SCOTTISH CENTRE FOR ADMINISTRATIVE DATA RESEARCH

Increased deaths at home in Scotland during COVID-19 pandemic

Jan Savinc, Dr Iain Atherton,
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UKRI Economic and Social Research Council
ADR SCOTLAND Data-driven change

Patients with terminal illnesses 'dying in pain' because of NHS Covid delays

Nine in 10 hospices seeing patients with untreatable illnesses, as Marie Curie warns that many are unable access palliative care in time

By Charles Hymas, HOME AFFAIRS EDITOR

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What is the context?

"With such an increase in the number of people dying at home during the pandemic, and despite the best efforts of health and social care teams, **we are concerned that many people may not have received some or all of the care and support they needed** in their final hours, days, weeks and months of life."

Richard Meade (Head of Policy, Marie Curie Scotland)

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What is the context?

- What makes a good death?
- Key ideas for this research:
  - Meeting needs / adequate care
  - Accompanied by family & friends
  - In the setting of one's choice
- Surveys show most people would prefer to die at home

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What is the aim?

- To understand the shift of deaths to home during the pandemic

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What are the benefits?

- Taking account of what happened in the pandemic
- Informing policy on care at the end of life
  - Home care focus
  - Adequate care provision in remote/rural areas

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What questions am I trying to answer?

- How were people dying at home during the pandemic different to those dying at home before?
  - Demography: urban-rural differences, living further from a hospital, living alone or with others
  - Health service use

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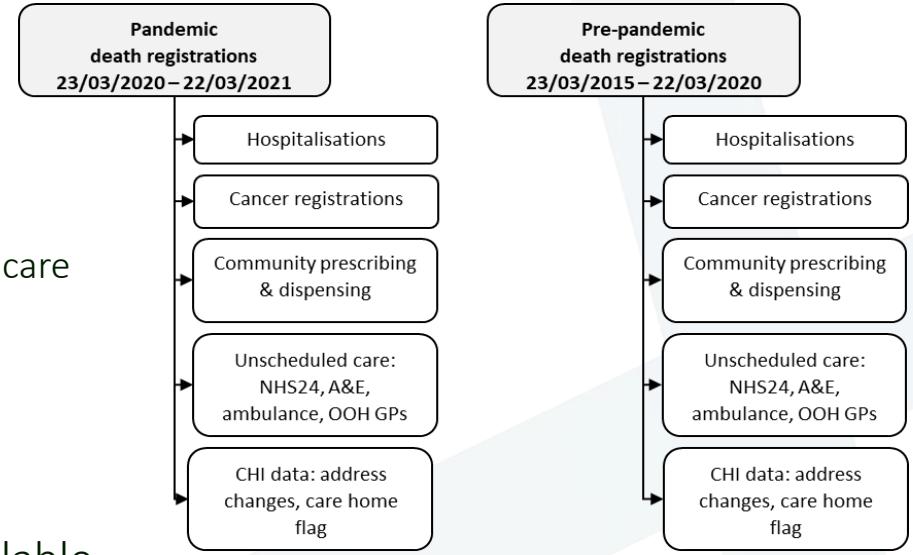
What data will I use?

- Death records
- Medical records in the last year of life
  - Hospital admissions
  - Cancer registrations
  - Prescriptions for medicines used in palliative care
  - NHS24 calls
  - Out-of-hours GP visits
  - A&E admissions
  - Ambulance call-outs
  - Registered addresses
- Unfortunately, social care data aren't available nationwide – future project!



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How will I access the data?

- Health data research is **slow** (on purpose) and **challenging** (not on purpose…)!
- Application to Public Benefit & Privacy Panel (PBPP)
  - Application started around March 2021…
  - Approved December 2021, data expected in 3-6 months
- Data extraction & linkage by eDRIS team within Public Health Scotland
  - Being done currently, hopefully ready soon!
- Once data are ready, accessible only:
  - Inside **T**rusted **R**esearch **E**nvironment (parental controls but for researchers)
  - Only named researchers who have completed training (needs renewed every 3 years)
  - Any outputs (tables, charts) need to be cleared before they can be taken out of safe haven

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What are

- Weekly dea
  Records of
- https://ww
  data/statist
  publication
  deaths/dea
  scotland

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What are the results so far?

- “Shift to death at home”
- 35% increase in home deaths since start of 2020, sustained throughout pandemic
- 2% of home deaths involved covid
- Areas with higher covid rate also had larger increase of home deaths
- Increased deaths at home due to Cancer, Circulatory, and “Other” causes

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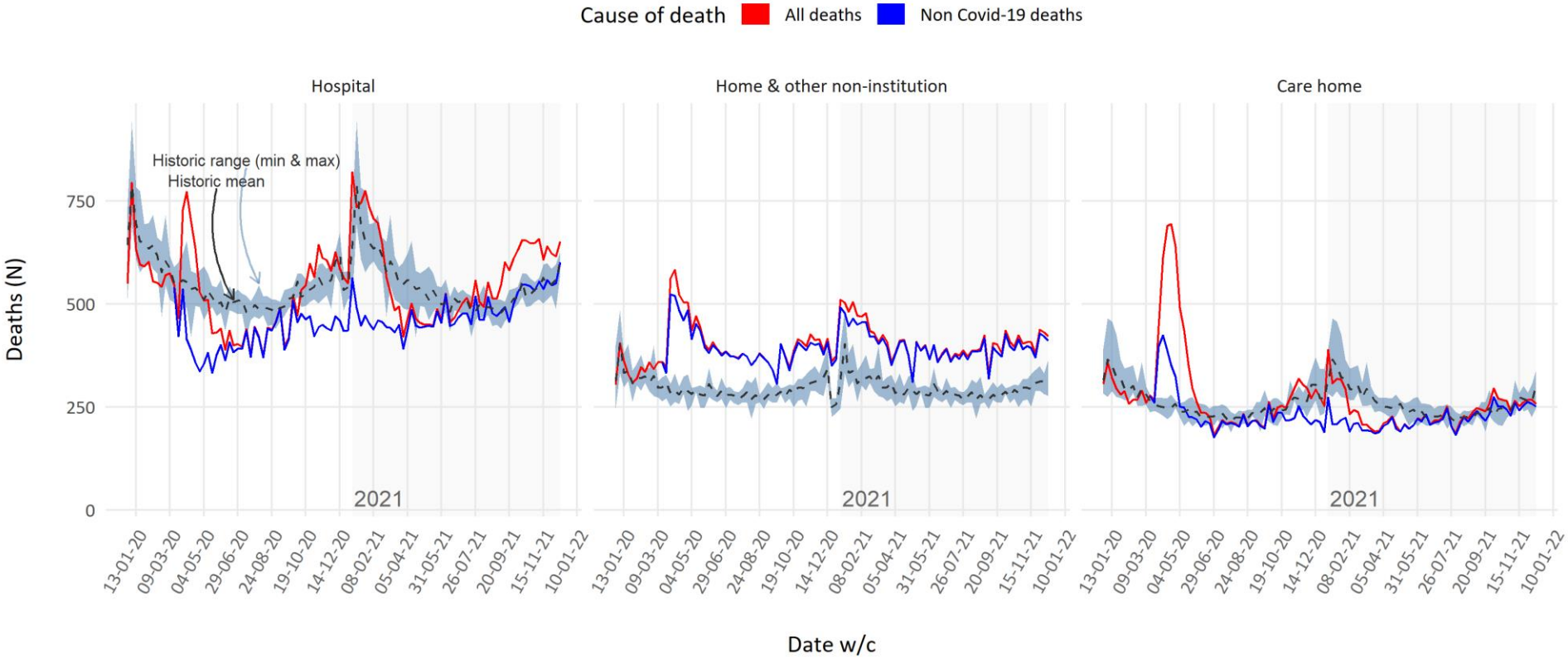
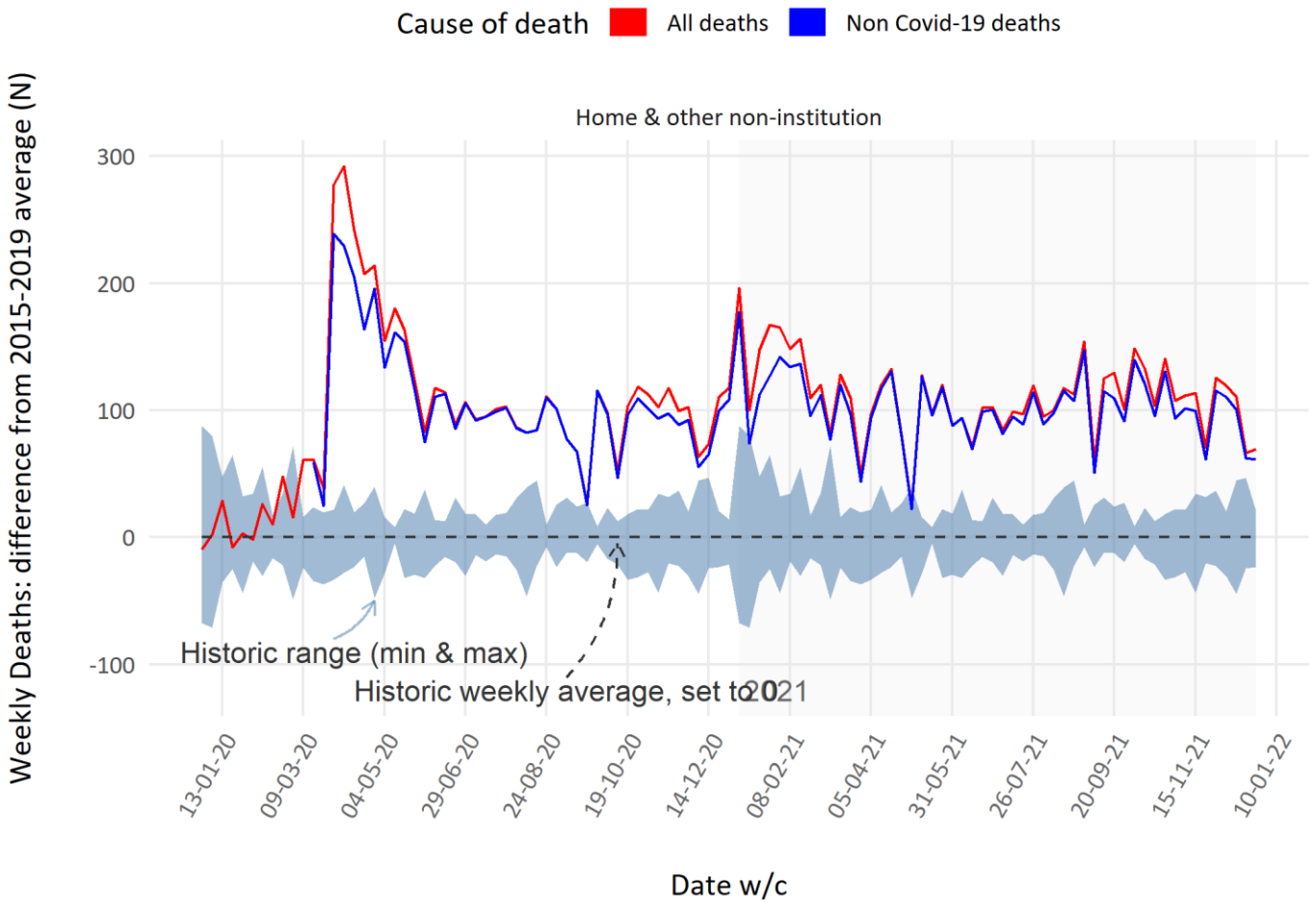
Data from w/c 30 December 2019 to w/c 13 December 2021 (inclusive).



Note: all figures are based on date of registration.
Excluding 'Other' institutional place of death, N=545 for weeks 1-53 in 2020 and 1-50 in 2021.
Source: National Records of Scotland

Data from w/c 30 December 2019 to w/c 27 December 2021 (inclusive).



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