slides: keepfaking.it/easst2022

Ethics and data use in UK social care

Presented at EASST 2022, Madrid, 6th July 2022

Cian O'Donovan | @cian | c.o'donovan@ucl.ac.uk

UCL, Department of Science and Technology Studies

with Melanie Smallman, James Wilson, Jack Hume | UCL

UCL

Work from the UK Pandemic Ethics Accelerator
UKRI grant: AH/V013947/1

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summary

1. A **data ethics heuristic** for evaluating radical, organisational, infrastructural data use in care

2. Valuable not as a normative framework –> something to be **applied across diverse contexts** and **complex systems**

3. Assessing digital transformation policies…
   …accelerating data infrastructures; NHS led integration and data linkage; workforce capability building

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PEOPLE MISSING IN CARE HOME DATA

A case study of data use in UK
social care

PART 1

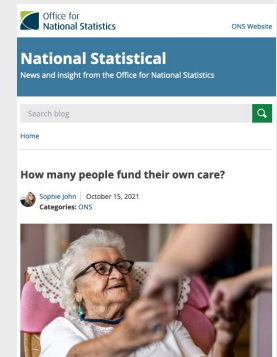# Coronavirus: Deaths among residents at Shetland care centre
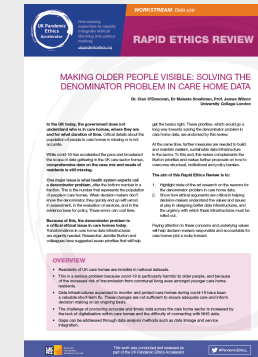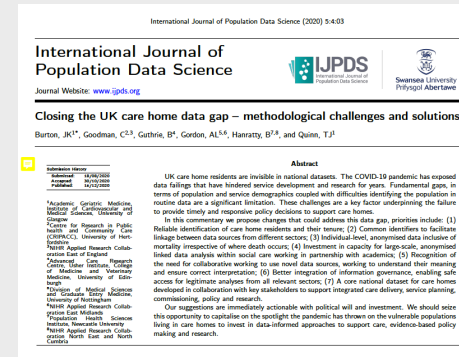
14 April 2020

"The Care Inspectorate said there had been deaths at Wastview Care Centre, but has not given an exact number."
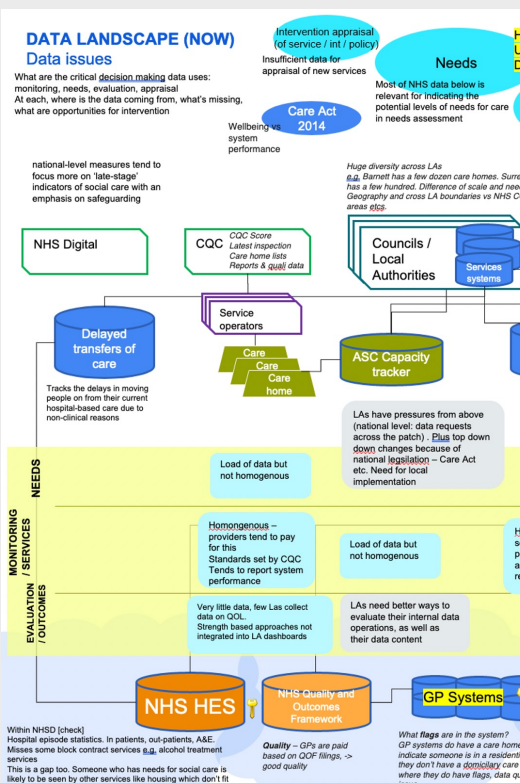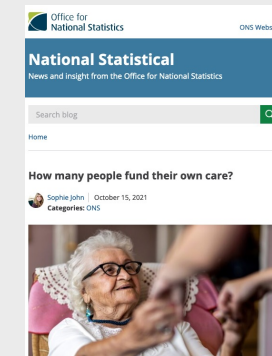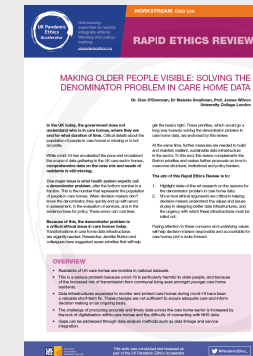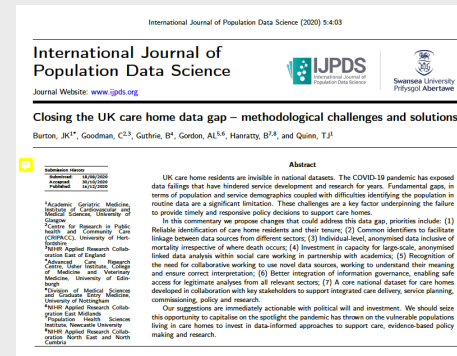
Wastview Care Centre, Shetland

Government did not know who was in care homes

Also missing from care data:

- Case mix and needs of residents

- People who pay for their own care

- People who don't receive care but should

- **Impact** - errors in: **assessment**; service evaluation; **evidence base for policy**

- People **died** because of these errors

Zooming out:
What data in complex care settings does

- Produces publics, communities, categories

- **Foregrounds**…
  - Needs (often via aggregate pop. health data)
  - Monitoring users, staff, resources, quality of services
  - System performance

- **Backgrounds**…
  - Measures of care like wellbeing
  - Appraising new services

- **Structures governance**
  - …permitting top-down, centralized action by govt., state, firms

O'Donovan, C. (2022). Accountability and neglect in UK social care innovation. *International Journal of Care and Caring*. https://doi.org/10.31235/osf.io/yr75f

this paper's
motivation

How do we build capacity
(ethics frameworks *and*
practices) so that people at all
levels can interrogate,
participate in and benefit from
data use?

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SO WHAT IS SOCIAL CARE EXACTLY?

Four perspectives on social care:;
organisational; infrastructural; radical;
grounded

PART 2

Social ordering

Social care is how society **orders** practices of care and distributes responsibilities and obligations for these practices between *markets*, *the welfare state*, *voluntary sectors* and *families*

Mary Daly and Jane Lewis (2000) 'The Concept of Social Care and the Analysis of Contemporary Welfare States', *The British Journal of Sociology* 51, no. 2, 281–98, https://doi.org/10/cgvrr4

Infrastructures of care

The social, material and technological systems of knowledge, people, relations, rules, resources and **data** required to imagine, build, maintain and deliver care practices

Infrastructures situate and structure obligations and agency. E.g. accountability

Langstrup, H. (2013). Chronic care infrastructures and the home. *Sociology of Health and Illness*, *35*(7), 1008–1022. https://doi.org/10/f48gwt
O'Donovan, C. (2022). Accountability and neglect in UK social care innovation. SocArXiv. https://doi.org/10.31235/osf.io/yr75f

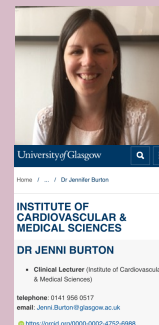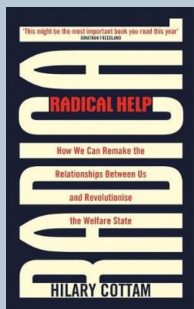# Radical, indispensable and invaluable work

Indispensable: It is work that makes all other work possible

Invaluable: society is incapable of valuing care properly

Recognizing the value and potential of care, socially as well as economically, depends on a different understanding of what care actually is: *not a service but a relationship that depends on human connection*

Grounded goals of system reformers

"So going forward, the priority should be: ensuring that health and social care **data are fit for purpose** in understanding care **requirements** and **outcomes** for care home residents more generally"

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A HEURISTIC FOR EVALUATING THE PRACTICES AND PROMISES OF DATA USE

Norms, values, complexity, scale
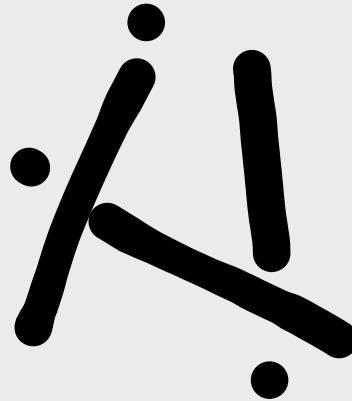
PART 3

heuristic for evaluating data use in care systems
(like a framework, just not as fully committed)

norms, values

What gets valued

complexity

How we understand change, cause and effect in complex systems

context and scale

Where where the action happens and what's at stake

Normative values and frameworks

- Value choices in policy (e.g. health vs social care)
- Existing (clinical) guidelines aimed at emerging AI, big data etc.
  - Focus: rights and individuals,
  - Assumptions: ethically sound data-use *is* possible
  - Neglected: social ordering effects
- Normative frameworks might help assess impacts on individuals
  - But erase context and complexity

Smallman, M. (forthcoming). *Multi Scale Ethics: Why we need to consider the ethics of AI in healthcare at different scales*.

Uncomfortable questions about who/what is valued:
(not just *better* measurement)

- Why are some people still missing from social care data?
  - … not important enough to be **datafied**?
  - … or not important enough to decision makers **because** they are missing from data?
- Is data use acknowledging uncertainty or shielding it?

place, context, scale

!!!

- Potential of **interactions at different scales** to generate new problems

- Social care action happens 'in the community'…
  - …but planning and resource allocation often happens at local or national government level

- **Across scales**: logics of population health vs care data use

TIME: What are the long-term consequences? Will future generations pay more than current generations? Will future generations face fewer choices as a result of this technology? Is there a risk of 'lock in'?

GLOBE: how does this technology affect the planet? How does it affect geopolitics Which nations does it benefit and which nations lose? Does it bring people together or increase divisions? Does it focus wealth in particular parts of the world? Will it make some nations more, or less, dependent on others?

NATION/SOCIETY: Does this technology reduce or increase inequality? Who benefits? How does it affect democracy? Does it respect national cultures and institutions? Does it allow profit to be moved/enable stateless profit?

SYSTEMS/INSTITUTIONS: Does the technology need particular infrastructure? Does it fit with how we want systems organized? (Local vs. central/levels of authoritarianism/ownership); Number &types of jobs; Access, Fairness, Privacy for whom? Who decides?

GROUPS/COMMUNITIES: Are people brought together or moved apart? Are some groups unfairly benefiting or being stigmatize or dis empowered Are group effects harming individuals' rights?

INDIVIDUAL: Who benefits/loses? Rights, privacy, fairness, access, individual responsibility.

FIGURE 1. Considering ethical issues and decisions at multiple scales, developed by Smallman [3]

Smallman, M. (forthcoming). *Multi Scale Ethics: Why we need to consider the ethics of AI in healthcare at different scales.*

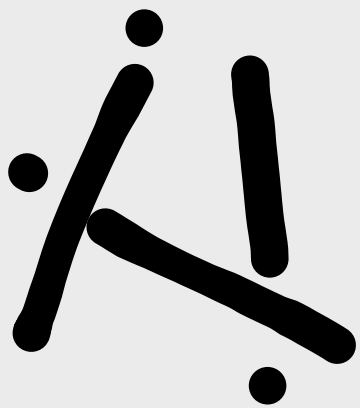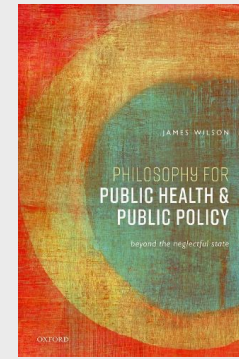# On the ground
- first, getting
the basics right

- 3 in 4 care homes are still paper based

- Data **capabilities** that matter to people working in care

- Data **infrastructures**: Minimum data sets

- **RISK**: in a rush to lock-in the data "gains" made during covid-19, the basics digital needs of the care sector are neglected – e.g. increased burdens on care workforces

Cian O'Donovan: Getting the basics right in digital social care transformations

November 9, 2021

Comment and opinion from The BMJ's international community of readers, authors, and editors

Study funded by the National Institute for Health Research (NIHR)

Complexity and performativity

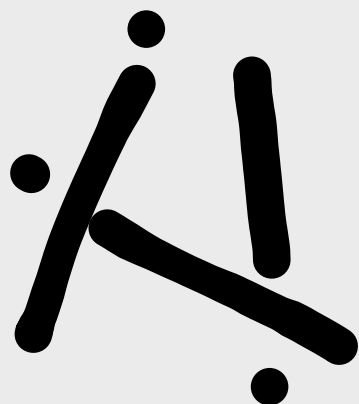(How we understand change in complex systems)

- **Command-and-control systems** often fail to anticipate their own systemic effects (**performativity**)
- **Change** understood as *interaction of mechanisms* (rather than assumed constant)
- "There are **no side effects** – only effects"
  - Side effects are not a feature of reality, but a sign that the boundaries of our mental models are too narrow, our time horizons too short.
- **Systemic harms** can occur without it needing to be the case that anyone intends to create harm or act unfairly
  - BUT: **neglectful states** can distract from systemic failings by framing systemic harms as failures of personal responsibility (Wilson 2021)
- Disincentive: more data makes **policy failure** more obvious

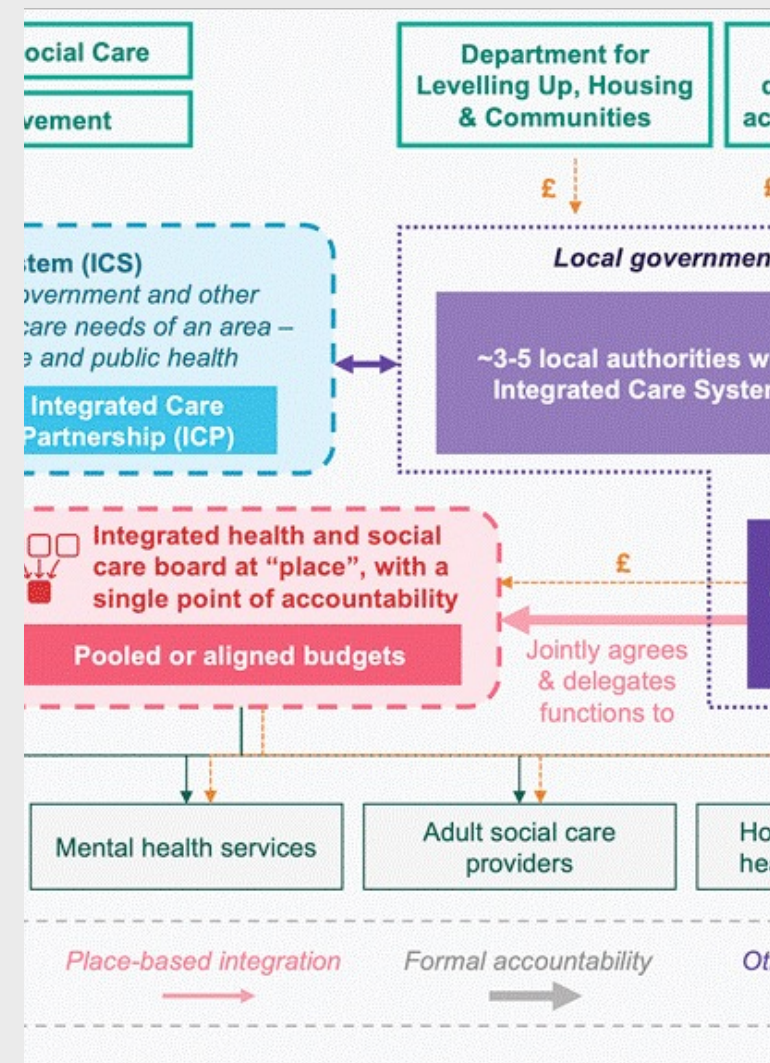Wilson, J. (2021, September 21). *The intervening state*. The RSA. https://www.thersa.org/comment/2021/09/the-intervening-state

Wilson, J. (2021). *Philosophy for public health and public policy: Beyond the neglectful state*. Oxford University Press.

Complexity –
challenging assumptions in digital transformation plans

Plans for *Integrated Care Systems* presume to…

- Improve access to resources

- Decrease burdens on front line staff

- Retain access to non-digital services

- Decrease risk / increase value for ICS players

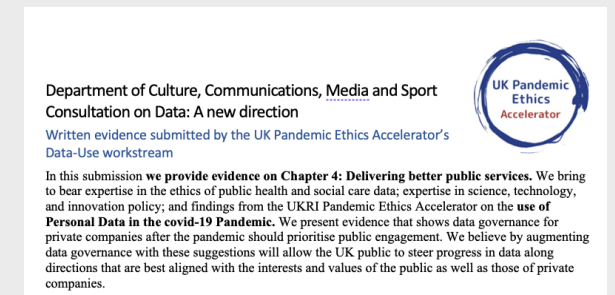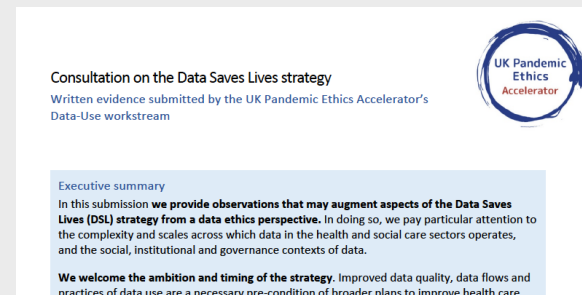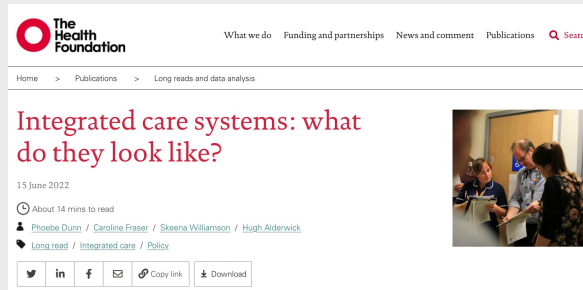Cutaway of integrated care system schematic

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Bringing things together

How we have used findings in the
UK Pandemic Ethics Accelerator

Some things recommended by us and others
(heterogeneity in social care systems)

- **Plans must spell out assumptions**
- Plans must distinguish between how **different groups in society** interact with health and social care data
- **Diverse groups / orgs will benefit differently**.
- **Priority**: building public trust in wider care system while broadening data use
- Acknowledge tension: "No one wants to reduce operational capacity to allow for transformational capacity"

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