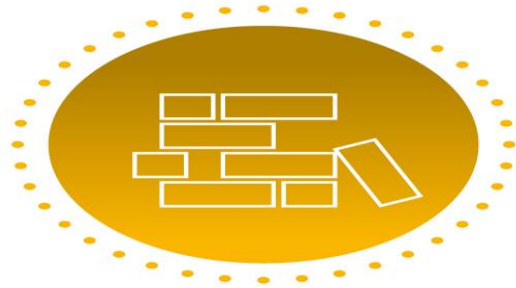# Care Home Review Workshop 14ᵗʰ March 2023 Insights from 4 Care Home Data Projects

Developing a Data Platform

Care Home Data Platform SBRI Innovation Foundation Challenge: Technical Feasibility that posed the question - 'What if a holistic digital picture of a resident's health, wellbeing and care needs could be created using care home data, to predict deterioration and be used for risk stratification and decision support?'

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

The GEARED UP project

LADDeR

Landscape Assessment of Data and Digital Readiness of Scottish Care Homes
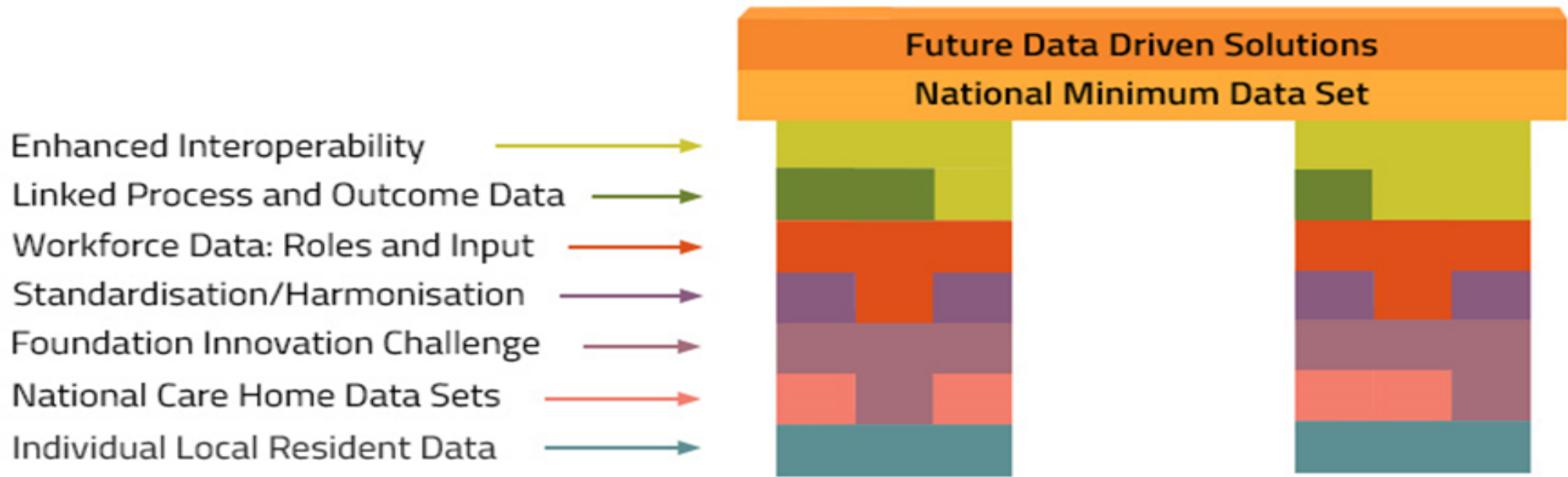
Partners and Funders and Project Leads

Lucy Johnston,
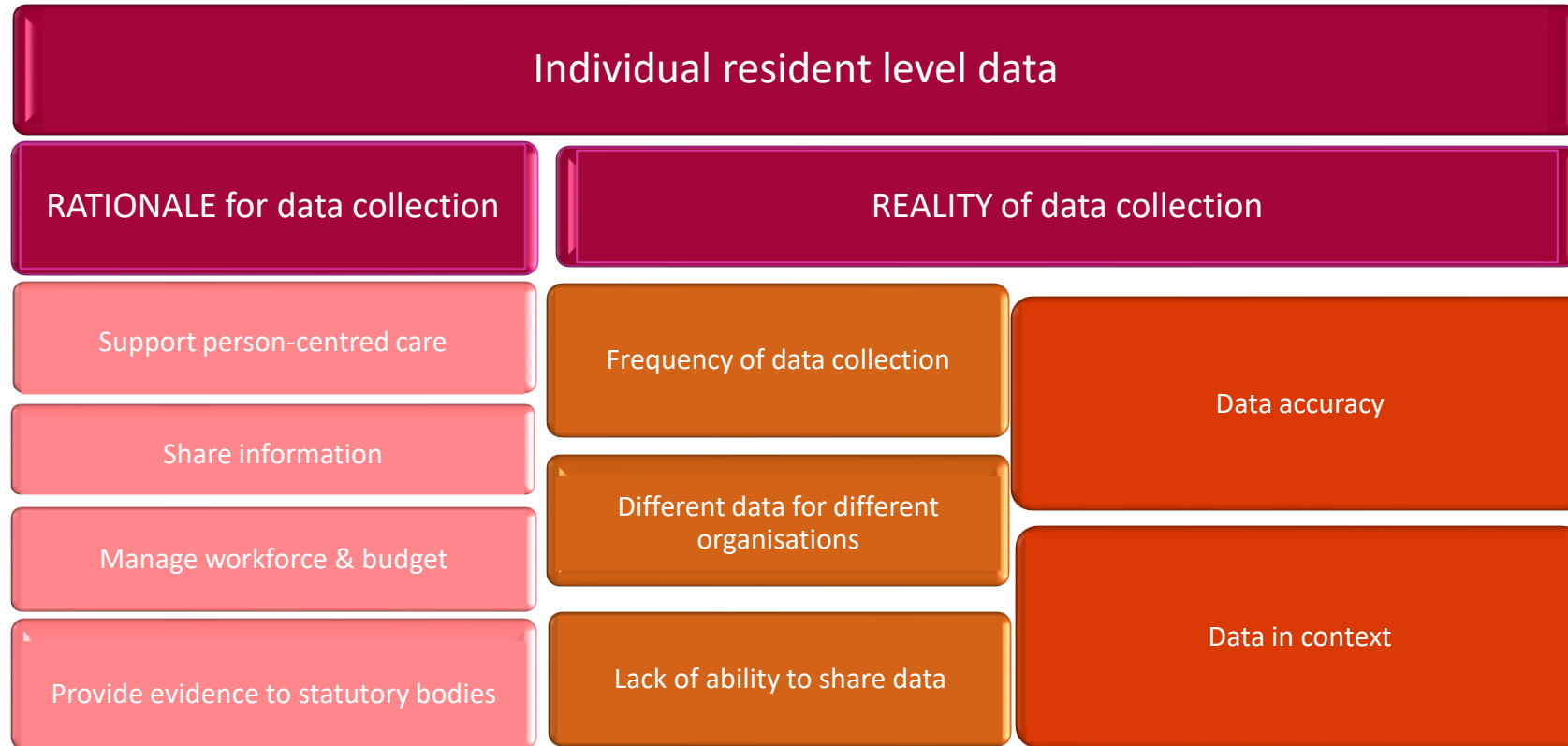Senior Research Fellow, Edinburgh Napier University
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Projects focussed on the foundations of care home data collection and use

Considerations for individual resident level data as the foundation for Care Home Data

Potential problem if the <u>Rationale and Reality</u> of care home data is not understood

National Data: Unstable Platform?

Table 1: Comparison of SCS and SCHC demographic categories

Data Variable	Social Care Survey	Scottish Care Home Census
Date of Birth	Date of Birth	Date of Birth
Age	Age	Not collected
Gender/Sex	Male or Female	Male, Female, or other
Ethnicity	White Mixed or multiple ethnic groups Asian, Asian Scottish, or Asian British African, Caribbean, or Black Other Ethnic Background not disclosed	White Other Ethnic group Not disclosed Not known
Client Characteristics	Dementia Mental Health Problems Learning Disability Physical Disability Addiction Palliative Care Carer's Problems arising due to infirmity of age Other	Requires Nursing care Dementia - medically diagnosed Dementia - not medically diagnosed Visual Impairment Hearing Impairment Acquired brain injury Learning disability Other physical disability or chronic illness Mental Health Problems Alcohol Dependency Drug Dependency None of these

Colours denote agreement across sources: Green = exact match, Amber = Similar match, Red = No match
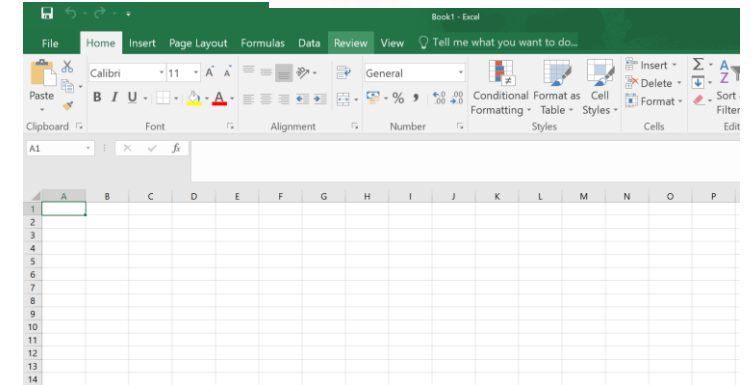
Local Data – not Standardised?

Table 6b: Assessment tools/measures used for "regularly used data"

	Area assessed	1	2	3	4	5	6
7	Wounds (new and ongoing)	Internal Chart	STAR Classification	Wounds assessment	Chart on PCS	NHS Wound Assessment Chart	Organisation Form
8	Frailty	CIRC	SPAR Tool	Edmonton Frailty Scale	Clinical Frailty Scale	Not collected	Not collected
9	Bowel Movement(s)	Bristol Stool Chart	Bristol Stool Chart	Chart on PCS	Bristol Stool Chart	Bristol Stool Chart	Organisation Form
10	Fluid intake	Internal chart	Organisation Form	Chart on PCS	Chart on PCS	Organisation Form	Organisation Form

Range of data collection methods

Care Home	No. of Beds	Sector	Data Collection Method
1	72	Independent	Caresys
2	72	Charity	iCare Health and e-med
3	63	Independent	Personcentred Software (PCS)
4	70	Charity	Personcentred Software (PCS)
5	61	Local Authority	Internal computer system and Kardex
6	80	Independent	Paper based and internal database (Excel)

And huge heterogeneity of data collected

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	Area assessed
1	Dependency/ indicator of need
2	Nutrition
3	Weight
4	Incidence and risk of falls
5	Incidence and risk of pressure sores
6	Infections
7	Wounds (new and ongoing)
8	Frailty
9	Bowel Movement(s)
10	Fluid intake
11(a)	Mood: Depression
11(b)	Mood: Delirium
12	Pain
13	Movement
14	Sleep
15	Observations/ Vital Signs

- 15 core data elements for data used routinely

- But… recorded in different ways in different care homes

Johnston L, Koikkalainen H, Anderson L, Lapok P, Lawson A, Shenkin SD (2022). Foundation Level Barriers to the Widespread Adoption of Digital Solutions by Care Homes: Insights from Three Scottish Studies. Int J Environ Res Public Health. 2022;19(12):7407. Available at: https://doi.org/10.3390/ijerph19127407

Shenkin SD, Johnston L, Hockley J, Henderson DAG (2022). Developing a care home data platform in Scotland: a mixed methods study of data routinely collected in care homes. Age Ageing. 51(12):afac265. Available at: https://doi.org/10.1093/ageing/afac265

And mostly on paper

LADDeR
Landscape Assessment of Data and Digital Readiness
of Scottish Care Homes

As well as Wi-Fi, **45%** of care homes use devices that connect to the internet via a cable and **10%** use a mobile internet connection

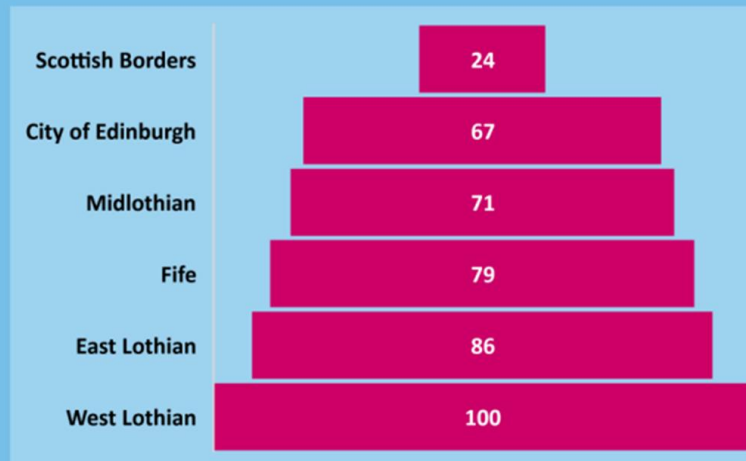**27%** One in 4 reported that internet connection is only available in some parts of the home

42% Only **2 in 5 care homes** described their internet connection as **'good'** – that is with fast loading times and no service interruptions

Nearly two thirds (58%) of the care homes reported that **remote electronic access** to resident information is not possible for **any** key health and community-based professionals

% paper-based care homes by area

Area	%
Scottish Borders	24
City of Edinburgh	67
Midlothian	71
Fife	79
East Lothian	86
West Lothian	100

The majority (88%) of the care homes using digital care planning were **privately owned**

However, **less than a third** of private care homes had currently such systems in place

No Local Authority care home was using an electronic care planning system

35% **One in three** care homes currently use an **electronic care management system**

43% **Two in five** use an **electronic medication management system**

65% Paper-based systems predominate across all care homes in all sectors

Which led us to ask……..

…………………………………………How can care home data be GEARed UP?

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

The GEARED UP project

The final report will be issued this month and we will liaise with CH Review Team to circulate it to you or contact l.johnston@napier.ac.uk

GEARed UP Summary of Recommendations

1. Create a **realistic and resourced action** plan to address the limitations and barriers of the current information and governance systems for care home research and data driven innovation projects

2. Engage with a wide range of stakeholders – with care home residents/families and workers the core – and ensure all are aware of the work across the sector

3. Ensure **high-level oversight and responsibility** for clear communication and coherence between local and national data initiatives

4. Fund a Scottish extension of the ongoing DACHA study to ensure that findings are relevant and implementable in Scotland

5. Provide adequate **financial and staffing resource to support collection and reporting** of summary care home statistics and individual resident-level data (care homes, PHS, RDS, Care Inspectorate)

6. Develop a robust national framework to support the review process for social care research and innovation, ensuring appropriate data provider, processor and subject involvement to establish a clear pathway for accessing, and seeking ethical and governance approval for using care home and other social care data

7. Clarify with care home residents (or their legal representatives) and service providers when consent processes are required for the re-use of data (identifiable/anonymised) for research and innovation purposes

8. Resource the completion of the **exemplar of data ingestion** from care homes to a trusted research environment for research/innovation use