



Feedback on DACHA study's 2021 consultation events

Introduction

Consultation with people who use care home data (care home staff, care home managers, commissioners, NHS practitioners, and academics) is threaded throughout the DACHA project. It recognises that different organisations and their representatives' have different priorities for data. Consultation events aim to ensure that early findings and resources produced by the research team address what is of core importance to different stakeholders both in how we communicate findings and ultimately the development of a prototype of a Minimum Data Set (MDS) for care homes.

The first five consultation events took place between February and June 2021. The DACHA team sent a [briefing document](#) to all consultation participants outlining the DACHA study's early findings, and examples of national and regional initiatives since March 2020 that were triggered by the pandemic. These were invitation-only online events facilitated by different members of the DACHA team. Participants were grouped according to their expertise (see below) to encourage discussion based on similar experiences and priorities. This report summarises key messages and insights from the information and feedback from 2021 consultation events.

Questions

The questions asked at the consultation events were:

- What care home resident data have you used and/or shared the most during the Covid-19 pandemic?
- Is there information on care home residents that you routinely collect but do not use/has limited value?
- If information about care home residents and staff was collected and accessed the same way by multiple organisations (commissioners, providers, practitioners, researchers, and care home staff), what would the challenges be?

Expertise groups

40 individuals in England and Wales participated in the 2021 consultation groups. The participants represented a wide range of disciplines and organisations who use care home data:

- 1- Local authority and CCG officials (England – 7 participants)
- 2- Researchers, old age psychiatrists, geriatricians (England – 6 participants)
- 3- Government officials (Wales - 1 participant)
- 4- Data analysts and data researchers (Wales – 3 participants)
- 5- Primary health care professionals (England – 6 participants)

- 6- Care home staff who use electronic records in care homes (England – 8 participants)
- 7- Senior operational and care home managers (England – 9 participants)

In addition to the above consultation events, DACHA researchers also had discussions with Care Quality Commission (CQC) officials to discuss some of the issues raised in the consultations.

Early findings

While there were recurring issues and topics across each group there was no clear consensus reflecting the different individual and organisational needs for residents' data. Answers to the questions about data currently used and data that would be helpful were influenced by recent learning during the pandemic about information gaps and the rapid implementation of standardised approaches to data capture. None of the groups identified data they currently had access to that they thought was redundant or of minimal use. The three dominant issues were:

- The local and national impact of the national NHS Capacity Tracker (CT) to collect Covid-19 data from care homes
- Data use at the individual and aggregate level of decision making and data organisation especially the need for interoperability between systems
- Staff capacity and duplication issues

Impact and learning about data use and usefulness from the national NHS Capacity Tracker

The Capacity Tracker (CT) - <https://www.necsu.nhs.uk/capacity-tracker/capacity-tracker-about-us/> - was originally developed as a single data capture platform to identify vacancies in care homes and expedite patients' discharge from hospitals. During the pandemic, it was mandated and used nationally to collect data on care homes' access to equipment, C-19 outbreaks, and workforce. Participants discussed the value of mandates, the level of analysis needed (regional, institutional, individual) who chooses what is included, information sharing and the unintended consequences of centralising data capture.

The CT demonstrated that it was possible to introduce a national system of data capture that was standardised. For some commissioners, the mandate and data obtained had transformed their understanding of care homes where previously they had struggled to obtain useable information. The CT had been instrumental in helping to identify care homes at risk of being understaffed or having limited access to PPE within a given region, reflecting advantages of the CT for care homes in being supported for local level decision making and policymaking rather than for resident level care. However, the layering of a new system on top of existing reporting systems exposed for almost all participants some unintended consequences of standardised data capture designed to create a macro level understanding of the sector. These were:

- The adverse impact of centralising data on pre-existing working relationships and systems of information exchange between Local Authority commissioners that generated detailed localised information.
- For care home managers, there was a lack of feedback and duplication of effort because of similar reporting requests from other external organisations (e.g. Public Health England).
- The further questions added without consultation or explanation. This was viewed as indicative of mission-creep that in turn led to disengagement and scepticism about how information was being used.

- For NHS practitioners and clinical researchers, they observed the additional demands on care home staff, which added to the burden of reporting and capacity to engage with additional resident-specific requests for information. The reliability and detail of CT information was not specific or accurate enough to inform their work and identify residents “at risk”.

Data use at the individual and aggregate level of decision making and data organisation

The groups discussed the kind of data essential for their work, what needs to be shared with different stakeholders, the need for transparency in how it is used and what facilitates access. Unsurprisingly, examples identified as core information were being able to collect and capture key events such as infections, mortality and changes in residents’ health. Care home staff in both groups stressed the volume of data that was already being collected. Data that documented changes in residents’ normal behaviour, such as sleep, eating, drinking and mood were important as the basis for decision making and care planning and there were advocates for standardised approaches to support comprehensive assessment. Other participants, notably the commissioners, and the care home staff highlighted that although they had audit data, they had very little information on residents’ lives in care homes, if they were happy or how workforce changes affected quality of care and life. Across the groups it was recognised that there was a lack of clarity about who owned the different types of data, how permissions to share with others were enacted and how frequently residents’ information is needed or used by organisations external to the care home.

Although questions focused on the content of data, participants across the groups stressed how data infrastructure and increasing digitalisation supported effective data sharing, and uptake. Care homes having a Unique Property Reference Number (UPRN) were identified by Welsh consultation participants as facilitating the rapid uptake of their capacity tracker with approximately 85% homes using it. Similarly, using e-records, care home staff having NHS email and the universal eMAR system (medication recording system) were reported as reducing errors, improving confidentiality, and improving communication between services about residents. Areas for ongoing improvement were how to communicate and share information with families, align data on residents’ needs with workforce and ensure people inputting the data knew the resident sufficiently well to capture their needs.

Staff capacity and duplication of effort

The growth in demands for information from care homes and the lack of coordination or standardisation were recognised by those working in care homes and those making the requests. There was hope that digitalisation would help to rationalise and streamline the process. However, there were several examples of how long these systems took to set up and how online data capture had increased the opportunity to add questions and new data fields without explanation or justification.

The need to support and train care home staff was acknowledged and those with experience of using e-records felt it had made their work easier and given them new skills in monitoring residents’ health and working with NHS professionals. Duplication of information was a persistent issue even with digital records if it was not possible to incorporate all assessment tools into one recording system.

Learning for DACHA

There is a need to build a shared understanding of the existing data being collected within care homes to support within and cross stakeholder group discussions and expectations of what is needed and achievable. There was clarity within groups about the information needed about residents’ health

status. All the groups recognised it was difficult to obtain data that meaningfully and consistently captured residents' quality of life.

As important as establishing MDS content is the infrastructure that supports it and how feedback is provided to those who collect the information. Participants with systems for sharing information as a basis for decision making, using e-records, and familiarity with different methods of standardised assessment stressed the value of the investment in staff training and preparation and trust that the data would be used. They also highlighted the lack of clarity about the frequency of reporting (both at the individual resident, care home, and aggregate level of information).

Future consultations

The original plan was that DACHA consultation events would be in-person regionally based meetings. With the C-19 limitations, the consultations were held online and had national engagement. The DACHA consultation captured regional differences within the discipline specific groups and highlighted the importance of understanding within group differences as well the different priorities and needs of practitioners, commissioners, the regulator and researchers. Participants could identify further information and methods of data organisation that could support their work but found it difficult to identify data that could be defined as 'least useful' or 'redundant' data.

The DACHA national survey of data that care homes currently complete has highlighted the huge amount of data already being recorded. Mapping what is available and in what formats is key to the identification of gaps and decisions about what data can be merged or deleted. The findings from the survey, the reviews of the content of international MDS, and their implementation reinforce the value of ongoing consultation with different stakeholders about what should be included in a genuinely minimum (as opposed to maximum) data set for care homes to complete.

Second consultation events

The next round of consultation events is planned to take place between March and June 2022, where possible with the same participants who joined the first round of consultations. These consultations will be more structured to help inform a prototype for a future minimum data set (MDS), which will be piloted as the final work package of the DACHA project. They will share information that could be included in an MDS for discussion and ranking. We will be promoting these events and circulating invitations to participate at the beginning of 2022.

Abbreviations

ASC – Adult Social Care

C-19 – COVID-19

CCG – Clinical Commissioning Group

CQC – Care Quality Commission

CT – NHS Capacity Tracker

LA – Local Authority

MDS – Minimum Data Set

PPE – Personal Protective Equipment

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Appendix – Consultation Matrix

	Capacity Tracker (CT) and Covid-19 data	Incentives and policies	Types of data & governance	Capacity and duplication
<p>Local authority, CCG (England)</p> <p>7 participants</p>	<ul style="list-style-type: none"> - No agreement about the value of the CT - Commissioners with established relationships with local care homes and systems of data capture disliked it because it affected working relationships and centralised information, duplicated effort and was over-complicated. - Some authorities had their own trackers prior to the pandemic. - Information on workforce issues in care homes is not offered on CT - CT might be serving national rather than local needs, i.e. lack of local indicators 	<ul style="list-style-type: none"> Financial incentives to complete the CT perceived as key but do not guarantee uptake and completion 	<ul style="list-style-type: none"> - Who owns and shares CT data is unclear. Care providers recognise that the results might influence commissioning e.g. number of vacancies and reputation, e.g. how many deaths. - Scope to add data on care homes' underproviding of services or under-recruitment issues. 	<ul style="list-style-type: none"> Too many questions on the CT. Unclear to local authorities how information is used
<p>Researchers, old age psychiatrists, geriatricians (England)</p> <p>6 participants</p>	<ul style="list-style-type: none"> CT needs to include agreed Early warning signals to identify care homes "at risk". For a clinician and researcher, the CT does not provide useful data. Unclear to them how all CT information is used. 	<ul style="list-style-type: none"> Inclusion of Comprehensive Geriatric Assessment (CGA) data about residents would be very helpful in a dataset. 	<ul style="list-style-type: none"> Scope to add data on: <ul style="list-style-type: none"> - Soft signs (how does a resident move, talk, eat?) - Information on residents' functional baseline as they come into hospital - Longitudinal data on trends 	<ul style="list-style-type: none"> Data needs to be manageable and minimal to not overburden care home staff. The pressure on care homes to collect data should be minimised.
<p>Government officials, data analysts and data researchers (Wales)</p> <p>4 participants</p>	<ul style="list-style-type: none"> -A capacity tracker for use by care homes themselves was rapidly launched in March 2020 with approximately 85% homes in Wales using it. Each care home is attached to a Unique Property Reference Numbers (UPRN). -There is no NHS Capacity Tracker in Wales but there has been a 'Covid Information Portal', which could be accessed by PH Wales and NHS Wales staff only. 	<ul style="list-style-type: none"> - Covid-19 has accelerated data sharing where the framework was already there. - In Wales, there is a mandate for filling in data but there are no sanctions attached to non-completion. - Requires national legislation change, In Wales, a minimum staffing legislation has been introduced. 	<ul style="list-style-type: none"> - Most important data collected from care homes are: mortality/how much excess mortality, infection rates, data around recovery times. - Scope to add data about: nurse's administration data - Frequency of data collection depends on the type of data: Clinical frailty can be collected once a year, but infections need to be collected weekly. 	<ul style="list-style-type: none"> - During Covid-19, care homes were being asked for data from several organisations. The Government used the data provided from track and trace and testing instead of asking directly to care homes. - Effective data collection requires a good working relationship with care home staff who understand the importance of the data.
<p>Primary health care professionals (England)</p>	<ul style="list-style-type: none"> Care homes were already expected to submit lots of data during Covid-19; in addition to Capacity 	<ul style="list-style-type: none"> - nhs.net email for every care home can be nationally implemented for continuity in data flow 	<ul style="list-style-type: none"> - Data that is important to access easily: Advanced care plan, 	<ul style="list-style-type: none"> - Care homes submit duplicate/similar data.

<p>6 participants</p>	<p>Tracker, CQC data & ASC survey. CT became challenging.</p>	<p>and communication between NHS staff.</p> <ul style="list-style-type: none"> - Training can be standardised in all care homes. A standardised tool can document staff training and skills and would be helpful for visiting NHS staff working with them. 	<p>infection status, Covid-19 status, vital signs.</p> <ul style="list-style-type: none"> - An implemented data set must be parallel to workforce planning. 	<ul style="list-style-type: none"> - Care home staff need to understand why they are collecting the data. - Trends tracking: Care homes can take measurements, but they do not have the ability to make longer term projections. E.g. if a resident is steadily losing weight every month, a warning will only be prompted if they lose over 2kg in one month, not 1.8kg each month for a year.
<p>Care home staff working with electronic records (England)</p> <p>8 participants</p>	<p>During Covid-19, there was daily input of oxygen saturation (SATS), temperatures, and observations.</p>	<p>n/a</p>	<ul style="list-style-type: none"> - Daily information recorded: food, monitoring moods, fluid charts several times a day; bowel charts to check no one is constipated; early warning sepsis chart. - Care homes report the number of deaths and number of falls to CQC, however care homes are not told what implications there are for that data. - With e-records, mental health professionals receive better logs of their emotional support and see the trends better. - Due to using e-records on tablets and smartphones, confidentiality of resident data has improved compared to paper records sitting in the resident's room. 	<ul style="list-style-type: none"> - A lot of older carers are not IT savvy and fearful of using the digital systems. - The 'dependency tool' in care homes is filled in by the management because e-record data cannot be transferred onto the tool. This creates duplication. - Care staff learned new skills using the electronic system, e.g. carrying out wound care and insulin administration, through remote communication with the community nursing teams. - Duplication is an issue with care plans. - Care home staff spend lots of time to provide families and relatives calling daily to ask for detailed information on residents. - The hospital admission form takes up time.
<p>Senior operational and care home managers (England)</p> <p>9 participants</p>	<ul style="list-style-type: none"> - During COVID-19, daily phone calls have been received each day to ask for testing data. - With capacity tracker, care homes do not know why those data are needed, and they don't receive any feedback. - Public Health information reporting back to care homes was not always accurate, in terms of COVID. 	<ul style="list-style-type: none"> - The longer-term plan is: MyCare will integrate with care home systems to minimise the need to send PDFs to multiple organisations. - The universal eMAR system (medication recording system) has revolutionised things and minimised medication errors. 	<ul style="list-style-type: none"> - Care homes share data with the CCGs on how many additional hours they had to put in when a resident care needs change, and related business impacts. - Care homes use data for clinical governance and audit. Comparisons of daily notes and care plans are used in root cause analysis (RCA). - Seeking permissions for large care organisations' systems 	<ul style="list-style-type: none"> - With e-records, the carers can record and consult notes both remotely and on site. - During the pandemic, there has been a lot of duplication, e.g. repeating data about ethnicity and sexuality each week. - Key clinical data is collected in the CH system each month, however CCG requests the same information on their own system

			<p>to talk to other systems is a barrier.</p> <ul style="list-style-type: none"> - GP information (GP Connect) would be very useful to access from care homes. - Information Governance is a challenge. E.g. getting NHS email access for all staff is an issue. 	<p>because of the format incompatibility.</p> <ul style="list-style-type: none"> - Lots of duplication around testing. Care homes sent information to local health board, but they still received phone calls each day about testing data.
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