorist attacks in Tunisia, Paris and Brussels. Final report*. London: Policy Innovation Unit, Department of Health Services Research & Policy, London School of Hygiene & Tropical Medicine. Available at: https://piru.ac.uk/projects/completed-projects2/screen-and-treat-programme-evaluation.html (accessed on 4 April 2024).

Danso A, Danso Y (2021). 'The complexities of race and health'. *Future Healthcare Journal*, vol 8, no 1, pp 22–7. Available at: https://doi.org/10.7861/fhj.2020-0225 (accessed on 3 April 2024).

Easthope L (2022). *When the dust settles: stories of love, loss and hope from an expert in disaster*. United Kingdom: Hodder & Stoughton.

Elguenuni F, Doran R, Elguenuni B, Elcock N (2020). 'Learning the lessons from Grenfell'. Blog. The King's Fund website, 9 March. Available at: www.kingsfund.org.uk/insight-and-analysis/blogs/learning-the-lessons-from-grenfell (accessed on 3 April 2024).

Felter N, Chauhan K (2024). 'Organisational anxiety and what leaders are (or aren't) doing about it'. Blog. The King's Fund website, 3 May. Available at: www.kingsfund.org.uk/insight-and-analysis/blogs/organisational-anxiety-leaders (accessed on 19 June 2024).

Fenney D, Chikwira L, Chauhan K (2023). 'Transforming power relationships in partnership working'. The King's Fund website. Available at: www.kingsfund.org.uk/insight-and-analysis/long-reads/transforming-power-relationships-partnership-working (accessed on 3 April 2024).

Gilburt H, Lamming L, Buck D, Mallorie S (2024). *Commissioning community champions: lessons from a pandemic*. London: The King's Fund. Available at: www.kingsfund.org.uk/insight-and-analysis/reports/commissioning-community-champions-pandemic (accessed on 12 June 2024).

Grenfell Action Group (2016). 'KCTMO – Playing with fire'. Blog. Grenfell Action Group. Available at: https://assets.grenfelltowerinquiry.org.uk/TMO00835660_GAG%20blog%20post%20-%20KCTMO%20Playing%20with%20fire..pdf (accessed on 27 June 2024).

Grenfell Tower Inquiry (2019). *Grenfell Tower Inquiry: phase 1 report*. Report of the Public Inquiry into the fire at Grenfell Tower on 14 June 2017. HC 49–I. London: Her Majesty's Stationery Office. Available at: www.grenfelltowerinquiry.org.uk/phase-1-report (accessed on 3 April 2024).

Hodkinson S (2018). 'Grenfell foretold: a very neoliberal tragedy' in Needham C, Heins E, Rees J (eds), *Social Policy Review*, 30, pp 5–26. Bristol University Press, Policy Press. Available at: https://doi.org/10.51952/9781447350019.ch001 (accessed on 4 April 2024).

House of Lords Integration of Primary and Community Care Committee (2023). *Patients at the centre: integrating primary and community care*. House of Lords Integration of Primary and Community Care Committee. Report of session HL 18 (2023–24). London: House of Lords. Available at: https://committees.parliament.uk/committee/649/integration-of-primary-and-community-care-committee/publications (accessed on 4 April 2024).

Hui A, Latif A, Hinsliff-Smith K, Chen T (2020). 'Exploring the impacts of organisational structure, policy and practice on the health inequalities of marginalised communities: illustrative cases from the UK healthcare system'. *Health Policy*, vol 124, no 3, pp 298–302. Available at: https://doi.org/10.1016/j.healthpol.2020.01.003 (accessed on 4 April 2024).

Independent Grenfell Recovery Taskforce (2017). *The taskforce initial report – 31 October 2017*. Independent Grenfell Recovery Taskforce. Available at: https://assets.publishing.service.gov.uk/media/5ff4838fe90e0776a8d56151/171031_Independent_Grenfell_Recovery_Taskforce_initial_report.pdf (accessed on 4 April 2024).

Marmot M (2020). 'Society and the slow burn of inequality'. *The Lancet*, vol 395, no 10234, pp 1413–14. Available at: https://doi.org/10.1016/S0140-6736(20)30940-5 (accessed on 3 April 2024).

Ministry of Housing, Communities & Local Government (2017). 'New taskforce to support recovery from Grenfell fire disaster'. Press release. Available at: www.gov.uk/government/news/new-taskforce-to-support-recovery-from-grenfell-fire-disaster (accessed on 17 June 2024).

Muslim Aid (2018). *Mind the gap: a review of the voluntary sector response to the Grenfell tragedy*. Available at: www.muslimaid.org/media-centre/news/grenfell-report/ (accessed on 21 June 2023).

Naylor C, Wellings D (2019). *A citizen-led approach to health and care: lessons from the Wigan Deal*. London: The King's Fund. Available at: https://assets.kingsfund.org.uk/f/256914/x/7f008d393b/wigan_deal_2019.pdf (accessed on 3 April 2024).

Naylor C, Cream J, Chikwira L, Gowar C (2024). *Realising the potential of integrated care systems: developing system-wide solutions to workforce challenges*. London: The King's Fund. Available at: www.kingsfund.org.uk/insight-and-analysis/reports/integrated-care-systems-workforce

NHS Confederation (2018). *When tragedy strikes: reflections on the NHS response to the Manchester Arena bombing and Grenfell Tower fire*. London: NHS Confederation. Available at: www.nhsconfed.org/system/files/media/When-tragedy-strikes_0.PDF (accessed on 4 April 2024).

NHS England (no date). 'Core20PLUS5 Community Connectors'. NHS England website. Available at: www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/core20plus5/core20plus5-community-connectors (accessed on 4 April 2024).

NHS England (2018). 'NHS to provide long term screening service for Grenfell community'. News. Available at: www.england.nhs.uk/2018/10/nhs-to-provide-long-term-screening-service-for-grenfell-community/ (accessed on 4 December 2023).

NHS England (2024). 'Martha's Rule'. NHS England website. Available at: www.england.nhs.uk/patient-safety/marthas-rule/ (accessed on 17 June 2024).

NHS Grenfell Health and Wellbeing Service (2022) 'Service User Consultants'. NHS website. Available at www.grenfellwellbeing.cnwl.nhs.uk/about/service-user-consultants (accessed on 27 June 2024).

NHS West London CCG (2019). 'A Health and Wellbeing Strategy for North Kensington to March 2024'. NHS West London Clinical Commissioning Group. Available at: www.grenfell.nhs.uk/application/files/2116/0025/0932/A_Health_and_Wellbeing_Strategy_for_North_Kensington_to_March_2024.pdf (accessed on 4 April 2024).

Osmany S, Mclennon A, Sudra A, Umar F (2020). Black Identity & Trauma Experience (BITE) report: a qualitative study into disengagement and the psychological wellbeing of Black service users at GHWS. Grenfell Health and Wellbeing Service (unpublished).

Plender A (2018). *After Grenfell: the faith groups' response*. Theos report. London: Theos. Available at: www.theosthinktank.co.uk/cmsfiles/Reportfiles/Theos-After-Grenfell.pdf (accessed on 4 April 2024).

Prescod C (2017). 'The "rebel" history of the Grove'. Blog. Institute of Race Relations, 6 June. Available at: https://irr.org.uk/article/the-rebel-history-of-the-grove (accessed on 4 April 2024).

Ridley CR, Baker DM, Hill CL (2001). 'Critical issues concerning cultural competence'. *The Counseling Psychologist*, vol 29, no 6, pp 822–32. Available at: https://doi.org/10.1177/0011000001296003 (accessed on 4 April 2024).

Roberts R (2017) 'Grenfell Tower blogger threatened with legal action by council after writing about safety concerns'. Blog. *The Independent*, 17 June. Available at: www.independent.co.uk/news/uk/home-news/grenfell-tower-fire-blogger-threatened-legal-action-kensington-and-chelsea-council-health-safety-concerns-a7792346.html (accessed on 3 April 2024).

Royal Borough of Kensington and Chelsea (2024). *Grenfell JSNA Refresh. Published Working Draft V1.0 (29/05/2024)*. JSNA website for Westminster & Kensington and Chelsea. Available at: www.jsna.info/document/grenfell-jsna-2024 (accessed on 27 June 2024).

Slovo G (2023). *Grenfell: in the words of survivors*. NHB Modern Plays. London: Nick Hern Books.

Snoussi D, Mompelat L (2019). *'We are ghosts': race, class and institutional prejudice*. London: Runnymede and CLASS (Centre for Labour and Social Studies). Available at: www.runnymedetrust.org/publications/we-are-ghosts-race-class-and-institutional-prejudice (accessed on 4 April 2024).

South J (2015). *A guide to community-centred approaches for health and wellbeing. Full report*. Public Health England/NHS England. Available at: https://eprints.leedsbeckett.ac.uk/id/eprint/1229/11/A%20guide%20to%20community-centred%20approaches%20for%20health%20and%20wellbeing%20%28full%20report%29.pdf (accessed on 4 April 2024).

South J, Bagnall A-M, Stansfield JA, Southby KJ, Mehta P (2019). 'An evidence-based framework on community-centred approaches for health: England, UK'. *Health Promotion International*, vol 34, no 2, pp 356–66. Available at: https://doi.org/10.1093/heapro/dax083 (accessed on 4 April 2024).

Strelitz J, Lawrence C, Lyons-Amos C, Macey T (2018). *Journey of recovery: supporting health & wellbeing for the communities impacted by the Grenfell Tower fire disaster*. London: JSNAs for Westminster & Kensington and Chelsea.

Sue DW (2001). 'Multidimensional facets of cultural competence'. *The Counseling Psychologist*, vol 29, no 6, pp 790–821. Available at: https://psycnet.apa.org/doi/10.1177/0011000001296002 (accessed on 3 April 2024).

The Royal Borough of Kensington and Chelsea (2019). 'Grenfell Recovery Strategy'. RBKC website. Available at: www.rbkc.gov.uk/grenfell-response-and-recovery/progress-grenfell-recovery/grenfell-recovery-strategy (accessed on 4 April 2024).

Thorstensen-Woll C, Wellings D, Crump H, Graham C (2021). *Understanding integration: how to listen to and learn from people and communities* [online]. The King's Fund website. Available at: **https://kingsfund.org.uk/insight-and-analysis/reports/understanding-integration-listen-people-communities** (accessed on 4 April 2024).

Walker D (2017). 'Agitprop: some pictures from the Mike Braybrook archive'. The Library Time Machine. RBKC local studies. Available at: **https://rbkclocalstudies.wordpress.com/tag/north-kensington/#:~:text=North%20Kensington%2C%20once%20called%20by,were%20locked%20in%20meeting%20halls** (accessed on 4 April 2024).

Watt RG (2017). 'Grenfell Tower fire – a tragic case study in health inequalities'. *British Dental Journal*, vol 223, no 7, pp 478–80. Available at: **https://doi.org/10.1038/sj.bdj.2017.785** (accessed on 4 April 2024).

Wellings D (2023). 'Patient experience: who is listening?' Blog. The King's Fund, 19 October. Available at: **www.kingsfund.org.uk/insight-and-analysis/blogs/patient-experience-who-is-listening** (accessed on 4 April 2024).

Wellings D, Ansari L (2023). 'Not a "nice to have" – the importance of working with people and communities'. Blog. The King's Fund, 23 June. Available at: **www.kingsfund.org.uk/insight-and-analysis/blogs/importance-working-with-communities** (accessed on 4 April 2024).

Wilcox FJ (2018). 'Regulation 28: report to prevent future deaths'. HM Senior Coroner, Inner West London, Westminster Coroner's Court. Available at: **www.judiciary.uk/wp-content/uploads/2018/09/Grenfell-Tower-2018-0262.pdf** (accessed on 4 April 2024).

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