

## Data and Social Care

A pandemic data strategy for social care does not exist.<sup>1</sup> Even eight months into COVID-19, work by the Social Care Working Group of SAGE (SCWG) has not informed anything usable. Quite aside from the acknowledged legacy of neglect in investment, the sector is highly disparate in terms of providers and modes of provision. Addressing these factors on a practical, informational level would enable or provide pathways for other issues to be resolved at the same time.

While many bodies have statutory responsibilities in this area, the Secretary of State's power to create **information standards** for social care (HSCA 2012, Part 9, Chapter 1) is delegated to the **statutory safe haven** for data *from* social care, i.e. the Health and Social Care Information Centre\* (HSCIC, currently trading as NHS Digital) as created by Part 9, Chapter 2.

*“Apply the following test. Recall the face of the poorest and the weakest, the most digitally-disengaged social care recipient whom you may have (never) seen, and ask yourself if the step you contemplate is going to be of any use to them. Will they gain anything by it? Will it restore them to a control over their own life and destiny? Will they have the information to make an informed decision?”*

– [with apologies to Gandhi and Martha Lane-Fox](#)

The pending ‘reset’ of local authorities – and of social care itself – provides an opportunity to reset the technical infrastructure of the social care system at the same time, and to improve care quality and effectiveness. That large parts of social care have very little meaningful technical infrastructure makes this a relatively low risk / high reward activity, but it will require clear political leadership.

### **Build something that works soon, and then iterate**

NHS Digital (aka HSCIC) has succeeded in delivering NHSmail to a massively expanded number of care homes since the pandemic began.<sup>2</sup> The mechanism this creates can be used as a building block, using something as simple as an Office365 form<sup>3</sup> for now. Our remit in this paper is limited to the organisations for whom NHSmail is available – there are others for whom similar approaches could be taken, but without quite such immediate accessibility.

Rather than focusing on outputs – a shiny ‘dashboard’ for social care, an ‘all-seeing’ dataset (socialcare.data?) – real world change, such as QOF for social care, requires a rigorous focus on both care quality and on data quality. Learning from the datafication of GP practice, and using data from those delivering it in quality high enough to be able to develop practical measures, the goal must be to safely collect data and put it to *operational* use for all, while providing three levels of support: **incentives** that enable homes to invest in their own data infrastructure (a QOF for social care<sup>4</sup>); **help** to get this right; and the data **tools to deliver better care** developed through this coordinated process.

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<sup>1</sup> While DCMS' National Data Strategy announced that “NHSX is developing a Data Strategy for Health and Social Care in Autumn 2020”, this is not the same as - or even close to - a data strategy for social care under COVID. Health and social care are very different in terms of data needs, as well as data maturity.

<sup>2</sup> <https://digital.nhs.uk/news-and-events/news/number-of-care-providers-using-nhsmail-increases-tenfold>

<sup>3</sup> <https://www.microsoft.com/en-gb/microsoft-365/online-surveys-polls-quizzes?rtc=1>

<sup>4</sup> Everyone must be assisted to get to a baseline (90%?) quality level *before* statistics are first published, or they will simply be seen as divisive. Similarly, financial incentives must be solely additive, never subtractive.

## Standards follow action

For several decades, the NHS has been trying to make the transition to the data it wants, from the data it can get; this transition is still a long way from completion. In large segments of the social care sector, e.g. where chronic underfunding results in “five minute care” visits, the capacity to record large amounts of data is far lower.

Using SNOMED CT<sup>5</sup> as a standard would not be a low-impact approach, although it is possibly the best there is for clinical coding and its associated resources. The same is not necessarily the case for social care coding, in which there are often broadly repetitive tasks, with minor differences on a day-to-day basis.

High-level questions around data standards are interesting, but without meaningful, usable data infrastructure (that is used), they are largely irrelevant. The adoption of SNOMED has taken so long because it requires many transitions of a type in which social care has no legacy. In places where there is no EHR, it will take even longer.

With some 311,000 terms in SNOMED, it is likely some of those terms can be reused for social care – in some cases several together, used for the same act of care. Which terms to use will in practice emerge from the infrastructure(s) used to perform them. Given the need for investment to digitise the infrastructure available to large parts of the social care workforce, both the tools *and the data standards* should be appropriate to them. This is not a new lesson...

Any approach to ‘digitising social care’ must learn lessons from two types of experience:

- 1) The process for installing an EHR, for institutions which don’t already have one;
- 2) The process for rationalising onto a single EHR, for institutions which have many of them.

Neither of these processes have had significant data standards problems – instead, successful projects focussed on **staff buy-in**; sufficient and appropriate **resources** of all kinds; and strong **institutional commitment** to practical success.

(We will update our NHS data net assessment for the post-COVID era, but a similar net assessment should be done across HMG, and for social care.)

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<sup>5</sup> <https://www.snomed.org/our-customers/member/united-kingdom>

## Starter questions

No approach will achieve blanket coverage from the start, but even a minimal web-form questionnaire can begin to usefully structure and help provide consistent data from those establishments on NHSmail.

### Monthly Questions:

1. What is the postcode of your establishment? [human-checkable unlike assigned IDs]
2. What is the NHSmail e-mail address of your care home?
3. Compared to this time last week, do you have more or fewer residents?
4. How many residents died in October? [the previous calendar month]

### One-off questions:

5. How many rooms / beds do you have?
6. How many rooms have an en-suite bathroom?
7. When was your main building built?
8. Do you have access to the GP record systems for your residents?

(Other questions could be asked in future, as interest or utility expands, and contentious questions could be addressed using [existing powers](#) when the approach has been validated.)

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### \*Why the Health and Social Care Information Centre?

- Whatever name it currently goes under – and we have forced it to change before<sup>6</sup> – HSCIC is the Statutory Safe Haven for health and social care data. Choosing to vest the data anywhere *but* HSCIC would require strong justification.
- HSCIC understands duty of care and other obligations around data in a way other parts of the system simply do not; it also has (improving) transparency, a safe setting and existing IG processes, which would have to be applied to whatever data it holds.
- CQC is a regulator. It has neither the competence nor the resources to hold all the data, and it must in any case maintain complete independence from operational delivery, if it is to provide an assurance function.

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<sup>6</sup> Without blowing our own trumpet too much, medConfidential knows and has paid close attention to HSCIC for years – and (bits of) HSCIC know us well, know that we know what we're talking about, and talk to us. We may not be a statutory 'watchdog' like CQC, ICO or NDG but we can put the fear of God into the right people when and where necessary *without breaking things completely*.