Opportunities for a post-pandemic programme of research and surveillance to reduce infection in care homes: findings from a roundtable discussion held on 30th July 2021

ABSTRACT

There is a unique opportunity to build on the achievements of the last 16 months and create a positive legacy from the pandemic, by developing a programme of post-pandemic surveillance and research in care homes. This would put social care research at the forefront of policy planning and emergency preparedness and response for generations to come, and provide the care sector and policy-makers with critical insights to address the health and social care needs of our ageing population.

CONTENTS

Executive summary

A roundtable meeting was set up to consider a vision for a future programme of research and surveillance in care homes that builds on the VIVALDI study and momentum created by the pandemic, and to consider some of the major barriers to achieving this vision. The aim of the meeting was to generate ideas for how we might address these challenges to inform a project plan / roadmap.

The first section of this report provides background information on the VIVALDI study and outlines a proposal for a programme of surveillance and research in care homes "The Care Home Observatory." The second section summarises key findings from the roundtable and the third section draws conclusions.

There was broad support for establishing a programme of research and surveillance in Care Homes and recognition of the benefits that this could bring the Sector. Key issues raised included:

- the importance of equal partnerships between researchers and care home stakeholders to create a shared research vision;
- the critical importance of delivering research which is framed from the perspective of social care and benefits residents, staff, relatives and providers;
- the need to select outcome measures which capture health, social and economic outcomes;
- consensus that the Observatory should focus on infection, but that there may be scope for a broader research agenda in the longer-term;
- the need for clarity about how data will be used and appropriate governance and oversight;
- there is support for voluntary sharing of data between providers, academics and policymakers in principle, but it is important to recognise that data sharing is a risk for providers, particularly if the data are not contextualised;
- the importance of a realistic view of the costs associated with research and appropriate recompense for providers;
- opportunities for synergies with existing studies and new and existing infrastructure including the UK Health Security Agency.

There are a range of complex issues that need to be addressed to build the Observatory. Our intention over the next six months is to use insights from the roundtable and coproduce a roadmap to create the Observatory working in partnership with providers, relatives, residents (where possible), staff, policymakers and academics. The roadmap will consider how the Observatory should be structured, mechanisms for governance and oversight, development of a research vision and strategy and the intended outputs.

PART 1: A proposal for a programme of research and surveillance in care homes that builds on the legacy of the VIVALDI study and data infrastructure resulting from the pandemic

1.1 Why create a Care Home Observatory?

Before the pandemic, research or data relating to infection in care homes in England (or anywhere in the UK) were limited. COVID-19 has exposed the extreme vulnerability of care homes to severe infection and the fragmented nature of social care datasets by comparison with the NHS.

More positively, the pandemic has catalysed new research (e.g. the VIVALDI study), investment in data infrastructure, and a testing programme - all of which have made it possible to measure COVID-19 infection and vaccine uptake in care home staff and residents, and strongly influenced the national policy response. However, if testing and research in care homes stops we will rapidly return to a March 2020 scenario, with no oversight of infection or vaccine effectiveness in staff and residents and extreme vulnerability to outbreaks and pandemics.

There is a unique opportunity to build on the achievements of the last 16 months and create a positive legacy from the pandemic, by developing a programme of post-pandemic surveillance and research in care homes. This would put social care research at the forefront of policy planning and emergency preparedness and response for generations to come, and provide the Care Sector and policy-makers with critical insights to address the health and social care needs of our ageing population. The programme would also support better preparation for emerging and seasonal infection risks including influenza.

1.2 What research on COVID-19 has taken place in care homes? What is the VIVALDI study?

The VIVALDI study was established in June 2020 to investigate infection and immunity in care home staff and residents in order to support the national pandemic response, and is funded by the Department of Health and Social Care. VIVALDI was initially set up in 100 care homes that were owned by a single Provider and has since expanded to >300 care homes including “For Profit” and “Not for Profit” care home chains and a number of independent providers. The study is funded until April 2022.

VIVALDI is a longitudinal cohort study which follows up care home staff and residents for up to 24 months. The study has three main components:

1) Collection of repeat blood samples from staff and residents at regular (approx. 2-4 month) intervals to measure the immune response following natural infection and vaccination.
2) Retrieval of PCR test results (undertaken through the national testing programme) for staff and residents and associated data (e.g. viral sequencing).
3) Linkage to routine datasets to look at outcomes of infection (hospital admission, death) and vaccination status (type and date of vaccination) in staff and residents.

1.3 How has VIVALDI informed the pandemic response?

The VIVALDI study team have been at the forefront of care home research during the pandemic and have demonstrated how timely research can shape policy. Examples of how research from VIVALDI has influenced Government policy in protecting care homes include:

- *Preventing infection:* The VIVALDI survey suggested it was more effective to focus limited testing capacity on staff rather than residents. VIVALDI also highlighted some of the main challenges faced by care homes in the first wave of the pandemic (e.g. difficulty isolating residents with dementia, balancing the risk to residents of low staffing ratios versus the risk of importing infection via agency staff).
- *Workforce strategy:* Findings on staff sickness pay supported the decision to establish the Infection Control Fund so staff could afford to self-isolate when unwell. VIVALDI highlighted the importance of limiting staff movement across care homes to limit infection, and provided evidence to support control measures such as staff cohorting.
- *Vaccine effectiveness and immunity:* VIVALDI was one of the first studies to test the real-world effectiveness of vaccination in care home residents (who were excluded from vaccine trials). Findings built confidence in the effectiveness of the vaccine in residents and staff and supported efforts to increase vaccine uptake. VIVALDI has also provided insights into the immune response following natural infection and vaccination.

1.4 The opportunity: What might be achieved over the next 3+ years if we continued surveillance and research in care homes?

Figure 1 sets out initial ideas for a programme of surveillance and research in care homes beyond the current study (end date: April 2022). Figure 2 provides an overview of how the research programme might be structured.

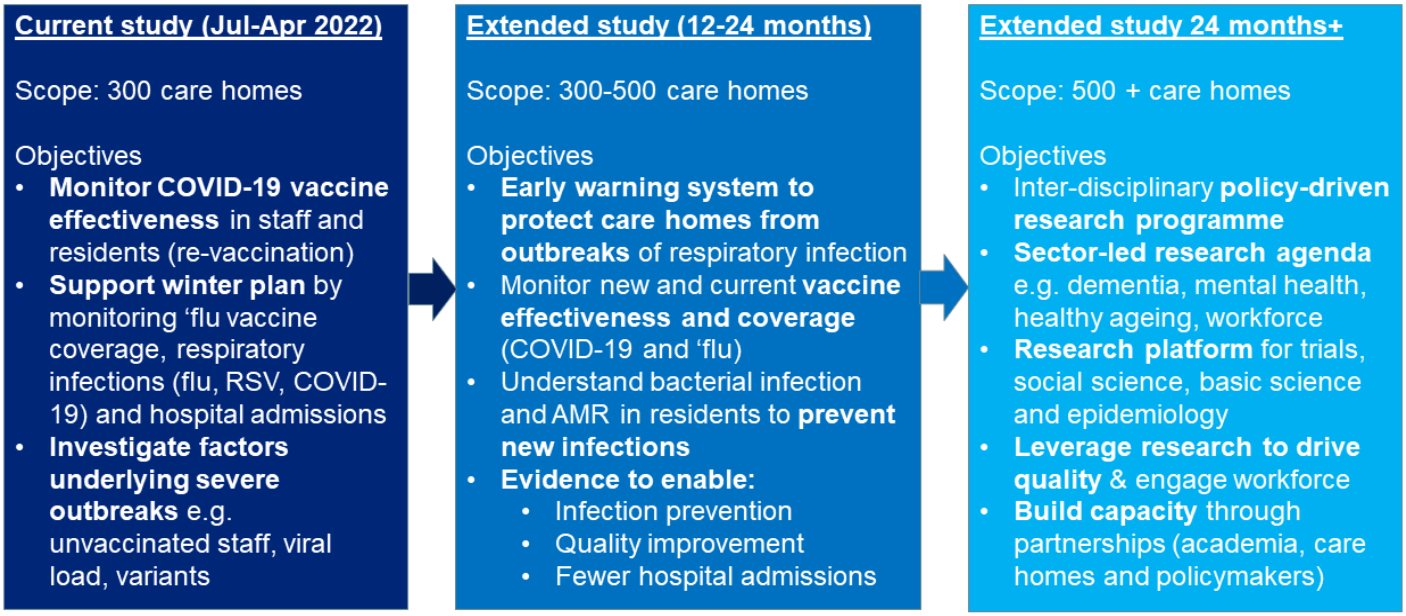

Figure 1. Short, medium and long-term outputs from the proposed surveillance and research programme

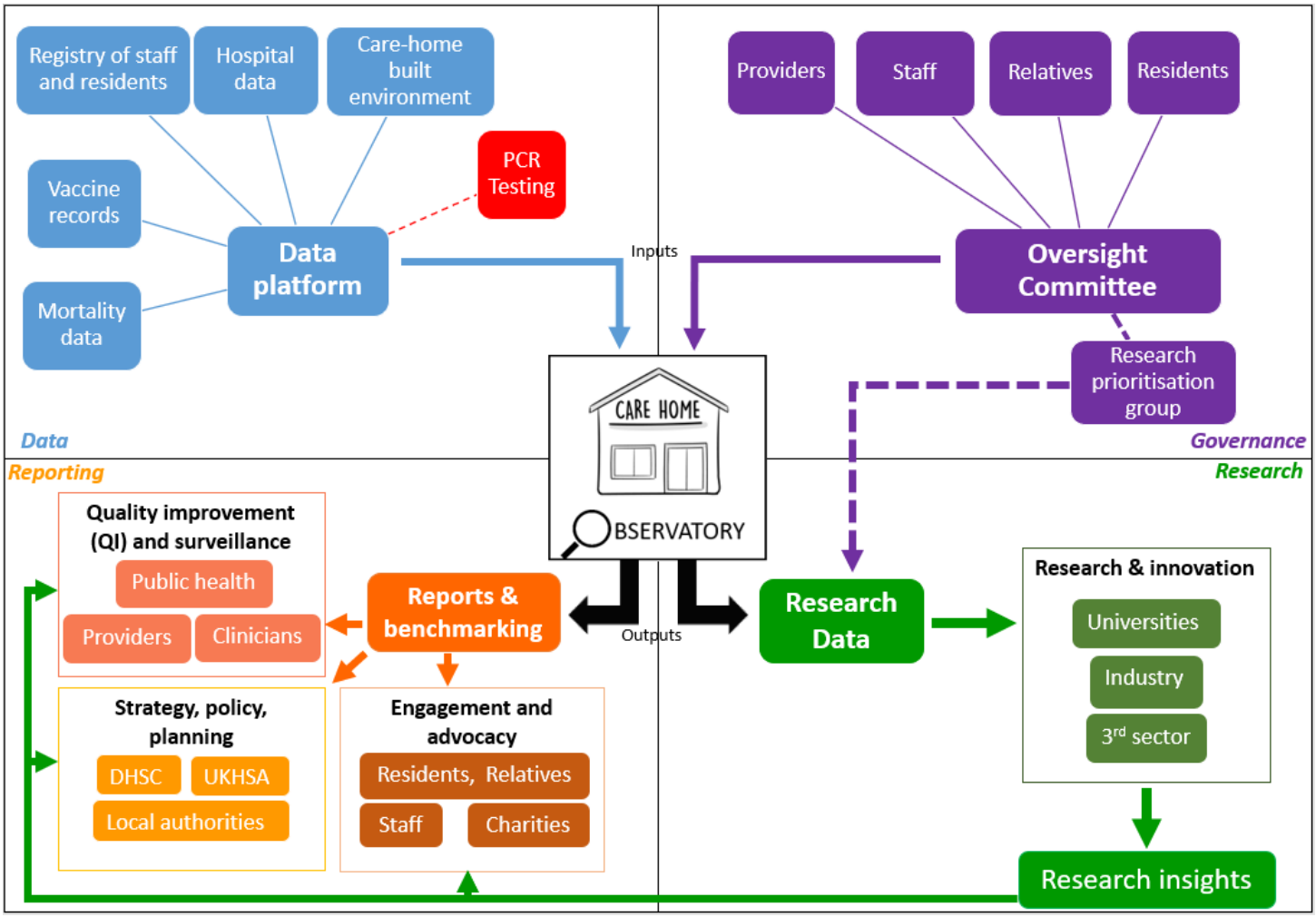

Figure 2. Visualisation of the Care Home Observatory's proposed structure

Currently we are in the top left quadrant of figure 2 as a result of regular PCR testing in care homes and data linkage undertaken through the VIVALDI study. However, if we want to continue accessing data from care home staff and residents in this way, we need to establish a new process for ingesting data directly from care homes that is independent of the current PCR testing programme (top right quadrant). We also need to agree a mechanism for data sharing and oversight that is acceptable to people living and working in care homes and allows them to shape the research agenda (top right quadrant). If this can be achieved the Observatory would provide information that is relevant for a variety of stakeholders (bottom left quadrant) and data for use by approved researchers (bottom right quadrant).

1.5 How would this programme benefit the care sector and policymakers?

Figure 3 shows how different types of studies could be hosted within the Observatory to enable delivery of research which benefits people living and working in care homes. In the short term (blue section of the pyramid) we would use routinely available data to measure infection and monitor infection related outcomes. The red section shows how other types of studies (surveys, interviews, biological collection of samples) might be "layered on" to provide more detailed insights to inform policy and quality improvement activities. The green section illustrates the longer-term ambition for the Observatory to host more complex studies such as clinical trials. These studies would be co-developed with people living and working in care homes, to ensure they address research questions that matter to the care sector and can deliver benefits for staff and residents, Table 1.

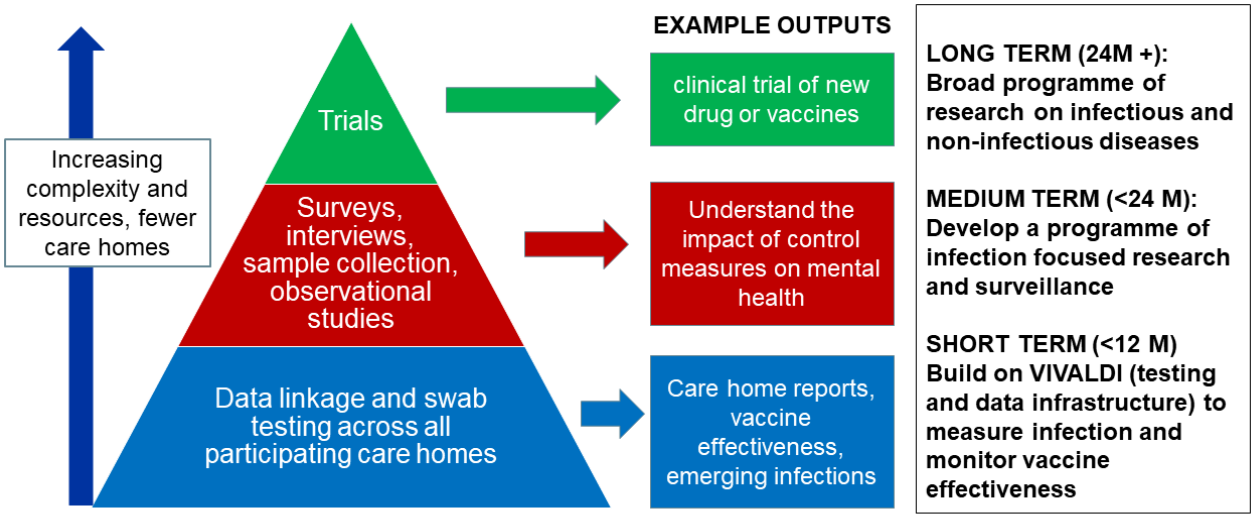

Figure 3. Short, medium and long-term vision for a programme of inter-disciplinary research in care homes

Timescale	Benefits for staff and residents
Short term < 12 months	Monitor vaccine effectiveness against variants and duration of immunity, support winter planning
Medium term 12-24 months	Surveillance and research to reduce the impact of infection on staff and residents. Evidence on the costs and benefits of different disease control measures and how to implement them effectively
Long term > 24 months	Programme of research that is led by the care sector. Increased parity of esteem relative to the NHS. Opportunities for training and career development for social care staff. Evidence to support the delivery of high quality care.

Table 1: Examples of outputs that might be delivered by the Observatory

PART 2: Barriers to developing a programme of research and surveillance in care homes

Expert stakeholders (providers, policymakers, academics) were invited to a virtual Round table discussion on 30th July 2021. Stakeholders were divided into three groups and asked to consider three specific challenges which would need to be addressed in order to create the proposed programme of research and surveillance.

2.1. Challenge 1: How can we engage care homes in research?

- The group reflected on the considerable challenges of undertaking research in care homes (diversity of providers, large number of small providers, lack of research infrastructure). However, they also acknowledged that it used to be very challenging to conduct research in the NHS, and that NIHR has played a pivotal role in transforming the delivery of research in this setting over the last 20-30 years. NIHR represents a potential model for how to build research infrastructure and capacity in social care.
- Research in care homes "works" most effectively when it is co-created, care homes are equal partners, and there is a shared vision and purpose. Research must deliver tangible benefits for people living and working in care homes, and it must enhance the experience of residents and staff. For example, involvement and leadership of research could lead to career progression for staff.
- It is essential to communicate research findings back to the care home in an accessible format, and to be transparent about the timelines for results.
- Strong relationships and trust between researchers and care home managers are critical, but building these relationships is time consuming.
- Participation in research requires training, staffing and realistic understanding of the resources that are required by the care homes.
- Involvement in research has potential to enhance care homes' reputation and relationship with the public as a positive legacy of COVID-19.
- There is an opportunity to re-connect academic and "service" public health to better integrate surveillance and policy in care homes.

2.2 Challenge 2: What do we need to put in place to enable providers to share data on their residents and staff?

- There are substantial risks associated with data sharing and subsequent publication of reports, particularly when information is not put in context. For example, the Care Quality Commission recently made care home mortality data publicly available (following FOI requests), but there was no accompanying information on the type of care homes or

residents which will have had a major bearing on mortality rates, and could lead to misinterpretation of the data. Outputs from Capacity Tracker have also been used for purposes that were not clearly outlined or agreed at the outset. This makes providers concerned about how individual-level data from staff and residents might be used, and highlights the need for robust governance and oversight.

- There is a potential tension between the needs and priorities of providers and those of policymakers. This tension should be acknowledged and considered. Many providers dislike the idea of mandatory data collection, but they also recognise the value of a shared minimum dataset to compare across care homes. The issue is the type of data that is collected, how it might be used, and who decides. A "hearts and minds" approach to voluntary data collection, which inspires participation is more likely to harness the enthusiasm of front-line workers and produce better quality data.
- There are parallels with data sharing in primary care and previous experience in this setting has shown the importance of involving providers in governance discussions from the outset considering opt-in versus opt-out approaches.
- Providers, residents, relatives and staff members must be able to dictate the purposes for which their data is used and there must be real engagement with the sector to contextualise and interpret research findings.
- Obtaining informed consent from residents is extremely onerous and likely to be a potential barrier to participation in research.
- There is a tendency to focus on measuring outcomes that are relevant to the NHS which may be of limited relevance to people living and working in care homes. If we wish to use data from care home staff and residents, it must be used for research "on things that matter to people living and working in care homes".
- The technical challenges of data sharing should not be underestimated. NHS has huge data infrastructure which does not exist across social care. Processes for sharing data must not be onerous for providers.
- Providers of care home data systems are potentially a key enabler for data sharing (as is the case in primary care). There are also specific issues to address and opportunities for new research as we transition from the pandemic to post-COVID-19 research.

2.3 Challenge 3: How can we integrate VIVALDI into the existing research landscape and capitalise on momentum that has been created by the pandemic? Which research questions should be prioritised?

- A key consideration is the need to consider the social and financial outcomes when formulating research questions, rather than focusing only on healthcare outcomes. This will also open up new funding opportunities. For example, there is consensus that the

Observatory should focus on research addressing infection, but from a Provider perspective there are important considerations about how infection impacts on financial stability / the care home market. A crucial issue is who gets to ask the questions and ensuring that these are framed from the perspective of social care.

- A major strength of VIVALDI has been the focus on infection. This has galvanised activity in a single disease area and demonstrated the potential of research in care homes. A caveat is that it remains challenging to include small providers. Moving forward it makes sense to capitalise on infrastructure that is available through the ENRICH network, and although the scope must be broader than COVID-19, it is sensible for the Observatory to focus on infection.
- VIVALDI should continue to link with existing studies, and there are clear synergies particularly with DACHA (https://dachastudy.com), AFRI-C and PROTECT-CH. It is important to consider opportunities to investigate care home populations using routine data, which was previously extremely difficult based on postcode matching, but is becoming increasingly possible. It is also important to look for efficiencies in research so care homes are not required to duplicate effort, or test out policies or initiatives that cannot be sustained with current resources. Obtaining informed consent for collection of biological samples from residents (or nominated consultees) is challenging and resource intensive.
- The NIHR School for Social Care Research is a potential funding stream, but there may be opportunities for Industry funding and UKRI or Wellcome depending on the research question. One option to develop the Observatory is to develop studies and infrastructure to address current priority research questions and then seek funding, potentially in collaboration with existing studies.
- The new UK Health Security Agency (UKHSA) is an opportunity to build infrastructure for care home research and surveillance, as PHE did not have a social care surveillance programme. This would help to address inequities between health and social care. There is a clear and growing need for surveillance and evidence to inform care home policy. A good example of this is the challenges associated with deploying infection-control interventions that have been designed for healthcare settings in care homes.
- Developing a model to support the social care equivalent of NHS costs would be a key research enabler and set a powerful precedent for future research in care homes. VIVALDI recompensed all Providers for their time.
- Consideration needs to be given to how to the Observatory is structured and how it can enable equal partnerships between providers, policymakers and academia. Are there examples of successful partnerships that we can learn from, for example. Health Protection Research Units (HPRUs)?
- Collective engagement with care homes is challenging due to the large number of providers and pre-pandemic, it was very difficult to get care homes to speak with one voice. Recently the National Care Forum has taken on this role, but not all providers are represented.

PART 3: Conclusions and next steps

The roundtable highlighted the complexity of moving from VIVALDI's current system of data collection and linkage (established during the pandemic) to a new approach based on voluntary sharing of data with providers. However, there was strong support for our proposal to establish the Observatory, and recognition that there is a unique, time-limited opportunity to capitalise on momentum created by VIVALDI and the pandemic. There was also consensus that the Observatory should "play to its strengths" and focus on research and surveillance of infection.

A key finding was the importance of working in equal partnership with providers, and ensuring that research questions are framed from the perspective of social care, rather than from an NHS perspective. There was also recognition of the challenges associated with voluntary sharing of data for the purposes of research, and the potential risks to providers if data are used for purposes that are not agreed at the outset. Providers made the important point that it is comparatively easy to get people to take part in research during a pandemic, and it will be critical to identify research questions that really matter to the care sector if we are to continue to engage them in research beyond COVID-19. We will also need to ensure that care homes are appropriately reimbursed for the time taken to participate in research, and consider how we can work with networks such as ENRICH to support recruitment to studies. There is a well-established and generous social care research community who are willing to support development of the Observatory, and share insights from their work and experience and we should identify synergies with existing studies. We should also capitalise on opportunities for funding and collaboration through the recently established UK Health Security Agency, and with the NIHR School for Social Care Research.

Our intention over the next three to six months is to build on findings from the roundtable and coproduce a roadmap to create the Observatory. Working in partnership with Providers, relatives, residents (where possible), staff, policymakers and academics, we will consider how the Observatory should be structured, mechanisms for governance and oversight, development of a research vision and strategy and the intended outputs. This work will be co-led by UCL and the Care Policy and Evaluation Centre at the London School of Economics.

List of participants

Name	Role
Helen Atkinson	Director of Public Health for Portsmouth, Social Care Lead for Association of the Directors of Public Health
Borscha Azmi	Vivaldi Study Team, UCL
Jenni Burton	Clinical Lecturer and Academic Geriatrician, University of Glasgow
Jo Chataway	Professor and Head of Department of Science Technology, Engineering & Public Policy, UCL
Adelina Comas	Assistant Professorial Research Fellow, LSE
Andrew Copas	Professor of Trials in Global Health, UCL
Jeremy Farrar	Professor of Tropical Medicine & Director of the Wellcome Trust
Claire Goodman	Professor of Healthcare Research, University of Hertfordshire
John Hatwell	Director of Covid-19 Surveillance and Immunity Studies Joint Biosecurity Centre, DHSC
Aidan Irwin-Singer	Vivaldi Study Team, DHSC
Andrew Hayward	Professor of Infectious Disease Epidemiology, UCL
Liz Jones	Policy Director, National Care Forum
Martin Knapp	Professor of Health & Social Care Policy, LSE
Maria Krutikov	Clinical Research Fellow, VIVALDI study team, UCL
Lorraine Mcgarry-Wall	Four Seasons Healthcare
Julienne Meyer	Professor Emeritus of Nursing: Care for Older People, City University
Uma Moorthy	Deputy Director, Social Care Data and Analysis, DHSC
Paul Moss	Professor of Haematology, University of Birmingham
Eamonn O'Moore	SRO Adult Social Care Team, Public Health England
Geoff Mulgan	International Public Policy Observatory, UCL
Joanne Reeve	Professor of Primary Care Research, University of Hull
James Robson	Change Delivery Director, Four Seasons Healthcare Group
David Seymour	Alliance Executive Director at Health Data Research UK
Laura Shallcross	Professor of Public Health, UCL
Natalie Tarbatt	Head of Data Services, NHS England and NHS Improvement