NCF
THE NATIONAL CARE FORUM

Response to the COVID Public Inquiry request re SAGE Care Working Group October 2022

24 October 2022

Dear Sir/Madam,

Re: Response to Rule 9 Request Letter as Part of the COVID-19 Public Enquiry

Thank you for the opportunity to respond to the enquiry as part of a Rule 9 request relating to my role as part of the SAGE Care Working Group. I have responded to each of your questions in turn below.

1. **A brief overview of your qualifications, career history, professional expertise and major publications.**

I have a 2:1 honours degree in English Language & Literature from Manchester University. I have subsequent qualifications in coaching and management. My career began with working in homelessness services for Manchester City Council in 1991, followed by working in housing regeneration and supported housing. I was seconded to the civil service in 2001 to work on the Supporting People programme. In 2007 I moved to Nottingham City Council where I had various roles in partnership policy and corporate policy, becoming Head of Policy in 2012 providing policy support to the CEO, the executive team and senior councillors. In 2014, I moved to MHA (Methodist Homes), the largest charitable care provider in England, to set up their policy, research & insight and external affairs service. I then had a year with the Youth Sport Trust, supporting their research & insight function to create a research consultancy arm to drive commercial income generation to support the financial sustainability of the charity as well as strengthening their influencing and partnership capabilities reputation and brand.

In 2019 I moved to my current role as Policy Director with the National Care Forum (NCF). In my current role, I lead the work of our policy team, working closely with our CEO on our stakeholder influencing and advocacy work and parliamentary affairs work on behalf of our not-for-profit members. I also lead our programme of membership engagement and support to ensure we are closely connected to the voice of our members, reflecting their experience and expertise in our influencing work. Alongside that, I lead on developing our research capability and research partnership opportunities. I am not a professional academic so do not have major publications in that sense, although I will no doubt have contributed to various research articles as a key partner.

2. **A list of the groups (i.e. SAGE and/or any of its sub-groups) in which you have been a participant, and the relevant time periods.**

I began to attend the Sage Care Working Group in June/ July 2020. At that point it was an informal sub group of SAGE which was originally a Care Home Working Group and then widened its remit to cover the broader care sector. The group was chaired initially by Jenny Harries, one of the Deputy Chief Medical Officers at the time and subsequently co-chaired by

Professor Ian Hall from the University of Manchester and Dr Eamonn O'Moore from the UK Health Security Agency/ Public Health England. I was not involved in any other SAGE related groups. My records show that I first attended the Sage Care Home Working Group in June 2020 and then a fair proportion of subsequent meetings between then and April 2022 when the group was stood down. The Department of Health & Social Care (DHSC) provided the secretariat for the group and will no doubt have more detailed records.

3. **An overview of your involvement with those groups between January 2020 and February 2022, including:**

   a. **When and how you came to be a participant**

I was not formally invited to join the Sage Care Working Group and I do not know how it was originally created nor the criteria on which invitations to participate were based. The existence of the group began to be mentioned in calls with officials from the DHSC; I cannot recall which official mentioned it, but once I was aware of it, I asked several times to attend the group in June 2020 to raise some key policy questions. On 2 June 2020 I contacted DHSC to ask if it was possible to talk to the sub group of SAGE that was focussing on care homes so that I could feed in some key requests from our members in terms of some hot topics that they would really appreciate some more evidence/ advice on:

- Better evidence on the issues of keeping BAME people safe in care settings (staff and residents) – given the latest analysis by PHE at the time, it was clear that the care sector needed all the help it could get in terms of the evidence base around risk to these groups in our communities and the ways in which we can manage this risk (beyond what we already knew)
- Better understanding of the longevity of the presence of COVID and how long people remain infectious for (again for staff and residents/ people using services)
- What are the plans for Sage to use and share early warning data to influence advice – eg the fact that nursing homes are having greater levels of infection and deaths than residential settings?

In response, after a few repeated requests, I attended a meeting of the group on 25 June 2020 to raise the topics above. My email records show that following that I received invitations to some of the subsequent meetings in July & August 2020. I attended where I could. The group seemed to be a grouping of a range of scientific experts with specialisms in modelling, virology, public health and infectious disease, epidemiology, research into care / care homes and anyone else who might be useful. I am not clear how they were selected to join the group, nor how the group was initially created.

The remit of the group was then reviewed in September 2020 to widen the focus to cover the wider social care sector in general, rather than care homes, including care that falls outside of CQC regulations, including services such as day care and unpaid care. I worked with Professor Jackie Cassell, a member of the group who is an expert in infectious diseases and has some experience of advising care homes in this context, on a 'definition of adult social care' document to help the group understand the breadth & diversity of the care & support sector. The remit of the group was then defined as a subgroup of SAGE to act as a scientific advisory forum to inform policy on the social care sector as a whole. The inquiry will have a copy of the TOR which was produced in September 2020.

The membership of the group was also reviewed, as the DHSC advised that it had grown to 100+ members and they wanted to make it a more manageable size. Members were all asked to complete a survey indicating if they wanted to be classed as a core member and why. I applied to be a core member as I was the sole representative voice of the care and support sector. My role at the NCF means that I have direct and frequent contact with our not-for-profit care and support providers and was able to share that front line experience and expertise with the Sage group. It seemed imperative to me that this eminent group of academics and scientists also had the voice of care & support providers at the table when considering their advice on policy. The voice of people using care and support & their families was also missing.

b. **The number of meetings you attended, and your contributions to those meetings;**

DHSC will be able to confirm attendance more accurately. Between 25 June 2020 and the end of August 2020, I went to 5 meetings. There were also, on occasions, sub group meetings, so it is entirely possible that there were some sub groups meetings that I was not invited to.

Following the revamp of the group in September 2020, once I was invited as a regular core member, I endeavoured to attend when I could. My records suggest that between 4 September 2020 and the end of December 2020 I went to around 75% of the meetings. I continued to attend where I could during 2021 and 2022.

My contributions focussed on the reality of the daily and weekly experience of those operating and providing care and support services, sharing the insights from that experience, the suggestions and asks from those expert providers on the frontline and providing direct, unvarnished feedback on the impacts of existing government policy, gaps in that policy and considerations in relation to potential policy options.

It seemed vital that this eminent group of academics and scientists also had the voice of care & support providers at the table when considering their advice on policy. It is hard to judge how much my voice and my representations were listened to at the group as the meetings were not minuted and participants were not given a regular update on previous meetings if they were unable to attend. However, I attended when I could to bring the voice of the care & support sector to the discussions of the group.

b. Your role in providing research, information and advice.

The role I played was to offer my expertise, derived from the direct experiences of care in COVID which we at the NCF had via the very regular contact (daily and weekly) and feedback from not-for-profit care & support providers who are members of the NCF. This provided a direct, real-time route of feedback of the frontline reality of the COVID experience and its devastating impacts, the immediate and longer-term impact of government policy, the gaps in that policy, and constructive ideas about what might help on the frontline as well as the insights from the senior leaders in the NCF membership organisations.

Like many aspects of the government response to COVID, the voice of care providers, and their advocacy for the people they support & their families as well as their staff, seemed to be rarely heard and acted upon. My attendance at the SAGE care working group offered an opportunity to bring it to the table and seek to make the voice of those operating and managing adult social care services recognised and heard.

When I started attending the group, it became clear that there was limited experience of the realities of frontline care operations, both in general and more specifically in relation to the COVID experience, and there was no other social care provider voice there. It seemed important to me to join the group to bring this essential perspective to its considerations. My view was and remains that it is essential that this eminent group of academics and scientists should also have the voice of care & support providers at the table when considering their advice on policy. I also believe that the group needed more engagement with the care and support sector to understand real world implications of their advice, both intended & unintended.

A small number of the members had extensive experience of research in care homes in England (such as Professor Adam Gordon, Professor Jackie Russell, Professor Laura Shallcross and Adelina Comas as well as some colleagues from the devolved nations) so brought a valuable understanding from that perspective and some of the Public Health England attendees had also worked with care homes, but there was little direct experience or direct regular connection with care providers.

There was also little understanding of the wider care & support sector beyond just care homes; this was mirrored in so much of the government response during and indeed prior to the pandemic in terms of informed policy making. I believe it was important to bring a perspective to the group of the breadth and diversity of the care & support sector and the people it supports every day. Without this understanding, the scientific advice provided risked being unable to gauge the challenges and impacts of that advice in frontline implementation.

I also provided challenge to some aspects of the way the group was run. For example, we would regularly see the latest intelligence from PHE – I think it was their dashboard view of pandemic data, the latest ‘sit rep’ type update. Much of this data was provided by the care sector via the Capacity Tracker. I regularly asked for an edited version of these weekly slides to share with the care sector to provide a real time, up to date aggregate picture of how that data was looking but I was consistently advised that this was not allowed as this was restricted information that could not be shared. This reluctance to share the real time aggerate data picture seemed ill judged; care providers were submitting their data individually on a weekly basis via the Capacity Tracker to support the PHE intelligence reporting and yet care providers could not see the real time aggregate data picture themselves. This was totally unacceptable in my view and I raised this issue repeatedly and continue to do so even now, as there continues to be a lack of data transparency and data accessibility for care providers in relation to the Capacity Tracker. At the NCF, we have been campaigning and advocating about the importance of care providers being able to benefit from & use the aggregate data picture that their regular data submissions create and we will continue to do so.

4. **A summary of any documents to which you contributed for the purpose of advising SAGE and/or its related subgroups on the Covid-19 pandemic. Please include links to those documents where possible.**

The DHSC have provided the list of public facing documents below. I would have to make a detailed check of all my email records to provide a full list of which ones I commented on and what those comments were. I have not done that forensic sift through my records but in general my comments would have been related to the reality of implementation, challenging assumptions about how care & support services actually work in practice as well as assumptions about staff expertise, the capacity of the sector to manage yet more change/ restriction/ new policies/ practice without a clear rationale and direct support and the challenges of translating the latest scientific advice into manageable, implementable policy.

Consensus statement on the association between the discharge of patients from hospitals and COVID in care homes - (26 May 2022)

SCWG Chairs: Summary of role of shielding - (20 December 2021)

SCWG: What are the appropriate mitigations to deploy in care homes in the context of the post vaccination risk landscape - (26 May 2021)

The Adverse effects of social isolation and loneliness on psychological and physical health outcomes in care home residents during Covid-19 - (20 August 2021)

SCWG: Consensus statement on family or friend visitor policy into care home settings - (2 November 2020, republished 20 August 2021)

SCWG Update Paper - (21 September 2020)

There are three documents I can provide more detail on in terms of my contribution:

The consensus statement on hospital discharge: I, representing the National Care Forum, absented us from the consensus statement regarding hospital discharge. There were some key reasons for this. Despite the adoption of some of my comments in the various drafting versions, I concluded that the statement needed to address two key issues much more strongly

- a much stronger articulation of the limitations of the various studies due to the lack of testing in Wave 1 & the wider data issues in those studies
- a clear acknowledgment that while hospital discharge may not have been the dominant cause of ingress, it was one cause of ingress and most importantly, an entirely avoidable one. This must never happen again and this is a key learning for any future pandemic handling.

I did also draw the group's attention to our vocal criticism of the Public Health England report on hospital discharge when it was issued in 2021 and I felt that all the concerns we raised about that report remained valid and this statement did nothing to address them. I did also ask about publication plans for this consensus statement and advised that we would put our comments about absenting ourselves from the statement in the public domain. My records show that this statement was drafted over a number of months in late summer/ autumn of 2021 but then not published till May 2022.

The consensus statement on visitor policy: I would have to check my records for my detailed comments, but I was a strong advocate of ensuring balance in this policy advice. We had seen first-hand from our members the impact of restrictions on visitors to care homes and the devastating impact it had on both families & residents. I regularly reminded the group that it was essential to balance the risk of harm of COVID with the risk of harm of isolation and lack of connectedness with loved ones. The NCF did a huge amount of partnership work with our members and other key partners during the summer and autumn of 2020 as well as into 2021 to influence the government to review its blanket policy on visiting restrictions (I can provide more detail if needed) and this work would have underpinned my contribution to the Sage group discussion and the paper.

The paper about the adverse effects of social isolation and loneliness: again, I would need to check my records for my detailed comments, but this was a paper that I welcomed and I expect I will have provided comments as set out above.

The publications were a mix of papers containing the latest research/ opinions and consensus statements. I do not recall the process for publishing the research/ advice papers as I did not contribute to them all but for the consensus statements, there were some opportunities to review and comment and either support or absent from. Like much of the work done during the pandemic, the SAGE care working group was operating at pace and under pressure and the processes for finalising documents for publication were not entirely clear at the time.

5. **A summary of any articles you have written, interviews and/or evidence you have given regarding the work of the above-mentioned groups and/or the UK's response to the Covid-19 pandemic. Please include links to those documents where possible.**

I do not recall any interviews or articles specifically related to my role in the Sage Care Working Group. The NCF has been vocal about many aspects of the impact of government policy – or lack of – throughout the last two years but as far as I can recall, none of that specifically related to the work of the Sage Care Working Group.

6**. Your views as to whether the work of the above-mentioned groups in responding to the Covid-19 pandemic (or the UK's response more generally) succeeded in its aims**.
This may include, but is not limited to, your views on:

a. The composition of the groups and/or their diversity of expertise;

My experience of the group was that it was a grouping of a range of scientific experts with specialisms in modelling, virology, public health and infectious disease, epidemiology, research into care / care homes and anyone else who might be useful. I am not clear how they were selected to join the group, nor how the group was initially created.

There was an attempt in September 2020 to bring a bit more structure to the group, but certainly to start with it seemed to me to be an informal grouping of academics and scientists, bringing their expertise to questions posed by the DHSC policy makers.

It lacked a care & support provider voice until I joined and I am sure it would have benefitted from a more diverse range of provider voices and local authority colleagues. The voice of people using care and support & their families was also missing. I regularly advised that it was very important to get the views of care and support providers in relation to the advice they were offering as implementation and implementability would be key to adoption of policy based on their advice.

b. The way in which the groups were commissioned to work on the relevant issues;

I do not feel especially well equipped to answer this as I do not have detailed understanding of how this process worked.

c. The resources and support that were available;

Again, I do not have enough knowledge about this – all I can share are my observations which were that it seemed to operate on very little resource and a lot of good will. Colleagues gave a lot of their time, at very short notice, to respond to urgent requests and while this is to be commended, it was perhaps not very sustainable. The TOR clarify that the secretariat for the group was provided by the DHSC and that the group's meetings are not officially minuted. This seems different to the main SAGE group and I do not know why; colleagues at the DHSC may be able to explain why. Resources to support this group did seem very limited. Colleagues who joined the group from the very beginning will no doubt have more information on this point but like much of the work during COVID, it was operating at pace, under pressure with little formal resource and support.

d. The advice given and/or recommendations that were made;

See comments above in section 4. See also the point in section 3b about the inability of the group to share the real-time aggregate data picture from the PHE intelligence reports derived in part from provider data from the Capacity Tracker.

e. The extent to which the groups worked effectively together;

The Sage Care Working Group seemed to me to work very effectively as a group in the sense of collaboration, respect, knowledge sharing, challenge & debate. The missing parts, as I say, were stronger voices from the provider sector and from local authorities.

f. The extent to which applicable structures and policies were utilised and/or complied with and their effectiveness.

I am a little unclear about this question. I was not familiar with any specific processes or policies for the group. There was a Terms of Reference and a collaborative approach to developing group statements and agreeing sign off but I have no idea if there was a formal process that should have been followed.

7. Your views as to any lessons that can be learned from the UK's response to the Covid-19 pandemic, in particular relating to the work of the above-mentioned groups. Please describe any changes that have already been made, and set out any recommendations for further changes that you think the Inquiry should consider making.

My responses to this question are framed by restricting my answers to my participation in the Sage Care Working Group. I think it is essential to note that I have a far wider range of views about the lessons that must be learned from the UK's response to pandemic because of my role with NCF. It would be inappropriate to confuse the two roles here, but NCF will be seeking Core Participant status for number of the modules as we believe we have relevant evidence to provide to the inquiry about the government response, as well as a significant interest in the issues to be considered and any recommendations made or lack of in some circumstance and are keen that our voice as the not-for-profit care and support sector is heard.

The Sage Care Working Group was a grouping of academics and scientists that included a range of scientific experts with specialisms in modelling, virology, public health and infectious disease, epidemiology, research into care / care homes and anyone else who might be useful. It lacked a care & support provider voice until I joined and I am sure it would have benefitted from a more diverse range of care & support provider voices and local authority colleagues as well as the voice of people using care and support and their families.

The surprise to me was the lack of understanding of the breadth and diversity of the care & support sector and the wide range of people and their families who rely on it. This problem is a microcosm of the broader challenges the government, especially the DHSC faces, as it tries to develop policy for a sector it does not understand. This is hugely frustrating and can be easily resolved by ensuring that the wider principles of engagement, be that in an emergency or in business as usual, always include care & support providers/ their representatives and people using care & support & their families/ their representatives. Being the sole voice from the provider sector was challenging and it is hard to gauge how much influence I was able to bring to bear on the work of the group.

A key learning is the importance of a fully inclusive approach to the care & support sector within pandemic preparation and policy response. Current mechanisms for the involvement of the sector remain underdeveloped and future pandemic preparedness and as well as day-to-day policy making needs better mechanisms to involve the sector.

As I have mentioned in section 3b, it was hugely frustrating that there seemed to be no way or desire to provide a real time aggregated data picture for care and support providers in terms of the PHE intelligence and data being shared with the group.

A key learning is that this PHE aggregated data picture should have been shared regularly with care providers so that they could benefit from the real time aggregated data picture they were helping to inform. This cannot happen again. There must be a requirement to share such data with the care and support sector.

Another key learning is that a much better understanding of the care and support sector is essential for effective policy making. As well as hindering the effectiveness of the policy response to the emergency that the pandemic presented for the care and support sector, the lack of understanding about the care and support sector also seemed to feed into some unhelpful perceptions and assumptions about the effectiveness of care and support providers and their staff in infection prevention and control, ability to implement testing, issues around vaccination and issues around visiting.

A further key learning is to respect and recognise the skill and expertise of those working in the care & support sector. Care staffed are highly skilled. Low pay does not equate to low skills and care providers, certainly the ones I spoke to in my NCF network, spent a huge amount of time, effort and resource seeking to implement the very best approaches to IPC, testing, vaccination and visiting, often despite government and local health protection advice, not because of it. There did seem to be a misunderstanding about the knowledge within the care and support sector about infection prevention and control; in my experience, care & support providers do have a good understanding of IPC measures but the COVID experience highlighted the importance of sharing new emerging thinking quickly and the importance of resourcing new measures required promptly.

8. **A brief description of documentation relating to these matters that you hold (including soft copy material held electronically). Please retain all such material. I am not asking for you to provide us with this material at this stage, but I may request that you do so**

in due course.

There were no formal minutes from the meetings although DHSC may have some notes. In the future, there is clearly value in a more systematic approach to such groups, with clear minutes/ notes circulated following the meetings.

Yours faithfully

Liz Jones

Policy Director, National Care Forum