Care Home Data Review

Stakeholder Engagement Workshop

Tuesday 14th March 09:30 – 13:00











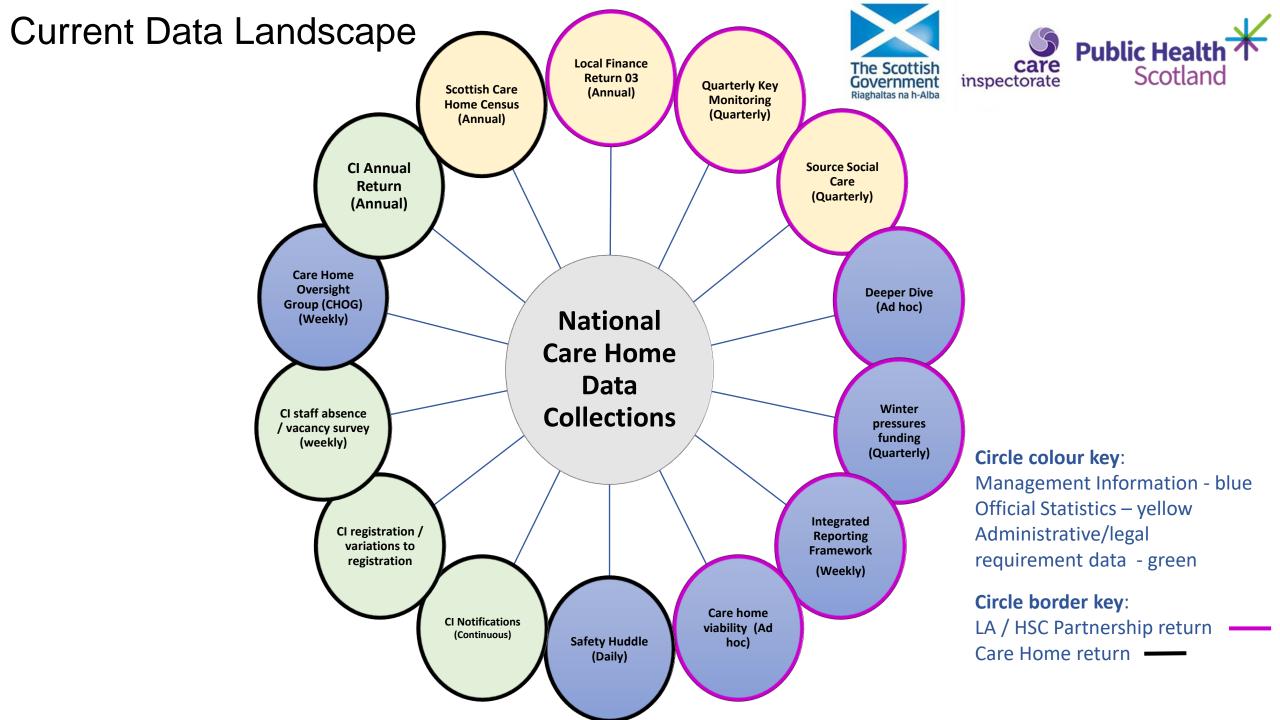


Care home data review

Multi-agency review to look across entire care home data landscape to ensure a coherent suite of data collections, reduce the burden on data providers and meet the existing and emerging needs of data users.

Key elements of the review are to:

- Map the current care home data landscape and consider improvements around the content, quality and frequency of current data collections, and/or alternative methods of data collection, to ensure stakeholder needs are met as comprehensively and efficiently as possible.
- Reduce the ask of data providers and ensure we both balance the need for evidence with respondent burden and maximise benefit for providers.
- · Identify and prioritise actions to address any key gaps in care home data.
- Establish a network of data providers/users and processes for ongoing stakeholder engagement to understand emerging needs/issues.



Setting the Scene



Mapping National Adult Social Care and Care Home Data Sources in Scotland

Baseline understanding & future potential

Scottish Gov Rigghaltas n

September 2022





A HUMAN RIGHTS-BASED PERSPECTIVE ON CREATING VALUE IN SOCIAL CARE DATA



Systemic Review Programme

Adult social care statistics in Scotland

February 2020











Age and Ageing 2018; 47: 322–323 doi: 10.1093/ageing/afx200 Published electronically 16 January 2018

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EDITORIAL

Identifying who lives in a care home—a challenge to be conquered

Care home residents in the UK outnumber hospital inpatients threefold [1] and yet our knowledge about their needs, care and outcomes is staggeringly poor, not least because there is no central register of care home residents. Identifying who lives in a care home is therefore difficult. Large care data collection systems which have been adopted by care home providers in North American and Europe for service evaluation and research, such as the Inter-RAI (resident assessment instrument) [2] and Minimum Dataset (MDS) [3] are not routinely used in the UK [4]. These data can be extracted and linked to hospital data to evaluate outcomes.

recording of addresses than will happen in other organisations. As the matching relies on similarities, this may influence the findings and so further external validation across a larger range of organisations is required.

Care home research in the UK has tended to rely on well-conducted studies, recruiting individuals in selected care homes, gathering bespoke data [8–10]. While this approach has commendable rigour, included populations may not be representative of the wider care home population and this approach cannot support real-time use for improvement. While focused, smaller-scale research involv-



Closing the UK care home data gap - methodological challenges and solutions $% \left(1\right) =\left(1\right) \left(1\right$

Burton, J.K. (a), Goodman, C., Guthrie, B., Gordon, A.L., Hanratty, B. and Quinn, T.J. (b) (2020) Closing the UK care home data gap-methodological challenges and solutions. International Journal of Population Data Sciences, 5(4), 3. (doi: 10.2988/jipds.v5i4.1391)



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Abstract

UK care home residents are invisible in national datasets. The COVID-19 pandemic has exposed data fallings that have hindered service development and research for years. Fundamental gaps, in terms of population and service demographics coupled with difficulties identifying the population in routine data are a significant limitation. These challenges are a key factor underpinning the failure to provide timely and responsive policy decisions to support care homes. In this commentary we propose changes that could address this data gap, priorities include: (1) Reliable identification of care home residents and their tenure; (2) Common identifiers to facilitate linkage between data sources from different sectors; (3) Individual-level, anonymised data inclusive of mortality irrespective of where death occurs; (4) Investment in capacity for large-scale, anonymised linked data analysis within social care working in partnership with academics; (5) Recognition of the need for collaborative working to use novel linked data analysis within social care working in partnership with academics; (5) Recognition of the need for collaborative working to use novel data sources, working to understand their meaning and ensure correct interpretation; (6) Better integration of information governance, enabling safe access for legitimate analyses from all relevant sectors; (7) A core national dataset for care homes developed in collaboration with key stakeholders to support integrated care delivery, service planning, commissioning, policy and research. Our suggestions are immediately actionable with political will and investment. We should seize this poperturity to capitalise on the spotlight the pandemic has therown on the vulnerable populations living in care homes to invest in data-informed approaches to support care, evidence-based policy making and research.



Some key themes of review

The Scottish Government Riaghaltas na h-Alba





Accessiblity

Make analysis and data more accessible - currently too difficult to access and not joined up.

Data Governance & Sharing (incl. ethics)

Key to maximising value & potential of data collected and allowing data to be collected once and used many times.

Data Standards

Ensuring terms mean the same in different areas/collections

Rationalisation & Explanation

Cutting number of data collections and having clear purpose for collection, explaining the benefits from data.

Data collection processes

Put in place a process to ensure data requirements are considered at a strategic level and met in an appropriate way

Data Gaps

What are the key areas where data does not exist or is of insufficient quality/granularity to meet needs.

Communications

Data provider - Opportunities to feedback, provider networks, clarity on timings & reasons for asks
Data user - need to make it easier for users to understand sources of data and how they fit together.

Timeliness of data

How do we ensure accurate, quality assured data in appropriate timescales (appropriateness based on need).







Feedback from Care Home Data Review questionnaire.....

"For what it is worth... this is the third group or initiative that is now asking us what we do so it can be consolidated. This kind of things is now becoming as tedious as the data requests themselves. We are not going to see anything come out of this...."

Anon

Aims of the day







- Deeper dive into the experience & challenges of providing and using care home data in the current landscape.
- Identify ways to improve access to, and insight from, data currently available – also understanding what data is no longer needed.
- Identify data not currently available that needs to collected to improve understanding of key questions.
- Prioritise issues and produce actionable potential solutions / next steps to take forward data improvement – in short, medium & longer term.
- Start to create network of data providers & users to inform the review and take forward next steps in more specific work streams.

Next Steps







- Take away and write up all input provided today:
 - circulate a summary of the day, highlighting potential solutions to some of the priority issues identified
 - publish a summary on the Care Home Data Review section of SG website – the place to keep up with progress on the review and ask questions.
- Make links between points raised today regarding potential workstreams of CHDR with wider work going on relating to social care data improvement.
- Set up more focussed workgroups/SLWG's to take forward potential solutions proposed today.
- Set up wider network of providers and users to take forward these issues.

Longer term - incorporate feedback into write up of full report with recommendations.

Thank you very much for your time today







There are 3 key ways you can continue to contribute to the review:

1) Fill in our **online questionnaire** if you haven't already

How to participate

Please complete the questionnaire at:



https://bit.ly/ScotCare2022

Or email <u>SWStat@gov.scot</u> to provide feedback or ask to be kept updated about the review.



3) Email us

For further information, or to provide further comments/feedback, please contact:

- Social Care Analytical Unit (SCAU): David Cruickshank, <u>David.Cruickshank@gov.scot</u>
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