

Care Home Data: **G**overnance, **E**thics, **A**ccess and **R**eadiness
through an **E**xemplar **D**emonstration

The GEARED UP project

Executive Summary

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Edinburgh Napier
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health
innovation
South East Scotland

 THE
DATALAB
value from data

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MANAGEMENT TEAM

DataLoch

Introduction and Rationale

This is the Executive Summary of a report setting out learning and recommendations from work undertaken to source individual care home resident level data gathered as part of routine care for repurposing/re-use within a Small Business Research Initiative (SBRI). **GEARed Up: Care Home Data Governance, Ethics, Access and Readiness Demonstration** was established to identify potential routes and required processes for public sector and commercial company use of care home data, and to explore data sources. It was funded by the CSO innovation catalyst fund and aligned to the SBRI Care Home Data Innovation Foundation Challenge. The fuller report can be accessed here [Full Report](#)

Large amounts of individual-level data are collected in care homes. As set out in the Scottish Government's Health and Care Data Strategy, there is great potential to use these data assets to improve services, support research and increase data driven innovation that benefits care home residents and providers. The findings inform preparations for improved data capture necessary for Scotland's National Care Service and the recommendations enhance the prospect of the use of routinely collected care home data used to support care decisions, improve services, inform research and increase data driven innovation.

The issues identified by the GEARed Up project are important for three main reasons. Firstly, it identifies the **Governance** and **Ethical** issues that arise in the vacuum created because, in Scotland, there is currently no consensus or defined route for the legal, ethical and efficient access to permit reuse/re-purposing of care home data for research, service evaluation and Innovation Challenge/Test Bed work. Secondly, it highlights problems that arise when using the current routes to data acquisition, by demonstrating the practical challenges of navigating the **Access** routes and the issue of data **Readiness**. Thirdly, it is important because **care home residents are important**. We must not lose sight of the fact that the data collected about them should first and foremost add value to their lives and the services they use.

What can be done now to 'GEAR up' care home data?

Scottish Government's Data Strategy for Health and Social Care¹ aspires to empower innovators, industry and researchers who can deliver new technology and data driven insights to improve and inform policy and practice. Calls for improvement to information and governance systems more broadly have been made. However, there

¹ Scottish Government. Data Strategy for Health and Social Care: Consultation Paper. Available at: <https://www.gov.scot/binaries/content/documents/govscot/publications/consultation-paper/2022/05/data-strategy-health-social-care/documents/data-strategy-health-social-care-consultation-paper/data-strategy-health-social-care-consultation-paper/govscot%3Adocument/data-strategy-health-social-care-consultation-paper.pdf>

is a need now for significant work to make this a reality in social care, and particularly for care home data.

We propose below the priority practical steps needed to strengthen the data foundations and ensure that the currently available care home data can be used, while working to maximise the future potential of this valuable asset.

1. Overall, we recommend the **creation of a realistic and resourced plan of action** to address the limitations and barriers of the current information and governance systems specifically for care home research and data driven innovation projects. DHI suggest that this may involve agile, short-life groups including representatives from national and local stakeholders to provide expertise and help navigate this complex area. This could be based on recommendations of the Goldacre Review², which focussed on the use of health data for research and analysis, but the detailed and practical recommendations should be reviewed and extended to social care, and particularly care home data.
2. **Key Scottish stakeholders** required to implement improvement represent a diverse mix, including national policymakers, regulators, charitable organisations, academic researchers, clinicians, and commercial innovators, each with different aims and plans for using care home data. It is essential that all key stakeholders and delivery partners are involved in decisions. Care homes are however the most significant and most central cog. We must therefore ensure the mechanisms for including them in decisions and hearing their views and experiences are prioritised and built in. This input cannot rely as it does currently on the goodwill, enthusiasm and interest of individual managers and staff. **Care home involvement must be resourced and supported** – and we envisage a key role for **ENRICH Scotland** in this.
3. Identifying who has **high-level oversight and responsibility for ensuring clear communication and coherence between local and national data initiatives**. This should take into account plans for the National Care Service, and the Data Strategy, as well as wider whole system coordination from the foundations up. This will be essential to ensure the identified wheel of stakeholders all turn in the same direction and at the same time. ENRICH Scotland should be considered a natural partner. It is a multi-disciplinary team of professionals from nursing, medicine, psychology, and social care backgrounds with a breadth of knowledge and experience in relation to care home research.
4. **Scotland would benefit from the NIHR funded DACHA study**³ At present, this study to develop research resources and minimum data set for care homes does not encompass the Scottish Care Home sector, although one of the co-investigators is based in Scotland and can provide a Scottish perspective. Without direct Scottish involvement, the study will be unable to address in full the specific Scottish laws, regulation and governance and research frameworks. Its potential to shed light on the questions raised by GEARed Up is

² Goldacre, B (2022). Better, Broader, Safer: Using Health Data for Research and Analysis. UK Government Department of Health & Social Care. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1067053/goldacre-review-using-health-data-for-research-and-analysis.pdf

³ DACHA study website. Available at: <http://dachastudy.com/>

- high if closer links, Scottish based fieldwork and analysis were to be resourced by Scottish Government and dovetailed to the work of this expert study team.
5. **The role major agencies such as Public Health Scotland, Care Inspectorate and Research Data Scotland play in relation to developing care home data – and other data from social care – must be enhanced.** There needs to be clarity in what data should be collected for what purpose, and the process should be made as simple as possible for care home staff who should only be required to enter data once to allow it to be used for multiple purposes (with appropriate consent), both at the aggregate care home level, and the individual resident level.
 6. There is a need for **a clear pathway for accessing, and seeking ethical and governance approval, for care home – and other social care – data.** To a large extent, this can only be produced after a line-by-line review of the mandates, processes and guidance provided by governance bodies is undertaken to ensure that social care in general, and care home studies in particular, are correctly routed through the infrastructure and supported by accurate detailed advice and signposting. From our experience we suggest this could be started by ensuring that the addition of the words “and social care” within all systems are supported by sound definitions and supplemented by sufficient detailed support to those seeking to use care home data for research and innovation.
 7. The **proof-of-concept data ingestion work** of individual resident data from care homes, initiated by the GEARed Up team, should be continued with an exemplar to establish that it is feasible. It would benefit from being at a larger scale to inform a model for national use. This should be done in collaboration with the Scottish Government's Care Home Data Review Team as it will provide an opportunity for the utility, quality, and functionality of such care home data to be developed, then tested, evaluated and interrogated by researchers and innovators for the first time.

There is rightly a lot of interest in trying to foster the best conditions and processes for high quality data driven innovation and research. Progressing the recommendations set out will enhance the systems needed to ensure high quality data driven research and innovation at scale for the benefit of care home residents, their families and the staff who care for them. It is essential they are not excluded because of solvable problems with current processes and policies.

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