vivaldi
Preventing COVID-19 in care homes

Care Homes Staff perceptions of data-sharing

Aims and objectives

The VIVALDI study team conducted interviews with staff members from various care homes. The aim of these interviews was to understand their perception and experience of data-sharing.

Key objectives of the interviews:

- Engaging care homes staff in VIVALDI 2022 and going forward
- Explore staff's understanding, attitudes, and willingness to share data
- - Find out how best to explain to staff how we use their data? (e.g. flyers, videos, meetings)

Recruitment

A poster which included a QR code to a registration form - was circulated via email to all HC-One care homes and posters were displayed around workplaces. Staff who had registered their interest were allocated time slots on a first-come, first-serve basis. All interviews were conducted via Zoom in a one-to-one format. Participants were reimbursed for their time.

Semi-structured interviews

VIVALDI team members conducted individual semi-structured interviews lasting 45 min with care home staff to explore their own experience of taking part in VIVALDI and on data sharing for research in general. The below questions were asked while allowing for flexibility to follow-up on any new information:

- Do you know how your data is used in VIVALDI? (how it is collected and analysed)

- Why is health data needed for care homes research?

- What do you think are the benefits to residents and staff of sharing data? What's in it for you? And what's in it for all? What concerns would you have about sharing data?

- Would you support data sharing for future care homes research (COVID-19 and other diseases/infections)/Do you think most/some/any staff will want to opt out of data sharing

- What do you think about the format of the drop ins (we are keen to engage with staff)? Would you want to be involved in discussions about these matters going forward?

Overarching themes

Understanding data sharing in VIVALDI	Participants described their understanding of "data sharing." Respondents explicitly mentioned data being shared with researchers for VIVALDI study. Many respondents did not have sufficient detailed understanding of the process of data sharing, and when asked they focused on their motivation. "We didn't understand the exact process, but we knew that data from our testing and blood samples was used to check if we had the virus and if we had immunity and antibodies" "Yes, we would support data sharing. I think most staff members wouldn't mind sharing data if they are supported to do so" "Yes, I wasn't very clear but one of the phlebotomists was very helpful at explaining how the data is used"
Motivation for data sharing-Role of care home data in research and priorities	Most respondents were motivated to agree to data sharing to protect themselves and help their residents and/or improve research. "It was important to use the data to understand what is happening. It was very scary, and we were hearing of residents dying, we even had staff members in HC-One dying. So, we understood the importance of doing it" "If we look at UTIs, even though it is an infection that can be treated by 3 days of antibiotics, however we know the outcome on older vulnerable residents can last for months, like deliriums, distress, which can cause pressure on staff too. So, if we explained the need for that data-sharing to staff members, they will know the importance and the benefits for everyone in the care home, both staff and residents. Some of the priorities that I can think of: - Effects of using purifiers"
Research results dissemination	Many of the respondent agreed that current ways of the study's dissemination are not meeting their need, and have proposed different ways of feeding study results to the participants: "Yes, we would support data sharing. I think most staff members wouldn't mind sharing data if they are supported to do so. But we really need to understand the results of this research, for example, it was very useful to get the results in text messages whether we have covid or not. I don't remember seeing other results" "Short videos that we can share at our staff meetings, or that we can embed in our training platform that everyone has access too. We prefer short high-level summary for example: " getting your booster will improve your immunity". Organising learning events would be helpful, so staff get out of their day-to-day role. Staff haven't had a chance to socialise, so face to face events would be