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Finding the voice of the people in the pandemic

An ethnographic account of the work of local Healthwatch in the first weeks of England's COVID-19 crisis

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On 23 March 2020, the UK government issued a broad range of advice and regulations intended to curb the spread of COVID-19 and prevent the National Health Service (NHS) from being overwhelmed by people needing care. At that time, our research team was in the midst of a 30-month study aimed at exploring the work of Healthwatch, England's statutory organisation with responsibility for championing the views of citizens in the commissioning and provision of health and social care services in each of the country's 152 local authorities (see Box 6.1).

The core of our study was a year-long ethnography (started in August 2019) of five Healthwatch groups, focusing on their daily activities and relationships with key stakeholders locally. Alongside our work in the five study sites, our study relied on a panel of 15 Healthwatch representatives, both staff and volunteers, to increase the breadth and generalisability of our ethnographic findings.

After the pandemic hit, we moved our research online. We kept in regular contact with Healthwatch staff, board members, volunteers, and local stakeholders, and observed them in the virtual meetings they attended. We also carried out one-to-one virtual interviews with 13 of our panel members and held a virtual meeting attended by 14 of them

**Box 6.1 The six statutory functions of local Healthwatch
(adapted from Healthwatch website)**

Local Healthwatch are funded by and accountable to local authorities to:

- Obtain the views of people about their needs and experience of local health and social care services. They make these views known to those involved in the commissioning and scrutiny of care services.
- Make reports and make recommendations about how those services could or should be improved.
- Promote and support the involvement of people in the monitoring, commissioning, and provision of local health and social care services.
- Provide information and advice to the public about accessing health and social care services and the options available to them.
- Make the views and experiences of people known to Healthwatch England, supporting its role as national champion.
- Make recommendations to Healthwatch England to advise the Care Quality Commission (CQC) to carry out special reviews or investigations into areas of concern.
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to discuss how their organisations were adjusting their work during the pandemic. Here we draw on data collected in the first six weeks of the national lockdown to describe how the COVID-19 crisis impacted the work of local Healthwatch.

The United Kingdom government, the pandemic, and Healthwatch

For Healthwatch organisations in England, the new ‘stay-at-home’ regulations had immediate effects. Healthwatch staff began doing just that, all face-to-face intelligence-gathering activities with the public were suspended and ‘Enter and View’ visits to hospitals, care homes, and GP surgeries were cancelled. Local governance fora attended by Healthwatch were also largely suspended in the initial phases of the pandemic.

In adjusting the ways in which they worked, Healthwatch staff chose which of their statutory functions to prioritise. In the first few weeks of the COVID-19 crisis, the priority of the health and care system was for people to adhere to the new regulations in order to protect its ability to cope under the strain of an already high number of hospital admissions. Most local Healthwatch were immediately enlisted by their local health and care systems to disseminate official information through different channels, including their websites, bulletins, and newsletters. Some also reported compiling lists of NHS and government websites, creating directories of voluntary sector organisations, and signposting members of the public to appropriate support agencies.

However, the lockdown posed practical challenges in Healthwatch’s ability to fulfil some of its functions. Healthwatch were no longer able to access public and patient views as they used to, nor could they contribute to health and social care scrutiny and decision-making at a formal level because boards and committees either were no longer meeting, or were meeting in new configurations (eg virtual meetings arranged at short notice), which excluded Healthwatch.

In this context, many Healthwatch groups described a shift in the relative emphasis placed upon their statutory functions. Whereas before the pandemic most Healthwatch regarded the provision of information and signposting of local services as a marginal part of their role, these functions moved centre-stage. In the initial phases of the crisis, ‘acting as a messenger’, as one Healthwatch CEO put it, led Healthwatch to primarily become a voice of the system *to* the people. But what spaces

were then left for conveying the voice *of* the people to the system at this time?

This question provoked dilemmas for Healthwatch staff. Talking about her frustration about the lack of interest shown by overwhelmed local organisations to engage with feedback, a Healthwatch CEO in the Northeast of England, told us:

‘I think at the moment [...] the explanation to come back, [...] is “look, we just can’t do anything at the moment, we have to deal with this”. But, for us, it would be “well let’s just see how long that [explanation] goes on for because life still goes on, there’s people still needing operations, there’s still people getting diagnosed with cancer and other different illnesses and things, they still need that help”’.

To discuss how local Healthwatch tried to tackle such dilemmas, we draw on our ethnographic data to provide three examples of innovative strategies deployed by Healthwatch to ensure that the voice of local people was still heard by local systems in the early days of the pandemic.

Finding the voice of the people

Healthwatch A: Socially distanced public engagement

Soon after the beginning of the pandemic, Healthwatch A moved its engagement activities online and set up two types of weekly ‘engagement and support’ Zoom meetings open to residents to attend. The first type of meeting was aimed at gathering feedback from specific local communities, for example unpaid carers, people with learning disabilities, Black and minority ethnic communities, and young people. For this work, Healthwatch A linked up with community organisations, working closely with them to collate the experiences of ‘different demographics and different communities’.

The second type of ‘engagement and support’ Zoom meeting was open to all residents to join. Participants were encouraged to share experiences and challenges in accessing services during the pandemic and to ask questions

about COVID-19 and local health and social care planning and provision. In organising this work, Healthwatch A's manager, described focusing most of his efforts on liaising with local stakeholders, including patient experience teams at local hospitals, commissioners, council staff, and quality accreditation officials. Once the fora were set up, he invited these officials to propose relevant topics for discussion. For example, Healthwatch A's manager told us that his local contacts in the CQC proposed dedicating a forum to discussing the drop in the number of people contacting GPs and community healthcare providers. According to the CQC, there was a risk that some health conditions, like diabetes or cancer, could go undetected if the trend continued. The discussion at Healthwatch A's Zoom meetings highlighted how people were indeed more reluctant to contact healthcare providers in the first few weeks of the pandemic. Most forum attendees said that this was because they did not want to put extra pressure on local NHS services. As a consequence, the CQC was considering whether 'the messaging needed to be changed slightly' to help address this attitude.

Healthwatch B: Virtual intelligence gathering

Healthwatch B initially stopped gathering data about local residents' experience of the health and care system and feeding them back to the NHS or local authorities: 'they do not want to hear anything right now', Healthwatch B's CEO told us. However, shortly after, she said that her position was changing. Talking with senior managers at the local hospital, she learned that they were actually keen to hear how people were coping with the pandemic and gaps in care or services.

Healthwatch B found two ways of gathering people's experiences while complying with physical distancing. First, the team designed and circulated an ongoing online survey to residents. Second, they asked to join the WhatsApp groups of the numerous mutual aid societies established by local residents to identify and support people who were self-isolating. After joining the WhatsApp groups, Healthwatch staff encouraged their members to feed back their views

to them. They also monitored members' exchanges in the groups to identify trends or themes of concern.

By the end of April 2020, Healthwatch B had already produced two reports presenting the analysis of this data and made recommendations as to how the local authority and NHS might address emerging issues. The topics covered a broad range relating to residents' health and wellbeing during the pandemic. These included physical, mental, and economic wellbeing, understanding of government advice, and experiences of accessing health and social care services.

The reports received considerable attention from elected officials in local government, and from healthcare providers. Healthwatch B's CEO was asked to present the findings regularly to the local authority's pandemic committee, a central coordination body bringing together local health and social care leaders, and the only health-related local authority committee meeting running at the time. The reports seemed to have real influence on the local provision of some services. For instance, Healthwatch B found that pregnant women, classed as a vulnerable group, were reporting high levels of anxiety and would welcome a tailored programme of information provided through midwives and health visitors, as well as online consultations instead of phone consultations. The local maternity service providers responded by committing to redesign their work to take account of these wishes.

Healthwatch C: Coordinating local administrators to address inconsistencies in system responses

At the beginning of the pandemic, Healthwatch C received numerous telephone calls from members of the public who reported being unsure about the government's advice on COVID-19. In particular, these people reported inconsistencies in who was categorised as 'vulnerable', and which regimes of isolation applied to different categories of vulnerability.

Through their contacts in the local system, Healthwatch C's staff began investigating the information local administrators were using to identify people especially vulnerable to COVID-19. Healthwatch C found out that

the local authority, which is responsible for social care and public health, was using different sources of information from the one used by the local NHS, which is responsible for healthcare services and for officially categorising people according to clinical risk. As the CEO of Healthwatch C described, by taking up the role of the ‘go-between between the local authority and the [service commissioners] who were doing completely their own thing’, Healthwatch C helped ensure better communication between key stakeholders in an area with a history of weak cooperation. This eventually helped the public in having clearer instructions about what to do and what support was available to them.

Healthwatch C’s CEO also realised the need to similarly facilitate coordination between local officials and the voluntary sector. This was particularly important regarding small community groups, including condition-specific support groups (eg diabetes), faith-based associations, and street-based neighbourhood groups, of which the council had been hitherto unaware. Healthwatch C collated a database of voluntary sector activity during the pandemic, which included these smaller community groups and made it available to the council and to the local organisation responsible for coordinating local voluntary sector activity. By facilitating communication between grassroots groups, the voluntary sector, the council, and the NHS, Healthwatch C addressed the need of local people to access support and information tailored to their needs.

Discussion

Health and social care in England, as elsewhere, have been radically reorganised to deal with the pandemic. In normal times, such sweeping changes (eg cancelling all elective surgery, moving primary care consultations online, relaxing hospitals’ discharge obligations to patients) would likely have required formal consultation with the public, and would certainly have attracted a great deal of public scrutiny.

As shown through the three examples earlier, even in the first weeks of the pandemic when traditional avenues to feed

the voice of the people into local decision-making processes had become unavailable, local Healthwatch embraced new innovative strategies to continue providing this essential function. By either directly engaging local people through technology (eg video calls and WhatsApp) or helping with coordinating institutional responses to the pandemic, Healthwatch mobilised quickly to ensure local peoples' experiences could still be heard. This allowed Healthwatch to address gaps in services and highlight how already-vulnerable and seldom-heard groups of people (for example people with learning disability, ethnic minorities, and pregnant women) were being adversely affected by a pandemic response that produced inequitable outcomes. Despite their different approaches, most local Healthwatch involved in our study remained committed to resisting and ultimately overcoming the potential for the pandemic to transform their organisation into one that primarily conveyed the voice of the system *to* the people, rather than fulfilling their mandate to deliver the voice *of* the people to the system.

Crucial to Healthwatch's ability to act in this way was its formally mandated position in England's health and social care system. For instance, as in Healthwatch B's example, involvement in mutual aid groups' WhatsApp chats allowed access to the views and experiences of people (such as those who were self-isolating), which might otherwise be difficult to access. But it was Healthwatch's status as a formal statutory organisation (as well as the expertise, reputation, and relationships built up over time as a result of that status) that provided it with a direct channel through which to communicate these views back to people with decision-making power in the health and social care system.

Healthwatch C's expanded coordinating role similarly demonstrates the uniqueness of Healthwatch in the English health and social care governance landscape. Combined with its broad and deep knowledge of the local voluntary sector, Healthwatch C was able to gather feedback from residents, seek answers from and coordinate information between health and council agencies. A statutory organisation like Healthwatch is well positioned to mobilise relationships with different stakeholders because of the status provided

by Healthwatch's legal mandate. The changes experienced by Healthwatch during the pandemic and their implications for its longer-term role in championing public voice require further investigation and analysis – and this will be crucial post-pandemic for understanding how public health actions and planning can ensure equitable outcomes for all.

What needs to be done

- Better awareness should be raised about the function of Healthwatch in local health and care systems. This will ensure that local people's voices are taken into account in the planning and provision of services beyond the COVID-19 crisis.
- Post-pandemic, health and care systems at both local and regional level should enhance Healthwatch's role as the main channel to seek and hear a diversity of local people's voices. This will ensure that local decision-making processes are transparent and service planning for local people is effective.
- Healthwatch should be formally encouraged to cultivate the coordinating role between key stakeholders (both statutory and from the voluntary sector) in local health and care systems. This will support democratic, equitable, and fully representative decision-making in the aftermath of the pandemic.

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