Utilising and Developing Methods for Routinely Collected Data in Health Research

Alex Christopher Garner

A thesis submitted for the degree of

Doctor of Philosophy

Lancaster Medical School

Faculty of Health and Medicine

Lancaster University

June 2024

Utilising and Developing Methods for Routinely Collected Data in Health Research

Alex Christopher Garner MSc

Lancaster Medical School

A thesis submitted for the degree of *Doctor of Philosophy*

Abstract

The UK's National Health Service (NHS) is at a turning point, the organisation is still recovering from the ongoing impact of the COVID-19 pandemic and healthcare worker strikes have further increased pressures on healthcare delivery. Technological advancements and improvements in data usage both provide significant opportunities and challenges for the NHS's near future.

Data is collected for almost every patient interaction with the NHS, this is routinely collected data (RCD). There are vast amounts of RCD held within NHS systems, with massive potential for health research. Enabling large scale usage of this data requires complex data infrastructure along with streamlining of data access procedures, while ensuring patient data remains anonymous and confidential. Developing this infrastructure is a technological undertaking in itself.

Presented in this thesis are three projects conducted using RCD demonstrating opportunities of using this data in research while providing findings to impact healthcare provision. The first project uses linked NHS data in a State Sequence Analysis to investigate patterns of healthcare usage of care home residents around COVID-19 testing events, demonstrating that vulnerable residents received high impact inpatient stays despite known risks. The second project evaluates a digital technology intervention in care homes using a Generalised Linear Mixed Model framework, finding a reduction in unplanned secondary care usage for residents registered on the technology. The third project uses administrative emergency department data in a survival analysis framework, finding improvements in patient flow on strike days are likely due to increased inpatient capacity made available.

Improved access to NHS routine data is crucial to ensuring that researchers can undertake responsive analysis to current pressures, such as those presented in this thesis, providing evidence to support optimised patient care throughout the NHS.

Contents

List of Tables

List of Figures

List of abbreviations

CDDFT	County Durham and Darlington NHS Foundation Trust
COVID-19	Coronavirus Disease 2019
CPRD	Clinical Practice Research Datalink
ECDS	Emergency Care Data Set
ED	Emergency Department
EHCH	Enhanced Health in Care Homes
EHR	Electronic Health Record
EPR	Electronic Patient Record
GDPR	General Data Protection Regulation
GLM	Generalised Linear Model
GLMM	Generalised Linear Mixed Model
GP	General Practice
HES	Hospital Episode Statistics
HDRUK	Health Data Research UK
ICB	Integrated Care Board
NEWS2	National Early Warning Score 2
NHS	National Health Service
OHDSI	Observational Health Data Sciences and Informatics
OMOP	Observational Medical Outcomes Partnership
PHE	Public Health England
RCD	Routinely Collected Data
SDE	Secure Data Environment
SPA	Single Point of Access
SSA	State Sequence Analysis
SUS	Secondary Use Service
TRE	Trusted Research Environment

Acknowledgements

I would like to thank my supervisors Prof. Jo Knight and Prof. Nancy Preston (the 'dream team') for not only convincing me to do this PhD, but fiercely supporting me through the entire journey. Their gentle 'nudges' have made sure I have made the most of every opportunity that has come my way.

The entire staff and students of CHICAS, who we have turned into a wonderful community, despite some locational difficulties... Thank you to everyone who provided cake (sometimes in date), for our Wednesday coffees. Thank you to all of my office buddies up on D-floor, I have loved distracting you all. In particular, Rachael, who I think I distracted most of all - for teaching me statistics, lending an ear and giving incredible book recommendations.

I would like to thank my family, in particular my parents, for supporting my academic endeavours financially and somewhat enthusiastically. I would like to thank Michael for his continued support, even from 10,000 miles away. Finally I would like to thank Rosie, for being my best friend, for her unwavering support and being with me through everything.

Thank you all, because of you I have learned much more than just statistics these last three years.

Declaration

I declare that the work presented in this thesis is the result of my own work. Collaborators are specifically indicated for each chapter. The material has not been submitted, either in whole or in part, for a degree at this, or any other university.

This thesis does not exceed the maximum permitted word length of 80,000 words including appendices and footnotes, but excluding the bibliography. An approximate estimate of the word count is: 55,000.

Chapters 2 and 3 were approved by Lancaster University Faculty of Health and Medicine Research Ethics committee, reference *FHM-2022-3318-RECR-2*. Chapter 4 was approved by Lancaster University Faculty of Health and Medicine Research Ethics committee, reference *FHM-2023-3868-DataOnly-1*.

This thesis comprises of three research papers. The publication status and specific contributions to each paper are as follows:

Chapter 2
Understanding health service utilisation patterns for care home residents during the COVID-19 pandemic using routinely collected healthcare data
Alex Garner, Nancy Preston, Camila C. S. Caiado, Emma Stubington, Barbara Hanratty, James Limb, Suzanne M. Mason and Jo Knight
Published in *BMC Geriatrics* Volume 24 Article 449 (2024)
10.1186/s12877-024-05062-6
Contribution: Led and conducted the analysis. First author of manuscript.

Chapter 3
The impact of digital technology in care homes on unplanned secondary care usage and associated costs
Alex Garner, Jen Lewis, Simon Dixon, Nancy Preston, Camila C. S. Caiado, Barbara Hanratty, Monica Jones Jo Knight and Suzanne M. Mason
Published in *Age and Ageing* Volume 53, Issue 2 (2024)
10.1093/ageing/afae004
Contribution: Led and conducted the analysis for the healthcare utilisation outcomes. First author of manuscript. The economic evaluation section used data that I had processed, and followed my methodology framework for the other outcomes, but was conducted by Jen Lewis and Simon Dixon. They wrote the first

draft of economic sections and I incorporated them in the manuscript.

Chapter 4
Evaluating the Impact of NHS Strikes on Patient Flow through Emergency Departments
This manuscript will be submitted after the the submission of the thesis.
Contrubution: Led and conducted the analysis. First author of manuscript.

Chapter 2 & 3 Data Access Statement
Data was collected from CDDFT and stored in a Trusted Research Environment (TRE) managed by Durham University. Informed consent was not possible as the data was anonymised. The Trust shared anonymised data after undertaking a Data Privacy Impact Assessment and a Data Transfer Agreement. Data supporting this study is not publicly available due to ethical considerations around accessing linked patient level healthcare data. The authors can no longer access the data used in this analysis.

Chapter 4 Data Access Statement
Data was collected from LTH NHS Trust and accessed through the prototype SDE run by LTH. The Trust shared anonymised data through a service evaluation framework. Informed consent was not possible as the data was anonymised. Data supporting this study is not publicly available due to ethical considerations around accessing patient level healthcare data.

Additional Work

Over the course of the PhD, in addition to the central work presented in this thesis, I also contributed to three other research projects. These projects are presented in the appendices. They are detailed here.

Appendix A

Long term care facilities in England during the COVID-19 pandemic — a scoping review of guidelines, policy and recommendations

Danni Collingridge Moore, **Alex Garner**, Natalie Cotterell, Andrew J. E. Harding and Nancy Preston

BMC Geriatrics Volume 24 Article 394

I was second reviewer and second author for this systematic scoping review of COVID-19 care home policy. This chapter links with Chapter 2. Published.

Appendix B

Impact of the HOPE initiative on hospital admission for self-harm across Liverpool: A longitudinal synthetic control study

Pooja Saini, **Alex Garner**, Rachael Mountain, Konstantinos Daras, Catherine Mills, Cecil Kullu and Benjamin Barr

I was the lead analyst and second author for this project. This analysis uses Hospital Episode Statistics, a type of NHS commissioning dataset discussed in the thesis Introduction. Under submission.

Appendix C

Estimating the number of children with palliative and end-of-life care needs who are currently receiving care in North West England

Catherine Walshe, **Alex Garner** and Maddy French

I was the lead analyst for this project. This used data specifically collected data for the study. The report was presented to NHS Integrated Care Boards.

Chapter 1

Introduction

The UK's National Health Service (NHS) is at a turning point in its history. Multiple external forces are applying pressure on healthcare practice in the UK. The NHS is still recovering from the after-effects of the COVID-19 pandemic, while also dealing with healthcare worker strikes and a large waiting list for elective care. As the world is becoming more data driven, the NHS is still yet to fully embrace the role of data and technology.

Research plays a key role in the running of the NHS, from improving direct patient care, to targeting public health initiatives. The organisation holds a vast amount of routinely collected data (RCD) that is growing every day. This data has the potential to be used for both medical and health services research. However, it is often siloed in legacy systems and locked away behind bureaucratic procedures that are difficult to navigate. Accessing and learning from this data could be instrumental in future developments of the NHS. Effective data systems can potentially enable rapid evaluation and feedback on current NHS pressures that would allow to the organisation to adapt efficiently and help direct investment to ensure optimal patient service is delivered and health outcomes are improved [1].

This thesis will discuss the current usage of NHS RCD in research, including opportunities, and challenges of using this data going forward. It will provide examples with three novel projects, each using NHS RCD in responsive analyses to unplanned changes experienced by the NHS: COVID-19, rapid uptake of telehealth in care homes and the NHS stikes. The thesis will put forward a case for further usage of NHS RCD in research, and therefore improvements in accessing this data.

1.1 Routinely Collected Data

Routinely collected health data refers to data collected without a specific research question developed prior to the data collection [2]. This generally refers to data that is collected in the day-to-day activities at health institutions such as hospitals and General Practices (GPs) in the UK. A large portion of routinely collected health data in the NHS is derived from point of care data, patient attendance records or GP notes. Data could also be that collected by wearable devices, health insurance companies and other organisations that collect individuals' health information routinely.

The NHS is the largest publicly funded healthcare system in the world and holds health data on the vast majority of the UK's 68 million residents with the earliest electronic patient records introduced in the early 2000s [3]. The NHS has an abundance of administrative, investigative, diagnostic, and personal information from almost all UK residents over this time period. The range of information captured varies from organisation to organisation within the NHS. This massive supply of data means there is potential for huge study sizes with representative samples, spanning almost the entire population [4], including those with rare health conditions.

In the past, studies have relied on specifically collected data, such as through surveys or clinical observations of participants. This data collection phase can be costly and require considerable planning to ensure results are generalisable [5]. The usage of routinely collected data allows for large scale, representative study data, to produce population level findings without the costly data collection phase.

Since routinely collected data is often recorded at point of care, the data is observational. In a single dataset, observations would refer to interactions within a specific system. This makes RCD useful for healthcare utilisation research, since outcomes related to changes in usage of certain health service are clearly apparent in routinely collected data - even when de-identified and aggregated.

The population-based nature of routinely collected data means it is particularly useful for evaluating policy, since RCD can describe the far-reaching impact of policy decisions across the affected population [6]. Routine data is also used in risk factor identification studies [7] and in development of tools to aid decision making based on previous patient experiences [8, 9]. Additional data sources can be linked with RCD to allow for almost any kind of analysis.

Natural limitations of routine data collection in healthcare settings must be considered. Data recording issues and missingness is a common problem [10]. Most RCD is recorded by a clinician as a secondary aspect of their responsibilities. They are often under intense time constraints, even in non-urgent settings. A clinician's responsibility is to the patient's wellbeing – not necessarily perfectly capturing the information about each presentation. These factors can also lead to misclassification biases and underreporting in certain routinely collected datasets [5].

The observational, ever growing nature of RCD means that assumptions and decisions surrounding an analysis need to be made by the researcher. For instance, follow up times must be defined by a time period or a specific event, and patients are not regularly monitored during this time. For instance, the study period of an intervention evaluation is often decided by the researcher retrospectively after the data is collected [11]. Assumptions may be made in order to define a treatment and control group – typically as an external factor, such as geographical location surrounding the base of an intervention. Often, causal inference methods, such as a difference in difference analysis with matched controls, are needed to attempt to allow comparison against a control group over time [12].

Despite the NHS theoretically being available to the entire UK population, there are still barriers to accessing healthcare. Only users of the health services are included in the data in the UK, and patients who access more healthcare are represented as such in healthcare data. There are significant inequities in healthcare usage, with differing service use across sectors. More socially disadvantaged people generally use healthcare services more frequently, while more wealthy patients tend to access more preventative care [13]. The wealthiest members of the population may also be more likely to access private healthcare, thus would not be included in NHS data. Some of the poorest and most vulnerable patients may struggle to access healthcare at all due to factors such as travel costs, prescription costs and a lack of health literacy. This would lead to huge inequities in representation in RCD and therefore certain groups may not be accounted for in policy changes made using evidence from this source, potentially perpetuating inequalities [5]. This is arguably more of an issue in specifically collected study data, but this should be considered when interpreting results of research using routinely collected data.

There are strict information governance rules and data sharing protocols around the usage of NHS data, focusing on patient privacy due to the sensitive nature of health data. Despite these necessary governance practices, there are always ethical concerns with sharing of patient data [14]. Patients need to be aware that their health data is being used for research purposes and give consent. The current system is the national opt-out scheme, which assumes a patient's consent for their anonymised data to be used in research and other secondary uses unless they specifically opt-out. This can add additional complexity to data use in research, and there are concerns that specific groups of patients may be more, or less, likely to opt-out – skewing results from this research [15]. The latest data as of June 2024 indicates that around 5% of the population registered with a GP have opted out of their data being shared [16].

Ensuring the public are informed about how their data is used and the benefits their data can provide is key to fair data sharing. Patient engagement is important in studies using NHS data, to ensure that patients are represented in the research process [17]. They can input into research that is conducted using their data and ensure on behalf of the public that they are happy with how their information is being used. Public trust is a current priority for the NHS, with a large 'National public engagement on the use of health and care data' project currently being undertaken by NHS England [18].

The significance of the opportunity provided by NHS routine data has been recognised. *Health Data Research UK* (HDRUK) was formed by the Medical Research Council (MRC) in response to this opportunity as the UK's national health data science in 2017 [19]. The organisation aims to enable access to health data for use in research - this involves connecting the data and researchers and promoting infrastrucutre for improved data sharing. They have a large number of initiatives to do so, one such is the HDRUK *Innovation Gateway* [20], a catalogue of datasets available from data providers to give researchers an understanding of data available to answer their research questions. HDRUK also fund a number of flagship projects using NHS routinely collected data [21], demonstrating the research that can be conducted and giving chance to identify any challenges that need to be addressed.

1.2 Primary and Secondary Care Data in the UK

In the UK, primary care data sharing is complex. General practices are required to submit specific datasets to NHS Digital, but each GP's data is stored locally and separately from each other. Sharing data across GPs can require data-sharing agreements in each GP practice [4]. There are approximately 6,291 General Practices in England as of April 2024 [22]. GPs typically cover a small geographical area, meaning there are many small data collections spread across a large number of sources. These organisations use electronic patient records such as *Vision* or *EMIS Web* [23, 24]. GPs are also smaller organisations and are less likely to have capacity to engage in research, therefore data sharing agreements on an individual GP level are more difficult to acquire. Unification of data sharing between GPs is a priority of the regional Integrated Care Systems that were established in 2022, as part of their aims to share information between all care providers [25].

The *Clinical Practice Research Datalink* (CPRD) is one of the largest collections of primary care data in the UK. It holds longitudinal, anonymised data covering over 60 million patients. This comes from around 700 practices who have opted into sharing their data into this database. The CPRD contains data on patient demographics, clinical information and test results [26].

Secondary care data is made up of emergency and elective hospital care data. Emergency care data is data collected from emergency departments. NHS Digital's data standard for emergency data is the Emergency Care Data Set (ECDS) [27]. Emergency care lends itself to research using routine data due to the nature of emergency department (ED) attendances being unplanned, generally independent events. The timings of events themselves are informative. The target measure of many interventions is reducing emergency care usage [28]. This assumes that if patients are receiving the correct care problems will not develop to require immediate emergency care. Inpatient care can be linked to ED through patients being admitted from the emergency department, and also contains overnight patients for non-urgent treatment. Inpatient data generally contains administrative information and patient diagnosis codes. Outpatient care is scheduled referrals to specialists. Diagnoses are generally not recorded in outpatient data since the information is included in the referral data held by the General Practice (or other service) the patient was referred from.

Secondary care (generally referring to more specialised care) is run by local trusts that are responsible for one, or a small number of sites. There are 209 trust organisations in the UK, 71 of which are acute care providers, providing mostly hospital-based care [29]. Trusts cover a large geographical area meaning a large amount of secondary care data is concentrated in one organisation. Therefore it is often easier to access larger amounts of secondary care data with only one data sharing agreement in place. Communication between trusts, however, is a similar issue to that of GPs. NHS trusts are required to provide data to NHS Digital for commissioning and national datasets. However, each trust's system is different. Some collect different data and some use completely different systems such as *EMIS* and *SystmOne*. Much research using NHS data is focused on one geographic area for this reason [30, 31]. Close local collaboration can allow for more detailed data scrutinization, but results are less representative and generalisable to the entire population. Local characteristics should be considered to understand results in the context of the rest of the population.

While most secondary care data access is through trusts, data is also made available through NHS Digital, where most data comes from the Secondary Use Service (SUS). SUS is the data collection and processing hub for the NHS [32]. Required datasets are sent from trusts to the SUS. SUS makes data available for research in the form of different datasets through NHS Digital. One such dataset is Hospital Episode Statistics (HES). This dataset contains information on all hospital episodes in the UK, including inpatient admissions, outpatient care and emergency department attendances [33]. This data is completely anonymous, so only specific research questions can be addressed with this data. Research looking at outcomes for specific patients is not possible with this data since it is aggregated and does not contain patient identifiers.

By definition, routinely collected data is collected for purposes other than research. NHS data is collected by different organisations for a range of reasons. The primary collection purpose can impact aspects of data quality, and possibly invoke biases, so should be considered when using RCD for analysis. A large amount of data in national datasets (such as Hospital Episode Statistics) comes from commissioning datasets. Commissioning datasets are reported from Trusts to NHS Digital, allowing for reimbursement based on hospital activity [34]. For this reason, activities with associated costs, such as investigations and procedures are often better coded compared to other variables. Alternatively, datasets that are collected to assess performance, such as the fulfilment of the four-hour target in the Emergency Department may be subject to recording biases to ensure targets are recorded as being met [35].

1.3 Accessing Routinely Collected Data

Strict guidelines are necessary to ensure patient data is held and used responsibly. UK data usage laws such as GDPR and the Data Protection Act (2018) need to be followed and legal basis for any project needs to be cited [36, 37]. The *five safes* is a widely used data access framework applied to the use of NHS data in research. The NHS's future plans for data access routes cite that they will adhere to the five safes [38]. Project accordance with the five safes generally ensures all of the necessary information governance and data protections are followed.

Data used in a project should be minimised, so only information necessary to answer the research question is made accessible to the researcher. The data should be as anonymised as possible. Pseudonymisation is a possible anonymisation technique that maintains links between same-patient observations, allowing linkage with other datasets. This is agreed and accounted for in Information Sharing Agreements between parties. It is also important that data is stored securely, and can be accessed safely by researchers. Recently, this has led to the use of *Trusted Research Environment* (TRE) systems. Most TREs are secure, cloud-based environments that the researcher can access remotely, without storing any sensitive data on a local machine. Analysis tools such as R and python are made available within the TRE so that analysis can be performed without ever moving the data from the TRE [39]. Other secure methods of accessing research data are discussed in Section 1.4.

Researchers need to be appropriately trained before they handle the data. Online certifications are often used, including university specific training courses. Certain platforms, such as the Office for National Statistics' Secure Research Service, require completion of a short, in-house training course before researchers can access the platform. Projects are checked by the data holders to ensure that project aims are within the best interest of the public. This is typically through ethical approvals – the NHS have their own ethics approval system and most universities have one too. Finally, the outputs of the projects need to be non-disclosive, so individuals in the study cannot be identified. This means small counts of individuals are suppressed.

1.4 NHS Data Going Forward

The need for improved NHS data infrastructure became quickly apparent during the COVID-19 pandemic, with demand for large projects with quick turnarounds [40]. An efficient NHS data sharing system would allow for rapid responses and up-to-date data on public health crises such as the COVID-19 pandemic, allowing evidence-based policy to adapt quickly, forming the basis of the nation's response to crises like the COVID-19 pandemic or rapid unplanned change such as strikes. RCD could also be used to inform system improvement such as the adoption of digital technologies in NHS organisations. This would lead to the NHS being able to adapt to external changes more quickly, continuously adapting to ensure optimisied care in all situations.

The government-commissioned Goldacre review [1] highlighted the need for improved data in the UK and outlined recommendations to get there. It outlined the need for a complete overhaul of the way the NHS manages and shares its data, and the need for this infrastructure to be scalable as it is shared with more organisations over time. At the time of the report, the UK government announced £200 million for health data research and development and stated that their response to the Goldacre review would be included in their final data strategy document [41].

One of the primary recommendations of the report is the use of Trusted Research Environments. These recommendations have been transformed into the Secure Data Environment (SDE) scheme – an adaptation of the traditional TRE framework that the Department of Health and Social Care committed to in their *Data Saves Lives* policy paper [42]. Plans are in place for multiple regional SDEs and a centralised SDE for the whole of the UK. These SDEs would consist of data infrastructure and pipelines to feed data into centralised systems for analysis. Data would remain held by the trusts, but feed their data in through the pipelines when needed. This centralised approach would allow the SDEs to act as a hub for linkage between NHS datasets, as well as with external datasets.

The SDE programme is already underway. According to the HDRUK Innovation Gateway as of June 2024, datasets are registered with three regional SDEs; London, Yorksire and Humber and West Midlands, as well as the national SDE [19]. The

SDE program is also underway in more areas, including the North West. Lancashire and South Cumbria also have had a prototype SDE up and running since 2022. The Clinical Practice Research Datalink (CPRD) - the large dataset of primary care data from the UK - also now uses the TRE data access model to make their data available to researchers [43].

Data infrastructure and pipelines are required to flow data into SDEs where data from different organisations can be linked and combined. This requires standardisation of data, specified data models would be required to ensure data can be linked effectively. The SDE programme has decided to use the Observational Medical Outcomes Partnership Common Data Model (OMOP), produced by Observational Health Data Sciences and Informatics (OHDSI) [44]. This requires work from all data providers to ensure that their data is standardised to this model. With multiple SDEs holding standardised data, federated analysis can be performed on these datasets, without the need for any data linkage or movement of the data. This would mean analyses can be run on each regional SDE separately, while the regional outputs (such as model parameters) can be combined to produce results that represent the entire country [45], producing powerful analyses and improving generalisability of findings across the population.

The SDE program will require collaboration on many fronts, between policy makers, trusts, the wider NHS, data scientists and the technology industry. In addition to the technology infrastructure needed, another is challenge is ensuring information governance is maintained and the five safes are followed (see Section 1.3). The aim of the SDEs is to facilitate research with improved data access avenues, but it is vital to ensure patient privacy is retained, and proper governance procedures are followed at all points in the programme.

SDEs are not the only possible future avenue for more efficient access to NHS data. During the COVID-19 pandemic, multiple avenues of NHS data access models were fast-tracked. One of these models was exemplified by *OpenSAFELY* [46]. This method is similar to TREs, however, the raw data is never handled or viewed by the researchers or analysts. A synthetic version of the necessary raw data is provided to the analyst. This synthetic data is produced to be representative of the overall characteristics of the 'real' raw data, but all observations are simulated. The analyst can then write code based on this data to ensure there are no bugs. The code is then submitted and run on the raw data, supervised by someone with access to the data. This way the analyst can receive results corresponding to that of the raw data without ever needing access to the data. This can lead to a shorter process to get permission to run the analysis, since the researcher does not directly handle patient data at any point.

1.5 Statistical Methods for Routinely Collected Data

Research using routinely collected data can use a range of statistical methods. The methods used depend on the nature of the investigation and the data that is being used in the analysis. Standard summary statistics of routinely collected data are often extremely useful clinically. Basic data on demographics of service users and outcome measures such as average length of stay are hugely informative from a clinical perspective [47].

Standard inferential statistical methodologies such as regression and survival analysis allow quantification of relationships. In routinely collected health data studies, these kinds of analyses are frequently used to find relationships between variables, while controlling for confounding factors. Causal inference techniques can be used but the non-experimental nature of data collection means it can be difficult to infer causality. Due to the observational nature of routinely collected data, variations upon these general techniques are typically required to ensure assumptions are satisfied and methodology is used correctly [48].

Novel methodologies are starting to be used with routinely collected data. One example is State Sequence Analysis (SSA). This methodology aims to cluster categorical sequences based on a similarity metric, and was initially developed to be applied to gene sequences. More recently, this has started to be applied to patient care sequences [49]. This allows investigation of links between long term care sequences and patient characteristics. [50, 51]. Investigating long-term care requires longitudinal routinely collected data. There are not currently any well-established methods for longitudinal investigation of patient pathways through care. SSA gives a good starting point for further research investigating longitudinal usage patterns using this kind of data.

Network analysis is a well-established branch of methodology that shows promise for usage in routinely collected health data methodology. The breadth of sources of routinely collected NHS data allows applications such as investigating longitudinal care pathways similar to SSA [52], tracking the spread of disease, and identifying specific subgroups of patients to target interventions [53].

Going forward, machine learning methodologies such as natural language processing and computer vision can be used to gain insights from unstructured data to add more information and power to analyses. Unstructured routine data can take the form of any patient or organisational data that is held in any of the NHS systems [54]. Examples include referral letters sent to patients or diagnostic imaging from patient scans. Successful implementation of these techniques would mean that information are able to be mined from these additional sources and used in conjunction with other sources of routine data for extremely powerful analyses. Artificial intelligence and machine learning techniques show promise for the analysis of routinely collected health data. However, the lack of transparency of these methodologies mean they should be used with caution on patient data. Interpreting model parameters to understand relationships is almost impossible. This means models can perpetuate existing systematic biases and factors influencing model decisions cannot be fully explored [55].

1.6 Thesis Aims

This thesis aims to demonstrate the current state of routinely collected data in research through application in three projects. Each project will provide it's own actionable implications for health service policy, developing RCD methodologies and highlighting challenges and limitations of using RCD for research. The three projects are as follows:

1. **Understanding health service utilisation patterns for care home residents during the COVID-19 pandemic using routinely collected healthcare data**
   An analysis of care pathways of care home residents during the COVID-19 pandemic using data from a number of data sources.

2. **The impact of digital technology in care homes on unplanned secondary care usage and associated costs**
   An evaluation of an NHS digital technology data sharing intervention in care homes on secondary care usage, linking multiple sources of routinely collected data.

3. **Evaluating the Impact of NHS Strikes on Patient Flow through Emergency Departments**
   An evaluation of how recent strikes have impacted emergency departments using a single routinely collected emergency care dataset.

Chapter 2

Understanding health service utilisation patterns for care home residents during the COVID-19 pandemic using routinely collected healthcare data

BMC Geriatrics

Alex Garner[1], Nancy Preston[3], Camila C. S. Caiado[4], Emma Stubington[1], Barbara Hanratty[5], James Limb[6], Suzanne M. Mason[2] and Jo Knight[1]

[1] Lancaster Medical School, Lancaster University
[2] School of Health and Related Research, The University of Sheffield
[3] Division of Health Research, Lancaster University
[4] Department of Mathematical Sciences, Durham University
[5] Population Health Sciences Institute, Newcastle University
[6] County Durham and Darlington NHS Foundation Trust, Darlington

Garner, A., Preston, N., Caiado, C. C. S., Stubington, E., Hanratty, B., Limb, J., Mason, S. M., & Knight, J. (2024). Understanding health service utilisation patterns for care home residents during the COVID-19 pandemic using routinely collected healthcare data. BMC Geriatrics, 24(1), Article 449. https://doi.org/10.1186/s12877-024-05062-6

Abstract

Background: Healthcare in care homes during the COVID-19 pandemic required a balance, providing treatment while minimising exposure risk. Policy for how residents should receive care changed rapidly throughout the pandemic. A lack of accessible data on care home residents over this time meant policy decisions were difficult to make and verify. This study investigates common patterns of healthcare utilisation for care home residents in relation to COVID-19 testing events, and associations between utilisation patterns and resident characteristics.

Methods: Datasets from County Durham and Darlington NHS Foundation Trust including secondary care, community care and a care home telehealth app are linked by NHS number used to define daily healthcare utilisation sequences for care home residents. We derive four 10-day sets of sequences related to Pillar 1 COVID-19 testing; before [1] and after [2] a resident's first positive test and before [3] and after [4] a resident's first test. These sequences are clustered, grouping residents with similar healthcare patterns in each set. Association of individual characteristics (e.g. health conditions such as diabetes and dementia) with healthcare patterns are investigated.

Results: We demonstrate how routinely collected health data can be used to produce longitudinal descriptions of patient care. Clustered sequences [1,2,3,4] are produced for 3,471 care home residents tested between 01/03/2020 – 01/09/2021. Clusters characterised by higher levels of utilisation were significantly associated with higher prevalence of diabetes. Dementia is associated with higher levels of care after a testing event and appears to be correlated with a hospital discharge after a first test. Residents discharged from inpatient care within 10 days of their first test had the same mortality rate as those who stayed in hospital.

Conclusion: We provide longitudinal, resident-level data on care home resident healthcare during the COVID-19 pandemic. We find that vulnerable residents were associated with higher levels of healthcare usage despite the additional risks. Implications of findings are limited by the challenges of routinely collected data. However, this study demonstrates the potential for further research into healthcare pathways using linked, routinely collected datasets.

2.1 Introduction

The COVID-19 pandemic had a major impact on adult social care. There was substantial excess mortality in care homes in the UK during the first phase of the COVID-19 pandemic, deaths were estimated 20% higher than previous years, a large portion of which are not registered as due to COVID-19 [1, 2]. The highest proportion of deaths involving COVID-19 of UK care home residents in wave one was in the North East of England (30% of deaths involved COVID-19) [2]. Care homes and long term care facilities have been disproportionately affected by the COVID-19 internationally [3, 4]. Best policy for care homes was uncertain at the beginning of the pandemic. International studies have shown long-term decline in health related quality of life and functional decline in older patients who were hospitalised for COVID-19 globally [5]. Healthcare for vulnerable people required a fine balance, to ensure necessary healthcare was maintained while minimising exposure to COVID-19 which was particularly pertinent in care homes [6].

During the early stages of the pandemic, policy recommendations for care homes were updated and revised rapidly. Between the initial COVID-19 guidance on 25th February 2020 and £850 m social care grant to councils on 16th April 2020, Public Health England and the Department of Health and Social Care provided numerous additional frameworks and guidance documents [7]. These were often vague and difficult to follow [8]. Criticisms have described the UK's policy response in adult social care as 'slow, late and inadequate' [9]. Criticisms of many countries' pandemic responses with respect to long term care facilities have been made [10].

On 17th March 2020 NHS England advised that all non-urgent elective operations should be postponed, and for all medically fit inpatients to be discharged to free-up capacity [11]. Grimm et al. found that UK care home residents' use of inpatient care decreased in the early stages of the pandemic and suggest these reductions may result in substantial unmet healthcare need [12]. Internationally, healthcare utilisation decreased by around a third during the pandemic [13]. In a global survey in the early stages of the pandemic, two-thirds of health care professionals for chronic diseases stated moderate or severe effects on their patients due to changes in healthcare services [14].

Our study aims to investigate how care home residents received care in the period immediately surrounding COVID-19 tests. We aim to investigate how care home residents used health services and whether patients were moved around between different care settings. Trajectories of care are mapped over time, with time periods defined by their COVID-19 testing events. We cluster these trajectories to find groups of residents with similar care patterns. To achieve these aims we use a novel method for care pathway analysis, State Sequence Analysis. This allows us to investigate potential shared characteristics between these clusters that may drive the observed care patterns.

Care home residents have high levels of physical dependency, cognitive impairment, multiple morbidity, and polypharmacy [15]. Comorbidities such as diabetes and dementia are prevalent in the population and require ongoing high levels of care from staff and specialists [16, 17]. Dementia was the most common pre-existing condition for residents who died of COVID-19 before the end of 2021 and diabetes was a common comorbidity for male residents who died of COVID-19 in the same period [2]. Dementia patients are prone to confusion and struggle to adhere to social distancing and other restrictions. Hence, investigating how these two characteristics affected use of health services by patients having had a COVID-19 test is of particular interest. Furthermore, diabetes and dementia are not respiratory problems and therefore will be able to be viewed independently of COVID-19. We hypothesise that residents' frailty and/or the presence of long-term conditions such as diabetes and dementia will influence the care a resident will receive.

There is a lack of patient-level data from care homes themselves and it is difficult to identify care home residents from administrative hospital data [18]. This limits studies using routinely collected hospital data on care home residents and reduces the possible evidence base for policymakers [19]. This study is, to our knowledge, the first to investigate resident-level care pathways for care home residents during the COVID-19 pandemic. Synthesising patient-level care pathways during the COVID-19 pandemic is important for policy makers to get an empirical understanding of how residents were cared for overall and allows us to understand how characteristics may impact a patient's care pathway. Understanding patient specific driving factors for decisions made by care staff about how residents were treated can lead to additional policy and guidelines being introduced when used in conjunction with other research in the area. We demonstrate the application of a novel methodology that can be used for further health pathway analysis using routinely collected data in more settings in the future.

2.2 Methods

We produce longitudinal sequences of daily healthcare utilisation in the days before and after COVID-19 testing events for care home residents. We cluster these sequences to find residents with similar patterns of healthcare utilisation around their testing events. We then investigate cluster trajectory characteristics, size as well as associations with resident characteristics. We present our work corresponding to the RECORD guidelines [20].

2.2.1 Data Source

We utilised data from the Health Call Digital Care Homes app that began rollout in the North East of England 3rd August 2018 and covered all homes in the area by the end of the data period in August 2021, the sample size is essentially the complete population of adults in care homes who had Pillar 1 COVID-19 tests. Health Call is a digital referrals app used by care home staff to gather information and request review from a clinician. Three care home datasets from Health Call covering resident enrolment, home enrolment, and app uploads are used in this study.

We also use eight routinely collected datasets from County Durham and Darlington NHS Foundation Trust hospitals (CDDFT), including A&E, inpatient, outpatient, and community data (primary care data is not included). Pillar 1 COVID-19 testing in the region is also utilised.

All these datasets were initially stored within the Trust, so could be pseudonymised together via patient/resident NHS number. These datasets were then transferred to a Trusted Research Environment for the researchers to access remotely and securely. We then linked theses datasets together using patients' pseudonymised NHS numbers. In total eight of the datasets refer to patient healthcare events. Three datasets include additional information about residents and homes. A description of each dataset is contained in the Chapter 2 Supplementary Table 2.4 (both chapters used the same datasets).

The COVID-19 testing data used for this analysis is Pillar 1 PCR test results. Pillar 1 testing is classed as 'swab testing in Public Health England (PHE) labs and NHS hospitals for those with a clinical need, and health and care workers' [21]. The testing data consists of tests when a resident is an inpatient, or when a resident is symptomatic or believed to have been exposed to someone with suspected COVID-19.

Since the focus of the analysis is on identifying resident's healthcare observations (interactions with healthcare systems) missingness was generally not an issue, see the Discussion section for further elaboration. The Charlson Comorbidity index was missing for a proportion of patients but is likely to be missing not at random and unreliable to impute. We only used cases where it was present and accounted for this in our interpretation. Each observation contained a pseudonymised NHS number and timestamp. Those along with which dataset the data had come from can be used to make longitudinal care sequences.

2.2.2 Dataset Descriptive Statistics

Monthly numbers of observations are calculated for each of the datasets. Locations of COVID-19 tests and rates of test results at the different location types were calculated and independence of these two factors was tested with a chi-squared test (see Supplementary Section 2.6.2.3).

2.2.3 Defining Cohort and Trajectories

Since the data contains the healthcare interactions of all CDDFT service patients, a cohort of care home residents was defined. Presence of individuals' NHS numbers in the Health Call enrolment (activation) dataset indicate care home residency. Observations in other datasets referring to a resident living in the set of Health Call care homes are used to identify additional care home residents. Residents are included in the study from the identified timepoints at which they became a care home resident to when they died or moved out of the home. All individuals identified as care home residents are included in the cohort. Resident characteristics such as age, gender and comorbidities are also drawn from the available datasets (see Supplementary Section 2.6.1.8 methods). The limitations of using routinely collected observational data to compile resident characteristics are discussed in the Discussion section.

We define a resident's healthcare trajectory as the sequence of care they received each day. To ensure only one state per day, we prioritise more 'significant' types of care. The possible states (in order of significance) are:

- A&E Attendance
- Inpatient stay in hospital
- Outpatient attendance
- Appointment in the community
- Care home visit by community healthcare staff
- Care home - no action in the datasets

2.2.4 Sequence Analysis

Four different 10-day sub-sequences of resident trajectories were investigated using index events defined by the available COVID-19 tests. The two index events used are a resident's *first COVID-19 test* and a *resident's first positive COVID-19 test*. The sequence length of 10 days corresponds to the UK government recommended isolation period for individuals who test positive for the majority of the study period. Residents without a COVID-19 test were not included. Sequences exceeding the boundaries of the study period or a resident's time in the cohort were excluded from the analysis.

Pairwise distances were calculated between sub-sequences in each of the four sets using the Optimal Matching distance algorithm [22]. Insertion and deletion costs of 1 were used, and substitution costs were based on the transition rate between the two states (see Supplementary Section 2.6.1.11 for more information). The sequences were clustered based on the calculated dissimilarity between them using hierarchical clustering and Ward's criterion. State Sequence Analysis was implemented in R using the *TraMineR* package [23].

Potential associations between cluster assignment and resident characteristics were investigated to provide insight into which factors are associated with the care a resident received. Specific characteristics were investigated: 28-day mortality after the COVID-19 test and Charlson Comorbidity Index, as well as the prevalent comorbidities: diabetes and dementia. Additional associations with wave of the pandemic and COVID-19 test result are included in the supplementary materials.

Chi-squared tests for independence were used for each of the characteristics separately (or Fisher's exact test when counts in the elements of the table are ≤ 5)

[24], with an adjusted significance level $\alpha = 0.00143$ as a simple Bonferroni multiple testing correction from $\alpha = 0.05$ (total number of tests presented in the main paper and supplementary materials = 45, 16 are included in the main paper).

2.2.5 Cluster Transitions

Since the sequences defined lead to, and follow on from, index events we use Sankey diagrams to visualise the movement between clusters.

2.3 Results

In total from all the datasets there were $10,701,759$ observations of 612,408 individual patients who have used the services between April 2018 and August 2021. $8,702$ care home residents (those with observations in the Health Call datasets and those discharged to a care home) were identified from 122 care homes. Table 2.1 provides a summary of the cohort demographic information.

Table 2.1: Summary statistics for the cohort of care home residents.

	Median		**IQR**	
Age*	85		79-90	
Number of Observations	58		29-109	
Months in the cohort	19		11-31	
	Male		**Female**	
Gender	3,086 (35%)		5,616 (65%)	
	True		**False**	
Died (within the study period)	2,549 (29%)		6,153 (71%)	
	0	**1-2**	**3-4**	**$\geq$5**
Charlson Comorbidity Index**	324 (8%)	2,111 (52%)	1,292 (32%)	3-4 (8%)

*We do not have age information for 1,394 of the residents.
**We could not calculate a Charlson Comorbidity Index for 4,671 residents due to them not having registered ICD-10 codes from their inpatient stay.

Table 2.2 summarises 11 datasets, consisting of routinely collected data. The data comes from the CDDFT's secondary care, community database, observations taken inside the care home on the Health Call app, and COVID-19 testing data. This data includes residents in the study cohort.

Trajectories were defined from the set of healthcare interactions included in the

Table 2.2: Counts of observations and individuals in each data set, filtered for the cohort of care home residents.

Data Set	No. of Observations	No. of Individuals	Proportion of Cohort
A&E	25,399	6,608	76%
Inpatient	33,676	5,898	68%
Inpatient Observations	527,771	5,501	63%
Outpatient	32,707	5,013	58%
Ward Episodes	38,849	5,948	68%
Community	848,495	8,494	98%
Health Call	72,261	6,318	73%
COVID-19 Testing (P1)	24,272	4,767	55%
Additional Data Sets			
Discharges	13,736	4,297	49%
Health Call Referrals	15,936	8,702	100%
Health Call Implementation	125	-	-
Total	743,163	8,702	-

*Individuals can be in more than one dataset hence the proportions do not equal 1.

dataset. Figure 2.1 visualises a resident's care trajectory throughout their time in the study cohort. The longer blue periods represent an inpatient stay.

Sequences for clustering were specified based on the COVID-19 testing index events. 4,767 residents have a recorded Pillar 1 COVID-19 PCR test in the dataset, and are therefore included in the analysis, 3,938 were ineligible for analysis due to no testing events. Of these, 1,049 residents test positive for COVID-19 at some point in time and their first tests are used as the index events for the pair of sequences before and after a first positive COVID-19 test.

Sequences before the test are not included when a resident moves into the home in the 10 days before the test (198 removed before first positive test, 1,296 removed before a first test). Sequences after the test are not included when the resident dies in the 10-days after the test, or their test is less than 10 days before the end of the study period (316 removed after a first positive test, 1,547 removed after a first test).

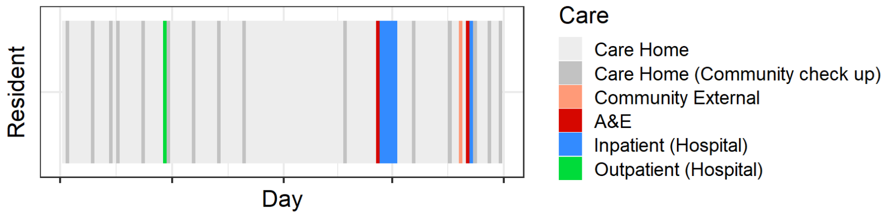

Figure 2.1: A 5-month sample of a single resident's care trajectory, with coloured blocks for each day representing the care the resident received each day.

The number of residents included for each sequence specification is [1] before a first positive test: 851 [2], after a first positive test: 733 [3], before a first test: 3,345 [4], after a first test: 3,220. The total number of individual residents that appear in the analysis is 3,471. This selection of analysis sequences is visualised in a flow diagram in Supplementary Figure 2.5.

A visualisation of the four 10-day sequences in their assigned clusters can be seen in Figure 2.2. The clusters are generally characterised by a single state. Sequences both before and after the first positive test [1, 2] are demonstrated by two clusters: an *inpatient* cluster, and a *home* cluster. The before and after first test sequences [3, 4] are characterised by three clusters each, *home*, *community*, and *inpatient* states and *home*, *inpatient to home transfer* and *inpatient* sequences respectively. The large number of residents in the *inpatient* cluster after the first test is likely due to testing upon hospital admission. The inclusion of an *inpatient to home transfer* cluster after a first test may indicate that these tests were testing on discharge from the hospital.

Characteristics of the residents in these clusters were assessed. The relative frequencies of the characteristics within each of the clusters can be found in Table 2.3. The combinations found to be non-independent through the chi-squared test are highlighted in grey. All p-values for these tests can be found in the supplementary materials. A higher proportion of residents with diabetes are found in clusters indicating a higher level of care for all four sequences ([1] $p = 0.00026$, [2,3,4] $p < 0.0001$). For example in the 10 days before a resident's first positive test 35% are diabetic of 142 in the *inpatient* cluster compared to 21% of 709 in the *home* cluster. A similar pattern is found after both *all* and *positive* tests for dementia patients ([2] $p = 0.00036$, [4] $p < 0.0001$). *Before all first tests* a higher proportion of those in the community cluster have frailty scores of 3 and above (73% of 140 versus 41%

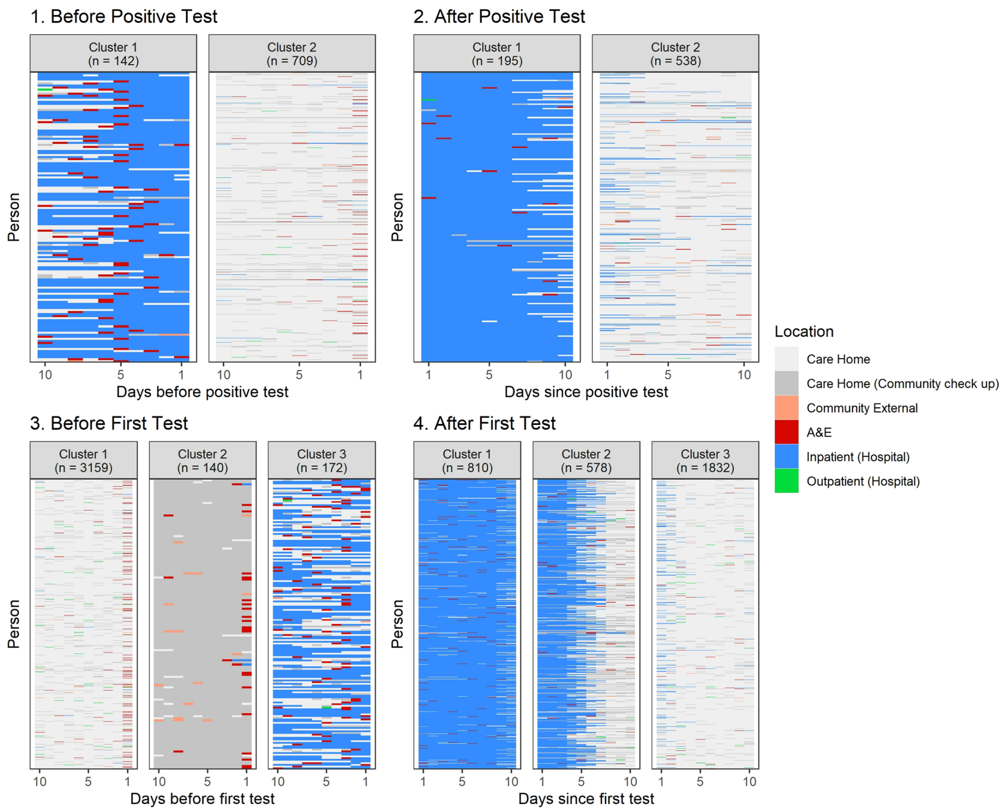

Figure 2.2: Sequence cluster assignments representing types of care received in the 10 days before (1) and after (2) a resident's first positive COVID-19 test, and the 10 days before (3) and after (4) a resident's first COVID-19 test (of any result). The clusters represent the groups of similar sequences, where each sequence represents one resident's care over the 10 days.

and 43% for 3,159 in the home and 172 in the inpatient cluster respectively).

Twenty-eight-day mortality is only associated with clusters 10 days *after all tests* ([4] p < 0.0001); residents in the *inpatient* and *inpatient transfer* cluster have a slightly higher 28-day mortality than those in the *home* cluster (8% of 810 and 8% of 578 versus 3% of 1,832). The two clusters with inpatient stays have the same 28-day mortality rate, despite one of the clusters demonstrating a discharge from hospital around halfway through the 10-day period ([4] $p < 0.0001$).

Flow between clusters before and after the positive test were displayed in a Sankey diagram 2.3. Transitions between these clusters may indicate changes in care based on the positive test. The 'Died' after test group here is not the same as presented in the cluster associations previously. Here we identify whether they died within 10 days of their test and were therefore not included in any of the clusters.

Table 2.3: Table of associations between cluster assignments for each of the sub-sequence groups and resident characteristics/sequence outcomes.

		28-Day Mortality		Diabetes		Dementia		Charlson CI (Proportion with a CCI)				
		T	F	T	F	T	F	N*	0	1-2	3-4	≤5
10 Day Before First Positive	Cluster 1 (Inpatient) n = 142	0.22	0.78	0.35	0.65	0.27	0.73	n = 136	0.07	0.45	0.35	0.13
	Cluster 2 (Home) n = 709	0.23	0.77	0.21	0.79	0.21	0.79	n = 386	0.08	0.52	0.32	0.8
10 Day After First Positive	Cluster 1 (Inpatient) n = 195	0.14	0.86	0.37	0.63	0.31	0.69	n = 187	0.06	0.49	0.34	0.11
	Cluster 2 (Home) n = 538	0.10	0.91	0.17	0.83	0.19	0.81	n = 253	0.08	0.51	0.32	0.09
10 Day Before All First Tests	Cluster 1 (Home) n = 3,159	0.12	0.88	0.21	0.79	0.22	0.78	n = 2025	0.08	0.51	0.32	0.09
	Cluster 2 (Community) n = 140	0.11	0.89	0.82	0.18	0.29	0.71	n = 121	0.03	0.24	0.56	0.17
	Cluster 3 (Inpatient) n = 172	0.14	0.86	0.35	0.65	0.20	0.80	n = 161	0.07	0.50	0.34	0.09
10 Day After All First Tests	Cluster 1 (Inpatient) n = 810	0.08	0.92	0.32	0.68	0.25	0.75	n = 748	0.08	0.47	0.35	0.10
	Cluster 2 (Inpatient/Home) n = 578	0.08	0.92	0.33	0.67	0.33	0.67	n = 492	0.06	0.50	0.33	0.12
	Cluster 3 (Home) n = 1,832	0.03	0.97	0.17	0.83	0.17	0.83	n = 875	0.09	0.53	0.32	0.07

*The number of residents with a calculated Charlson Comorbidity Coefficient in each group can be seen in the 'N' column. Where a Charlson Comorbidity index could not be calculated, we did not include those residents in the proportions and association calculations relating to the index. 'Has diabetes' and 'has dementia' refer to whether the patient has been observed to have any of the dementia or diagnosis criteria. The combinations found to be non-independent through the chi-squared test are highlighted in grey.

The majority of residents both start and end in the care home cluster. More die within 10 days than are transferred to a stay in hospital. A similar proportion from inpatient care and care homes died within 10 days.

2.4 Discussion

For care home residents the common patterns of healthcare before and after a positive Pillar 1 COVID-19 test generally consisted of residents who stayed in the care home for the whole sequence duration, and those who had the entire duration in hospital. The clusters of healthcare before any first COVID-19 test contain an additional group of residents receiving regular community care across the 10-days before. Clusters after first COVID-19 tests included an additional group of residents who were discharged halfway through the sequence.

Diabetes was always associated with clusters representing higher levels of care. Dementia is associated with inpatient care after a testing event and appears to

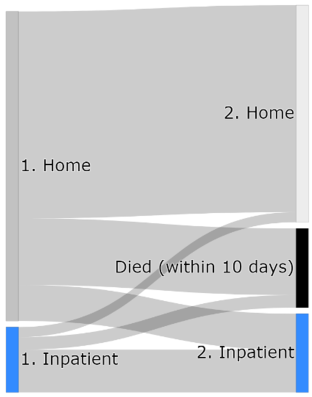

Figure 2.3: Sankey diagram demonstrating flow between states before and after a resident's first COVID-19 positive test.

be highly correlated with a short-term discharge from hospital. Residents who were discharged from inpatient care during the 10-days after their first test appeared to have a similar 28-day mortality rate than those who stayed in hospital. Charlson comorbidity coefficient was found only to be associated with the set of sequences where there was a high level of community care cluster. This may have been due to smaller sample sizes since these calculations only included patients with ICD-10 codes.

NHS secondary care use fell during the pandemic. However, the cluster assignments for all the sequences of care before and after COVID-19 tests and positive COVID-19 tests contain a substantial specific inpatient cluster. There was still a group of residents in hospital, despite the decrease in secondary care use for care home residents at the start of the pandemic [12].

Dementia is associated with the cluster assignments in the '*after*' event cluster assignments. After the tests there are more residents with dementia in the clusters characterised by the inpatient state, in both the '*positive tests*' and '*all tests*' cases, indicating a significant proportion of residents with dementia have transferred into hospital after their test. Residents with dementia are most often in the *inpatient to home transfer* cluster after a first test, which implies that residents with dementia may be more likely to have a shorter stay in hospital. Deciding whether to send residents with dementia for an inpatient stay may be difficult; studies indicate that hospitalisations can be detrimental for individuals with dementia as evidence suggests they are linked with advanced stage of dementia and deterioration of active daily living, among other factors [25, 26]. Evidence suggests that residents with dementia were challenging to care for during the pandemic due to difficulties in adhering to social distancing in both the care home and hospital setting, this may have led to increased hospitalisation as well as high levels of discharge back into homes [27].

The Sankey diagram in Figure 2.3 demonstrates movement of residents between clusters before and after their positive test. We see that a similar proportion of residents from the home cluster and the inpatient cluster die within 10 days of their test (and therefore aren't clustered after their test). This finding could also be an artefact of the usage of Pillar 1 testing data, providing a sample of positive tests that are more likely to be symptomatic in care homes and more routine in hospitals. Alternatively, it may suggest that more residents in the care home should receive hospital care, but also could suggest that the level of care in hospital is not an improvement. We cannot account for how ill a resident is, so this could play a part in increasing inpatient mortality rates.

We provide, to our knowledge, the first in-depth investigation into healthcare patterns of care home residents during the COVID-19 pandemic. Other research provides information on care in the homes during the pandemic, such as that done by Shallcross et al. investigating care home-level risk factors among other work [28]. Our findings can be used in context with research on other aspects of residents' care during the pandemic, to provide thorough policy guidelines for caring for this vulnerable group of the population.

This study demonstrates evidence of movement of positive and suspected positive (Pillar 1 tested) care home residents between care settings in the days surrounding their tests. We also see evidence of residents with dementia experiencing short stays in hospital around the time of their tests. The nature of short stays in hospital for this vulnerable set of patients is likely to be detrimental to patients' health, in general and within the context of nosocomial infection risk for the resident and the whole home. To our knowledge there was no specific guidance relating to secondary care for residents with dementia during the pandemic. We highlight that this group moved around between high-risk care locations and future policy could be targeted to avoid this in the case of local or more widespread outbreaks.

Our results also imply that residents in hospital are equally likely to die within

10 days of their test as those in the home beforehand and therefore suggests that hospital may not provide significantly improved outcomes. Hospital appointments are potentially disruptive to care home residents' wellbeing, so should be considered carefully [29]. Future policy could indicate that in the early stages of a novel pandemic with an unvaccinated population, it should be encouraged to keep residents in an environment they are used to. The extra care may not be worth the distress of a hospital visit. We observe that patients with comorbidities such as diabetes are disproportionately represented in the group of patients who receive hospital care for all of the time periods investigated.

This study highlights a need for more admission and discharge guidance on sending residents to secondary care for care home residents in the early stages of the pandemic. guidance should include more consideration of the vulnerabilities of care home residents – such as residents with dementia. Some guidance was released related to the issue of hospital admissions, such as the guidance. One such issue was *Overview of adult social care guidance on coronavirus (COVID-19)* [30]. As was the case with most guidance, admission and discharge from hospital guidance was generally from an infection prevention and control perspective. Further research is needed into the impacts of secondary care admissions for care home residents during the COVID-19 pandemic to fully understand the implications of sending vulnerable patients to hospital. The negative effects of hospitalisation of care home residents are well documented [29, 31]. These effects may be heightened during a large-scale pandemic. Despite the fact that we see a drop in secondary care usage in our cohort at the start of the pandemic (Supplementary Figure 2.7, this paper highlights the fact that with the (relative lack of) guidance in place at the start of the pandemic, vulnerable residents attended secondary care and moved between care settings. Protocol is needed surrounding this for future infectious disease outbreaks.

One of the strengths of this study is the unique dataset allowing visualisation and analysis of healthcare for care home residents during the COVID-19 pandemic. Data from community care captures much home-based care, but the lack of primary care data means that some information is absent. We have derived some resident characteristics from secondary and community care history and our record of age and gender is incomplete. Diabetes and dementia are drawn from diagnosis codes for hospital stays and community procedures, hence we are likely to identify subset of residents who have more advanced disease or who have accessed external care.

This is particularly pertinent in the case of dementia, as hospital admission is more likely to be for management of co-occurring conditions rather than dementia being a primary diagnosis [32]. This "missing data" is a known limitation of using observational, routinely collected data. Additional data sources such as primary care would be more likely to give a more complete, reliable set of patients with these comorbidities since they often contain more background information on patients than those from secondary care sources. A further limitation is that the COVID-19 testing data contains only Pillar 1 tests processed in the Trust's hospital labs. This may bias the sequences we define (relating to a resident's first positive COVID-19 test and first COVID-19 test in general), since a large portion of Pillar 1 testing was testing on admission to hospital. Testing outside of hospitals was for those with a clinical need, and are therefore more likely to be tests for symptomatic residents [21]. This is the case when looking at test result rates for the different testing locations, with tests in care homes much more often positive than those in hospital settings (see Supplementary Section 2.6.2.3 for breakdown). We find a large portion of the residents in inpatient care before their first positive test, remain in inpatient care afterwards – suggesting COVID-19 may not have been the reason for their admission, but tested positive on arrival. The location of testing differs between wave 1 and wave 2 of the pandemic, we investigated breaking down the clustering analysis into the two waves and found it did not significantly impact the results. The use of Pillar 1 COVID-19 testing allows a consistent level of testing throughout the pandemic, since Pillar 1 testing was introduced first and was conducted over the whole pandemic period. However, a more complete – routine set of COVID-19 tests would give a more accurate description of how residents were treated in general and would allow us to identify residents' first test and positive test more reliably.

Health services such as the National Health Service of the United Kingdom have large pools of untapped data that can be used for large scale, impactful analyses [33]. Research such as this work is needed to demonstrate the work that can be done going forward using linked, routinely collected datasets. The novel methodology demonstrated can be used in more settings to gain insights to other longitudinal care pathways such as what characteristics define what patterns of long-term cancer care patients receive or a patient's pattern of outpatient care within a specific system such as neurology [34]. Implications from this study are limited by the nature of Pillar 1 COVID-19 testing. Further updates to this analysis could involve using additional primary care data to generate more complete pictures of pathways and characteristics allowing for more comprehensive results. Additional work on more recent testing data that is less stratified could also provide additional insights, however this would need to be viewed in the context of more recent COVID-19 policies. Comparisons between healthcare patterns during the pandemic and those outside of the pandemic could also give further insight into how typical decision making was altered by pandemic policy. Above all, this study demonstrates the potential for large scale linkage of routinely collected healthcare data to investigate longitudinal pathways of care for future studies going forward.

2.5 References

[1] J. Hollinghurst *et al.*, "The impact of COVID-19 on adjusted mortality risk in care homes for older adults in Wales, UK: A retrospective population-based cohort study for mortality in 2016–2020," *Age and Ageing*, vol. 50, no. 1, pp. 25–31, Jan. 2021, ISSN: 0002-0729. [Online]. Available: https://doi.org/10.1093/ageing/afaa207 (visited on 05/17/2023).

[2] O. for National Statistics, *Deaths involving COVID-19 in the care sector, England and Wales*. (visited on 07/21/2021).

[3] S. H. Dykgraaf *et al.*, "Protecting Nursing Homes and Long-Term Care Facilities From COVID-19: A Rapid Review of International Evidence," *Journal of the American Medical Directors Association*, vol. 22, no. 10, pp. 1969–1988, Oct. 2021, Publisher: Elsevier, ISSN: 1525-8610, 1538-9375. [Online]. Available: https://www.jamda.com/article/S1525-8610(21)00675-7/fulltext (visited on 03/26/2024).

[4] F. Crotty, R. Watson, and W. K. Lim, "Nursing homes: The titanic of cruise ships – will residential aged care facilities survive the COVID-19 pandemic?" *Internal Medicine Journal*, vol. 50, no. 9, pp. 1033–1036, Sep. 2020, ISSN: 1444-0903. [Online]. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7436225/ (visited on 03/26/2024).

[5] M. M. Walle-Hansen, A. H. Ranhoff, M. Mellingsæter, M. S. Wang-Hansen, and M. Myrstad, "Health-related quality of life, functional decline, and long-term mortality in older patients following hospitalisation due to COVID-19," *BMC Geriatrics*, vol. 21, no. 1, p. 199, Mar. 2021, ISSN: 1471-2318. [Online]. Available: https://doi.org/10.1186/s12877-021-02140-x (visited on 06/26/2023).

[6] The Health Foundation, "Adult social care and COVID-19: Assessing the policy response in England so far - The Health Foundation," Tech. Rep. [Online]. Available: https://www.health.org.uk/publications/reports/adult-social-care-and-covid-19-assessing-the-policy-response-in-england (visited on 05/27/2022).

[7] The Health Foundation, *COVID-19 Policy Tracker*. [Online]. Available: https://covid19.health.org.uk/home (visited on 06/02/2022).

[8] K. Spilsbury *et al.*, "SEeking AnsweRs for Care Homes during the COVID-19 pandemic (COVID SEARCH)," *Age and Ageing*, vol. 50, no. 2, pp. 335–340, Mar. 2021, ISSN: 0002-0729. [Online]. Available: `https://doi.org/10.1093/ageing/afaa201` (visited on 05/15/2023).

[9] M. Daly, "COVID-19 and care homes in England: What happened and why?" *Social Policy & Administration*, vol. 54, no. 7, pp. 985–998, 2020, ISSN: 1467-9515. [Online]. Available: `https://onlinelibrary.wiley.com/doi/abs/10.1111/spol.12645` (visited on 02/01/2022).

[10] D. Grinspun, J. H. Matthews, R. Bonner, T. Moreno-Casbas, and J. Mo, "COVID-19 pandemic in long-term care: An international perspective for policy considerations," *International Journal of Nursing Sciences*, vol. 10, no. 2, pp. 158–166, Mar. 2023, ISSN: 2096-6296. [Online]. Available: `https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10063321/` (visited on 03/26/2024).

[11] NHS England and NHS Improvement, *Next steps on nhs response to covid-19*, Letter, Mar. 2020.

[12] F. Grimm, K. Hodgson, R. Brine, and S. R. Deeny, "Hospital admissions from care homes in England during the COVID-19 pandemic: A retrospective, cross-sectional analysis using linked administrative data," *International Journal of Population Data Science*, vol. 5, no. 4, p. 1663, Jul. 2021, ISSN: 2399-4908. [Online]. Available: `https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8267611/` (visited on 02/02/2022).

[13] R. Moynihan *et al.*, "Impact of COVID-19 pandemic on utilisation of healthcare services: A systematic review," *BMJ Open*, vol. 11, no. 3, e045343, Mar. 2021, Publisher: British Medical Journal Publishing Group Section: Health services research, ISSN: 2044-6055, 2044-6055. [Online]. Available: `https://bmjopen.bmj.com/content/11/3/e045343` (visited on 07/21/2021).

[14] Y. V. Chudasama *et al.*, "Impact of COVID-19 on routine care for chronic diseases: A global survey of views from healthcare professionals," *Diabetes & Metabolic Syndrome*, vol. 14, no. 5, pp. 965–967, Oct. 2020, ISSN: 1878-0334.

[15] A. L. Gordon, M. Franklin, L. Bradshaw, P. Logan, R. Elliott, and J. R. Gladman, "Health status of UK care home residents: A cohort study," *Age and Ageing*, vol. 43, no. 1, pp. 97–103, Jan. 2014, ISSN: 0002-0729. [Online]. Available: https://doi.org/10.1093/ageing/aft077 (visited on 06/20/2022).

[16] Diabetes UK, "Good clinical practice guidelines for care home residents with diabetes," Tech. Rep., Jan. 2010. [Online]. Available: https://www.diabetes.org.uk/resources-s3/2017-09/Care-homes-0110_0.pdf (visited on 06/14/2022).

[17] "Home from home: A report highlighting opportunities for improving standards of dementia care in care homes," 2007. [Online]. Available: https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/home_from_home_full_report.pdf.

[18] A. Schultze *et al.*, "Identifying Care Home Residents in Electronic Health Records - An OpenSAFELY Short Data Report," Wellcome Open Research, Tech. Rep. 6:90, Apr. 2021, Type: article. [Online]. Available: https://wellcomeopenresearch.org/articles/6-90 (visited on 05/26/2022).

[19] B. Hanratty, J. K. Burton, C. Goodman, A. L. Gordon, and K. Spilsbury, "Covid-19 and lack of linked datasets for care homes," *BMJ*, vol. 369, p. m2463, Jun. 2020, Publisher: British Medical Journal Publishing Group Section: Editorial, ISSN: 1756-1833. [Online]. Available: https://www.bmj.com/content/369/bmj.m2463 (visited on 07/21/2021).

[20] E. I. Benchimol *et al.*, "The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) statement," *PLoS medicine*, vol. 12, no. 10, e1001885, Oct. 2015, ISSN: 1549-1676.

[21] Department of Health and Social Care, *Coronavirus (COVID-19) - Scaling up our testing programmes*, Apr. 2020. [Online]. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/878121/coronavirus-covid-19-testing-strategy.pdf.

[22] A. Abbott and J. Forrest, "Optimal Matching Methods for Historical Sequences," *The Journal of Interdisciplinary History*, vol. 16, no. 3, pp. 471–494, 1986, Publisher: The MIT Press, ISSN: 0022-1953. [Online]. Available: https://www.jstor.org/stable/204500 (visited on 12/16/2021).

[23] A. Gabadinho, G. Ritschard, N. S. Müller, and M. Studer, "Analyzing and Visualizing State Sequences in R with TraMineR," *Journal of Statistical Software*, vol. 40, no. 1, pp. 1–37, Apr. 2011, Number: 1, ISSN: 1548-7660. [Online]. Available: `https://www.jstatsoft.org/index.php/jss/article/view/v040i04` (visited on 07/23/2021).

[24] M. L. McHugh, "The Chi-square test of independence," *Biochemia Medica*, vol. 23, no. 2, pp. 143–149, Jun. 2013, Publisher: Medicinska naklada, ISSN: 1330-0962, 1846-7482. [Online]. Available: `https://hrcak.srce.hr/clanak/152608` (visited on 04/07/2022).

[25] J. Lehmann *et al.*, "The Impact of Hospitalization on Readmission, Institutionalization, and Mortality of People with Dementia: A Systematic Review and Meta-Analysis," *Journal of Alzheimer's Disease*, vol. 64, no. 3, pp. 735–749, Jan. 2018, Publisher: IOS Press, ISSN: 1387-2877. [Online]. Available: `https://content.iospress.com/articles/journal-of-alzheimers-disease/jad171128` (visited on 06/16/2022).

[26] D. Wolf, C. Rhein, K. Geschke, and A. Fellgiebel, "Preventable hospitalizations among older patients with cognitive impairments and dementia," *International Psychogeriatrics*, vol. 31, no. 3, pp. 383–391, Mar. 2019, Publisher: Cambridge University Press, ISSN: 1041-6102, 1741-203X. [Online]. Available: `https://www.cambridge.org/core/journals/international-psychogeriatrics/article/abs/preventable-hospitalizations-among-older-patients-with-cognitive-impairments-and-dementia/5B0CE9958C1B20F6E86D159EA00776CB` (visited on 06/20/2022).

[27] A. Scerri, C. Borg Xuereb, and C. Scerri, "Nurses' Experiences of Caring for Long-Term Care Residents With Dementia During the COVID-19 Pandemic," *Gerontology and Geriatric Medicine*, vol. 8, p. 23 337 214 221 077 793, Jan. 2022, Publisher: SAGE Publications Inc, ISSN: 2333-7214. [Online]. Available: `https://doi.org/10.1177/23337214221077793` (visited on 09/09/2022).

[28] L. Shallcross *et al.*, "Factors associated with SARS-CoV-2 infection and outbreaks in long-term care facilities in England: A national cross-sectional survey," *The Lancet Healthy Longevity*, vol. 2, no. 3, e129–e142, Mar. 2021, Publisher: Elsevier, ISSN: 2666-7568. [Online]. Available: `https://www.thelancet.com/journals/lanhl/article/PIIS2666-7568(20)30065-9/abstract` (visited on 07/21/2021).

[29] S. M. Friedman, D. A. Mendelson, K. W. Bingham, and R. M. McCann, "Hazards of Hospitalization: Residence Prior to Admission Predicts Outcomes," *The Gerontologist*, vol. 48, no. 4, pp. 537–541, Aug. 2008, ISSN: 0016-9013. [Online]. Available: `https://doi.org/10.1093/geront/48.4.537` (visited on 03/29/2024).

[30] Department of Health and Social Care, *Overview of adult social care guidance on coronavirus (COVID-19)*, Aug. 2020. [Online]. Available: `https://www.gov.uk/guidance/overview-of-adult-social-care-guidance-on-coronavirus-covid-19`.

[31] C. H. Hirsch, L. Sommers, A. Olsen, L. Mullen, and C. H. Winograd, "The Natural History of Functional Morbidity in Hospitalized Older Patients," *Journal of the American Geriatrics Society*, vol. 38, no. 12, pp. 1296–1303, 1990, ISSN: 1532-5415. [Online]. Available: `https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1532-5415.1990.tb03451.x` (visited on 03/29/2024).

[32] A. Sommerlad, G. Perera, A. Singh-Manoux, G. Lewis, R. Stewart, and G. Livingston, "Accuracy of general hospital dementia diagnoses in England: Sensitivity, specificity, and predictors of diagnostic accuracy 2008–2016," *Alzheimer's & Dementia*, vol. 14, no. 7, pp. 933–943, 2018, ISSN: 1552-5279. [Online]. Available: `https://onlinelibrary.wiley.com/doi/abs/10.1016/j.jalz.2018.02.012` (visited on 03/02/2023).

[34] F. Biggin, Q. Ashcroft, T. Howcroft, J. Knight, and H. Emsley, "Discovering patterns in outpatient neurology appointments using state sequence analysis," *BMC Health Services Research*, vol. 23, no. 1, p. 1208, Nov. 2023, ISSN: 1472-6963. [Online]. Available: `https://doi.org/10.1186/s12913-023-10218-y` (visited on 06/13/2024).

[35] J. Roux, O. Grimaud, and E. Leray, "Use of state sequence analysis for care pathway analysis: The example of multiple sclerosis," *Statistical Methods in Medical Research*, vol. 28, no. 6, pp. 1651–1663, Jun. 2019, Publisher: SAGE Publications Ltd STM, ISSN: 0962-2802. [Online]. Available: `https://doi.org/10.1177/0962280218772068` (visited on 07/22/2021).

[36] V. Vogt, S. M. Scholz, and L. Sundmacher, "Applying sequence clustering techniques to explore practice-based ambulatory care pathways in insurance

claims data," *European Journal of Public Health*, vol. 28, no. 2, pp. 214–219, Apr. 2018, ISSN: 1464-360X.

[37] A. Vanasse *et al.*, "Healthcare utilization after a first hospitalization for COPD: A new approach of State Sequence Analysis based on the '6W' multidimensional model of care trajectories," *BMC Health Services Research*, vol. 20, no. 1, p. 177, Mar. 2020, ISSN: 1472-6963. [Online]. Available: https://doi.org/10.1186/s12913-020-5030-0 (visited on 07/21/2021).

[38] S. B. Needleman and C. D. Wunsch, "A general method applicable to the search for similarities in the amino acid sequence of two proteins," *Journal of Molecular Biology*, vol. 48, no. 3, pp. 443–453, Mar. 1970, ISSN: 0022-2836.

2.6 Supplementary Material

This section was published as supplementary material to the main paper.

2.6.1 Methods

2.6.1.1 Data Description

Table 2.4: Description of each dataset used in the analysis.

Healthcare Interaction Datasets	**Description**
A&E	Details of attendances at 5 A&E departments covered by CDDFT including the two major acute hospitals: Darlington Memorial Hospital and University Hospital of North Durham. Date and location of attendance is included, along with details of investigative procedures carried out on the patient and diagnosis codes.
Inpatient	Details of inpatient spells in the CDDFT hospitals. Dates for duration of overall stay and ward episodes within the stay are included. ICD-10 (International Statistical Classification of Diseases and Related Health Problems 10th Revision) codes detailing diagnosis and comorbidities.
Inpatient Observations	Early Warning Scores of inpatients during their hospital stay (no constituent vital sign observations). Includes ward code of stay, date and time observation was made.
Outpatient	Details of outpatient appointments. Includes date and duration of interaction. Includes specialty of staff responsible for the patient.
Ward Episodes	Details of patient ward episodes during their hospital stays. Includes the ward code of the episode.

Community	Details of community appointments and callouts in the County Durham and Darlington area. Date and location type (conducted at patient's home, in community hospital etc) are included, along with care plan details indicating the reason for the interaction.
Health Call	EWS observations of care home residents logged on the Health Call app by carers. Contains the separate observations that contribute towards calculating an EWS score and the time the observations were taken.
COVID-19 Testing (P1)	Pillar 1 ('swab testing in Public Health England (PHE) labs and NHS hospitals for those with a clinical need, and health and care workers' 1), COVID-19 PCR test results from the Trust's Pathology Lab beginning in March 2020. Includes age at date of test and date of test.
Additional Data Sets	
Discharges	Summary dataset of hospital visits, including number of hospital visits and dates of discharge from hospital. Also includes care home (if applicable) of patient mined from hospital records, and date of death (if applicable) contained in hospital records of the patient. Used as a lookup table for patient death dates.
Health Call Referrals	Dates of activation and deactivation of care home residents on the Health Call system. Activation dates refer to the date they are first put onto the Health Call system, may be when Health Call first goes live in the care home, or when the resident first moves to the care home. Conversely, deactivation dates may refer to the date a resident leaves the care home (moves care home or goes back to own accommodation) or dies. The data identifies the most recent care home each resident has been assigned to, providing an indicator of each resident's care home.
Health Call Implementation	Dates each Health Call care home 'went live' and implemented Health Call. This is the only non-patient level dataset.

2.6.1.2 Defining Cohort

2.6.1.3 Identifying Individuals

Since the datasets contain information on the majority of CDDFT hospital interactions, not just care home residents, we need to define the cohort of care home residents we are investigating. We can use the common set of pseudonymised NHS numbers to identify this set of individuals through all of the available datasets.

We primarily use the Health Call activations to define the cohort of care home residents, since this contains all residents registered on the Health Call system.

This activations data will not include any residents that died before Health Call went live in the home, since they are not registered on the system posthumously. In order to combat this we identify additional residents of the Health Call homes using their presence in other datasets:

- Hospital discharge data to an associated Health Call home
- COVID-19 tests in Health Call homes (over 65s)

We do not include any residents in the cohort who do not have any healthcare interactions (no observations in the healthcare interactions datasets) at all after they are identified.

2.6.1.4 Date of Addition to Cohort

We identify the date at which a resident can first be confirmed to be a care home resident, and therefore the date they are added to our cohort, by looking for the first date at which they were observed to be in a care home. This may be before Health Call was introduced in the care home. The date of addition to the cohort is defined as the earliest of the following types of observations:

- COVID-19 tests in care homes
- Activation on the Health Call system or any Health Call uploads
- Inpatient discharge to care homes or to address of a care home in discharge dataset

- Inpatient admission from care homes
- Community contact in residential or nursing homes

2.6.1.5 Date of Death

In order to identify when a person has died, we use three sources. The main source of death dates is the discharge dataset, which contains details of deaths known to the trust. We also identify death dates as the discharge date of a resident whose discharge method was “Died”, or when there was a registered community appointment for which the care plan sub-category was “Verification of death”.

2.6.1.6 Date of Removal from cohort

Some residents may move out of the area/group of care homes under investigation. Our death data is likely not comprehensive. We can remove residents from the cohort when they are deactivated from the Health Call system and not reactivated again. If any of their activations have no deactivation date, they are considered still active. Residents who are removed at this point but not considered to have died unless we have a specific date of death. Their date of removal is whichever is earliest of their registered deactivation from the Health Call system, or their date of death defined previously.

2.6.1.7 Inclusion in Sequence Analysis

Sequences are removed when the sequence definition exceeds the boundary of a resident’s time in the cohort. Sequences before the test are not included when a resident moves into the home in the 10-days before the test (198 removed before first positive test, 1,296 removed before a first test). Sequences after the test are not included when the resident dies in the 10-days after the test, or their test is less than 10 days before the end of the study period (316 removed before a first positive test, 1,547 removed after a first test).

2.6.1.8 Identifying Resident Conditions

We have identified residents with certain conditions, so we can compare treatment, trajectories, and outcomes of these residents. The rules are shown in Table 2.6.

Table 2.6: Rules for condition identification.

Diabetes	Community care plan subcategories; 'diabetes care and management ongoing' and 'blood glucose monitoring' Outpatient appointments with staff type 'DIABETIC'
	Inpatient ICD-10 codes of; E08, E09, E10, E11, E13
Dementia	Inpatient ICD-10 codes of; F00, F01, F03
Frailty (Charlson Comorbidity Coefficient)	Calculated using the 'comorbidity' R package using inpatient ICD-10 codes

2.6.1.9 Location and Test Result Correlations

Since the COVID-19 testing data is from Pillar 1 testing, we can investigate rates of testing in each location as well as differences in positivity rates between the locations. Using the trajectories defined in the main paper, we observe an individual's highest level of care each day. We link this to the days the residents in the cohort appear in the COVID-19 testing data. We take one test per person per day and link to their activity on the same day.

We also separate out testing in wave 1 and wave 2 (using the ONS estimations of the start and end of each wave), in order to identify any differences in testing at different stages of the pandemic.

As in the main paper, we use a simple Bonferroni multiple testing adjustment to account for the fact that many tests are conducted in this document. We use an adjusted significance level of $\alpha = 0.000862$, from the original value of $\alpha = 0.05$and accounting for the 58 tests that are calculated in this document.

2.6.1.10 State Sequence Analysis Background

State sequence analysis is a clustering technique that groups similar sequences of states using a dissimilarity measure. State sequence analysis was used in a health setting by Roux et. al. who use sequences to describe treatment of multiple sclerosis patients, with states describing the level of care consumption within a period of time for each patient [35]. Vogt et. al. used the technique for treatment sequences of heart failure patients aiming to identify and describe common ambulatory care pathways between different providers [36]. Vanasse et. al. used multidimensional State Sequence Analysis to understand healthcare utilisation for COPD patients, aiming to identify any areas of the healthcare systems where healthcare utilisation can be reduced, and patient outcomes can be improved [37].

2.6.1.11 Optimal Matching

We use the optimal matching metric to measure similarity (or more accurately, dissimilarity) between two sequences. The optimal matching metric is calculated by transforming one sequence into another, by a sequence of three actions: insertion, deletion, and substitution of states, each with a corresponding cost. The dissimilarity between the two sequences is the (lowest possible) total cost of these actions2. More similar pairs of sequences will have smaller a smaller optimal matching metric.

In the case of this study, we set insertion and deletion costs to 1 for any state. The cost of substitution from one state to the other depends on which states are involved in the substitution. We create a symmetrical substitution matrix (n x n), where n is the number of possible states, to define substitution costs. We define the cost of substitution between state A and state B using the transition rate (occurrence of successive states) of state A to state B and state B to state A. States that occur consecutively more often have lower substitution costs. For example, community states are often seen in the middle of care home stays – the community (internal) and care home states often occur consecutively. Therefore replacing a care home state with a community state would likely have a lower substitution cost than the less common A&E state. The maximum possible substitution cost is 2, since this would be the same as deleting state A and inserting state B.

For example, if we have two sequences A & B, both 3 states long. Where A = {CareHome, CareHome, Community} and B = {CareHome, Community, CareHome}. Two ways we could transform B to A are:

1. Insert care home as state 1 of sequence B
   (a) A = {CareHome, CareHome, Community}
   (b) B = {CareHome, CareHome, Community, CareHome}
2. Delete final state of sequence B
   (a) A = {CareHome, CareHome, Community}

   (b) B = {CareHome, CareHome, Community}

Or

1. Substitue 2nd state of sequence B for CareHome
   (a) A = {CareHome, CareHome, Community}
   (b) B = {CareHome, CareHome, CareHome}
2. Substitute final state of sequence B for Community
   (a) A = {CareHome, CareHome, Community}
   (b) B = {CareHome, CareHome, Community}

Since we have more than one way to transform sequence B to sequence A, we choose the lowest cost method. The lowest cost method of transforming sequences is found using the Needleman-Wunsch algorithm[38]. The minimum cost of transforming from sequence A to sequence B is the same as the minimum cost of transforming sequence B to sequence A.

2.6.1.12 Number of Clusters Selection

Once we have performed hierarchical clustering on the sequences, we identify most and least similar sequences. In order to select the optimal number of clusters, we use the average silhouette metric to quantify the relative quality of cluster assignments. The average silhouette width compares the dissimilarities of within-cluster sequences and the between-cluster distances for each sequence. Higher average silhouette widths imply more consistent clusters, so we typically take the number of clusters that maximises average silhouette width.

However, this can be a trade-off since more clusters can make results more difficult to interpret. In each clustering, the trade-off between additional clusters and the additional complexity they bring into the results must be assessed. We used the size of the clusters that are created as an additional constraint on the number of clusters selected, since clusters with fewer than 50 sequences were disallowed, and the number of clusters is reduced by 1 if this criterion is met. The silhouette width

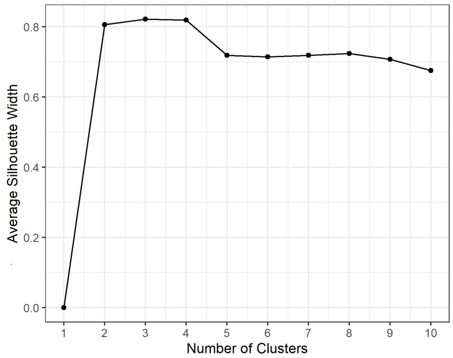

Figure 2.4: The average silhouette width for the number of clusters (1-10) in the Before First Positive Test sequences. 2 clusters were selected.

plot for selecting the number of clusters in the *before first positive test* sequences is shown in Figure 2.4.

2.6.2 Results

Table 2.7 shows the datasets used for this study. Numbers of observations are calculated for each of the datasets. Number of individuals is calculated through the number of unique NHS numbers.

2.6.2.1 Cohort and Selection Flow Diagram

See Figure 2.5 for a flow chart of cohort and sequence selection.

2.6.2.2 Cohort Growth

Since our cohort is identified observationally –as time goes on from the start of the study data, there are more data points available to identify our cohort with and the number of residents who fit the criteria increases over time. This is shown in Figure 2.6.

Figure 2.7 shows the monthly number of observations in each healthcare interaction dataset. Despite the gradually increasing cohort size seen in Figure 2.6, we still see a drop in observations of secondary and community care.

Table 2.7: Counts of observations and individuals in each complete data set.

Data Set	No. of Observations	No. of Individuals	Proportion of Cohort
A&E	675,500	306,750	50%
Inpatient	480,745	177,403	29%
Inpatient Observations	3,726,105	177,825	29%
Outpatient	1,770,173	328,638	54%
Ward Episodes	550,358	186,885	31%
Community	3,185,812	62,917	10%
Health Call	72,261	6,318	1%
COVID-19 Testing (P1)	240,805	94,531	15%
Additional Data Sets			
Discharges	47,982	20,530	3%
Health Call	15,936	8,785	1%
Health Call Implementation	125	-	-
Total	10,701,759	612,408	-

*Individuals can be in more than one dataset hence the proportions do not equal 1.

2.6.2.3 Location and Test Result Correlation

Overall

We can see the association between where residents have been tested, and the result of the test. We take one test per resident per day and link to their activity on the same day. This results in 14,005 tests. Results indicate that the tests in our dataset are not spread evenly across the locations. The most common location for tests was inpatient with 53% (7,477) of the tests, with A&E the second most common with (23%). The least common was outpatients, with 0.1% (16) of the tests. It also appears that the test result is associated with the location of the test (chi-squared test for independence $p \leq 0.0005$). Tests with a community interaction (both internal and external) on the same date were positive 26% of the time. The rest of the interactions are generally around 5% positive.

The correlations between where residents have been tested, and the result of the test can be found in Table 2.8.

Table 2.8: Table of proportions of test results in each of the locations where the residents received a COVID-19 test.

Overall	Positive	Negative	Not tested	Total
Care Home	6%	91%	3%	2,447
Care Home (Community check up)	19%	78%	3%	2,156
Community External	17%	80%	3%	82
A&E	6%	92%	2%	4,889
Inpatient (Hospital)	4%	94	3%	12,842
Outpatient (Hospital)	-	100%	-	28
Wave 1				
Care Home	56%	42%	2%	155
Care Home (Community check-up)	53%	45%	2%	641
Community External	57%	43%	0%	21
A&E	24%	72%	4%	302
Inpatient (Hospital)	23%	74%	2%	316
Outpatient (Hospital)	NA	NA	NA	0
Wave 2				
Care Home	3%	94%	3%	1,083
Care Home (Community check-up)	7%	99%	5%	473
Community External	0	94%	6%	17
A&E	7%	92%	2%	1,482
Inpatient (Hospital)	4%	93%	3%	3,705
Outpatient (Hosptial)	0	100%	0	7

There is a large difference between where the tests are conducted during the first wave and the second wave. The COVID-19 testing in the (pillar 1) data is more often conducted in the care homes during the first wave, whereas the testing is much more common in hospital settings (inpatient and A&E) during the second wave of the pandemic. Overall rates of positive tests in the residents reduce dramatically in the second wave.

2.6.2.4 Cluster Associations Table

Included here are the raw numbers of crossover between characteristics and clusters and p-values of the chi-square tests for independence between the resident characteristics/outcomes and the cluster assignments of the sequences.

Table 2.9: Table of p-value of chi-squared test of independence between the cluster assignments and corresponding outcomes and comorbidities.

	Mortality	Diabetes	Dementia	Charlson CI
10 Day Before Positive	0.71	0.00026	0.15	0.27
10 Day After Positive	0.12	1.0×10^{-8}	0.00036	0.83
10 Day Before All First Tests	0.68	2.0×10^{-64}	0.088	1.4×10^{-8}
10 Day After All First Tests	9.3×10^{-8}	1.1×10^{-24}	4.7×10^{-17}	0.0092

2.6.2.5 Further Cluster Associations

Association with Test Result

Associations between test result and the cluster assignments were investigated in order to better understand the testing regime.

Association with Wave of Pandemic

Inpatient clusters are more common during Wave 2 of the pandemic, for the sequences both before and after a resident's first positive COVID-19 test. Only a small number of residents' first tests occur within Wave 2, which is likely why the association between wave and cluster assignment before a resident's first test is not significant. However, the cluster assignments after a resident's first test appear to still be statistically significant, in-keeping with the trend of more residents receiving higher levels of care during the second wave.

2.6.2.6 Clustering Waves Separately

Wave 1

The clustering in Figure 2.8 looks similar to the overall one in the main paper. There is a slightly smaller proportion of inpatients in each assignment.

The cluster assignments for the testing in the first wave and characteristics of the residents shown in Tables 2.12 and 2.13 generally have fewer significant associations than the full clustering. This is likely due to the smaller sample size.

Diabetes is generally significantly associated with the higher care consumption clusters as seen previously, however the before the first positive test this is not the case. The percentage difference looks to fit the trend, however, is not large enough to be significant. Half of the residents in the care home after their test, tested positive, while only 24% of the residents who were an inpatient after their test were positive.

Dementia was not found to be significant for any of the cluster assignments, indicating residents with dementia were significantly treated in one particular.

Charlson comorbidity index was found to be significant for the care before first COVID-19 test, with residents with a higher index being more often in higher levels of care. This is, likely due to the presence of the inpatient cluster. The residents in hospital were also frailer than those who stayed in the home.

Wave 2

Clustered sequences for Wave 2 are shown in figure 2.9.

The sequence associations with resident characteristics are shown in Tables 2.14 and 2.15. 'After positive test' sequence definition in the second wave is the only set where the care home cluster is not the most common cluster. This reflects the fact the pillar 1 testing in the second wave is more routine testing on arrival to hospital. The inpatient clusters include a larger proportion of the residents in the

'After' sequences than in the overall testing clusters, evidencing this further.

There appears to be no statistically significant relationship between diabetes and the clusters for the sequences before and after a resident's first positive test. This is also likely due to the sample size, as we still see the residents with diabetes in the clusters relating to higher levels of care.

After a resident's first test, residents with dementia make up 31% of the community cluster and make up a similar proportion of residents in the two inpatient clusters and are more prevalent than they are in the home cluster.

From the tests in the second wave, residents who have been an inpatient after their test have the highest rate of deaths. This is intuitive, since residents receiving the highest levels of care are likely to be the highest mortality risk.

2.6.2.7 Limitations of State Sequence Analysis

State sequence analysis in this application quantises care into discrete states, with one per day- collapsing down any days where more than one event occurs. We use a resolution of 10 days that attempts to balance complexity/length of the sequences and how well it represents the events happening during the sequence. Smaller time units would allow a more precise description of events but can result in sequences and clusters that are to interpret over longer time periods. Additional contextual information is also not included in the analysis, so specific circumstances/reasons for each healthcare event are not included.

The sequences are treated as a whole, where patterns of states are identified. A transition matrix is used to define the substitution costs through the transition rates between the states, however order forwards and backwards in the sequences are treated equally. The sequence analysis does not have a temporal component other than the order of the sequence, and therefore transitions backwards are treated equally to transitions forwards.

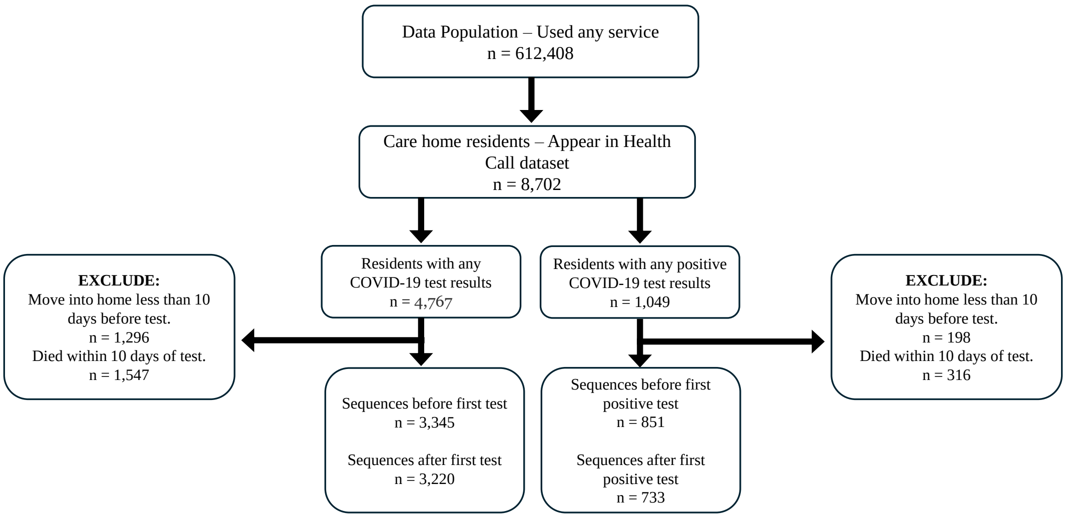

Figure 2.5: Flow chart demonstrating selection of the cohort, and sequences used in the analysis.

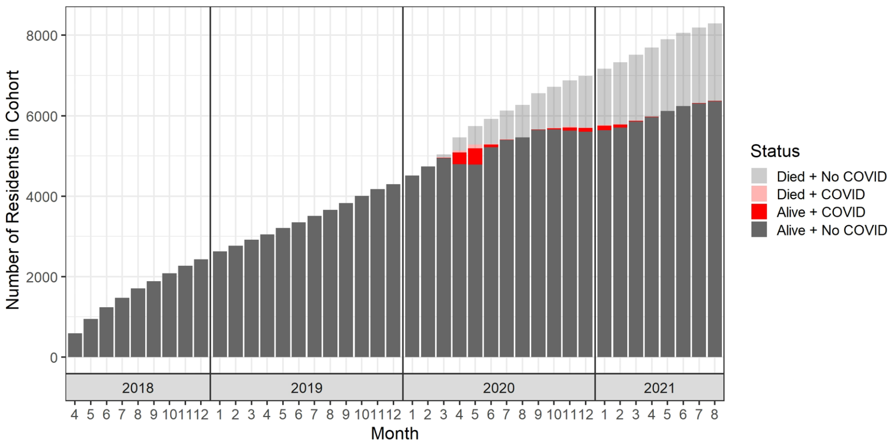

Figure 2.6: Number of residents in the cohort over time, also indicating the total number of residents that have died and how many tested positive for COVID-19 each month.

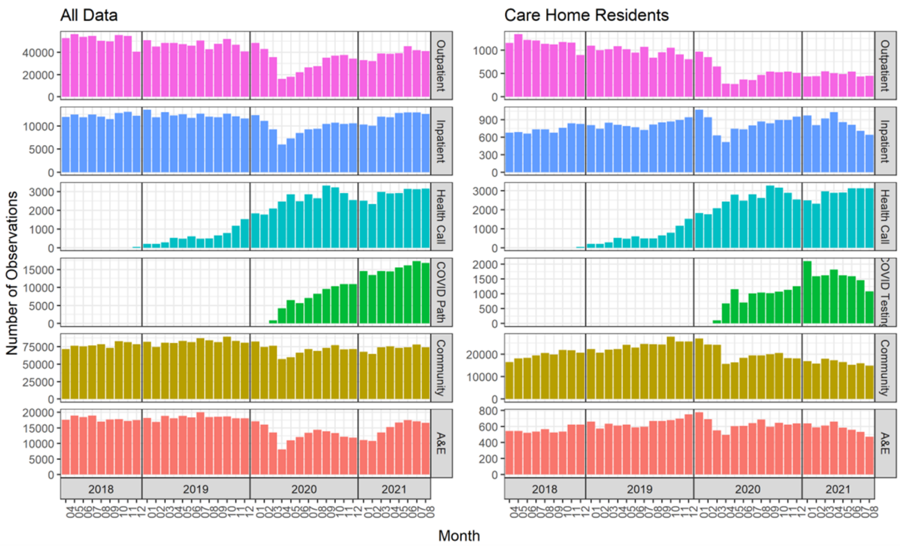

Figure 2.7: Numbers of observations in each dataset over the study period. Broken down by entire dataset population and the cohort of care home residents.

Table 2.10: Table of associations between cluster assignments and test result of index event.

		Test Result		Test Result
		Pos	Neg	
10 Days Before First Positive	Cluster 1 (Inpatient) n = 142	NA	NA	NA
	Cluster 2 (Home) n = 709	NA	NA	
10 Days After First Positive	Cluster 1 (Inpatient) n = 195	NA	NA	NA
	Cluster 2 (Home) n = 538	NA	NA	
10 Days Before All First Tests	Cluster 1 (Home) n = 3,159	81	81	0.00035
	Cluster 2 (Community) n = 140	94	94	
	Cluster 3 (Inpatient) n = 172	86	86	
10 Days After All First Tests	Cluster 1 (Inpatient) n = 810	92	92	3.0e-31
	Cluster 2 (Inpatient/Home)	93	93	

Table 2.11: Table of associations between cluster assignments and wave the test occurred in.

		Wave		p-value
		1	2	
10 Days Before First Positive	Cluster 1 (Inpatient) n = 142	22	78	2.2e-16
	Cluster 2 (Home) n = 709	76	24	
10 Days After First Positive	Cluster 1 (Inpatient) n = 195	32	68	2.2e-16
	Cluster 2 (Home) n = 538	80	20	
10 Days Before All First Tests	Cluster 1 (Home) n = 3,159	42	58	0.016
	Cluster 2 (Community) n = 140	29	71	
	Cluster 3 (Inpatient) n = 172	48	52	
10 Days After All First Tests	Cluster 1 (Inpatient) n = 810	28	72	8.35e-20
	Cluster 2 (Inpatient/Home) n = 578	32	68	
	Cluster 3 (Home) n = 1,832	49	51	

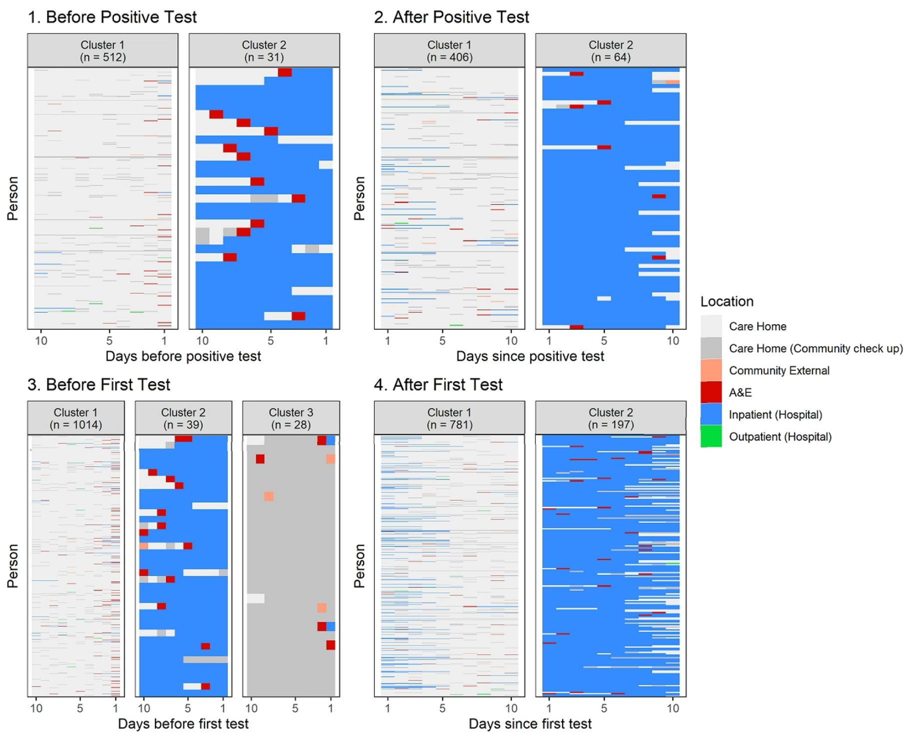

Figure 2.8: Cluster assignments describing typical patterns of care before and after residents' first positive tests and first tests during the first wave of the pandemic.

Table 2.12: Table of the associations between the cluster assignments of the trajectories before and after a resident's first positive test and a resident's first test, and the characteristics of the residents in the cluster. Filtered for wave 1.

		28 Day Mortality		Diabetes		Dementia		Charlson CI (Proportion of those with a CCI)			
		T (%)	F (%)	T (%)	F (%)	T (%)	F (%)	0 (%)	1-2 (%)	3-4 (%)	≥5 (%)
10 Day Before First Positive	Cluster 1 (Inpatient) n = 142	23	77	18	82	20	80	08	54	29	09
	Cluster 2 (Home) n = 709	23	77	35	65	23	77	00	53	33	13
10 Day After First Positive	Cluster 1 (Inpatient) n = 195	10	90	15	85	18	82	06	54	31	09
	Cluster 2 (Home) n = 538	19	81	38	62	33	67	05	55	29	11
10 Day Before All First Tests	Cluster 1 (Home) n = 3,159	15	85	18	82	20	80	08	52	30	10
	Cluster 2 (Community) n = 140	15	85	41	59	21	79	05	37	40	18
	Cluster 3 (Inpatient) n = 172	14	86	93	07	46	54	00	08	60	32
10 Day After All First Tests	Cluster 1 (Inpatient) n = 810	06	94	18	82	20	80	08	50	31	12
	Cluster 2 (Inpatient/Home) n = 578	07	93	32	68	25	75	06	47	36	11
	Cluster 3 (Home) n = 1,832	23	77	18	82	20	80	08	54	29	09

Table 2.13: Table of the p-values of the associations between the cluster assignments of the trajectories before and after a resident's first positive test and a resident's first test, and the characteristics of the residents in the cluster. Filtered for wave 1.

	Mortality	Diabetes	Dementia	Charlson CI
10 Day Before First Positive	0.95	0.017	0.76	0.93
10 Day After First Positive	0.058	4.1e-05	0.013	0.96
10 Day Before All First Tests	1	1.1e-22	0.0029	5.7e-0.6
10 Day After All First Tests	0.72	8.9e-06	0.07	0.63

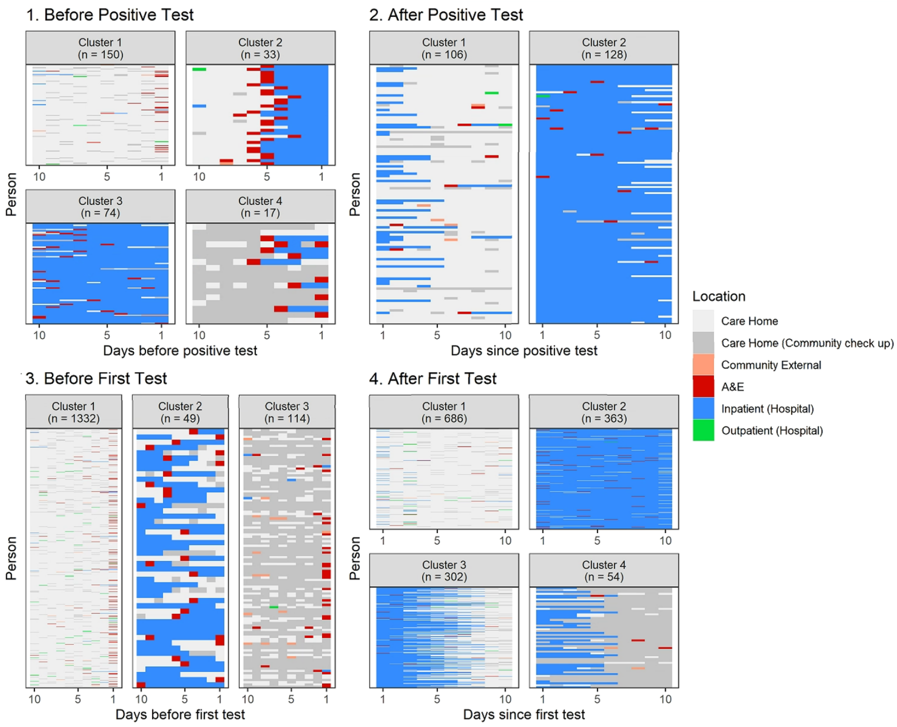

Figure 2.9: Cluster assignments describing typical patterns of care before and after residents' first positive tests and first tests during the second wave of the pandemic.

Table 2.14: Table of the associations between the cluster assignments of the trajectories before and after a resident's first positive test and a resident's first test, and the characteristics of the residents in the cluster. Filtered for wave 2.

		28 Day Mortality		Diabetes		Dementia		Charlson CI (Proportion of those with a CCI)			
		T (%)	F (%)	T (%)	F (%)	T (%)	F (%)	0 (%)	1-2 (%)	3-4 (%)	≥5 (%)
10 Day Before First Positive	Cluster 1 (Inpatient) n = 142	26	74	26	74	24	76	52	05	43	00
	Cluster 2 (Home) n = 709	18	82	27	73	33	67	52	14	27	07
10 Day After First Positive	Cluster 1 (Inpatient) n = 195	24	76	39	61	26	74	49	13	31	07
	Cluster 2 (Home) n = 538	12	88	59	41	24	76	32	26	42	00
10 Day Before All First Tests	Cluster 1 (Home) n = 3,159	09	91	25	75	18	82	12	44	38	07
	Cluster 2 (Community) n = 140	12	88	35	65	30	70	07	46	36	11
	Cluster 3 (Inpatient) n = 172	11	89	20	80	22	79	08	53	32	07
10 Day After All First Tests	Cluster 1 (Inpatient) n = 810	10	90	35	65	08	92	06	57	30	06
	Cluster 2 (Inpatient/Home) n = 578	11	89	56	44	22	78	09	35	41	15
	Cluster 3 (Home) n = 1,832	01	98	15	85	14	86	09	50	35	06

Table 2.15: Table of the p-values of the associations between the cluster assignments of the trajectories before and after a resident's first positive test and a resident's first test, and the characteristics of the residents in the cluster. Filtered for wave 2.

	Mortality	Diabetes	Dementia	Charlson CI
10 Day Before First Positive	0.56	0.44	0.72	0.44
10 Day After First Positive	0.73	0.11	0.05	0.67
10 Day Before All First Tests	0.99	1. 0e-17	0.079	0.016
10 Day After All First Tests	4.9e-04	1.7e-13	4.0e-08	0.21

Chapter 3

The impact of digital technology in care homes on unplanned secondary care usage and associated costs

Age & Ageing

Alex Garner[1], Jen Lewis[2], Simon Dixon[2], Nancy Preston[3], Camila C. S Caiado[4], Barbara Hanratty[5], Monica Jones[6] and Jo Knight[1], Suzanne M. Mason[2]

[1] Lancaster Medical School, Lancaster University

[2] School of Health and Related Research, The University of Sheffield

[3] Division of Health Research, Lancaster University

[4] Department of Mathematical Sciences, Durham University

[5] Population Health Sciences Institute, Newcastle University

[6] Faculty of Health and Medicine, University of Leeds

Garner, A., Lewis, J., Dixon, S., Preston, N., Caiado, C. C. S., Hanratty, B., Jones, M., Knight, J., & Mason, S. M. (2024). The impact of digital technology in care homes on unplanned secondary care usage and associated costs. Age and Ageing, Article afae004. https://doi.org/10.1093/ageing/afae004

Abstract

Background: A substantial number of Emergency Department (ED) attendances by care home residents are potentially avoidable. *Health Call Digital Care Homes* is an app-based technology that aims to streamline residents' care by recording their observations such as vital parameters electronically. Observations are triaged by remote clinical staff. This study assessed the effectiveness of the Health Call technology to reduce unplanned secondary care usage and associated costs.

Methods: A retrospective analysis of health outcomes and economic impact based on an intervention. The study involved 118 care homes across the North East of England from 2018 to 2021. Routinely collected NHS secondary care data from County Durham and Darlington NHS Foundation Trust was linked with data from the Health Call app. Three outcomes were modelled monthly using Generalised Linear Mixed Models: counts of emergency attendances, emergency admissions and length of stay of emergency admissions. A similar approach was taken for costs. The impact of Health Call was tested on each outcome using the models.

Findings: Data from 8,702 residents were used in the analysis. Results show Health Call reduces the number of emergency attendances by 11% [6–15%], emergency admissions by 25% [20–39%] and length of stay by 11% [3–18%] (with an additional month-by-month decrease of 28% [24–34%]). The cost analysis found a cost reduction of £57 per resident in 2018, increasing to £113 in 2021.

Interpretation: The introduction of a digital technology, such as Health Call, could significantly reduce contacts with and costs resulting from unplanned secondary care usage by care home residents.

3.1 Introduction

There are around 17,700 care homes in UK with around 430,000 residents. Most residents are over 80 years old with varying levels of complex healthcare needs. Hospital attendances and admissions can be hazardous for residents, with high rates of hospital-acquired infections, increased confusion and falls.

Generally, older patients prefer to be treated at their normal place of residence, but current NHS service configurations frequently struggle to achieve this. One aspect of the problem is high rates of Emergency Department (ED) attendance and hospital admissions. The NHS Long Term Plan [1] commits to better healthcare provision for care home residents.

The potential scope for reducing these, and the associated patient benefits and cost savings have been explored [2], and ready access to advice from healthcare professionals was cited as fundamental to delivering these reductions. Digital technology may be a scalable and cost-effective method to support timely advice, shared decision making and deliver closer working between agencies. However, evidence is needed to support these hypotheses along with an understanding of how to implement such tools to ensure appropriate uptake.

Health Call Solutions is a digital health initiative collaboratively run by seven NHS Foundation Trusts across North East England and North Cumbria. One of the solutions provided is the Health Call Digital Care Homes Application (app), designed for use by staff in care homes [3]. A primary goal of the app is to reduce avoidable secondary care for the residents in the homes, through timely access to clinical advice [4, 5].

The app provides a structured method for seeking clinical advice for the management of care home residents who become unwell. Upon implementation of the system, the staff are trained to use it to record residents' vital signs readings and other observations through a form on the app (see Supplementary Figure 3.5). A National Early Warning Score 2 (NEWS2) score is calculated from these observations on upload. The form also includes a section for free text describing a resident's condition using a Situation, Background, Assessment, Recommendation (SBAR) approach, which is a structured form of communication used to enable information to be conveyed accurately. Information uploaded to the app is automatically fed into the resident's Electronic Health Record (EHR) and a Single Point of Access (SPA) where clinical staff triage referrals with the context of the patients entire EHR and provide advice and next steps on the care for the residents. The SPA is monitored by clinical staff during working hours; outside of these hours, emergency presentations would require a more traditional approach.

The app replaces the traditional method of seeking advice through telephone calls with sometimes limited and incomplete information. It provides a faster response and advice for care home staff allowing staff and clinicians to work swiftly together on resident presentations, facilitating early identification of residents' health problems.

Health Call's pilot area was County Durham and Darlington, a mixed rural/urban area in North East UK. We evaluated the effectiveness of the Health Call app by looking for changes in the utilisation of unplanned secondary care as well as associated costs to service providers for care home residents before and after Health Call is implemented in their care homes. This was done using a large, linked dataset of healthcare interactions within County Durham and Darlington NHS Foundation Trust (CDDFT) and data from the Health Call app.

3.2 Methods

We utilised data from the Health Call app from its rollout in December 2018 until August 2021. Three care home datasets from Health Call covering resident enrolment, home enrolment and uploads on the app are linked to six routinely collected datasets from CDDFT, including ED, inpatient, outpatient and community nursing data. An additional dataset containing information on patients' hospital discharges was also used. See Table 2.4 for a description of each dataset. Recording practices for the data used in this study remained constant throughout the study period. Primary care and ambulance service data were not included.

3.2.1 Linkage and cohort selection criteria

Each dataset used a pseudonymised NHS number as an individual identifier, meaning the same individual could be identified across all of the datasets. We defined the study cohort using registration data from the Health Call app. The registration data include dates when a care home resident was 'activated' and 'deactivated' from the system and their care home's name. The activation date refers to when a resident was added onto the Health Call by the home. A resident is deactivated after they die or move away.

A resident was included in the study cohort from the first date at which an observation from any of the datasets placed them in the home that they were activated in. From this date they are a 'non-Health Call resident' until their activation date. If they had no deactivation (or death) date, they were assumed to still be living in a home using Health Call at the end of the study period. Residents were removed from the cohort when there was a 'deactivation date' or an identified death date for the resident in any of the datasets. A typical resident timeline is shown in 3.1. We also used observations to identify a small number of residents who were observed to be in the care homes that used the app, but were never 'activated' on the system who stayed as non-Health Call residents. Residents activated on Health Call who are not observed to have any healthcare interactions before their activation date are not included in the cohort.

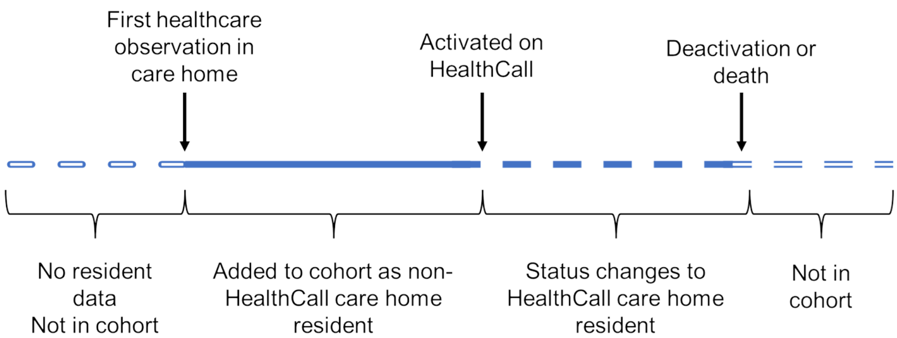

Figure 3.1: Diagram demonstrating residents' transitions into the cohort and subsequent activation as a Health Call Resident.

3.2.2 Primary Investigation

We investigated three co-primary outcomes as potential indicators of change in unplanned secondary care usage. We hypothesised that the introduction of Health Call impacted the way residents and staff interacted with secondary care; related to ED usage and recovery from hospital stays. We investigated the following:

1. Monthly emergency attendances

2. Monthly emergency admissions
3. Length of stay of emergency stays

Further details of these outcomes can be found in the Supplementary section 3.6.2.2.

We also provide an economic evaluation to calculate change in costs to service providers due to the introduction of Health Call.

Service costs related to ambulance journeys to EDs, attendance at EDs, emergency inpatient stays and outpatient attendances were assigned a unit cost. These were summed to produce a total cost, at 2019/20 price levels, for each patient each month they were part of the study cohort.

ED and outpatient activity were costed using their associated healthcare resource group and National Reference costs for 2019/2020 [6]. For inpatient stays, National Reference costs for 2017/2018 were used [7] and inflated to 2019/2020 price levels using the NHS Cost Inflation Index [8]; these costs represent the most recent for which a cost per day can be derived. Visits to care homes by healthcare professionals were costed as either by a district nurse or community matron, with 1 hour of time being assigned to in-person visits and 15 minutes for other types of visit [8]. The full set of unit costs are shown in Table 3.4.

3.2.3 Statistical modelling

We fitted a statistical model to each of the outcomes under investigation to understand typical patterns in these outcomes over time, and assess the impact of the introduction of the Health Call app. The gradual rollout of the app over the study period as well as the occurrence of the COVID-19 pandemic during the study period were key issues to address in the study design. These factors along with the retrospective nature of the study meant typical intervention evaluation methods, such as interrupted time series and difference-in-difference analysis would not suffice. They cannot account for issues such as the effect of the pandemic, many intervention time points and the dynamically changing cohort size.

To incorporate the different Health Call 'activation' times for each of the residents we fitted resident-level Generalised Linear Mixture Models (GLMM). We created baseline models that do not include Health Call as a predictor variable and compared to models including a binary variable indicating whether a resident is activated on the Health Call system. These models were fitted using the *lme4* package in R [9].

The baseline GLMM was fit to resident-level outcomes, without accounting for Health Call. This model included a random intercept for care homes, and a nested random intercept for each resident. This structure allowed for variations between care homes and residents and reflects that each resident resides in only one care home. We used a Poisson model specification with a log-link function for the three patient outcome models.

The model contained five fixed effects variables, to account for typical seasonal patterns in outcomes as well as the impact of the COVID-19 pandemic, which occurred during the study period. The variables were a yearly harmonic pair (two sinusoidal curves to model cyclic fluctuations over the course of a year); month number (number of months passed of the study period); monthly CDDFT COVID-19 bed days (proxy for local COVID-19 prevalence to account for the impact of the pandemic); and pandemic wave (categorical variable to account for fluctuations in impact over the course of the pandemic). A mathematical description of the baseline model can be found in the Supplementary Material in section 3.6.2.3.

For the economic outcome measure, costs were analysed in a similar fashion, but a two-part 'hurdle' model specification is used, given the nature and skew of these data; the best model based on a Cullen and Frey plot adopted logistic and gamma link-functions [10]. The logistic regression estimated the probability that a resident has zero costs in a given month, while the gamma regression estimated the costs contingent on a resident having non-zero costs. Cost per resident is then calculated based on the predictions of the two regressions. This was conducted using the *glmmTMB* package in R.

The impact of Health Call was modelled as both an immediate step effect (binary main effect in the model) and an additional ongoing effect (as an interaction term between the binary Health Call variable and the linear month number variable). We conducted likelihood ratio tests (LRT) to assess the impact of including the step (baseline vs step model), then additionally the ongoing effect in the model (step model vs step and interaction term model). Due to the analysis of costs requiring a two-part model, step and ongoing impacts of Health Call were assessed for each of the associated regressions.

3.3 Results

A total of 8,702 care home residents were identified and added to the cohort. The cohort selection criteria is visualised as a flow chart in Supplementary Figure 3.6. The cohort selection criteria meant that the cohort grew over time as residents were identified based on appearances in observational datasets. The relative size of the group of non-Health Call residents depletes as residents are registered on Health Call over time. The overall cohort size and number of residents in each group can be seen in Figure 3.2.

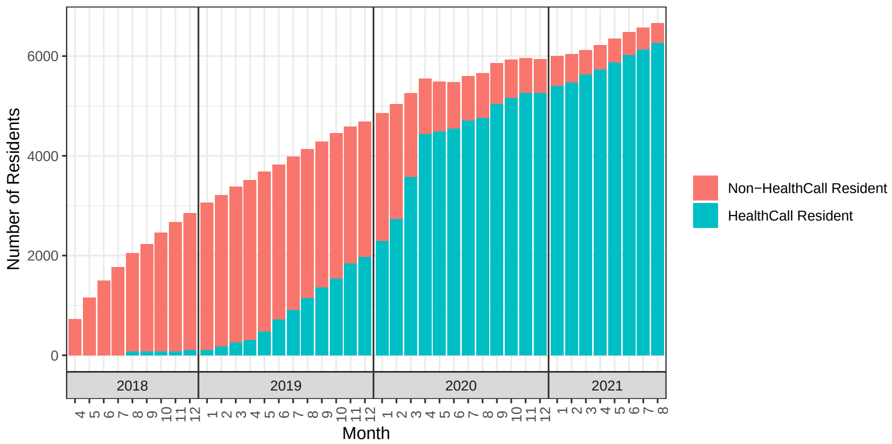

Figure 3.2: Number of residents in the cohort in each month of the study. The colours separate the groups of non-Health Call and Health Call residents.

Of the 8,702 residents, 2,549 died within the study period. The median resident age was 85. Some residents were deactivated from the Health Call system for other reasons, for example, if they moved to a non-Health Call home. A summary of the characteristics of the cohort can be found in Table 3.1. Plots of raw outcomes can be found in Supplementary Figures 3.7 - 3.20.

A demonstration of the model including the Health Call binary variable for monthly attendances fitted over the study period can be seen in Figure 3.3; this shows how the model varies over time and highlights the step change between the residents on the Health Call system (blue) and those that aren't (red). An ongoing change was not included in this model since it was not found to be significant, hence the parallel lines. Results of the LRT, and the associated relative risks (derived from the coefficients) can be found in Table 3.2.

Table 3.1: Characteristics of the cohort of care home residents included in the study.

	Median		IQR	
Age*	85		79-90	
Number of Observations	58		29-109	
Months in cohort	19		11-31	
Months as non-Health Call resident	13		5-19	
Months as Health Call resident	14		6-18	
	Male		**Female**	
Gender	3,086 (35%)		5,616 (65%)	
	True		**False**	
Died (within the study period)	2,549 (29%)		6,153 (71%)	
	0	**1-2**	**3-4**	**≥5**
Charlson Comorbidity Index **	324 (8%)	2,111 (52%)	1,292 (32%)	324 (8%)

*We do not have age information for 1,394 of the residents.
**We could not calculate a Charlson Comorbidity Index for 4,671 residents due to them not having registered ICD-10 codes from their inpatient stay.

Table 3.2: Results table showing estimated relative risk for the Health Call step (main effect) and monthly change (linear interaction term) and associated statistics. P-values presented here are those of the LRT of including each outcome in the model.

Outcome	Effect	Estimate (RR)	95% CI	LRT *p*-value
Emergency attendances	**Step**	0.892	0.846–0.941	≤0.001
	Ongoing	1.003	0.999-1.008	0.1923
Emergency admissions	**Step**	0.751	0.708–0.795	≤0.001
	Ongoing	1.015	1.009–1.021	1.000
Length of stay	**Step**	0.892	0.817–0.974	≤0.001
	Ongoing	0.719	0.665–0.755	≤0.001

Results discussed in this paper referring to the three outcomes are from the modelling. Raw results can be found in the supplementary materials. The number of ED attendances and admissions for residents on the Health Call system were typically 11 and 25% less than the non-Health Call residents. Length of emergency inpatient stays were reduced by 11%, with a slope indicating decreasing length of stay for Health Call residents of each month of the study reducing by 28% respective to the previous.

Health Call was estimated to produce an immediate 27% reduction in the odds of a resident-month incurring zero costs; however, there was an estimated long-term trend of increasing odds per-month of zero-cost resident-months of 3% (Table 3.3).

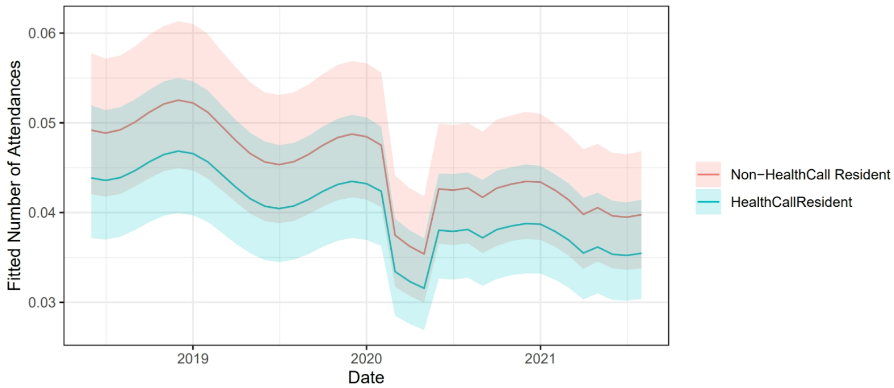

Figure 3.3: The expected number of ED attendances from the model over the study period for residents on the Health Call system and residents not on the Health Call system. Ribbons show 95% prediction intervals.

Health Call produced an immediate 24% reduction in non-zero costs. The longer-term trend in non-zero costs, while statistically significant, is small 0.03% (Table 3.3). Combined, these predictions show that there is an immediate decrease in the probability of a zero-cost and a reduction in non-zero costs, with the magnitude of the decreased costs becoming greater over time (Figure 3.4). The predicted values for each component part of the two-part model are shown in Figures 3.21 and 3.22. Predicted monthly costs per-resident for the four calendar years are shown in Table 3.4, and show a £57 reduction in cost per resident in 2018, increasing to a £113 reduction in 2021.

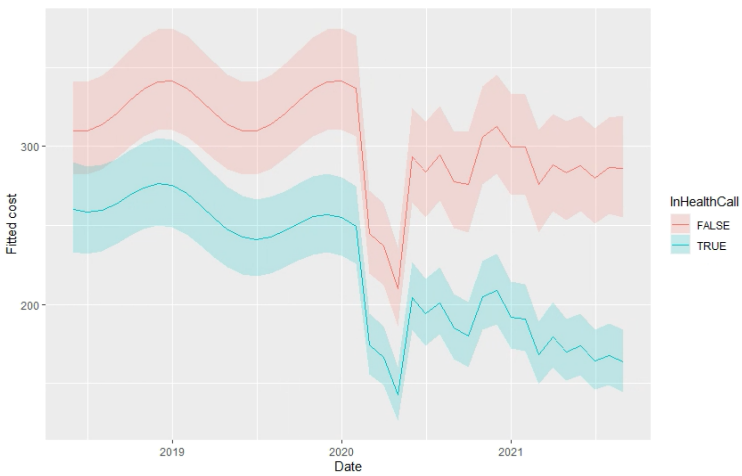

Figure 3.4: Predicted mean cost per resident of Health Call and non-Health Call homes over the study period.

Table 3.3: Impact of Health Call on non-zero costs and the probability of zero monthly costs in the form of odds ratio (OR) for zero cost models and relative risks for the magnitude of costs model (RR). P-values presented here are those of the LRT of including this variable in the respective model.

Outcome	Effect	Estimate (RR)	95% CI	LRT *p*-value
Zero-cost (OR)	**Step**	0.730	0.675–0.790	≤0.001
	Ongoing	1.026	1.023–1.029	≤0.001
Magnitude of non-zero cost (RR)	**Step**	0.762	0.675–0.790	≤0.001
	Ongoing	1.003	1.000–1.006	0.024

3.4 Discussion

This study suggests that the introduction of a digital technology intervention such as Health Call may significantly reduce contacts with and costs resulting from emergency care service use by care home residents. The modelling suggests an 11% reduction in estimated monthly number of ED attendances experienced by Health Call registered residents compared to non-Health Call registered residents. In addition, there was a 25% reduction in emergency hospital admissions further reducing impact on the hospital system. Health Call residents also experience 11% shorter emergency hospital stays, with an increasing reduction in stay over the study period of 29% compounded each month.

Improved communication between care home staff and the NHS, including NHS community nursing services, provides greater opportunity for joint decision making on the delivery of optimal care for residents, which we found led to a reduction in ED attendances and hospital admission. The associated qualitative study undertaken alongside this quantitative analysis [5] found that additional input from a multi-disciplinary team improves the confidence of care home staff by providing greater monitoring, and earlier identification of deterioration. This in turn may impact on the reduced length of hospital stay due to earlier detection and prompt management of illness.

The cost analysis indicates reduced health care costs for residents registered on the Health Call system, with the magnitude of this reduction increasing over time. This trend is driven by any given resident having an increasing probability of having zero costs over time. In the first year of operation, cost savings of £57 per resident-month were estimated, which equates to £247 million for the first year across UK, based on a care home population of 360,792 [4].

A key success of the paper is that the app was evaluated using routinely collected NHS data linked with observational data from the app. The methods presented attempt to minimise the impact of a challenging study period and gradual roll-out by modelling both intervention and non-intervention groups to calculate the impact of the intervention on outcomes. We demonstrate the research that can be done using a pragmatic approach to statistical analysis with routinely collected NHS data. The large amounts of data stored in NHS systems provide potential for more analyses such as this one.

As part of the NHS Long Term Plan, there was a promise to roll out Enhanced Health in Care Homes (EHCH), which highlights the use of technology for telehealth, remote monitoring and sharing of information to reduce uncoordinated care [11]. The Health Call system falls within this scope and this study demonstrates the impact of the technology on the healthcare system.

In a 2016 report, The Health Foundation stated that ED trips could be avoided by more data sharing between care homes and NHS services and use of clinical input in care homes [2]. Our results indicate that monitoring and administering of healthcare facilitated by the Health Call system could help address these issues. The report also highlights the challenges in accessing routinely collected data on care home residents. This study demonstrates the requirement of this linked data for appropriate evaluations and underlying the need to identify ways to make it more available such as the current NHS secure data environment program [12].

A number of digital interventions in care homes have been piloted in recent years, each with differing techniques to address the problems highlighted in the EHCH framework. The usage of telehealth has become particularly widespread since the start of the COVID-19 pandemic [13]. The Innovation Collaborative published a Rapid Review of remote monitoring technology in care homes [14]. The report identifies 19 remote monitoring technologies (including Health Call) used in the UK and Ireland, with 8 case studies and one published evaluation. There is a growing body of work on telehealth initiatives for older adults outside care homes [15]. The range of technologies becoming available highlights the need to evaluate their effectiveness using robust statistical methods, similar to those in this paper. Linkage of routinely collected hospital data with data collected through the usage of the technologies, as described here, provides a route for post-implementation evaluation of the technologies using only administrative data.

The study had a number of limitations. The data contained no timestamp of when a resident in the study first moved into long term care. Hospital discharge records were used to identify the date at which a resident was first observed to be in a care home. This identification method leads to a changing cohort size over time and class imbalances between the Health Call and non-Health Call residents. The study period was reduced prior to modelling to remove the months with the largest class imbalances. The model specification was used to account for the change in group sizes over time.

Residents were removed from the cohort when either deactivated from the Health Call system or they died. Since residents have generally been activated on the Health Call system before they are removed from the study (deactivation or death), a period of inactivity between actual and recorded deactivation could contribute to lower rates of healthcare utilisation, and therefore cost, for residents in the Health Call group.

Covariates in the model were limited by the available study data. Resident comorbidities and characteristics would be unreliable to identify using observational data. Linked home characteristics such as type of home and number of residents were also not included as they were found to not provide a significantly better fit to the model. Variation between residents and homes was instead captured by the hierarchical random intercept structure of the model.

This study was timely, as the onset of COVID-19 during the study period led to rapid uptake of Health Call. Our modelling aimed to disentangle the impact of Health Call from that of the COVID-19 pandemic on healthcare utilisation, by using a proxy for COVID prevalence and a pandemic wave variable. However, as the impact of the pandemic was immeasurable, results from this study may not reflect those that would have been observed during a non-pandemic period and type 1 error is possible.

For the costs analysis, two additional weaknesses are the lack of complete ambulance service data and the nature of the community contacts data. For ambulance data, only calls resulting in an ED attendance have been included in our cost estimates. For community contacts, length of contact was not available, and the profession of the health care worker was poorly defined, leading to imprecise allocation of unit costs to staff. However, these issues were consistent for both Health Call and non-Health Call residents, so confounding is likely to be minimal.

The estimated reduced costs reflect changes in the utilisation of NHS services. Not all changes across the health and social care system were included in our analysis, with the costs of the Health Call system and associated care home activities being the most prominent of those exclusions. While the cost of Health Call will be clear to Integrated Care Boards when purchasing the system, the potential costs to care homes are important to consider for successful implementation.

Our research provides key insights into how the introduction of a technology like Health Call impacts healthcare utilisation and cost outcomes. Future research could investigate the decision-making process in more detail, looking at decisions made from each individual upload from the app. This would allow for further investigation into the direct outcomes from the altered decision making provided by the app, to allow for a more detailed analysis of safety of decision-making.

The results shown in this paper are promising, but a definitive trial would help establish the true impact of the technology. Research over a larger area and longer time period, with more time before and after the intervention is introduced could improve reliability of results. The time period was limited by the data available. Randomisation of the Health Call roll-out over a wider area would be desirable to ensure findings are robust. Further research could also test technologies like Health Call in other settings such as mental health facilities.

3.5 References

[1] NHS England, "The NHS Long Term Plan," Tech. Rep., Jan. 2019. [Online]. Available: https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/ (visited on 02/23/2023).

[2] The Health Foundation, *Emergency admissions to hospital from care homes: How often and what for? - The Health Foundation*. [Online]. Available: https://www.health.org.uk/publications/reports/emergency-admissions-to-hospital-from-care-homes (visited on 09/03/2022).

[3] *Health Call Website*. [Online]. Available: https://nhshealthcall.co.uk/ (visited on 02/23/2023).

[4] NHS England and NHS Improvement, *SBAR communication tool - situation, background, assessment, recommendation*. [Online]. Available: https://www.england.nhs.uk/wp-content/uploads/2021/03/qsir-sbar-communication-tool.pdf (visited on 09/03/2022).

[5] S. Russell *et al.*, *Use of a digital application to enhance communication and triage between care homes and National Health Service community services in the United Kingdom: A qualitative evaluation*, Pages: 2023.03.02.23286669, Mar. 2023. [Online]. Available: https://www.medrxiv.org/content/10.1101/2023.03.02.23286669v1 (visited on 03/05/2023).

[6] NHS England, *2019/20 National Cost Collection Data Publication*, Jun. 2021. [Online]. Available: https://www.england.nhs.uk/publication/2019-20-national-cost-collection-data-publication/ (visited on 03/07/2023).

[7] N. Improvement, *Archived Reference Costs*, Feb. 2020. [Online]. Available: https://webarchive.nationalarchives.gov.uk/ukgwa/20200501111106/https://improvement.nhs.uk/resources/reference-costs/ (visited on 03/07/2023).

[8] L. A. Curtis and A. Burns, *Unit Costs of Health & Social Care 2020*. PSSRU, University of Kent, Dec. 2020, ISBN: 978-1-911353-12-6. [Online]. Available: https://www.pssru.ac.uk/project-pages/unit-costs/unit-costs-2020/ (visited on 01/17/2023).

[9] D. Bates, M. Mächler, B. Bolker, and S. Walker, "Fitting Linear Mixed-Effects Models Using lme4," *Journal of Statistical Software*, vol. 67, pp. 1–48, Oct. 2015, ISSN: 1548-7660. [Online]. Available: https://doi.org/10.18637/jss.v067.i01 (visited on 03/13/2023).

[10] M.-L. Delignette-Muller and C. Dutang, *Fitdistrplus: An R Package for Fitting Distributions*, Oct. 2022. [Online]. Available: https://cran.r-project.org/web/packages/fitdistrplus/index.html (visited on 03/05/2023).

[11] NHS England and NHS Improvement, *The Framework for Enhanced Care in Care Homes*, Mar. 2020. [Online]. Available: https://www.england.nhs.uk/publication/enhanced-health-in-care-homes-framework/ (visited on 02/23/2024).

[12] Department of Health and Social Care, *Secure data environment for NHS health and social care data - policy guidelines*. [Online]. Available: https://www.gov.uk/government/publications/secure-data-environment-policy-guidelines/secure-data-environment-for-nhs-health-and-social-care-data-policy-guidelines (visited on 07/03/2023).

[13] A. Seifert, J. A. Batsis, and A. C. Smith, "Telemedicine in Long-Term Care Facilities During and Beyond COVID-19: Challenges Caused by the Digital Divide," *Frontiers in Public Health*, vol. 8, 2020, ISSN: 2296-2565. [Online]. Available: https://www.frontiersin.org/articles/10.3389/fpubh.2020.601595 (visited on 01/17/2023).

[14] K. Masconi-Yule, "Rapid review of current remote monitoring in care homes across the UK," *Innovation Collaborative - Health Innovation Network South London*, Apr. 2022.

[15] S. Pahlevanynejad, S. R. Niakan Kalhori, M. R. Katigari, and R. H. Eshpala, "Personalized Mobile Health for Elderly Home Care: A Systematic Review of Benefits and Challenges," *International Journal of Telemedicine and Applications*, vol. 2023, p. 5 390 712, Jan. 2023, ISSN: 1687-6415. [Online]. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9871396/ (visited on 02/13/2023).

3.6 Supplementary Material

This section was published as supplementary material to the main paper.

3.6.1 Additional Health Call Information

Resident details are input through the form in the app. Figure 3.5 is an example of the form that will be filled out by the care home staff. The form is in the Situation, Background, Assessment, Recommendation structure. The information in this form is then sent to the clinicians at the Single Point of Access (SPA). The clinicians review the observations and action as appropriate. The resident's electronic patient record is also updated.

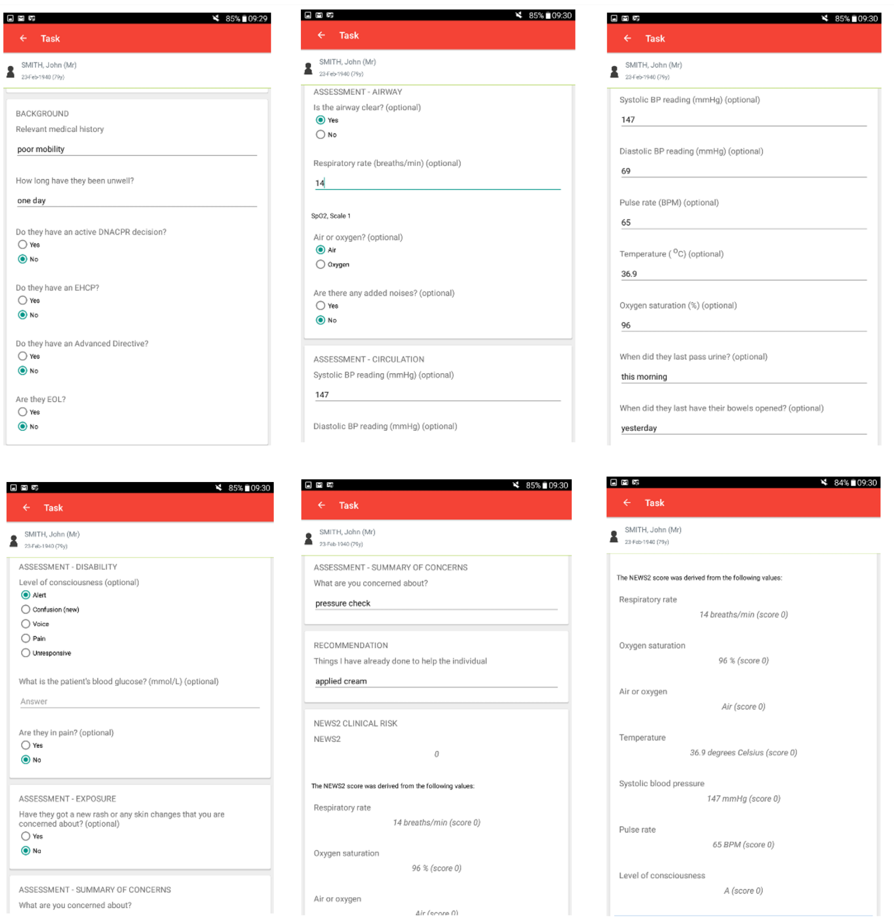

Figure 3.5: Screenshots of the Health Call app. They show the form for inputting resident status and readings.

3.6.2 Methods

3.6.2.1 Data Description

The datasets used in this analyses are the same as those from the previous chapter. See Table 2.4.

3.6.2.2 Outcome Definitions

Outcomes are modelled on a disaggregated resident-basis. The first two model estimates are an expected count for one resident in a month. The third is the length of stay. The outcomes are counted when the patient is classed as a care home resident at the point in time of their healthcare interaction (see main paper Section 3.2.1).

1. Monthly emergency attendances. Calculated from the ED data. Raw numbers are the count of attendances each resident experienced in each month of the study period.

2. Monthly emergency admissions. Calculated from the ED data. Raw numbers are the count of admissions to hospital from the ED that each resident experienced in each month of the study period.

3. Emergency length of stay. Calculated from the inpatient data, only including stays classed as emergency. In this outcome, residents can have multiple stays each month. Raw data is length of stay for each stay, grouped by admission month. Modelling is essentially expected length of stay for stays beginning in a given month. Lack of stays does not contribute to the model in this case (like a count of zero attendances in a month would).

3.6.2.3 Model Specification

Let y be the outcome variable of the investigation. i, $i = (1, ..., n)$ corresponds to a resident from care home j, $(j = 1, ..., g)$.

Outcome Y is the monthly count of events for each residents (this will vary dependent on the outcome we are modelling), we assume that these counts follow a Poisson distribution. In the length of stay outcome, it is a count of days for each stay, rather than events in a given time frame. λ is the estimated mean of the distribution. We use a log-link function between λ and outcome y.

The baseline model takes the form,

$$Y_{ijk} \sim \text{Poisson}(y_{ijk}; \lambda_{ijk}) \tag{3.1}$$

$$\eta_{ijk} = h(\lambda_{ijk}) = \beta_0 + \beta_1 x_{1ijk} + \beta_2 x_{2ijk} + ... + b_j + c_{ij} + \epsilon_{ijk} \tag{3.2}$$

$$b \sim \text{Normal}(0, \tau_b^2 I_g)$$

$$c_j \sim \text{Normal}(0, \tau_c^2 I_n)$$

$$\epsilon_{ijk} \sim \text{Normal}(0, \sigma_{ijk}),$$

where η is the linear predictor, β are the regression coefficients. x_{pijk} is the kth observation of variable p, of individual i from care home j. b_0 corresponds to variation on a care home level, and c_0 corresponds to variation on an individual level. The individual level random intercept is nested within the care home level since each individual lives in only one care home.

3.6.2.4 Economics Costs

Table 3.4: Unit costs and sources

Item of resource	Unit cost (£, 2019/20)	Source
District nurse face-to-face visit	49	PSSRU, 2020
District nurse other visit	25	PSSRU, 2020
Community matron face-to-face visit	59	PSSRU, 2020
Community matron other visit	30	PSSRU, 2020
Ambulance conveyance to emergency department	292	NRC, 2019/20
Emergency department attendance	Various	NRC, 2019/20
Outpatient attendance	Various	NRC, 2019/20
Inpatient cost per day (non-elective)	Various	NRC, 2017/28

3.6.3 Results

3.6.3.1 Cohort and Selection Flow Diagram

See Figure 3.6 for a flow chart of cohort and sequence selection.

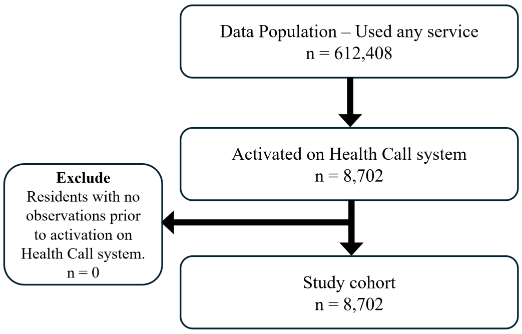

Figure 3.6: Flow chart demonstrating selection of the cohort, and sequences used in the analysis.

3.6.3.2 Raw Health Outcomes

We model expected counts of ED attendances and admissions on a resident-level. Looking at total numbers and total numbers (Figures 3.7 and 3.9) broken down by resident's Health Call status (Figures 3.7 and 3.10), we can see the impact of the changing cohort size. The changing cohort size can be seen in the main paper (Figure 3.2).

The length of stay analysis is essentially mean length of stay for stays beginning in a given month. Therefore, we have provided number of stays for each month (Figures 3.15 and 3.16), and number of bed days for each month (Figures 3.17 and 3.18). Then combined to find each month's overall mean (Figure 3.19) and broken down by Health Call status (Figure 3.20).

3.6.3.3 Monthly Emergency Attendances

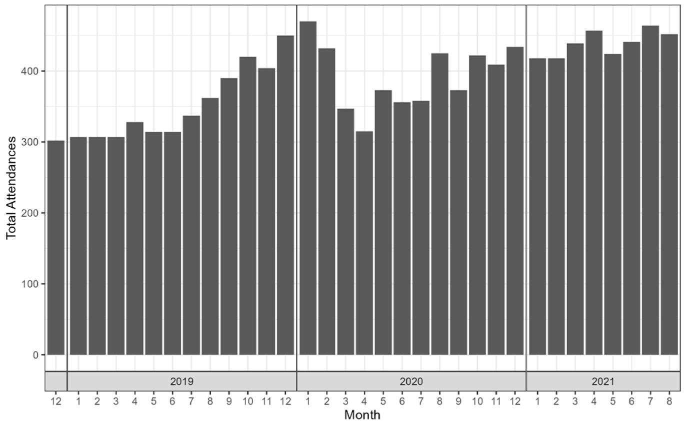

Figure 3.7: Total number of ED attendances each month during the study period for residents in the cohort.

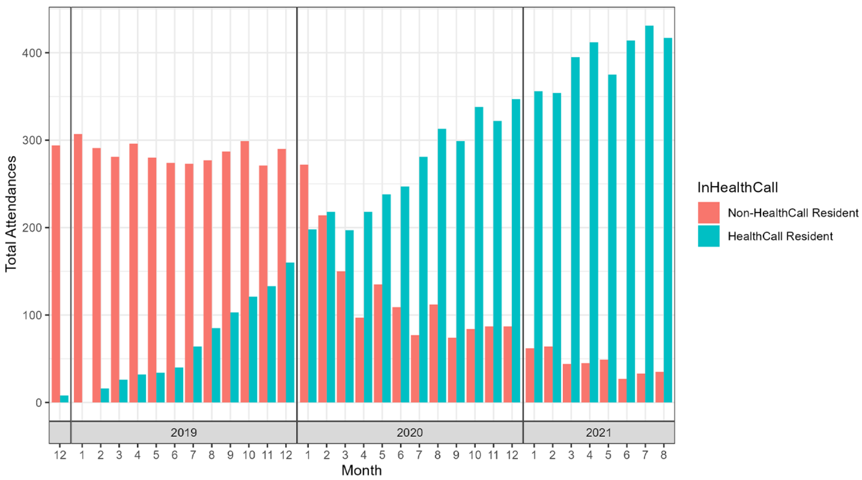

Figure 3.8: Total number of ED attendances each month during the study period for residents in the cohort, separated by residents' Health Call statuses.

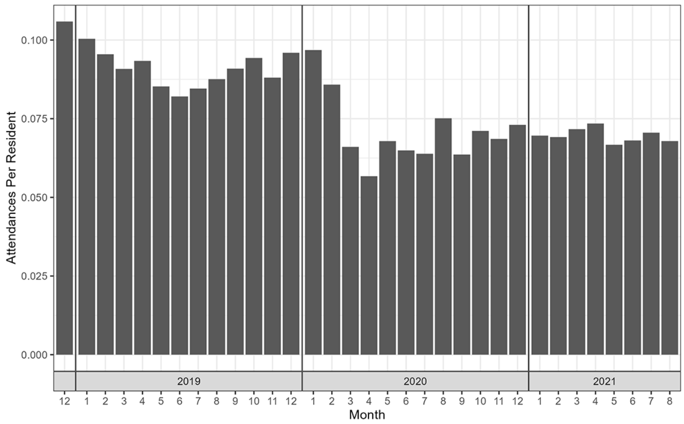

Figure 3.9: Number of ED attendances per resident for each month of the study period.

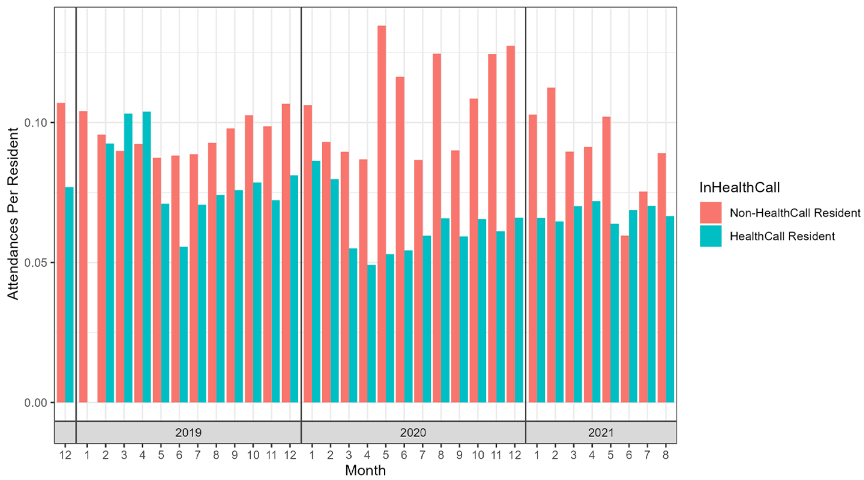

Figure 3.10: Number of ED attendances per resident for each month of the study period, calculated separately for residents on the Health Call system at that point and those who aren't.

3.6.3.4 Monthly Emergency Admissions

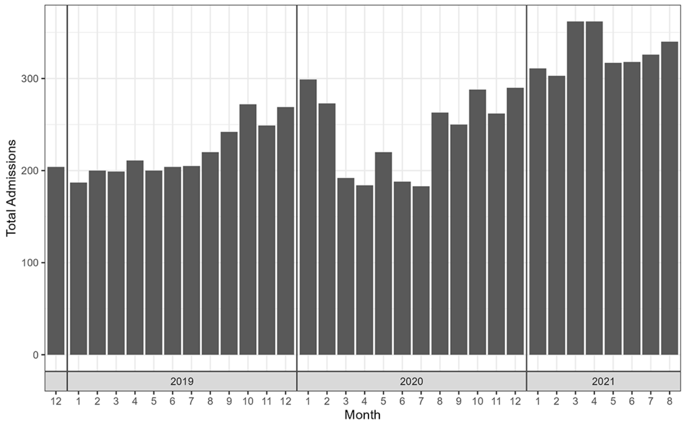

Figure 3.11: Total number of emergency admissions each month during the study period for residents in the cohort.

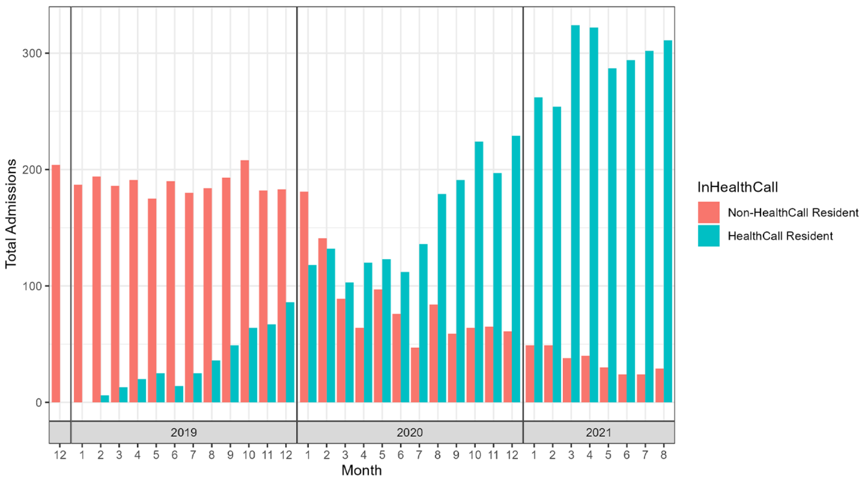

Figure 3.12: Total number of emergency admissions each month during the study period for residents in the cohort, separated by residents' Health Call statuses.

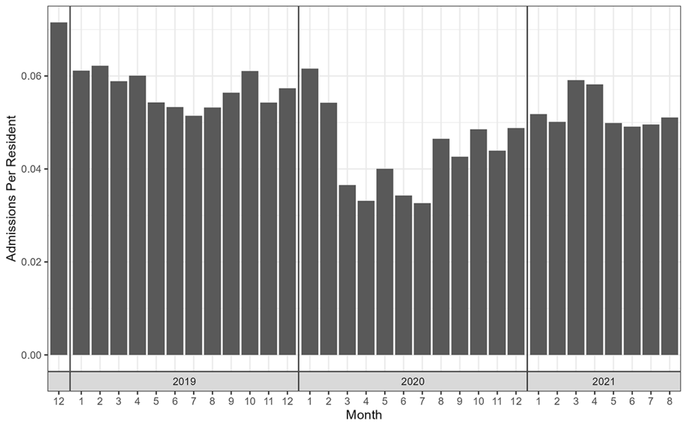

Figure 3.13: Number of emergency admissions per resident for each month of the study period.

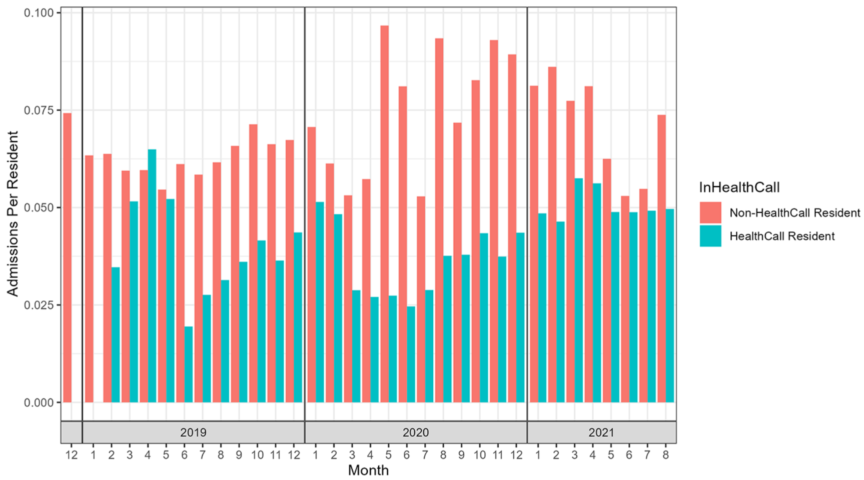

Figure 3.14: Number of emergency admissions per resident for each month of the study period, calculated separately for residents on the Health Call system at that point and those who aren't.

3.6.3.5 Length of Stay

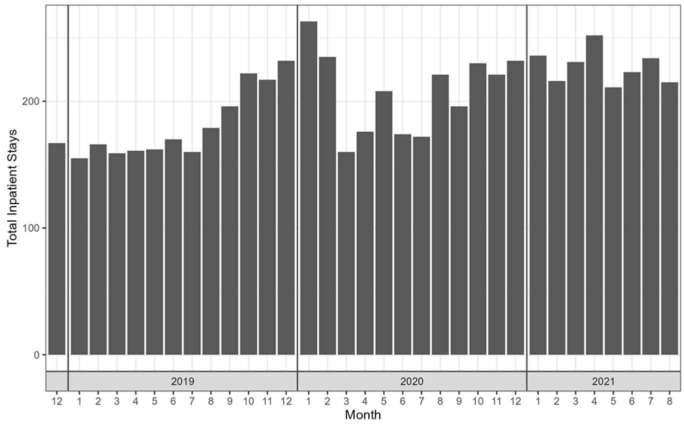

Figure 3.15: Total number of emergency inpatient stays each month during the study period for residents in the cohort.

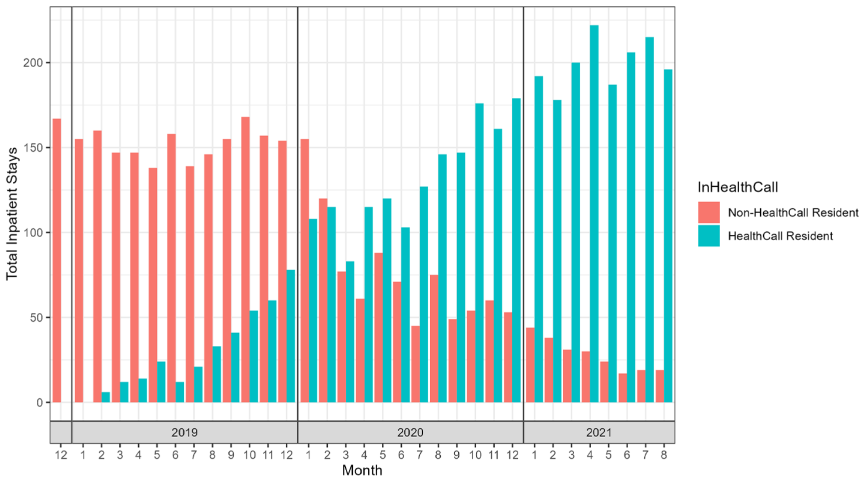

Figure 3.16: Total number of emergency inpatient stays each month during the study period for residents in the cohort, separated by residents' Health Call statuses.

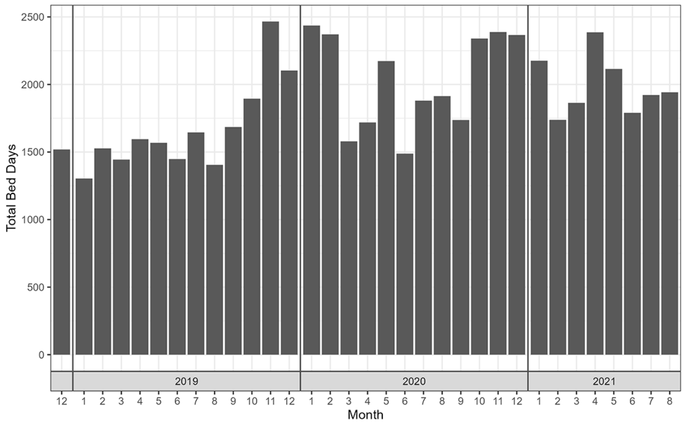

Figure 3.17: Total number of bed days for emergency inpatient stays each month during the study period for residents in the cohort.

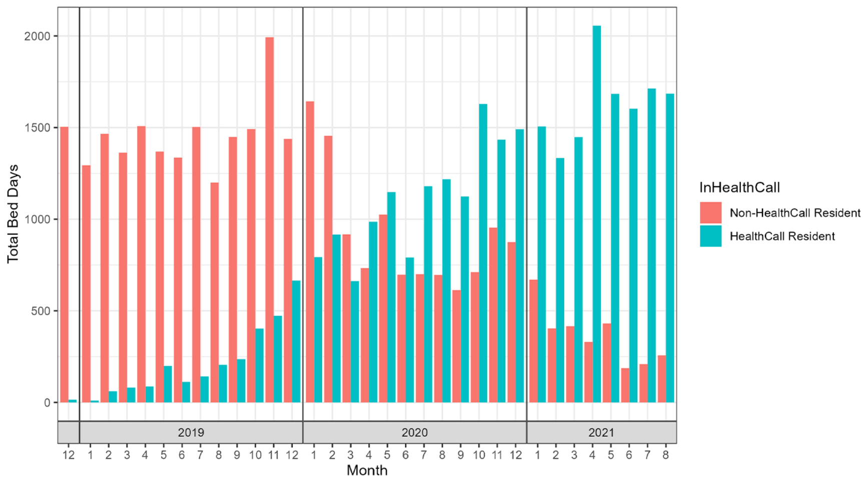

Figure 3.18: Total number of emergency inpatient bed days each month during the study period for residents in the cohort, separated by residents' Health Call statuses.

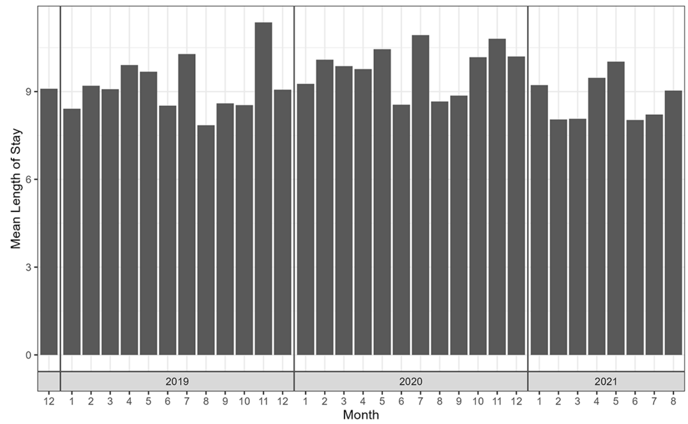

Figure 3.19: Mean length of stay for emergency inpatient stays each month for residents in the cohort.

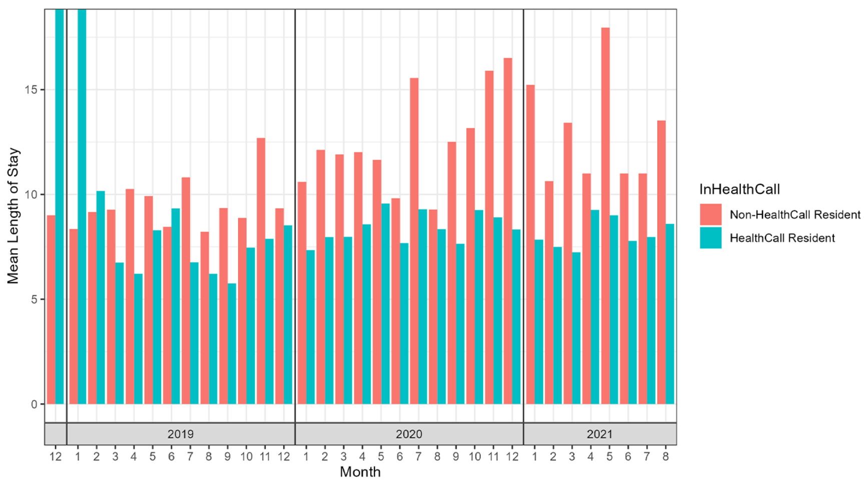

Figure 3.20: Mean length of stay of emergency inpatient stays each month during the study period for residents in the cohort, calculated separately for Health Call residents and non-Health Call residents.

3.6.3.6 Economics

Table 3.5: Predicted monthly cost (£) to the healthcare system for Health Call and non-Health Call residents by calendar year.

Year	Non-Health Call	Health Call	Difference
2018	322.96	265.95	57.01
2019	325.30	253.93	71.37
2020	284.51	197.24	87.27
2021	287.48	174.52	112.96

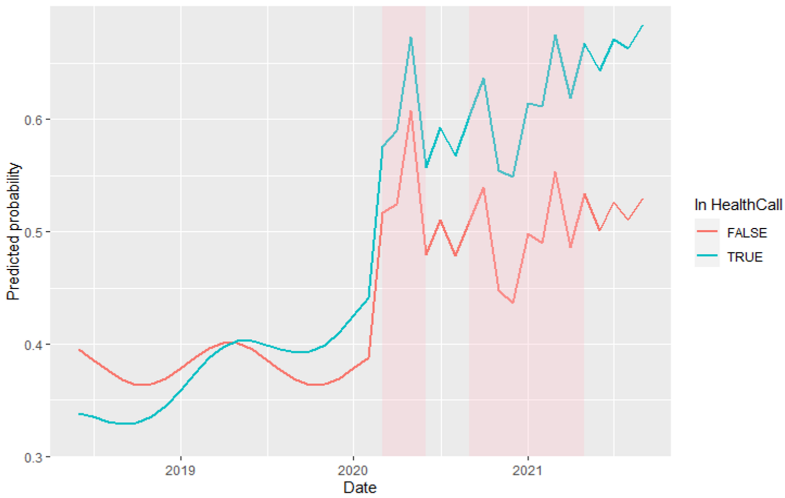

Figure 3.21: Predicted probability of resident having zero cost over the study period for Health Call and non-Health Call residents.

Health Call is associated with an immediate reduction in the probability of a resident having a zero cost relative to non-Health Call homes, as illustrated by the lower line in 2018 (OR=0.730, $p \leq 0.001$). However, the probability of a Health Call resident having a zero cost increases monthly relative to non-Health Call residents (OR=1.026, $p \leq 0.001$). Consequently, the probability of a resident having zero costs becomes greater in Health Call homes.

Health Call is associated with an immediate reduction in the predicted costs of residents with non-zero health care costs, relative to non-Health Call residents (PR=0.762, $p \leq 0.001$). This difference reduces marginally, over time (PR=1.003, p=0.024).

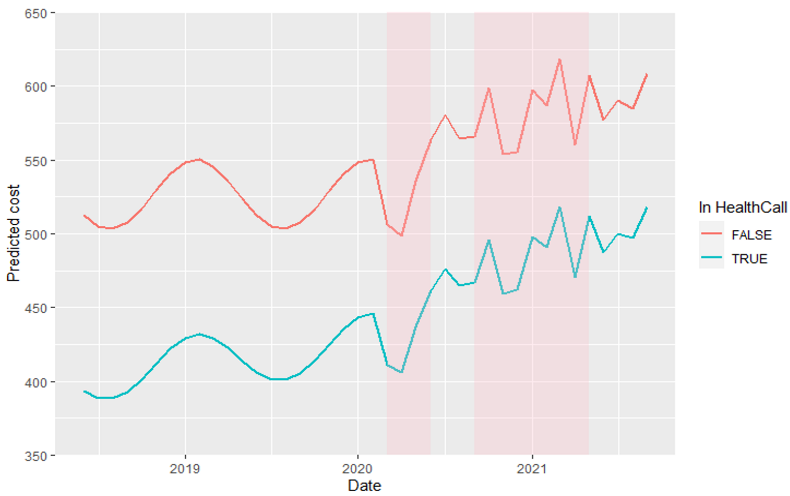

Figure 3.22: Predicted cost of residents with non-zero costs throughout the study period.

Chapter 4

Evaluating the Impact of NHS Strikes on Patient Flow through Emergency Departments

Draft

Alex Garner

Abstract

Background: Since December 2022, the NHS has experienced large-scale strikes over pay by staff. Strikes heavily impact elective care delivery, which has led to millions of cancellations. However, during this time emergency care is prioritised, and in a recent opinion piece, the president of the Royal College of Emergency medicine claimed the Emergency Department runs 'better than usual'. The aim of this paper was to investigate whether patient flow into hospitals is improved during the strike periods.

Methodology: Data from two different emergency departments (EDs) in the North West of England is analysed using Cox-regression to model time between patient arrival at the ED, and subsequent admission. Various systematic and patient-level factors are controlled for. The impact of different striking groups (nurses, junior doctors etc.) on patient time to admission is analysed.

Results: For the major ED, hazard ratios indicate that patients are admitted through the ED more quickly on strike days where any single group of staff were striking compared to non-strike days (HRs: 1.16-1.39, all $p \leq 0.003$. This increased flow was only seen for consultant strikes in the smaller ED.

Interpretation: This analysis suggests patients flow through the ED into hospital faster on strike days. Our results suggest this is due to reduced elective activity rather than any strike group-specific effects. These findings may indicate that increased inpatient capacity could improve turnaround time and reduce ED crowding.

4.1 Introduction

Since December 2022, the NHS has experienced large-scale strikes over pay by junior doctors, consultants and other staff [1]. In June 2023, nurse strikes in England ended due to low voter turnout. In April 2024, consultants agreed to end their strikes with a new pay deal from the government [2]. At the time of writing junior doctor pay deals are still unsettled [3]. By the end of 2023, the NHS estimated the costs of the strike amounted to around £1.5bn [4].

During strike periods, much routine care has been rescheduled and approximately 1 million appointments cancelled between February 2022 and January 2024 [5, 6]. These cancellations impact patient outcomes, with a survey by Healthwatch finding that 66% of people with cancelled care during 2023 said it had impacted their lives [7]. These strikes come at a time when the NHS is already under pressure, partially due to ongoing effects of the COVID-19 pandemic [8]. In February 2024, the number of referrals waiting for treatment was estimated to be 7.5 million [9]. Statistics from the Nuffield Trust show that by the end of 2023, patient time spent in ED has increased dramatically since 2019 [10]. Emergency care provided by the NHS is typically protected and prioritised during strikes. Non-striking staff are often drafted in to cover the emergency department (ED), and negotiations between the NHS and unions ensure enough staff to provide a minimum coverage for emergency departments [6]. The process by which patients are admitted to hospital through the ED typically does not change during strikes, only the mix of staff making the decisions.

Evidence from previous strikes has shown that strikes are associated with fewer emergency attendances, leading to less crowding in the emergency departments [11]. ED crowding is generally associated with an increased risk of in-hospital mortality, longer times to treatment of patients with certain conditions and a higher probability of leaving the ED against medical advice or without being seen [12]. Multiple sources suggest that the primary cause of ED crowding is access block [13, 14]. Access block is defined as when 'patients in the ED requiring inpatient care are unable to gain access to appropriate hospital beds within a reasonable time frame' [15]. Efficient patient flow through the ED department into hospital is critical to avoid long emergency department waits.

Studies indicate that healthcare worker strikes can speed up patients' waiting times in EDs globally [16]. In an opinion piece, Dr Adrian Boyle, president of the Royal College of Emergency Medicine, suggests that during some of the strikes ‘in the emergency department, everything works better than usual’ [17]. He alludes to streamlined decision making during the strike periods, while also suggesting wider hospital measures that make emergency department procedures more efficient during these times. One of these possible factors is more inpatient capacity due to the lack of elective activity in this period [17]. This may result in a reduction in the effects of access block and reduce crowding in the emergency departments during the strikes.

In this paper, we aim to investigate these claims, and provide quantitative evidence suggesting whether patients are moved through the emergency department more quickly during the strike days. We hypothesise increased patient flow and seek to provide evidence for the NHS to support consideration of changes in ED practice. In this paper we analyse data on time spent in two emergency departments based in the North West of England. We use survival analysis methodology to model patients’ time from arrival to admission from the ED. Using this framework, we can control for other influential variables and evaluate the impact of the strikes on typical times spent in ED.

4.2 Methods

4.2.1 Data

The dataset structure is based on the NHS Emergency Care Data Set specification, a national specification for datasets from NHS emergency departments, set by NHS England and the Royal College of Emergency Medicine [18]. The data covers attendances to two emergency departments in the North West of England between January 2022 and April 2024, giving time of arrival, time spent in ED, investigations performed and other demographic and diagnostic information. This time period was selected to minimise influence of old data which may have been influenced by other factors and to avoid needing to account for the COVID-19 pandemic in the model. The data was pseudonymised by NHS number and accessed remotely through a Secure Data Environment (SDE) hosted by Lancashire Teaching Hospitals. This data includes any attendance from patients who have not opted-out of their NHS data being used for research.

Both EDs are operated by the same trust. ED1 is a 24-hour, full-service ED with a major trauma service, ED2 is an adults only minor injuries unit with limited hours. People with major injuries arriving at ED2 hospital are sent to ED1. These are two quite different EDs and are analysed separately. This paper will primarily focus on the effects of the strikes at the major ED (ED1) as results will be more generalisable to many other EDs. Full results for ED2 will be found in the supplementary materials and findings will be discussed in the main paper.

4.2.2 Investigation

The outcome in this analysis was patient time spent in ED for patients who are subsequently admitted to hospital directly from their ED attendance. We define this as the time difference between the patient's departure time from ED and their arrival time to ED. The departure time is defined as the time a patient is discharged or transferred to from the emergency care attendance onto a ward as defined by the NHS data dictionary [19]. We use the subset of attendances that are transferred to a ward. From this point we refer to this as the "time in ED". We used patient's "time in ED" as an indicator for patient flow through the emergency department.

"Time in ED" can be thought of as *time to event* data that can be used in a survival analysis. In this case, since the endpoint of interest – admission to a ward after their arrival at ED – is an outcome that is preferred more quickly, a higher hazard ratio is favourable. A higher hazard implies patients flow more quickly through the emergency department i.e. higher frequency admissions.

Survival analysis looks at what proportion of the study population have not yet experienced an event (often death, as the name indicates) at timepoints over a study period. In this analysis, we investigated what proportion of patients remained in ED over a continuous time period starting at their arrival at the emergency department. Kaplan-Meier plots were used to investigate empirical differences between factors that we stipulate could impact patient flow through the emergency department. This displays the proportion of patients who were still not admitted at each timepoint to create a survival curve. Confidence intervals are calculated using Greenwood's formula to estimate variance of the estimate at each time point [20].

Cox-Proportional Hazards models were then used to produce a semi-parametric regression model fitted to time to admission from arrival at the hospital. The models were fitted using the lifelines package for python [21]. The explanatory variable of interest was strikes impacting the emergency department. We created two models (for each of ED1 and ED2), each with five strike groups of interest to investigate the impact of the following strikes: *junior doctor strike*, *consultant strike*, *junior doctor and consultant strike*, *nurse strike*, *ambulance strike*.

Strike days that directly impacted the emergency department were investigated. Regional strikes outside of Lancashire were not included and strikes that were for specific specialties were also not accounted for. (There were not any strikes specifically by ED staff.) The only complete strike database available at the time of the analysis was the online resource strikecalendar.co.uk. These dates were cross-referenced with a Wikipedia database of NHS strikes since the start of 2022, no discrepancies were found [22, 23]. A table of strike dates used in the analysis and associate striking groups can be found in the supplementary materials Table 4.3.

We used Kolmogorov-Smirnov two sample tests to assess whether there is significant difference in number of admissions per day and proportion of attendances admitted to a ward during strike days and non-strike days over the study period [24].

We also controlled for multiple variables in the model, to control for confounding factors that could influence patient flow on strike days, or factors that may alter an individual's time spent in ED, such as urgency of their presentation. Variables accounted for in the Cox-regression model are:

- ED Factors
  - Linear time effect
  - Seasonal effects - harmonic pair
  - Time of day - harmonic pair
  - 'Heat' - measure of number of patient in the ED scaled by urgency of those patients
- Patient Presentation Factors
  - Urgency of presentation
  - Referral service admitted to
- Patient Demographic Factors

- Age
- Ethnicity
- Gender

We used the Cox model with standard errors calculated robustly via a bootstrapping method [25, 26]. Hazard ratios were calculated for each variable in the model, including the strike variable. The magnitude of the hazard ratios for junior doctor strikes and other strikes were tested at an $\alpha = 0.005$ significance level - Bonferroni adjusted for the 5 strike types (compared to no strike) at each ED (10 tests). The proportional hazards assumption was assessed using log-log plots of empirical survival curves of the variables, and Schoenfeld residuals of the fitted Cox models [25].

4.3 Results

There were 174,961 emergency attendances in the study period, 119,553 were to ED1. Of those, 49,165 resulted in an admission to the hospital. Observations where hospital admission status, referral service or urgency were missing in the data were not included, resulting in 44,229 attendances in the sample for investigation.

Over the analysis period, we observed 61 separate strike days, the first was 15th December 2022. There were 3,219 admissions during the strike days. Most of these admissions (1,822) occurred during junior doctor strikes. We find that there is no significant difference between the number of attendances on strike days and non-strike days. We also find that there is no significant difference between proportion of attendances that are admitted on strike days and non-strike days.

We find that the median "time in ED" for the patients in the analysis (admitted to hospital from ED) was 18 hours 4 minutes (IQR: 8h 44m – 28h 47m). The median time before first contact with member of healthcare staff (*wait time*) is 2 hours 12 minutes. There is a high rate of admissions immediately before the four hour mark, which corresponds to patients being admitted immediately before the 4-hour target time set by the government [27]. This surge in admissions before 4-hours skews the distribution of patients' time spent in ED. A histogram of patients' "time in ED" is found in Figure 4.3 in the supplementary material. The median time on a strike day is found to be 13 hours (IQR: 6h 58m – 23h 34m).

Table 4.1: Demographic mix of patients overall and filtered for strike days.

Characteristic	Grouping	Count of individuals	% of overall cohort	Strike day count of individuals	% of strike day cohort
Age	(0, 18]	3716	12	263	12
	(18, 25]	1363	4	92	4
	(25, 30]	1081	3	88	4
	(30, 45]	3560	11	250	12
	(45, 65]	6498	21	415	19
	(65, 80]	7854	25	538	25
	≥ 80	7527	24	486	23
Gender	Female	15550	49	1067	50
	Male	16034	51	1063	50
	Not Known	15	0	≤ 5	0
Ethnicity	White	27460	87	1834	86
	Asian or Asian British	1807	6	116	5
	Black or Black British	313	1	23	1
	Mixed	311	1	19	1
	Other Ethnic Groups	329	1	27	1
	Not stated	1379	4	113	5

The Kaplan-Meier curves demonstrate empirical differences in "time in ED" curves for different groupings of categorical variables. The referral service curve, shown in Figure 4.1, demonstrates large variations in "time in ED" curves for the different services a patient is referred to. Paediatric had the fastest flow through the ED and General Medicine was the slowest, these different curves are likely to be in part the result of differing admission pathways between referral services. The *Other* category contained any referral services with fewer than 500 admissions during the study period, the full list of services included in this category can be found in the supplementary materials. The Kaplan-Meier curves for all the other explanatory variables are shown in the supplementary materials.

The fitted Cox-Regression models show a range of effect sizes for the different variables. Coefficients and hazards ratios for the strike types are found in Table

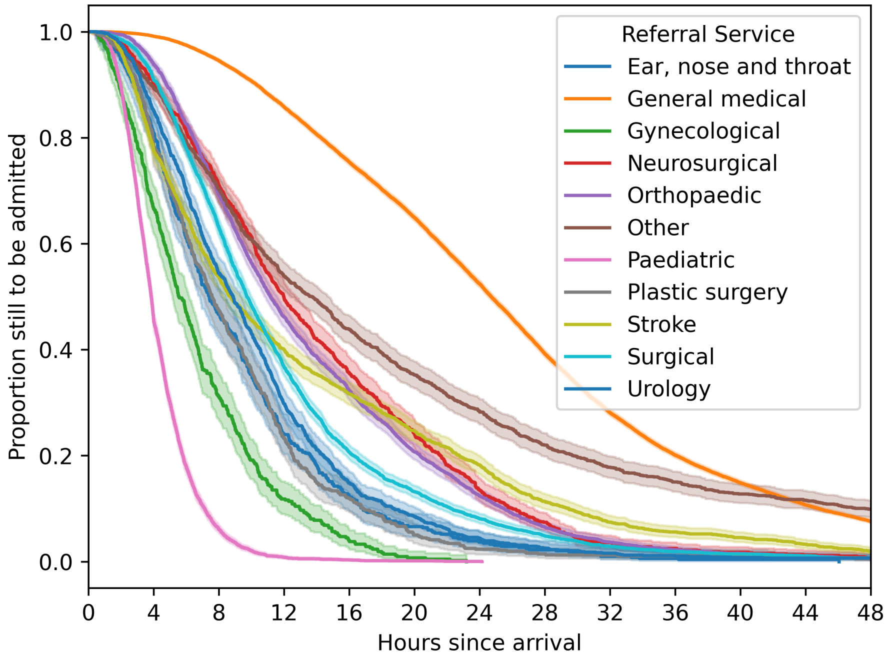

Figure 4.1: Kaplan-Meier curves of admitted patients' "time in ED", separated by referral service they are admitted to. The shaded area around each line represents the 95% confidence interval (CI) for the KM estimate at each point. These CI are very small for paediatrics and general medicine therefore not easily visible on the plot.

4.2. Forrest plots for all variables are found in supplementary Figure 4.9.

The Schoenfeld residuals against transformed time tests indicated that five of the variables included in the model significantly deviated from proportional hazards. Inspected visually, these were minor deviations that were likely only to be statistically significant due to large sample sizes. Results from these tests are found in the supplementary materials Figures 4.4-4.8 and considered further in the Discussion section.

The model controlled for the variables listed in the Methods section. The tests suggest that all strikes have a similar effect on patient "time in ED". The largest effect is for consultant strikes, with a hazard ratio of 1.34 suggesting that patients are 34% more likely to be admitted at any timepoint during their stay on a consultant strike day compared to a non-strike day. The fitted survival curves from the models for all the strike types are shown in Figure 4.2. Since this only included patients who were eventually admitted to a ward, this suggests that patients move through the emergency department into the hospital more quickly on strike days. Consistently

Table 4.2: Coefficients and hazard ratios for the strike variables in the Cox-proportional hazards model. Here, higher hazard refers to a higher likelihood of being admitted into the hospital. Since we only investigate patients who were admitted, higher hazard is a positive outcome that means patients were more likely to be admitted more quickly.

Strike Type	Coefficient	Hazard Ratio	95% CI		$p-$value
Baseline – No strike	-	-	-	-	-
Junior doctors	0.152	1.164	1.097	1.236	5.42e-07*
Consultants	0.329	1.389	1.194	1.617	2.20e-05*
Consultants and junior doctors	0.223	1.25	1.045	1.495	0.014
Nurses	0.219	1.245	1.14	1.36	1.11e-06*
Ambulance workers	0.189	1.208	1.066	1.37	0.0031*

* Statistically significant

higher probability of admission at any given point leads to higher rate of admission.

4.4 Discussion

We provide, to our knowledge, the first quantitative evidence of the impact of the NHS strikes on patient flow through the emergency department. This survival analysis finds an increase in hazards ratio (hazard of admission to hospital when in ED) for admitted patients on all strike days. This implies that patients have a higher probability of being admitted at any point during their “time in ED” on strike days than they do during non-strike days when accounting for ED and patient factors. This higher hazard ratio means that in general, a patient is moved through the emergency department into a ward faster during a strike day compared to a non-strike day.

It is important to note that during these strike periods, the hospitals were running unsustainable practices, and the authors do not suggest that healthcare worker strikes are positive for the NHS or emergency departments overall. The issues of cancelled scheduled care and rising costs to the NHS are well documented and have been raised in the introduction. However, these results suggest that there may be scope to improve patient flow through emergency departments and reduce patient time spent in ED. Understanding all the differences on strike days, can help create

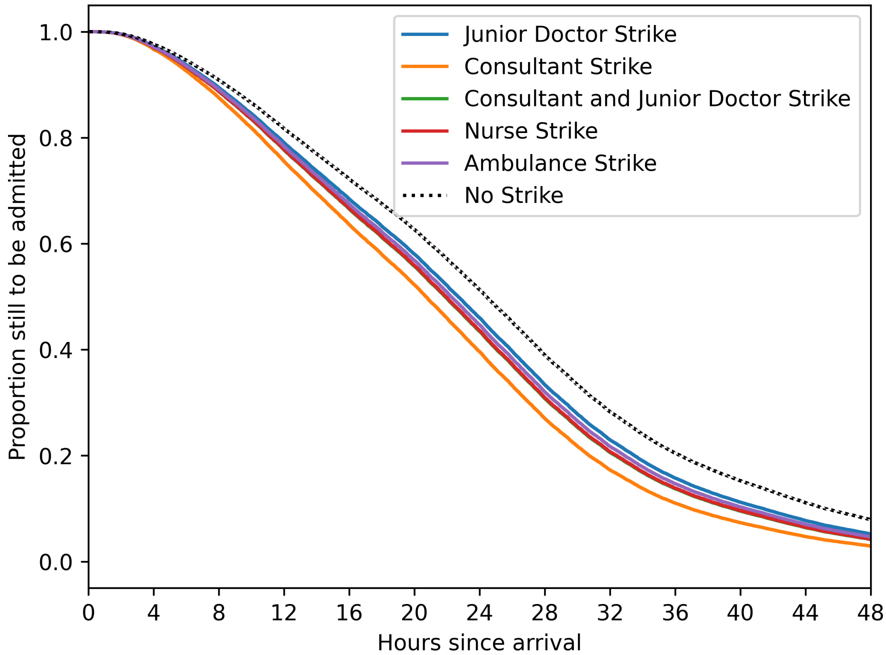

Figure 4.2: Fitted Cox-regression "time in ED" curves for each of the different strike types in the analysis.

change to ensure shorter wait times in NHS emergency departments.

One possible driver of the increased flow is the additional capacity for emergency care due to the reduction in elective activity in the hospital. The improved flow effect is the same for all categories, and staff seniority changes between the strike types, this indicates this is likely not a primary driver of this change. NHS hospitals during strikes typically run a 'Christmas day service' level, where much routine care is disrupted and emergency care is prioritised [6]. Consultants often have additional capacity to deal with emergency patients because there is less elective care activity [28].

The Royal College of Emergency Medicine reported in January 2024 that hospital bed occupancy rates were at the 'unsafe' level of 93% [29]. The increased inpatient capacity may have meant that the effects of access block were reduced during the strikes, allowing patients to be admitted to care on a ward more smoothly. Improved flow during strikes being due to reduced elective activity would support the hypothesis that access block is the main driver of ED crowding. Suggesting that when additional inpatient capacity is provided, flow into the hospital through the ED is increased.

This finding agrees with some previous findings in the literature that imply a reduction in patient wait time during strike periods globally [30, 31, 32]. These findings, however, are not consistent and depend on the country's healthcare system and the strike in question [16]. Evidence from previous NHS strikes shows the negative impact on services and patient outcomes, but does not investigate the effect on emergency departments [33, 34].

An additional finding of the paper is the large variation in "time in ED" curves for the different referral services . Many of the differences between the different categories and the baseline of 'orthopaedics' in the fitted model are statistically significant overall (and vary between each other). The variations in empirical Kaplan-Meier survival curves are shown in Figure 4.1. The differences in survival curves between referral destinations are likely due to hospital flow structures in place. Certain specialties have their own assessment units, and transfer to these unit will likely mark the end of their stay in ED. The general medical assessment unit (MAU), however, is classed as part of the emergency department and time in this MAU contributes to a longer patient "time in ED". Hence, the much longer survival curve for patients who go onto the general medical unit.

4.4.1 Limtations

This paper looks at patient flow through the emergency department using survival analysis to model the 'time to event' of a patient being admitted to hospital. The data used for this analysis spans several years, and covers two emergency departments in the North West of England. We provide a framework for assessing the impact of strikes in the emergency departments that can be used for further regions. These findings do agree with other, international, literature on patient flow and 'waiting time' during the strikes, however, this may not be the case across the entirety of the United Kingdom. The impact of the strikes will likely vary by hospital, and we cannot ensure our findings are generalisable across the entire country.

Furthermore, due to the previous literature on access block playing a key role in inflating patients' "time in ED", our analysis included only patients who were eventually admitted to the hospital. Our findings only correspond to patients that were admitted to hospital. The effects of the strikes may have differed for patients who were discharged or transferred to another hospital.

The times at which a patient is recorded to have arrived and been admitted are automatically logged when a healthcare worker updates the patient's data. This means there is some manual choice in when a patient is classed as admitted. This can be seen in the spike in admissions immediately before the four-hour mark, which is likely due to healthcare workers attempting to meet targets. This control of recording by healthcare workers may mean that patients' time may be skewed due to manual input, and different healthcare workers may have different recording practices. Information on the healthcare professional who is recording the data is not included in the dataset, and therefore not something we could account for. The mix of healthcare professionals recording the data is likely to change during strike periods, and therefore not fully reflect the real changes during the strike periods.

Our Cox-proportional hazards methodology has some limitations. Despite modelling choices taken to ensure the model was as robust as possible, the model falls short of completely satisfying the proportional hazards assumption. The assumptions were tested using Schoenfeld residuals and log-minus-log plots to assess validity of the results. These tests demonstrated minor deviations from the proportional hazards assumption, as can be seen in Figure 4.1, where lines in the Kaplan-Meier plots grouped by referral service (a covariate included in the model) clearly cross. However, it is well documented that the Cox-proportional hazards regression model is robust against such deviations from the model assumptions [25]. Our hazard ratio estimates were calculated using a robust, bootstrapping procedure to ensure maximum validity to our results. Despite these deviations, we believe that because of the robustness of the model and the model specification, our hazard ratios lie close to their true values.

4.4.2 Future Work

Further work should use inpatient data to investigate the relationship between changes in available inpatient capacity during the strikes and flow through the emergency department directly. This would further consolidate the implied relationship found in this study. Staffing data could also be included in further analyses, fully accounting for changes in staffing levels and staff seniority during the strike measures.

There is a lack of studies on the effects of strikes on the healthcare system in general. The wider impacts of the strikes should be further evaluated. The strikes provide an interesting counterfactual example to the status quo of NHS healthcare delivery. The unsustainable nature of service delivery during the strikes should be kept in mind when interpreting results. However, any changes during the strikes indicate that there may be a way to further improve the efficiency of NHS services. To fully understand our results, we suggest a qualitative study to gain perspectives from patients, clinicians and other members of the NHS workforce affected by the strikes.

4.5 References

[1] BMA, *BMA announces dates for new 96-hour walkout by junior doctors in England after Government failure to make any credible offer in talks*, Mar. 2023. [Online]. Available: https://www.bma.org.uk/bma-media-centre/bma-announces-dates-for-new-96-hour-walkout-by-junior-doctors-in-england-after-government-failure-to-make-any-credible-offer-in-talks (visited on 01/10/2024).

[2] Department of Health and Social Care, *End of NHS consultant strike action as government offer accepted*, Apr. 2024. [Online]. Available: https://www.gov.uk/government/news/end-of-nhs-consultant-strike-action-as-government-offer-accepted (visited on 04/07/2024).

[3] BMA, *Pay restoration for junior doctors in England*, B¡A. [Online]. Available: https://www.bma.org.uk/our-campaigns/junior-doctor-campaigns/pay/pay-restoration-for-junior-doctors-in-england (visited on 05/09/2024).

[4] NHS England, *Financial performance update*, Jan. 2024. [Online]. Available: https://www.england.nhs.uk/long-read/financial-performance-update-1-feb-24/ (visited on 04/07/2024).

[5] S. Anandaciva, *Counting The Cost Of NHS Strikes*, Feb. 2024. [Online]. Available: https://www.kingsfund.org.uk/insight-and-analysis/blogs/counting-cost-nhs-strikes (visited on 03/04/2024).

[6] NHS England, *Industrial action in the NHS*, Nov. 2022. [Online]. Available: https://www.england.nhs.uk/publication/preparedness-for-potential-industrial-action-in-the-nhs/#heading-3 (visited on 04/07/2024).

[7] Healthwatch, "Delays to NHS care: Understanding the impact," Healthwatch, Tech. Rep., Jul. 2023. [Online]. Available: https://www.healthwatch.co.uk/report/2023-07-27/delays-nhs-care-understanding-impact (visited on 04/07/2024).

[8] M. Warner and B. Zaranko, "One year on from the backlog recovery plan: What next for NHS waiting lists?" Institute for Fiscal Studies, Tech. Rep., Feb. 2023. [Online]. Available: https://ifs.org.uk/publications/one-

year-backlog-recovery-plan-what-next-nhs-waiting-lists (visited on 05/27/2024).

[9] *Statistical Press Notice NHS referral to treatment (RTT) waiting times data Febrary 2024*, Apr. 2024. [Online]. Available: https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2024/04/Feb24-RTT-SPN-Publication-PDF-only-445KB-08666.pdf (visited on 05/27/2024).

[10] N. Trust, *A&E waiting times*, Nuffield Trust. [Online]. Available: https://www.nuffieldtrust.org.uk/resource/a-e-waiting-times (visited on 05/27/2024).

[11] G. Stoye and M. Warner, "The effects of doctor strikes on patient outcomes: Evidence from the English NHS," *Journal of Economic Behavior & Organization*, vol. 212, pp. 689–707, Aug. 2023, ISSN: 0167-2681. [Online]. Available: https://www.sciencedirect.com/science/article/pii/S0167268123002184 (visited on 04/26/2024).

[12] S. L. Bernstein *et al.*, "The Effect of Emergency Department Crowding on Clinically Oriented Outcomes," *Academic Emergency Medicine*, vol. 16, no. 1, pp. 1–10, 2009, ISSN: 1553-2712. [Online]. Available: https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1553-2712.2008.00295.x (visited on 01/04/2024).

[13] I. Higginson, "Emergency department crowding," *Emergency Medicine Journal*, vol. 29, no. 6, pp. 437–443, Jun. 2012, Publisher: BMJ Publishing Group Ltd and the British Association for Accident & Emergency Medicine Section: Review, ISSN: 1472-0205, 1472-0213. [Online]. Available: https://emj.bmj.com/content/29/6/437 (visited on 01/04/2024).

[14] G. D. Kelen *et al.*, "Emergency Department Crowding: The Canary in the Health Care System," *Catalyst non-issue content*, vol. 2, no. 5, Sep. 2021, Publisher: Massachusetts Medical Society. [Online]. Available: https://catalyst.nejm.org/doi/full/10.1056/CAT.21.0217 (visited on 06/29/2024).

[15] D. M. Fatovich and R. L. Hirsch, "Entry overload, emergency department overcrowding, and ambulance bypass," *Emergency Medicine Journal*, vol. 20, no. 5, pp. 406–409, Sep. 2003, Publisher: BMJ Publishing Group Ltd and the British Association for Accident & Emergency Medicine Section: Original

articles, ISSN: 1472-0205, 1472-0213. [Online]. Available: https://emj.bmj.com/content/20/5/406 (visited on 01/09/2024).

[16] R. Essex, S. Ahmed, H. Elliott, D. Lakika, L. Mackenzie, and S. M. Weldon, "The impact of strike action on healthcare delivery: A scoping review," *The International Journal of Health Planning and Management*, vol. 38, no. 3, pp. 599–627, 2023, ISSN: 1099-1751. [Online]. Available: https://onlinelibrary.wiley.com/doi/abs/10.1002/hpm.3610 (visited on 01/11/2024).

[17] A. Boyle, "What the recent strikes can teach us about fixing emergency care," *BMJ*, vol. 381, p1047, May 2023, Publisher: British Medical Journal Publishing Group Section: Opinion, ISSN: 1756-1833. [Online]. Available: https://www.bmj.com/content/381/bmj.p1047 (visited on 01/10/2024).

[18] NHS England, *Emergency Care Data Set (ECDS)*. [Online]. Available: https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/emergency-care-data-set-ecds (visited on 06/10/2024).

[19] NHS England, *Data Dictionary - Lodging End Time*, dita. [Online]. Available: https://www.datadictionary.nhs.uk/attributes/lodging_end_time.html (visited on 04/16/2024).

[20] M. Greenwood, *A report on the natural duration of cancer* (Reports on public health and medical subjects). London: H.M.S.O., 1926, OCLC: 14713088.

[21] C. Davidson-Pilon, "Lifelines: Survival analysis in Python," *Journal of Open Source Software*, vol. 4, no. 40, p. 1317, Aug. 2019, ISSN: 2475-9066. [Online]. Available: https://joss.theoj.org/papers/10.21105/joss.01317 (visited on 05/09/2024).

[22] *UK Strike Action Calendar*. [Online]. Available: https://www.strikecalendar.co.uk/ (visited on 04/22/2024).

[23] *2022–present National Health Service strikes*, Page Version ID: 1220068455, Apr. 2024. [Online]. Available: https://en.wikipedia.org/w/index.php?title=2022%E2%80%93present_National_Health_Service_strikes&oldid=1220068455 (visited on 04/22/2024).

[24] W. W. Daniel, *Applied Nonparametric Statistics*. PWS-KENT Pub., 1990, Google-Books-ID: 0hPvAAAAMAAJ, ISBN: 978-0-534-91976-4.

[25] I. Persson, "Essays on the Assumption of Proportional Hazards in Cox Regression," 2002, Publisher: Acta Universitatis Upsaliensis. [Online]. Available: https://urn.kb.se/resolve?urn=urn:nbn:se:uu:diva-1628 (visited on 04/22/2024).

[26] M. J. Stensrud and M. A. Hernán, "Why Test for Proportional Hazards?" *JAMA*, vol. 323, no. 14, p. 1401, Apr. 2020, ISSN: 0098-7484. [Online]. Available: https://jamanetwork.com/journals/jama/fullarticle/2763185 (visited on 04/22/2024).

[27] S. Mason, E. J. Weber, J. Coster, J. Freeman, and T. Locker, "Time Patients Spend in the Emergency Department: England's 4-Hour Rule—A Case of Hitting the Target but Missing the Point?" *Annals of Emergency Medicine*, vol. 59, no. 5, pp. 341–349, May 2012, Publisher: Elsevier, ISSN: 0196-0644, 1097-6760. [Online]. Available: https://www.annemergmed.com/article/S0196-0644(11)01541-1/fulltext (visited on 05/09/2024).

[28] NHS England, *NHS briefing: Industrial action winter 2023*. [Online]. Available: https://www.england.nhs.uk/briefing-industrial-action-winter/ (visited on 04/26/2024).

[29] S. Draper, *Hospitals remain at unsafe levels of bed occupancy, as one in nine faced 12 hour waits in A&Es in December*, Jan. 2024. [Online]. Available: https://rcem.ac.uk/hospitals-remain-at-unsafe-levels-of-bed-occupancy-as-one-in-nine-faced-12-hour-waits-in-aes-in-december/ (visited on 06/21/2024).

[30] J. Sim, Y. Choi, and J. Jeong, "Changes in Emergency Department Performance during Strike of Junior Physicians in Korea," *Emergency Medicine International*, vol. 2021, no. 1, p. 1 786 728, 2021, ISSN: 2090-2859. [Online]. Available: https://onlinelibrary.wiley.com/doi/abs/10.1155/2021/1786728 (visited on 06/27/2024).

[31] G. Robinson, K. McCann, P. Freeman, and R. Beasley, "The New Zealand national junior doctors' strike: Implications for the provision of acute hospital medical services," *Clinical Medicine (London, England)*, vol. 8, no. 3, pp. 272–275, Jun. 2008, ISSN: 1470-2118.

[32] M. Harvey, M. Al Shaar, G. Cave, M. Wallace, and P. Brydon, "Correlation of physician seniority with increased emergency department efficiency during a resident doctors' strike," *The New Zealand Medical Journal*, vol. 121, no. 1272, pp. 59–68, Apr. 2008, ISSN: 1175-8716.

[33] D. Furnivall, A. Bottle, and P. Aylin, "Retrospective analysis of the national impact of industrial action by English junior doctors in 2016," *BMJ open*, vol. 8, no. 1, e019319, Feb. 2018, ISSN: 2044-6055.

[34] J. D. Kalbfleisch and R. L. Prentice, "Estimation of the Average Hazard Ratio," *Biometrika*, vol. 68, no. 1, pp. 105–112, 1981, Publisher: [Oxford University Press, Biometrika Trust], ISSN: 0006-3444. [Online]. Available: `https://www.jstor.org/stable/2335811` (visited on 05/07/2024).

4.6 Supplementary Material

4.6.1 Methodology

4.6.1.1 Strike Dates

Table 4.3: Truth table for which strike dates are classed as which strike.

Date	Nurse strike	Ambulance strike	Junior doctor strike	Consultant strike
15/12/2022	TRUE	FALSE	FALSE	FALSE
20/12/2022	TRUE	FALSE	FALSE	FALSE
21/12/2022	FALSE	TRUE	FALSE	FALSE
11/01/2023	FALSE	TRUE	FALSE	FALSE
18/01/2023	TRUE	FALSE	FALSE	FALSE
19/01/2023	TRUE	FALSE	FALSE	FALSE
23/01/2023	FALSE	TRUE	FALSE	FALSE
06/02/2023	TRUE	FALSE	FALSE	FALSE
07/02/2023	TRUE	FALSE	FALSE	FALSE
10/02/2023	FALSE	TRUE	FALSE	FALSE
01/03/2023	TRUE	FALSE	FALSE	FALSE
02/03/2023	TRUE	FALSE	FALSE	FALSE
03/03/2023	TRUE	FALSE	FALSE	FALSE
13/03/2023	FALSE	FALSE	TRUE	FALSE
14/03/2023	FALSE	FALSE	TRUE	FALSE
15/03/2023	FALSE	FALSE	TRUE	FALSE
20/03/2023	FALSE	TRUE	FALSE	FALSE
11/04/2023	FALSE	FALSE	TRUE	FALSE
12/04/2023	FALSE	FALSE	TRUE	FALSE
13/04/2023	FALSE	FALSE	TRUE	FALSE
14/04/2023	FALSE	FALSE	TRUE	FALSE
15/04/2023	FALSE	FALSE	TRUE	FALSE
14/06/2023	FALSE	FALSE	TRUE	FALSE
15/06/2023	FALSE	FALSE	TRUE	FALSE
16/06/2023	FALSE	FALSE	TRUE	FALSE

13/07/2023	FALSE	FALSE	TRUE	FALSE
14/07/2023	FALSE	FALSE	TRUE	FALSE
15/07/2023	FALSE	FALSE	TRUE	FALSE
16/07/2023	FALSE	FALSE	TRUE	FALSE
17/07/2023	FALSE	FALSE	TRUE	FALSE
18/07/2023	FALSE	FALSE	TRUE	FALSE
20/07/2023	FALSE	FALSE	FALSE	TRUE
21/07/2023	FALSE	FALSE	FALSE	TRUE
22/07/2023	FALSE	FALSE	FALSE	TRUE
11/08/2023	FALSE	FALSE	TRUE	FALSE
12/08/2023	FALSE	FALSE	TRUE	FALSE
13/08/2023	FALSE	FALSE	TRUE	FALSE
14/08/2023	FALSE	FALSE	TRUE	FALSE
24/08/2023	FALSE	FALSE	FALSE	TRUE
25/08/2023	FALSE	FALSE	FALSE	TRUE
19/09/2023	FALSE	FALSE	FALSE	TRUE
20/09/2023	FALSE	FALSE	TRUE	TRUE
21/09/2023	FALSE	FALSE	TRUE	FALSE
22/09/2023	FALSE	FALSE	TRUE	FALSE
02/10/2023	FALSE	FALSE	TRUE	TRUE
03/10/2023	FALSE	FALSE	TRUE	TRUE
04/10/2023	FALSE	FALSE	TRUE	TRUE
20/10/2023	FALSE	FALSE	TRUE	FALSE
21/10/2023	FALSE	FALSE	TRUE	FALSE
22/10/2023	FALSE	FALSE	TRUE	FALSE
03/01/2024	FALSE	FALSE	TRUE	FALSE
04/01/2024	FALSE	FALSE	TRUE	FALSE
05/01/2024	FALSE	FALSE	TRUE	FALSE
06/01/2024	FALSE	FALSE	TRUE	FALSE
07/01/2024	FALSE	FALSE	TRUE	FALSE
08/01/2024	FALSE	FALSE	TRUE	FALSE
25/02/2024	FALSE	FALSE	TRUE	FALSE
26/02/2024	FALSE	FALSE	TRUE	FALSE
27/02/2024	FALSE	FALSE	TRUE	FALSE
28/02/2024	FALSE	FALSE	TRUE	FALSE

4.6.1.2 Referral Destination Categories

Referral destination categories in the '*Other*' class are Geriatric, Cardiology, Nephrology, Obstetrics, Clinical oncology, Ophthalmology, Clinical oncology, Neurology, Rehabilitation, Endocrinology.

4.6.2 Additional ED1 Results

In Figure 4.3 we see a high, widespread distribution of patients' "time in ED". This is because we are looking at just patients who were admitted since 2022. Admitted patients generally are in ED for longer, and patient "time in ED" has increased over time.

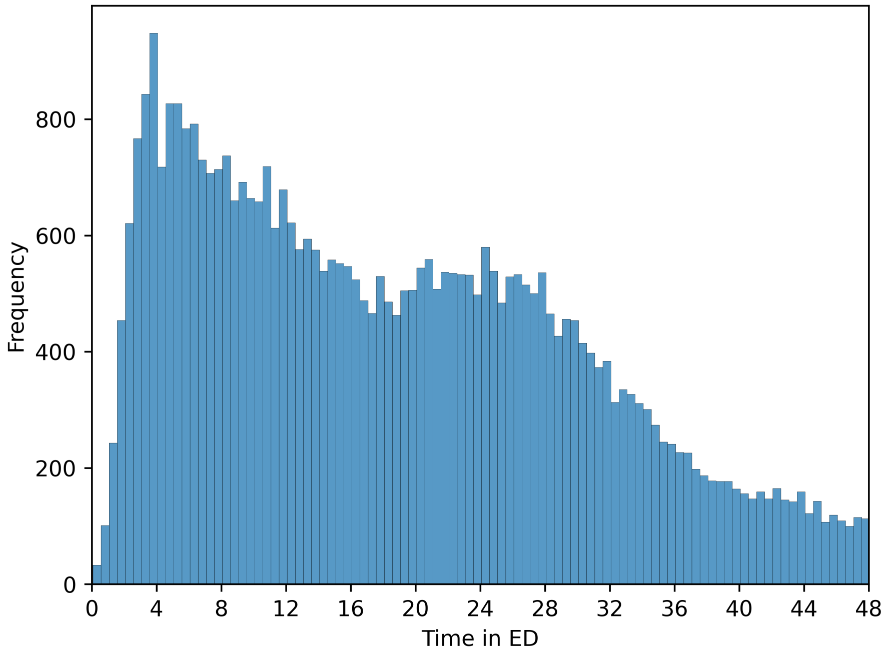

Figure 4.3: Histogram of admitted patients' time spent in ED.

4.6.2.1 Log-log plots

We produced log-log plots of the double-log transform of the survival curves against log-transformed time for each categorical variable in the model to test for proportional hazards. If the proportional hazards assumption holds each line will be parallel.

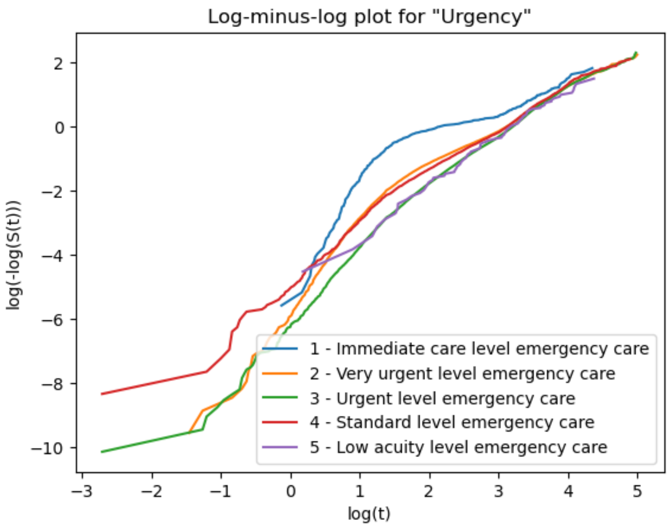

Figure 4.4: Log-log plot of urgency of patient presentations.

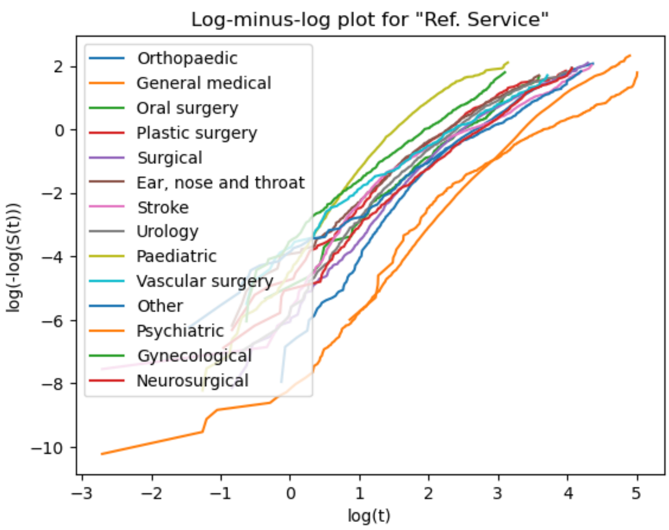

Figure 4.5: Log-log plot of referral service.

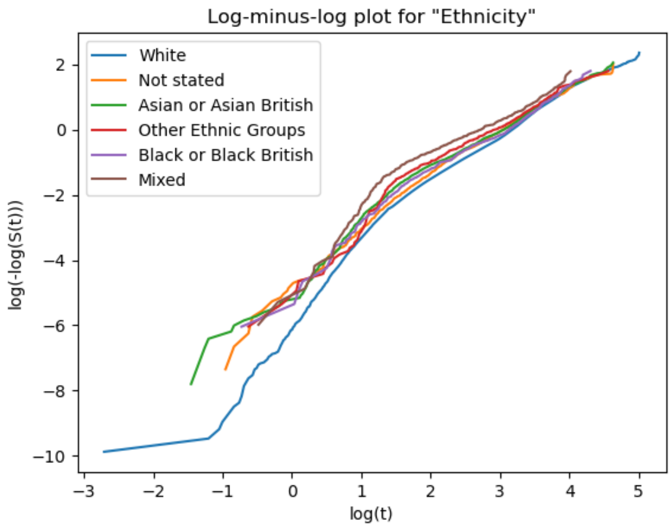

Figure 4.6: Log-log plot of ethnicity.

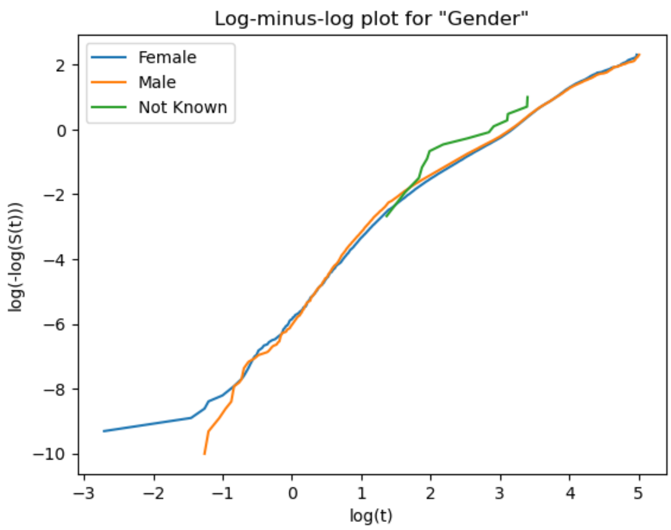

Figure 4.7: Log-log plot of gender.

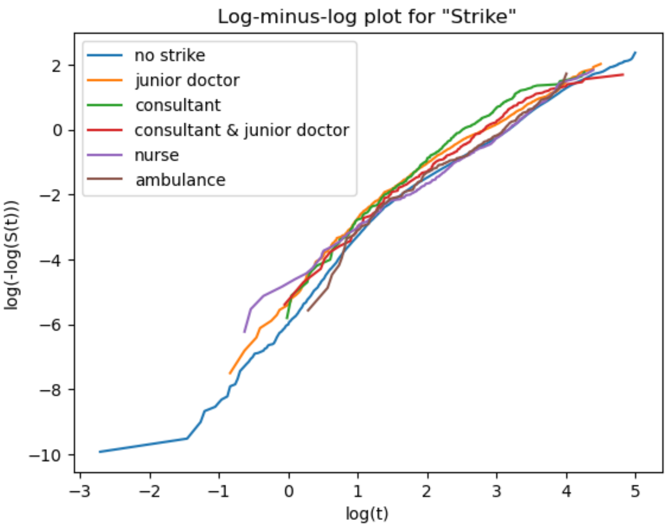

Figure 4.8: Log-log plot of strike type.

4.6.2.2 Cox Proportional Hazards Model

Table 4.4: Cox-Proportional Hazards Model summary, including model parameters, calculated hazard ratios with 95% confidence intervals, and p-value.

Term		Coef.	Haz. Rtio	95% CI		p
Linear Temporal Trend		0.008	1.008	1.007	1.01	2.74e-28
Year Harmonic (Sin)		0.02	1.021	1.004	1.037	0.012692
Year Harmonic (Cos)		-0.074	0.929	0.914	0.944	2.86e-19
Day Harmonic (Sin)		-0.011	0.989	0.974	1.004	0.150124
Day Harmonic (Sin)		0.008	1.008	0.993	1.024	0.301051
ED Heat		-0.013	0.987	0.986	0.988	1.19e-301
Urgency	2 - Very urgent level emergency care	-0.412	0.662	0.59	0.744	3.97E-12
Urgency	3 - Urgent level emergency care	-0.458	0.632	0.563	0.71	1.01E-14
Urgency	4 - Standard level emergency care	-0.397	0.673	0.597	0.758	8.38E-11
Urgency	5 - Low acuity level emergency care	-0.496	0.609	0.479	0.774	5.09E-05
Ref Service	General medical	-1.104	0.331	0.315	0.349	0
Ref Service	Oral surgery	0.204	1.226	1.041	1.443	0.014408
Ref Service	Plastic surgery	0.506	1.659	1.421	1.937	1.59E-10
Ref Service	Surgical	0.164	1.179	1.097	1.266	6.81E-06
Ref Service	Ear, nose and throat	0.529	1.697	1.481	1.944	2.53E-14
Ref Service	Stroke	-0.143	0.866	0.788	0.953	0.003197
Ref Service	Urology	0.445	1.56	1.402	1.736	3.27E-16
Ref Service	Paediatric	1.762	5.827	5.382	6.308	0
Ref Service	Vascular surgery	0.412	1.51	1.244	1.834	3.21E-05
Ref Service	Other	-0.383	0.682	0.594	0.783	4.88E-08
Ref Service	Psychiatric	-2.194	0.111	0.096	0.13	8.44E-177
Ref Service	Gynecological	1.094	2.988	2.645	3.374	1.25E-69
Ref Service	Neurosurgical	-0.152	0.859	0.782	0.943	0.00142
Age		-0.008	0.992	0.992	0.993	2.88e-132

Ethnicity	Not stated	-0.015	0.985	0.92	1.054	0.658329
Ethnicity	Asian or Asian British	0.015	1.015	0.97	1.062	0.520054
Ethnicity	Other Ethnic Groups	-0.058	0.944	0.841	1.058	0.321731
Ethnicity	Black or Black British	0.012	1.012	0.913	1.123	0.818006
Ethnicity	Mixed	0.049	1.05	0.944	1.167	0.368187
Gender	Male	-0.012	0.988	0.967	1.01	0.294745
Gender	Not Known	0.392	1.48	0.857	2.555	0.159825
Strike Type	Junior Doctor	0.152	1.164	1.097	1.236	5.42e-07
Strike Type	Consultant	0.329	1.389	1.194	1.617	2.20e-05
Strike Type	Consultant & Junior Doctor	0.223	1.25	1.045	1.495	0.014431
Strike Type	Nurse	0.219	1.245	1.14	1.36	1.11E-06
Strike Type	Ambulance	0.189	1.208	1.066	1.37	0.003135

4.6.3 ED 2 Results

Included here are the results of the analysis of ED2. With respect to this analysis, the main difference between ED2 and ED1 is that ED2 is a minor injuries unit with limited hours. High urgency care with specialist needs will be transferred to ED1. Since this investigation focuses only investigates admitted patients, the patients admitted to ED2 are specific subset of those in ED1.

4.6.3.1 Time in ED

The model for ED did not include referral service, due to low variance between categories and therefore convergence issues. This similarity between referral service "time in ED" curves can be seen in the Kaplan-Meier plot in Figure 4.11.

The results from the proportional hazards model for ED2 are less consistent. Most of the strikes appear to have no significant impact on flow. The only significant hazard ratio is for consultant strikes, with a hazard ratio of 1.36.

These "time in ED curves" are shown in Figure 4.12.

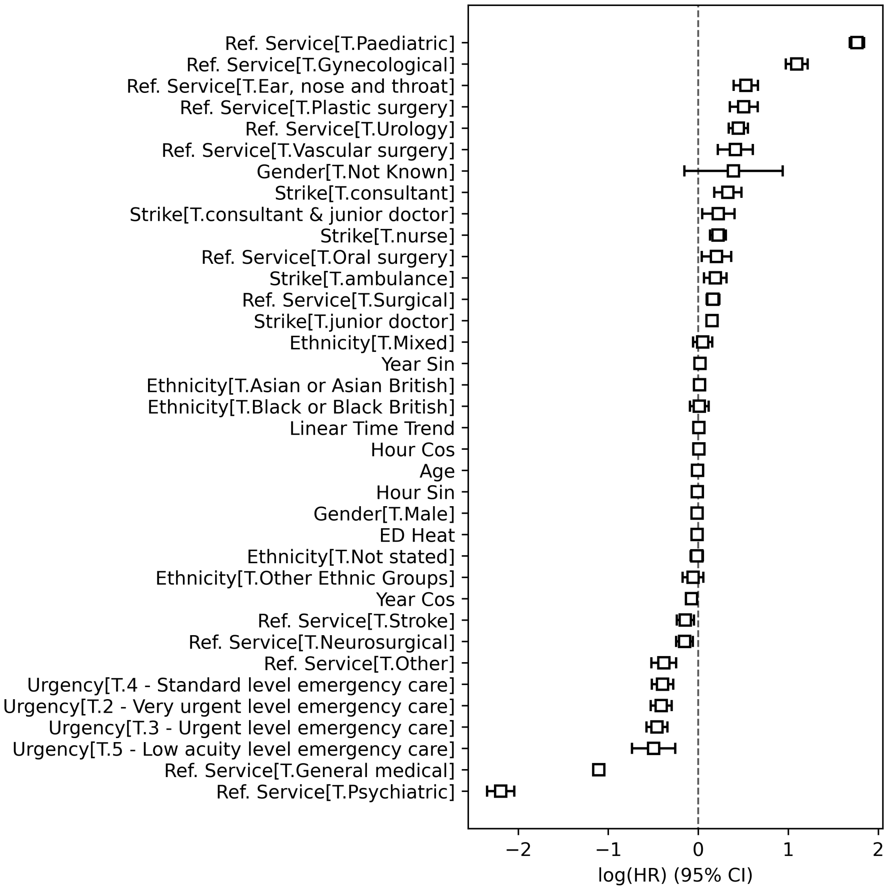

Figure 4.9: Forrest plot including all variables in the model.

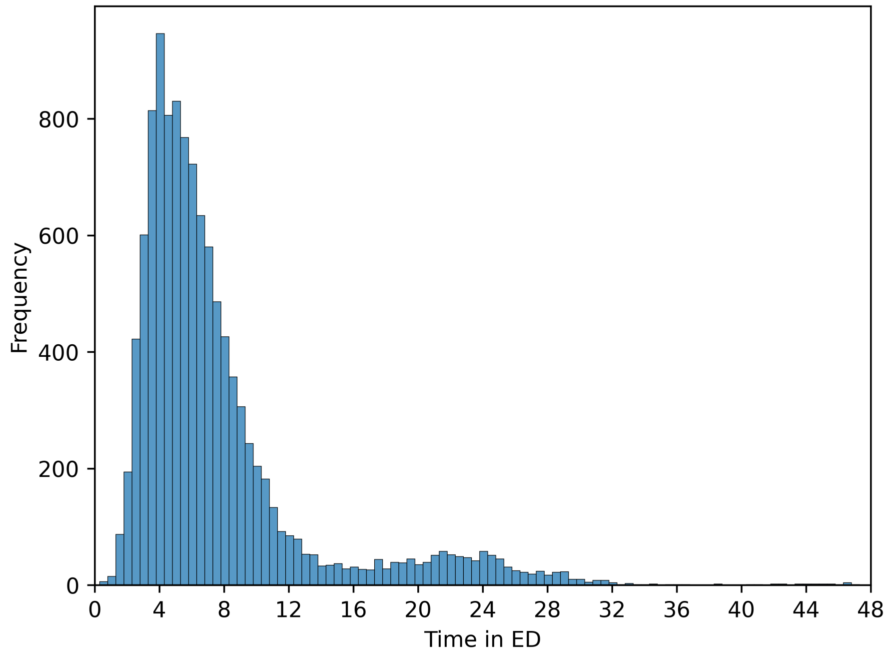

Figure 4.10: Histogram of admitted patients' time spent in ED for ED2.

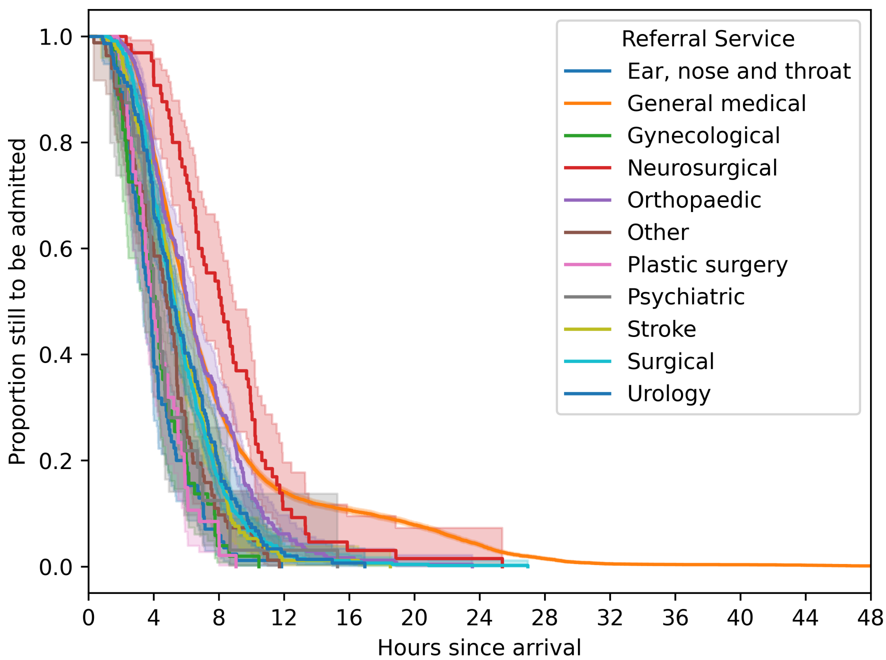

Figure 4.11: Kaplan-Meier curves of admitted patients' "time in ED", separated by referral service they are admitted to for ED2

Table 4.6: ED2: Coefficients and hazard ratios for the strike variables in the Cox-proportional hazards model. Here, higher hazard refers to a higher likelihood of being admitted into the hospital. Since we only investigate patients who were admitted, higher hazard is a positive outcome that means patients were more likely to be admitted more quickly.

Strike Type	Coefficient	Hazard Ratio	95% CI		$p-$value
Baseline – No strike	-	-	-	-	-
Junior doctor strike	-0.075	0.927	0.844	1.02	0.119217
Consultant strike	0.306	1.358	1.098	1.679	0.004686
Consultant and junior doctor strike	-0.264	0.768	0.599	0.985	0.037539
Nurse strike	-0.03	0.97	0.827	1.138	0.709028
Ambulance strike	0.283	1.327	1.065	1.653	0.011718

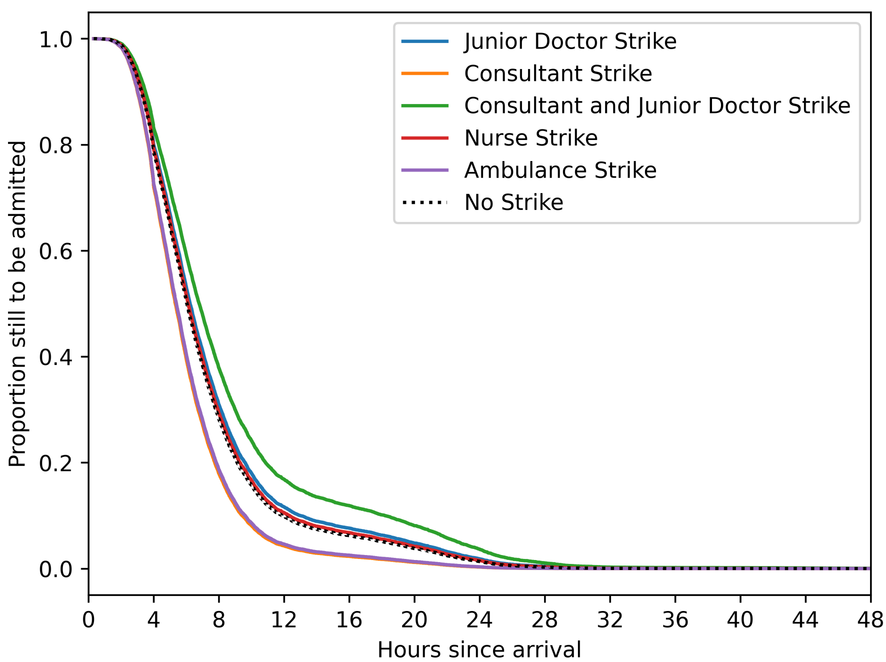

Figure 4.12: Fitted Cox-regression “time in ED” curves for each of the different strike types in the analysis to for ED2

Table 4.6: ED2: Cox-Proportional Hazards Model summary, including model parameters, calculated hazard ratios with 95% confidence intervals, and p-value.

Term		Coef.	Haz. Rtio	95% CI		p
Linear Temporal Trend		-0.039	0.962	0.959	0.964	1.40E-157
Year Harmonic (Sin)		-0.05	0.951	0.924	0.979	0.0007501
Year Harmonic (Cos)		-0.189	0.828	0.805	0.852	3.41E-39
ED Heat		-0.022	0.978	0.976	0.98	2.20E-94
Urgency	2 - Very urgent level emergency care	0.009	1.009	0.676	1.506	0.96575648
Urgency	3 - Urgent level emergency care	-0.089	0.915	0.614	1.365	0.664153129
Urgency	4 - Standard level emergency care	-0.118	0.889	0.595	1.328	0.566123953
Urgency	5 - Low acuity level emergency care	0.041	1.042	0.524	2.071	0.906591681
Age		-0.003	0.997	0.995	0.998	4.73E-10
Ethnicity	Not stated	-0.09	0.914	0.818	1.022	0.115351712
Ethnicity	Asian or Asian British	0.115	1.122	0.921	1.367	0.253371146
Ethnicity	Other Ethnic Groups	-0.099	0.906	0.687	1.195	0.483722617
Ethnicity	Black or Black British	-0.154	0.857	0.605	1.215	0.387172496
Ethnicity	Mixed	-0.231	0.793	0.517	1.218	0.28962183
Gender	Male	0.051	1.052	1.013	1.093	0.009273067
Gender	Not Known	-0.035	0.966	0.475	1.964	0.923696142
Strike Type	Junior Doctor	-0.075	0.927	0.844	1.02	0.119216525
Strike Type	Consultant	0.306	1.358	1.098	1.679	0.004686294
Strike Type	Consultant & Junior Doctor	-0.264	0.768	0.599	0.985	0.037539287
Strike Type	Nurse	-0.03	0.97	0.827	1.138	0.709027714
Strike Type	Ambulance	0.283	1.327	1.065	1.653	0.011718244

Chapter 5

Discussion

The chapters in this thesis serve as examples of what can currently be achieved using routinely collected data, discussing present limitations and prospects for further developments. Each chapter contains unique findings from responsive analyses to unplanned changes experienced by the NHS: the COVID-19 pandemic, rapid roll-out of digital technology and the NHS strikes, each with implications for health policy. Chapters 2[50] and 3[56] both demonstrate projects involving data linkage between an external source and NHS routinely collected secondary care datasets. Chapter 4 demonstrates the utility of a single secondary care dataset for a project with potential policy impact. Together in this thesis, they showcase the potential, and challenges, for the NHS to leverage the ever-increasing volume of routinely collected data that is becoming more accessible going forward.

5.1 Chapter Overviews

Chapter 2 demonstrates an application of a novel methodology, State Sequence Analysis, to describe care pathways through the health system. The breadth of linked data sources available from the County Durham and Darlington trust was utilised to develop comprehensive 'trajectories' of care for care home residents in the region. These trajectories were a longitudinal representation of care a resident accessed during the study period, sequences with a granularity of one day – allowing the identification of short-term and long-term patterns of care. These patterns were specifically investigated in 10-day time periods around the residents' COVID-19 testing events; their first positive test, and their first test overall. We used State Sequence Analysis to measure similarity of these 10-day sequences and identify groups of residents who experienced similar patterns of care around their testing events. We then used these groupings to investigate associations between these patterns and resident long-term conditions (dementia, diabetes and a frailty measure) as well as their 28-day mortality after the test in question. We found that patient long-term conditions were often strongly associated with higher levels of healthcare usage. Our analysis showed that a disproportionate number of patients with a short stay in hospital after their test were patients with dementia. Understanding how patient pathways were impacted during the COVID-19 pandemic was crucial, so responsive analysis such as this was invaluable for policymakers.

This methodology, developing care sequences and identifying patients with similar patterns of care has great promise for investigating long-term care. Care pathway analysis is still a developing field, and there are no standard approaches to the analysis of longitudinal sequences of healthcare events. The methodology fully utilises the breadth of sources available in this linkage and will become increasingly useful in future analyses with the promise of increased opportunities for data linkage through schemes to improve data sharing procedures such as the SDE programme [57].

Chapter 3 provides an evaluation of a digital technology, implemented in care homes, on residents' secondary care utilisation and economic impact for the NHS. The same linkage between the County Durham and Darlington trust routine data and the Health Call app data as in Chapter 2 was used for this project. The project evaluated whether the additional care and monitoring provided through the app led to a reduction in unplanned secondary care usage – measured through number of ED attendances, ED admissions and length of stay from emergency admissions. An economic evaluation of the app using the same framework was also included. Generalised linear mixed models (GLMMs) were fitted to each of these outcomes with usage of the Health Call app included as a variable to test its impact. The analysis found that Health Call reduced the amount of unplanned secondary care usage and saved costs for the NHS. This analysis was a rapid response to the increased roll out rate of the app due to the pandemic. Findings such as this are essential for directing further digital technology implementations in the NHS, so a timely evaluation of this initiative was important. When published, the paper in Chapter 3 received media attention, with multiple press releases, due to the impactful finding that support the use of telehealth in care homes in the UK. I presented this work to the HDRUK Quinquennial review panel in 2022 [58], which supported the successful HDRUK bid for 5 more years of funding (£70 million) - securing continued investment into the routinely collected health data research area.

This evaluation required innovative analysis. The observational nature of the data meant that no clear control group was included in the dataset, since the technology was rolled out in all homes included in the data over the study period. The COVID-19 pandemic during the study period meant that inclusion of a counterfactual estimate (control) was vital, since any changes in healthcare utilisation over this period could not be directly attributed to the app. Our approach used the GLMM framework to provide estimates of both users of the app and non-users at each point through the study period. The final model overcomes these challenges while utilising pre-collected data, is a cost-effective method of evaluating such initiatives. This kind of evaluation is vital to ensure that technological advancements currently faced by the NHS in many aspects of it's Long Term Plan [59] are done so effectively.

Chapter 4 is an investigation into the effects of NHS strikes on patient flow through two emergency departments in Lancashire. This study utilises data from Lancashire Teaching Hospitals through the prototype of the Lancashire and South Cumbria Secure Data Environment. Cox-proportional hazards models were produced to model patient time spent in the emergency department - from arrival until they are admitted to a ward. Factors impacting patients' time spent in the emergency department were investigated and accounted for in the analysis. The analysis finds that patients are moved through the ED into inpatient care more quickly on strike days, in agreement with the sentiment of an opinion paper written by the president of the Royal College of Emergency Medicine [60]. This is speculated to be attributed to the increased capacity due to lower levels of elective activity during these periods, suggesting that increased patient capacity in hospitals would reduce patient crowding in ED – in turn improving patient outcomes. This analysis was a rapid response to the current unplanned changes the strikes applied to NHS emergency care. These findings can be used to ensure actions are taken to provide optimal patient care in the ongoing strikes and beyond.

This analysis demonstrates the policy-relevant findings that can be produced by usage of a single ED dataset from one trust. Increased access to data like this for health researchers can greatly improve research output, increasing the evidence base for policy makers. Linkage to additional datasets through improved data pipelines could further improve the utility of this analysis, looking at eventual patient outcomes for those who are admitted during this period. Analysis of this data in a standardised regional SDE could also be done in a federated manor, to garner results from hospitals across more regions.

5.2 Implications for Healthcare Provision

Each project in this thesis uses RCD in a responsive analysis to current challenges due to unplanned changes faced by the NHS, each with healthcare implications. The findings in Chapter 2 have implications for the country's response to future public health crises, similar to the COVID-19 pandemic. These findings contribute to the body of studies on COVID-19 in care homes, showing that despite reduced healthcare usage overall [61] – there was still a large group of care home residents who were observed to have stays in hospital immediately before and after their COVID-19 tests. This demonstrates the lack of consistency of care for care home residents during the pandemic. Despite the known risks of inpatient stays for vulnerable patients, such as those with dementia [62], we show evidence that residents with dementia continued to be moved between care services during the pandemic. This implies that there should be dedicated policy adding more consideration to the movement of vulnerable patients between care settings and improve shielding policy for such patients in care homes.

Chapter 3 demonstrates an evaluation of a telehealth app used in care homes. The app reduced residents' emergency care service usage and reduced costs to the NHS. There are a number of similar interventions with similar targets globally [63] however their effectiveness is under-evaluated. Improving out-of-hospital care to reduce hospital care is a key part of the NHS's Long Term Plan [59], and evidence such as this supports digital technology usage for information sharing between care homes and hospital-based clinicians. This work has been presented directly to NHS clinical commissioning groups in regions that are planning to roll out the app in care homes.

Finally, the project in Chapter 4 responded to claims from senior clinicians that during the recent healthcare worker strikes 'in the emergency department, everything works better than usual' [60]. These claims were investigated and the analysis found that patients are moved more quickly through the emergency department during strike days, when controlling for confounding factors such as reduced activity on strike days. These findings agree with studies internationally, suggesting that patients spend less time in ED on strike days [64, 65]. The fact that these findings were the same for every group of striking clinicians suggests that the change was likely due to increased inpatient capacity due to reduced elective activity in the hospital. Other factors such as increased seniority of staff during junior doctor strikes would have introduced differences in flow between striking groups. We add to the body of work that demonstrates how flow through the emergency department is affected by the capacity of beds available [66]. Longer patient time in ED contributes to worse patient outcomes [67]. Until the capacity issue is managed, delays in admission to hospital from ED are likely.

Each of the chapters in this thesis has a particular focus on secondary care; in particular emergency care. One of the main aims of the NHS Long Term plan is to reduce pressure on emergency hospital services [59]. Each of the projects in the chapters of this thesis have specific implications for emergency care. Chapters 2 and 3 investigates how care home residents access emergency care, and potentially find ways to ensure they get the care they need before emergency care becomes necessary. This would have the twofold impact of improving the health of those targeted, while relieving strain on emergency departments. In Chapter 4, we conduct a deeper analysis of strain on emergency departments using ED data to provide recommendations to improve flow of patients into the hospital. Hospital based recommendations and patient level interventions such as those investigated in this thesis can be implemented in congruence to improve patient outcomes in emergency situations.

The findings from each analysis presented have potentially significant impact for health policy. Each of these analyses were conducted in rapid response to the current NHS challenges that they address. Future advancements in access to NHS RCD for researchers could enable analysis to be performed in near real time, finding increasingly impactful implications for health policy as analysis becomes more timely. Large amounts of timely evidence can result in a more adaptable NHS that can continually optimise patient care delivery in the face of unplanned changes.

5.3 Wider Implications for Research

5.3.1 Data Access

The NHS Long Term Plan highlights the importance of using routinely collected data for optimising care delivery, planning and aiding in modernising the national health service throughout [59]. This is backed up by the government commissioned Goldacre review, where this need is reinforced and methods for improving access to the data that the NHS already holds are discussed [1]. The UK Department of Health and Social Care has made commitments to improve the NHS data landscape in direct response to these recommendations in their Data Saves Lives policy framework [42]. The Secure Data Environment programme is already underway in this regard [57]. Collectively, the projects in this thesis demonstrate the benefits of this investment, showing that impactful work can already be done with the data that is available to researchers. Improvement to data sharing avenues will enable more of such research to be conducted, producing evidence for policymakers, and enabling powerful analyses with additional data linkage.

Improvements to data access routes would reduce barriers faced by researchers, speeding up access to data for researchers, enabling further responsive analyses. Increased timeliness of findings would increase health policy impact as results can be generated and learnt from quickly. The potential of streamlined access to RCD is clear, but efficient data access platforms are still being explored. Each project in this thesis was impacted by data access challenges that can be learnt from, for the good of future researchers accessing routinely collected data and in developing data access platforms.

Trusted Research Environments (TREs) are still developing, they allow for secure access to sensitive data, however connectivity challenges are still an issue that should be addressed in future developments. Chapters 2 and 3 used a Trusted Research Environment (TRE) managed by Durham University to access data. This was a completely isolated cloud-based environment. The TRE was a success in the sense that it allowed multiple linked datasets to be accessed securely, however lessons can still be learned from its implementation. The isolated nature of this environment meant that additional data with the potential to improve research findings – particularly for Chapter 2 - was not able to be added to the collection of datasets within the TRE. Only data coming through the trust, where the relationship was already set up between the data sharing parties was feasible within the time limitations of the two projects. Echoing the current issues of data access TREs aim to solve [45], the TRE almost acted as another silo for data to be stored in. This was an issue across all presented, which were using early versions of TREs. Going forward, the Secure Data Environments should provide data infrastructure to gather data from multiple sources internally and externally from the NHS.

Future TRE developments, such as the SDEs should also focus on longevity and research transparency. The Durham TRE was funded through the grants of the academic research projects that were utilising it. This caused data access problems itself. Chapter 3 was the final project used by the TRE, and additional post-analysis time was not accounted for in the funding of the project. This meant that data held in the TRE was lost at the end of the analysis period and further updates, for instance in response to peer review comments, were not possible. The lack of connectivity of the Durham TRE also meant that best practices for data science, such as publishing analysis code on GitHub was not possible, since internet access was not available inside of the TRE. Code sharing and ensuring reproducibility of results are key for open, transparent science [68]. Future data access methodologies should ensure safe access to web-based code-sharing and version control, to ensure researchers work can fit within current best practices. Furthermore, it is important that for new data platforms, data remains accessible for ten years after the project ends – in conjunction with the MRC's data retention framework [69], to allow for transparency of the research.

Data linkage can enable previously impossible analyses through combining information from different sources. Linkage between medical records and external datasets can be used to identify otherwise unidentifiable cohorts of patients within large datasets [70]. In Chapters 2 and 3, we demonstrate how linkage can be used to target analysis at groups that are difficult to access. There is a lack of resident data from care homes, it is often not collected - or difficult to access. It is also difficult to identify care home residents in hospital data [71], with it typically being identified by unreliable address-linkage methods [61, 72]. The data linkage used in Chapters 2 and 3 leads to the reliable method of identifying care home residents in routinely collected NHS data. It also demonstrates the opportunities of linking NHS data and external data to help identify hard-to-reach groups in large administrative healthcare databases. Using similar linkage methods, analyses can be potentially targeted at specific these groups and ensure they are represented in research. Future data access platforms should prioritise the ability to link data as it can provide powerful insight and shed new light on underrepresented groups of the population.

Unstructured data has the potential to uncover insights that are not possible using traditional data structures. In Chapter 3, we intended to investigate staff decision making using the data inputted into the Health Call app. This consisted of vital signs observations (such as blood pressure and body temperature), but also free text. The free text was the most potentially useful but often included sensitive information about the residents, including identifiable information such as residents' names. We produced a programme to remove common names, but data holders found results were unsatisfactory to share – meaning much of this data was not available to analyse and the analysis plan needed to be adapted. The potential amount of information contained in free-text that can be extracted using natural language processing is huge. This is already demonstrated through projects such as *CogStack*, an app that allows extraction of clinical concepts from unstructured data from NHS electronic health records [73]. Linking administrative data with scans, clinical notes and referral letters would enable further understanding of patient pathway decision making, enhancing projects such as in Chapter 2. Creating avenues to ensure unstructured routinely collected data can be accessed in a non-identifiable way would increase data available to analysts to provide powerful analysis that can investigate contexts of decisions made by care professionals.

5.3.2 Methodology for Routinely Collected Data

Each chapter in this thesis demonstrate methodological adaptations to statistical and machine learning frameworks to answer research questions using routinely collected data. Firstly, the application of State Sequence Analysis described in Chapter 2 shows promise for further use in care pathway analysis. Producing daily sequences of care over short periods of time around an index date (i.e. the date of their first (positive) COVID-19 test) was a novel application of this methodology. Finding associations between patient characteristics and their pathways through care provides much opportunity to improve patient care [74]. Investigating sequences of care with a single-day resolution holds immense potential for investigating patient healthcare utilisation patterns. Opportunities for use of this methodology will increase even further with improved data access and linkage opportunities for NHS data in the future.

The GLMM methodology used in Chapter 3 provides a good basis for intervention evaluation using RCD in challenging conditions. These analysis conditions where patients move from control and treatment groups throughout the study period meant that typical causal inference methods such as difference in difference or synthetic controls would not suffice. It utilises the properties of GLMMs, to include dynamic treatment groups throughout the study period, while the random intercept structure ensures that the model is robust to skew from outlying residents and homes. The algorithm we produced to identify the cohort of care home residents moving between the control and intervention groups, is applicable to any intervention evaluation and addresses one of the key limitations of using observational data in this situation [11]. This framework allows for effective evaluations using routinely collected data, without the need for a randomised control trial. The NHS Long Term Plan pledged to increase utilisation of digital technology to promote out of hospital care [59]. This methodology provides a framework for the evaluation of such technologies in a robust and pragmatic way – without the need for costly randomised controlled trials.

The application of survival analysis in Chapter 4 provides a further framework for measuring factors affecting patient flow through any part of NHS hospitals. The 'ED heat' variable – the count of patients in ED at one time weighted by the urgency of their treatment, that was controlled for in the analysis, gives an interesting measure of intensity in the emergency department. This was calculated at the arrival of each new patient in the ED, using their arrival and departure times. The efficient algorithm used to calculate this meant that it could be calculated in seconds on the original dataset containing hundreds of thousands of attendances, meaning that it can be investigated further in other analyses.

Each of the projects presented in this thesis further develop the field of healthcare research using routinely collected data. Development of novel methodologies for use with RCD, such as the State Sequence Analysis presented in Chapter 2, can further increase potential for future analyses using RCD. Initial development and application in an RCD setting means similar future analyses can be applied rapidly in response to pressures faced by the NHS. The framework for longitudinal intervention evaluation using GLMMs in Chapter 3 can be applied in future evaluations using RCD.

Adaptation and application of well established methods such as Cox-Proportional Hazards models used in Chapter 4 have the potential to produce timely findings, direcly impacting healthcare provision.

5.3.3 Regional and National Projects

Since the COVID-19 pandemic, there has been an increase of large-scale studies using routinely collected health data. Platforms such as OpenSAFELY - developed for fast, responsive analysis of NHS data in response to the pandemic – allow the usage of large databases of NHS data for powerful analysis [75, 76, 77]. These national projects provide powerful insights representing the whole UK.

While studies using these large data banks offer broad insights, regional studies such as those presented in this thesis are still essential to provide more targeted analyses. HDRUK, the national institute for health data science, support a range of regional and national projects. The project in Chapter 3 was one of the projects that constituted the HDRUK flagship the Better Care Partnership, and the project in Chapter 2 was also conducted in collaboration with HDRUK. Both were regional projects conducted on data from County Durham and Darlington in close collaboration with the local trust. The regional nature of the projects ensured that we could also conduct local Public and Patient Involvement and Engagement (PPIE) as part of the process, gaining insight from local stakeholders such as relatives of residents and care home staff from the area to ensure that the analyses we were producing were relevant to them.

Local studies can uncover local health patterns and inequities in health outcomes within the context of the region. Researchers can work closely with local trusts and other data providers to provide a collaborative and engaging data sharing environment. This kind of collaboration can lead to long-term data sharing between institutions and improve the data and research literacy of the trust. This has the potential to help them engage with more regional and national data sharing efforts such as the SDE programme. Any such closely collaborative work with local NHS organisations, including the projects included in this thesis, has a positive impact on the wider data sharing landscape of the NHS and the country.

5.4 Conclusion

The benefits of this thesis are twofold. Each chapter demonstrates separate evidence for healthcare provision. Collectively the research in the thesis demonstrates a case for further utilisation of routinely collected health data in research and continued improvement of data sharing avenues for the NHS. Three timely analyses are presented in response to unplanned changes that have affected the organisation: the pandemic, the rapid roll out of digital technologies, and healthcare worker strikes. These analyses provide insight into important, current challenges the NHS is facing, providing recommendations for policy. Streamlined data sharing of up-to-date data, such as proposed by the SDE programme, would allow analyses such as these to be performed in near-real time – providing immediate feedback and recommendations on ongoing challenges, with continuous improvement ensuring patient care remains optimised even in challenging conditions.

References

[1] B. Goldacre and J. Morely, *Better, broader, safer: Using health data for research and analysis*, Apr. 2022. [Online]. Available: `https://www.gov.uk/government/publications/better-broader-safer-using-health-data-for-research-and-analysis` (visited on 06/07/2024).

[2] R. A. Spasoff, *Epidemiologic methods for health policy.* New York: Oxford University Press, 1999, ISBN: 978-0-19-511499-7.

[3] M. Jones, "Learning the lessons of history? Electronic records in the United Kingdom acute hospitals, 1988-2002," *Health Informatics Journal*, vol. 10, no. 4, pp. 253–263, Dec. 2004, ISSN: 1460-4582, 1741-2811. [Online]. Available: `http://journals.sagepub.com/doi/10.1177/1460458204048508` (visited on 06/07/2024).

[4] J. Keith, F. Grimm, and A. Steventon, "How better use of data can help address key challenges facing the NHS," The Health Foundation, Tech. Rep., Jan. 2022, p. 16. [Online]. Available: `https://www.health.org.uk/publications/long-reads/how-better-use-of-data-can-help-address-key-challenges-facing-the-nhs`.

[5] L. G. Hemkens, D. G. Contopoulos-Ioannidis, and J. P. Ioannidis, "Routinely collected data and comparative effectiveness evidence: Promises and limitations," *CMAJ : Canadian Medical Association Journal*, vol. 188, no. 8, E158–E164, May 2016, ISSN: 0820-3946. [Online]. Available: `https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4868623/` (visited on 08/22/2022).

[6] E. H. Morrato, M. Elias, and C. A. Gericke, "Using population-based routine data for evidence-based health policy decisions: Lessons from three examples of setting and evaluating national health policy in Australia, the UK and the

USA," *Journal of Public Health (Oxford, England)*, vol. 29, no. 4, pp. 463–471, Dec. 2007, ISSN: 1741-3842.

[7] P. Przybyła, A. J. Brockmeier, and S. Ananiadou, "Quantifying risk factors in medical reports with a context-aware linear model," *Journal of the American Medical Informatics Association*, vol. 26, no. 6, pp. 537–546, Jun. 2019, ISSN: 1527-974X. [Online]. Available: https://doi.org/10.1093/jamia/ocz004 (visited on 09/01/2022).

[8] K. Best *et al.*, "Development of the Anticholinergic Medication Index (ACMI)," *Age and Ageing*, vol. 51, no. Supplement_1, afac035.825, Mar. 2022, ISSN: 1468-2834. [Online]. Available: https://doi.org/10.1093/ageing/afac035.825 (visited on 09/01/2022).

[9] R. Isba, N. Davies, and J. Knight, "Are child health information services a viable source of accurate vaccination data for clinicians working in paediatric emergency departments in England?" *BMJ Health & Care Informatics*, vol. 28, no. 1, e100486, Dec. 2021, Publisher: BMJ Publishing Group Ltd Section: Implementer report, ISSN: 2632-1009. [Online]. Available: https://informatics.bmj.com/content/28/1/e100486 (visited on 09/01/2022).

[10] M. von Lucadou, T. Ganslandt, H.-U. Prokosch, and D. Toddenroth, "Feasibility analysis of conducting observational studies with the electronic health record," *BMC Medical Informatics and Decision Making*, vol. 19, no. 1, p. 202, Oct. 2019, ISSN: 1472-6947. [Online]. Available: https://doi.org/10.1186/s12911-019-0939-0 (visited on 08/17/2022).

[11] G. M. Clarke, S. Conti, A. T. Wolters, and A. Steventon, "Evaluating the impact of healthcare interventions using routine data," *The BMJ*, vol. 365, p. l2239, Jun. 2019, ISSN: 0959-8138. [Online]. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6584784/ (visited on 06/12/2024).

[12] P. Saini *et al.*, "Impact of community-based chronic obstructive pulmonary disease service, a multidisciplinary intervention in an area of high deprivation: A longitudinal matched controlled study," *BMJ Open*, vol. 10, no. 5, e032931, May 2020, Publisher: British Medical Journal Publishing Group Section: Respiratory medicine, ISSN: 2044-6055, 2044-6055. [Online]. Available: https://bmjopen.bmj.com/content/10/5/e032931 (visited on 12/07/2021).

[13] R. Cookson, C. Propper, M. Asaria, and R. Raine, "Socio-Economic Inequalities in Health Care in England," *Fiscal Studies*, vol. 37, no. 3-4, pp. 371–403, 2016, ISSN: 1475-5890. [Online]. Available: `https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1475-5890.2016.12109` (visited on 06/27/2024).

[14] A. Kerasidou and C. Kerasidou, "Data-driven research and healthcare: Public trust, data governance and the NHS," *BMC Medical Ethics*, vol. 24, no. 1, p. 51, Jul. 2023, ISSN: 1472-6939. [Online]. Available: `https://doi.org/10.1186/s12910-023-00922-z` (visited on 06/07/2024).

[15] J. Tazare *et al.*, "NHS National Data Opt-Outs: Trends and potential consequences for health data research," *BJGP Open*, Mar. 2024, Publisher: Royal College of General Practitioners Section: Research, ISSN: 2398-3795. [Online]. Available: `https://bjgpopen.org/content/early/2024/02/29/BJGPO.2024.0020` (visited on 06/07/2024).

[16] NHS England, *National Data Opt-Out*. [Online]. Available: `https://digital.nhs.uk/services/national-data-opt-out` (visited on 06/07/2024).

[17] S. Todd, C. Coupland, and R. Randall, "Patient and public involvement facilitators: Could they be the key to the NHS quality improvement agenda?" *Health Expectations*, vol. 23, no. 2, pp. 461–472, 2020, ISSN: 1369-7625. [Online]. Available: `https://onlinelibrary.wiley.com/doi/abs/10.1111/hex.13023` (visited on 06/07/2024).

[18] NHS England, *Public attitudes to data in the NHS and social care*, May 2024. [Online]. Available: `https://digital.nhs.uk/data-and-information/keeping-data-safe-and-benefitting-the-public/public-attitudes-to-data-in-the-nhs-and-social-care` (visited on 06/09/2024).

[19] *HDRUK - FAQs*. [Online]. Available: `https://www.hdruk.ac.uk/about-us/what-is-health-data-research/your-questions-answered/` (visited on 06/27/2024).

[20] HDRUK, *Innovation Gateway*. [Online]. Available: `%5C%5Chttps://www.healthdatagateway.org/` (visited on 06/12/2024).

[21] M. Pirmohamed, *HDR UK North: What's to come?* Jun. 2020. [Online]. Available: `https://www.hdruk.ac.uk/news/hdr-uk-north-whats-to-come/` (visited on 06/27/2024).

[22] NHS England, *General Practice Workforce Sratistics*, Jun. 2024. [Online]. Available: https://digital.nhs.uk/data-and-information/publications/statistical/general-and-personal-medical-services (visited on 06/10/2024).

[23] *Vision — Cegedim Healthcare Solutions*. [Online]. Available: https://info.cegedim-healthcare.co.uk/vision-clinical-system (visited on 06/10/2024).

[24] *EMIS Web*. [Online]. Available: https://www.emishealth.com/products/emis-web (visited on 06/10/2024).

[25] A. Charles, *Integrated Care Systems Explained*, Aug. 2022. [Online]. Available: https://www.kingsfund.org.uk/insight-and-analysis/long-reads/integrated-care-systems-explained (visited on 06/10/2024).

[26] CPRD, *Clinical Practice Research Datalink*. [Online]. Available: https://www.cprd.com/ (visited on 09/02/2022).

[27] NHS England, *Emergency Care Data Set (ECDS)*. [Online]. Available: https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/emergency-care-data-set-ecds (visited on 06/10/2024).

[28] K. Van den Heede and C. Van de Voorde, "Interventions to reduce emergency department utilisation: A review of reviews," *Health Policy*, vol. 120, no. 12, pp. 1337–1349, Dec. 2016, ISSN: 0168-8510. [Online]. Available: https://www.sciencedirect.com/science/article/pii/S0168851016302688 (visited on 06/10/2024).

[29] NHS Providers, *The NHS provider sector*. [Online]. Available: https://nhsproviders.org/topics/delivery-and-performance/the-nhs-provider-sector (visited on 06/10/2024).

[30] R. Mountain, J. Knight, K. Heys, E. Giorgi, and T. Gatheral, "Spatio-temporal modelling of referrals to outpatient respiratory clinics in the integrated care system of the Morecambe Bay area, England," *BMC Health Services Research*, vol. 24, no. 1, p. 229, Feb. 2024, ISSN: 1472-6963. [Online]. Available: https://doi.org/10.1186/s12913-024-10716-7 (visited on 06/27/2024).

[31] C. O'Keeffe, S. Mason, R. Jacques, and J. Nicholl, "Characterising non-urgent users of the emergency department (ED): A retrospective analysis of routine ED data," *PLOS ONE*, vol. 13, no. 2, e0192855, Feb. 2018, Publisher: Public Library of Science, ISSN: 1932-6203. [Online]. Available: `https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0192855` (visited on 06/27/2024).

[32] NHS England, *Secondary Uses Service (SUS)*. [Online]. Available: `https://digital.nhs.uk/services/secondary-uses-service-sus` (visited on 06/10/2024).

[33] A. Boyd *et al.*, *Understanding Hospital Episode Statistics (HES)*, Apr. 2018. [Online]. Available: `https://closer.ac.uk/wp-content/uploads/CLOSER-resource-understanding-hospital-episode-statistics-2018.pdf` (visited on 06/10/2024).

[35] S. Mason, E. J. Weber, J. Coster, J. Freeman, and T. Locker, "Time Patients Spend in the Emergency Department: England's 4-Hour Rule—A Case of Hitting the Target but Missing the Point?" *Annals of Emergency Medicine*, vol. 59, no. 5, pp. 341–349, May 2012, Publisher: Elsevier, ISSN: 0196-0644, 1097-6760. [Online]. Available: `https://www.annemergmed.com/article/S0196-0644(11)01541-1/fulltext` (visited on 05/09/2024).

[36] Health Research Authority, *Legal basis for processing data*. [Online]. Available: `https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-detailed-guidance/legal-basis-processing-data/` (visited on 06/12/2024).

[37] V. Chico, "The impact of the General Data Protection Regulation on health research," *British Medical Bulletin*, vol. 128, no. 1, pp. 109–118, Dec. 2018, ISSN: 0007-1420. [Online]. Available: `https://doi.org/10.1093/bmb/ldy038` (visited on 06/10/2024).

[38] NHS England, *Five Safes Framework - Secure Data Environment*. [Online]. Available: `https://digital.nhs.uk/services/secure-data-environment-service/introduction/five-safes-framework` (visited on 06/11/2024).

[39] S. Kavianpour, J. Sutherland, E. Mansouri-Benssassi, N. Coull, and E. Jefferson, "A Review of Trusted Research Environments to Support Next Generation Capabilities based on Interview Analysis," *Journal of Medical Internet Research*, May 2022, ISSN: 1439-4456.

[40] A. Wood *et al.*, "Linked electronic health records for research on a nationwide cohort of more than 54 million people in England: Data resource," *BMJ*, vol. 373, n826, Apr. 2021, Publisher: British Medical Journal Publishing Group Section: Research, ISSN: 1756-1833. [Online]. Available: `https://www.bmj.com/content/373/bmj.n826` (visited on 06/10/2024).

[42] Department of Health and Social Care, *Data saves lives: Reshaping health and social care with data*, Jun. 2022. [Online]. Available: `https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data/data-saves-lives-reshaping-health-and-social-care-with-data` (visited on 06/12/2024).

[43] CPRD, *CPRD Trusted Research Environment*, May 2024. [Online]. Available: `http://www.cprd.com/cprd-trusted-research-environment` (visited on 06/12/2024).

[44] OHDSI, *Standardized Data: The OMOP Common Data Model*. [Online]. Available: `https://www.ohdsi.org/data-standardization/` (visited on 06/12/2024).

[45] H. Hallock *et al.*, "Federated Networks for Distributed Analysis of Health Data," *Frontiers in Public Health*, vol. 9, Sep. 2021, Publisher: Frontiers, ISSN: 2296-2565. [Online]. Available: `https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2021.712569/full` (visited on 06/12/2024).

[46] OpenSAFELY, *About OpenSAFELY*. [Online]. Available: `https://www.opensafely.org/about/` (visited on 06/12/2024).

[47] O. Alabi and T. Bukola, "Introduction to Descriptive Statistics," in *Recent Advances in Biostatistics*, IntechOpen, Sep. 2023, ISBN: 978-1-83769-804-2. [Online]. Available: `https://www.intechopen.com/chapters/1141192` (visited on 06/21/2024).

[48] A. Nichols, “Causal Inference with Observational Data,” *The Stata Journal*, vol. 7, no. 4, pp. 507–541, Dec. 2007, Publisher: SAGE Publications, ISSN: 1536-867X. [Online]. Available: https://doi.org/10.1177/1536867X0800700403 (visited on 06/13/2024).

[49] J. Roux, O. Grimaud, and E. Leray, “Use of state sequence analysis for care pathway analysis: The example of multiple sclerosis,” *Statistical Methods in Medical Research*, vol. 28, no. 6, pp. 1651–1663, Jun. 2019, Publisher: SAGE Publications Ltd STM, ISSN: 0962-2802. [Online]. Available: https://doi.org/10.1177/0962280218772068 (visited on 07/22/2021).

[50] A. Garner *et al.*, “Understanding health service utilisation patterns for care home residents during the COVID-19 pandemic using routinely collected healthcare data,” *BMC Geriatrics*, vol. 24, no. 1, p. 449, May 2024, ISSN: 1471-2318. [Online]. Available: https://doi.org/10.1186/s12877-024-05062-6 (visited on 06/17/2024).

[51] F. Biggin, Q. Ashcroft, T. Howcroft, J. Knight, and H. Emsley, “Discovering patterns in outpatient neurology appointments using state sequence analysis,” *BMC Health Services Research*, vol. 23, no. 1, p. 1208, Nov. 2023, ISSN: 1472-6963. [Online]. Available: https://doi.org/10.1186/s12913-023-10218-y (visited on 06/13/2024).

[52] J. Niyirora and O. Aragones, “Network analysis of medical care services,” *Health Informatics Journal*, vol. 26, no. 3, pp. 1631–1658, Sep. 2020, Publisher: SAGE Publications Ltd, ISSN: 1460-4582. [Online]. Available: https://doi.org/10.1177/1460458219887047 (visited on 06/13/2024).

[53] J. C. Brunson and R. C. Laubenbacher, “Applications of network analysis to routinely collected health care data: A systematic review,” *Journal of the American Medical Informatics Association : JAMIA*, vol. 25, no. 2, pp. 210–221, Feb. 2018, ISSN: 1067-5027. [Online]. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6664849/ (visited on 06/13/2024).

[54] K. Adnan, R. Akbar, S. W. Khor, and A. B. A. Ali, “Role and Challenges of Unstructured Big Data in Healthcare,” in *Data Management, Analytics and Innovation*, N. Sharma, A. Chakrabarti, and V. E. Balas, Eds., Singapore: Springer, 2020, pp. 301–323, ISBN: 978-981-329-949-8.

[55] K. Patel, "Ethical Reflections on Data-Centric AI: Balancing Benefits and Risks," *International Journal of Computer Engineering & Technology*, vol. 2, pp. 1–17, Jan. 2024.

[56] A. Garner *et al.*, "The impact of digital technology in care homes on unplanned secondary care usage and associated costs," *Age and Ageing*, vol. 53, no. 2, afae004, Feb. 2024, ISSN: 1468-2834. [Online]. Available: `https://doi.org/10.1093/ageing/afae004` (visited on 06/29/2024).

[57] Department of Health and Social Care, *Secure data environment for NHS health and social care data - policy guidelines*. [Online]. Available: `https://www.gov.uk/government/publications/secure-data-environment-policy-guidelines/secure-data-environment-for-nhs-health-and-social-care-data-policy-guidelines` (visited on 07/03/2023).

[58] HDRUK, *Quinquennial Review*. [Online]. Available: `https://www.hdruk.ac.uk/quinquennial-review/` (visited on 06/27/2024).

[59] NHS England, "The NHS Long Term Plan," Tech. Rep., Jan. 2019. [Online]. Available: `https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/` (visited on 02/23/2023).

[60] A. Boyle, "What the recent strikes can teach us about fixing emergency care," *BMJ*, vol. 381, p1047, May 2023, Publisher: British Medical Journal Publishing Group Section: Opinion, ISSN: 1756-1833. [Online]. Available: `https://www.bmj.com/content/381/bmj.p1047` (visited on 01/10/2024).

[61] F. Grimm, K. Hodgson, R. Brine, and S. R. Deeny, "Hospital admissions from care homes in England during the COVID-19 pandemic: A retrospective, cross-sectional analysis using linked administrative data," *International Journal of Population Data Science*, vol. 5, no. 4, p. 1663, Jul. 2021, ISSN: 2399-4908. [Online]. Available: `https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8267611/` (visited on 02/02/2022).

[62] J. Lehmann *et al.*, "The Impact of Hospitalization on Readmission, Institutionalization, and Mortality of People with Dementia: A Systematic Review and Meta-Analysis," *Journal of Alzheimer's Disease*, vol. 64, no. 3, pp. 735–749, Jan. 2018, Publisher: IOS Press, ISSN: 1387-2877. [Online]. Available: `https://content.iospress.com/articles/journal-of-alzheimers-disease/jad171128` (visited on 06/16/2022).

[63] K. Masconi-Yule, "Rapid review of current remote monitoring in care homes across the UK," *Innovation Collaborative - Health Innovation Network South London*, Apr. 2022.

[64] J. Sim, Y. Choi, and J. Jeong, "Changes in Emergency Department Performance during Strike of Junior Physicians in Korea," *Emergency Medicine International*, vol. 2021, no. 1, p. 1 786 728, 2021, ISSN: 2090-2859. [Online]. Available: https://onlinelibrary.wiley.com/doi/abs/10.1155/2021/1786728 (visited on 06/27/2024).

[65] G. Robinson, K. McCann, P. Freeman, and R. Beasley, "The New Zealand national junior doctors' strike: Implications for the provision of acute hospital medical services," *Clinical Medicine (London, England)*, vol. 8, no. 3, pp. 272–275, Jun. 2008, ISSN: 1470-2118.

[66] I. Higginson, "Emergency department crowding," *Emergency Medicine Journal*, vol. 29, no. 6, pp. 437–443, Jun. 2012, Publisher: BMJ Publishing Group Ltd and the British Association for Accident & Emergency Medicine Section: Review, ISSN: 1472-0205, 1472-0213. [Online]. Available: https://emj.bmj.com/content/29/6/437 (visited on 01/04/2024).

[67] S. L. Bernstein *et al.*, "The Effect of Emergency Department Crowding on Clinically Oriented Outcomes," *Academic Emergency Medicine*, vol. 16, no. 1, pp. 1–10, 2009, ISSN: 1553-2712. [Online]. Available: https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1553-2712.2008.00295.x (visited on 01/04/2024).

[68] M. R. Munafò *et al.*, "A manifesto for reproducible science," *Nature Human Behaviour*, vol. 1, no. 1, pp. 1–9, Jan. 2017, Publisher: Nature Publishing Group, ISSN: 2397-3374. [Online]. Available: https://www.nature.com/articles/s41562-016-0021 (visited on 06/28/2024).

[69] UKRI Medical Research Council, *Retention framework for research data and records*, Nov. 2022. [Online]. Available: https://www.ukri.org/wp-content/uploads/2023/03/MRC-100323-RegulatorySupportCentre-RetentionFrameworkResearchDataRecords.pdf.

[70] S. Reppermund *et al.*, "Cohort profile: A data linkage cohort to examine health service profiles of people with intellectual disability in New South Wales, Australia," *BMJ Open*, vol. 7, no. 4, e015627, Apr. 2017, Publisher: British Medical Journal Publishing Group Section: Mental health, ISSN: 2044-6055,

2044-6055. [Online]. Available: https://bmjopen.bmj.com/content/7/4/e015627 (visited on 06/28/2024).

[71] A. Schultze *et al.*, "Identifying Care Home Residents in Electronic Health Records - An OpenSAFELY Short Data Report," Wellcome Open Research, Tech. Rep. 6:90, Apr. 2021, Type: article. [Online]. Available: https://wellcomeopenresearch.org/articles/6-90 (visited on 05/26/2022).

[72] J. Hollinghurst *et al.*, "The impact of COVID-19 on adjusted mortality risk in care homes for older adults in Wales, UK: A retrospective population-based cohort study for mortality in 2016–2020," *Age and Ageing*, vol. 50, no. 1, pp. 25–31, Sep. 2020, ISSN: 0002-0729. [Online]. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7546151/ (visited on 06/27/2024).

[73] R. Jackson *et al.*, "CogStack - experiences of deploying integrated information retrieval and extraction services in a large National Health Service Foundation Trust hospital," *BMC Medical Informatics and Decision Making*, vol. 18, no. 1, p. 47, Jun. 2018, ISSN: 1472-6947. [Online]. Available: https://doi.org/10.1186/s12911-018-0623-9 (visited on 06/28/2024).

[74] F. Biggin, J. Knight, V. Chandrabalan, and H. C. A. Emsley, *Visualising patient pathways and identifying data repositories in a UK neurosciences centre*, Apr. 2024. [Online]. Available: https://preprints.jmir.org/preprint/60017 (visited on 06/07/2024).

[75] E. J. Williamson *et al.*, "Factors associated with COVID-19-related death using OpenSAFELY," *Nature*, vol. 584, no. 7821, pp. 430–436, Aug. 2020, Publisher: Nature Publishing Group, ISSN: 1476-4687. [Online]. Available: https://www.nature.com/articles/s41586-020-2521-4 (visited on 06/24/2024).

[76] H. Forbes *et al.*, "Association between living with children and outcomes from covid-19: OpenSAFELY cohort study of 12 million adults in England," *BMJ*, vol. 372, n628, Mar. 2021, Publisher: British Medical Journal Publishing Group Section: Research, ISSN: 1756-1833. [Online]. Available: https://www.bmj.com/content/372/bmj.n628 (visited on 06/24/2024).

[77] B. MacKenna *et al.*, "Risk of severe COVID-19 outcomes associated with immune-mediated inflammatory diseases and immune-modifying therapies: A nationwide cohort study in the OpenSAFELY platform," *The Lancet Rheumatology*, vol. 4, no. 7, e490–e506, Jul. 2022, Publisher: Elsevier, ISSN:

2665-9913. [Online]. Available: https://www.thelancet.com/journals/lanrhe/article/PIIS2665-9913(22)00098-4/fulltext (visited on 06/24/2024).

Appendix A

Long term care facilities in England during the COVID-19 pandemic — a scoping review of guidelines, policy and recommendations

BMC Geriatrics

Danni Collingridge Moore[1], **Alex Garner**[2], Natalie Cotterell[1], Andrew J. E. Harding[1] and Nancy Preston[1]

[1] Division of Health Research, Lancaster University
[2] Lancaster Medical School, Lancaster University

Collingridge Moore, D., Garner, A., Cotterell, N., Harding, A. J. E., & Preston, N. (2024). Long term care facilities in England during the COVID-19 pandemic-a scoping review of guidelines, policy and recommendations. BMC Geriatrics, 24(1), Article 394. https://doi.org/10.1186/s12877-024-04867-9

Collingridge Moore *et al. BMC Geriatrics* (2024) 24:394
https://doi.org/10.1186/s12877-024-04867-9

BMC Geriatrics

RESEARCH

Open Access

Long term care facilities in England during the COVID-19 pandemic—a scoping review of guidelines, policy and recommendations

Danni Collingridge Moore[1*], Alex Garner[2], Natalie Cotterell[1], Andrew J. E. Harding[1] and Nancy Preston[1]

Abstract

Background The disproportionate effect of COVID-19 on long term care facility (LTCF) residents has highlighted the need for clear, consistent guidance on the management of pandemics in such settings. As research exploring the experiences of LTCFs during the pandemic and the implications of mass hospital discharge, restricting staff movement, and limiting visitation from relatives are emerging, an in-depth review of policies, guidance and recommendations issued during this time could facilitate wider understanding in this area.

Aims To identify policies, guidance, and recommendations related to LTCF staff and residents, in England issued by the government during the COVID-19 pandemic, developing a timeline of key events and synthesizing the policy aims, recommendations, implementation and intended outcomes.

Method A scoping review of publicly available policy documents, guidance, and recommendations related to COVID-19 in LTCFs in England, identified using systematic searches of UK government websites. The main aims, recommendations, implementation and intended outcomes reported in included documents were extracted. Data was analysed using thematic synthesis following a three-stage approach: coding the text, grouping codes into descriptive themes, and development of analytical themes.

Results Thirty-three key policy documents were included in the review. Six areas of recommendations were identified: infection prevention and control, hospital discharge, testing and vaccination, staffing, visitation and continuing routine care. Seven areas of implementation were identified: funding, collaborative working, monitoring and data collection, reducing workload, decision making and leadership, training and technology, and communication.

Discussion LTCFs remain complex settings, and it is imperative that lessons are learned from the experiences during COVID-19 to ensure that future pandemics are managed appropriately. This review has synthesized the policies issued during this time, however, the extent to which such guidance was communicated to LTCFs, and subsequently implemented, in addition to being effective, requires further research. In particular, understanding the secondary effects of such policies and how they can be introduced within the existing challenges inherent to adult social care, need addressing.

Keywords Coronavirus, COVID-19, long-term care facilities, Care homes, Nursing homes, Health policy, Public health

*Correspondence:
Danni Collingridge Moore
d.collingridgemoore@lancaster.ac.uk
Full list of author information is available at the end of the article

Introduction

Across the majority of countries with ageing populations, the COVID-19 pandemic had a significant impact on older adults in long term care facilities (LTFCs) [1]. In England alone, during the first two months of the pandemic there were 12,526 deaths among LTCF residents either confirmed or suspected as related to COVID-19, with deaths in LTCFs increasing by 220% in the first ten weeks of the pandemic [2, 3]. In 2022, the LTFC population was nearly 8% lower than before the pandemic, falling from approximately 391,927 to 360,792, possibly due to widespread concern regarding the quality of care available in LTCFs [4]. Similar experiences occurred in Canada, Australia, and the United States [5–7]. In this paper, an LTCF is defined as a collective institutional setting where care is provided for the older people who live there, 24 h a day, seven days a week, for an undefined period, and can refer to care homes, nursing homes or residential aged care facilities [8, 9].

The timings of the COVID-19 pandemic varied by country, in terms of first cases, travel restrictions and lockdowns. In England, the first cases of COVID-19 were confirmed 31st January 2020, and the national response to the pandemic can loosely be described in four stages; the first national lockdown (23rd March 2020 to 13th May 2020), autumn/winter 2020 restrictions and the second national lockdown (14th October 2020 to 4th January 2021), the third national lockdown (5th January 2021 to 8th March) and Plan B (8th December – 27th January 2022). (see Table 1).

In hindsight, the likely effect of the COVID-19 pandemic on a relatively vulnerable LTCF population could have been predicted. Compared to older adults living privately in the community, LTCF residents are more likely to be frail, have existing comorbidities including dementia or some form of cognitive impairment, with an average age of over 80 years [141, 142]. Such characteristics are now associated with being more susceptible to, and to subsequently die from, COVID-19 infection [143]. In addition, contact between residents and staff, both in private rooms and in communal areas, is frequent, making isolating, segregating, or shielding residents and staff problematic [144]. The COVID-19 pandemic created additional burdens to maintaining an LTCF workforce, which was already characterised by comparatively low pay, high staff turnover, and limited opportunities for training, support and development which are largely dependent on the leadership and management of individual LTCFs [145].

Developing national policies to manage COVID-19 across such settings is challenging. During the pandemic, LTCFs reported difficulties in accessing and using personal protective equipment (PPE), managing COVID-19 related staff absences and the impact of the pandemic on health and wellbeing, and in reducing the use of agency staff across multiple sites [146–150].

Like most high and middle income countries, the UK government published national guidelines to tackle the spread of COVID-19 in LTCFs in England, including hastening hospital discharge, restricting visitation from family and friends and promoting remote primary care, among others [19, 31, 59]. At present, there has been no systematic synthesis of these policies, or of their aims, implementation or intended outcomes, within the wider context of the pandemic. Given the growing likelihood of future pandemics, and ongoing criticism at how the pandemic response was managed in LTCFs in England, reflecting on UK policies is imperative to understand why LTCFs were affected as they were, and how LTCFs can be managed during pandemics in the future both in the UK and internationally [151].

Aims and objectives

Publicly available policy, guidance and recommendations from the UK government related to LTCFs in England during the COVID-19 pandemic are explored in this scoping review. Firstly, it aims to provide a timeline of key events related to LTCFs, and secondly it aims to synthesise the aims, recommendations, implementation, and intended outcomes of the guidance identified.

Methods

A scoping review approach, as developed by Arksey and O'Malley, was used to synthesise key policy documents [152]. The five-stage approach included; identifying the research question, identifying relevant studies, study selection, charting the data and collating, summarizing and reporting the results [152].

Identifying the research question

Firstly, the primary research question was discussed and refined, and the two review questions were identified.

Identifying relevant studies

The UK government website was searched for policy, guidance and recommendations, using the key terms "COVID-19", "Coronavirus", "care home" and "adult social care", in October 2022 [153]. The results included policy or strategy documents, white papers, guidance or working papers. Included documents could either be published papers or online webpages. The approach was informed by recommended review methods for grey literature, and a snowballing strategy was used to identify sources referenced or linked to within included documents [154, 155]. Where required, an internet archive

Table 1 Timeline of issued guidance related to wider UK and international events (left column) and the management of COVID-19 in LTCFs in England (right column), from December 2019 to June 2022

First cases of COVID-19 in China reported [10]	31-Dec	Dec 19		
WHO declares COVID-19 a public health emergency of international concern [10]	30-Jan	Jan 20	30-Jan	NHS England declares a Level 4 National Incident [11]
First cases of COVID-19 in England are confirmed [12]	31-Jan			
		Feb 20	25-Feb	'Guidance for social or community care and residential settings on COVID-19'[a] [13]
First COVID-19 death in England is confirmed [14]	05-Mar	Mar 20	03-Mar	'COVID-19 action plan' published [15]
WHO defines COVID-19 as a pandemic [16]	11-Mar		16-Mar	CQC announce immediate cessation of routine inspections [17]
Social distancing measures announced [18]	16-Mar		17-Mar	'Next Steps on NHS Response to COVID-19'—freeing up inpatient and critical care capacity [11]
			19-Mar	'COVID-19: hospital discharge service requirements'[a] [19]
			19-Mar	'Responding to COVID-19: the ethical framework for adult social care'[a] [20]
First lockdown in England begins [21]	23-Mar		23-Mar	Appeal to recruitment agencies to work with social care providers [22]
			27-Mar	LGA/ADASS raise concerns regarding PPE provision for adult social care [23]
			29-Mar	COVID-19 testing to support retention of NHS staff [24]
			30-Mar	CQC release joint statement on advance care planning [25]
WHO guidance published on asymptomatic transmission [26]	02-Apr	Apr 20	02-Apr	'COVID-19: admission and care of people in care homes'[a] [27]
			04-Apr	'COVID-19: management of staff and exposed patients and residents in health and social care settings'[a] [28]
			09-Apr	'Coronavirus (COVID-19): looking after people who lack mental capacity'[a] [29]
			10-Apr	CQC requires care homes to report COVID-19 deaths [30]
			15-Apr	'COVID-19: our action plan for adult social care'[a] [31]
Lockdown extended for "at least" three weeks [32]	15-Apr		15-Apr	Deaths involving COVID-19 in care homes in England: transparency statement published [30]
			17-Apr	COVID-19: how to work safely in care homes[a] [33]
			23-Apr	Adult social care recruitment care campaign launched [34]
			27-Apr	Death in service benefits for frontline NHS and social care staff [35]
			28-Apr	Daily briefing – "government will now publish data on deaths in care homes" [36]
			30-Apr	CQC launches Emergency Support Framework [37]
Conditional plan for lifting lockdown announced [38]	10-May	May 20	01-May	NHS sets out clinical service model for care home support [39]
			06-May	Dedicated app for social care workers launched [40]
			11-May	Government publishes 'Our Plan to Rebuild' [41]
			15-May	Coronavirus (COVID-19): support for care homes [42]
			19-May	Health and wellbeing of the adult social care workforce[a] [43]
			20-May	Bereavement scheme extended to dependents of social care workers [44]
			21-May	Social care staff exempt from immigration health surcharge [44]
			26-May	'Join Social Care' tool launched to speed up social care recruitment [45]
English primary schools encouraged to re-open [46]	01-Jun	Jun 20	06-Jun	NHS Volunteer Responders scheme extended to social care staff [47]
			07-Jun	Government meets its target to offer COVID-19 tests to every care home for over-65 s [48]
			08-Jun	Government announces Social Care Sector COVID-19 support taskforce [49]
Non-essential retail re-opened [50]	15-Jun		09-Jun	'About the Adult Social Care Infection Control Fund'[a] [51]
The first local lockdown is introduced in Leicester [52]	29-Jun		19-Jun	"Coronavirus (COVID-19): reducing risk in adult social care"[a] [53]

Table 1 (continued)

Restrictions are eased in England [54]	04-Jul	Jul 20	03-Jul	Repeat testing strategy for LTCF staff (weekly) and residents (every 4 weeks) [55]
			17-Jul	'The next chapter in our plan to rebuild' [56]
WHO issues a policy brief to prevent and mitigate the impact of COVID-19 across all aspects of long-term care [57]	24-Jul		20-Jul	'COVID-19 supplement to the IPC resource for adult social care' [58]
			22-Jul	'Visiting arrangements in care homes'[a] [59]
			31-Jul	'Personal protective equipment: illustrated guide for community and social care settings'[a] [60]
		Aug 20	25-Aug	Overview of adult social care guidance on coronavirus (COVID-19)'[a] [61]
Social gatherings above six banned in England [62]	14-Sep	Sep 20	11-Sep	Letter to social care providers highlighting the importance of testing and PPE [63]
			18-Sep	'Adult social care: our COVID-19 winter plan 2020 to 2021'[a] [64]
Pubs and restaurants in England to close at 22:00 [65]	24-Sep		18-Sep	Government publishes the Social Care Sector COVID-19 Support Taskforce's report on first phase of COVID-19 pandemic [66]
Three-tier system of restrictions begins in England [67]	14-Oct	Oct 20	01-Oct	'Adult Social Care Infection Control and Testing Fund: round 2'[a] [68]
			06-Oct	CQC sets out its transitional regulatory approach [69]
			13-Oct	'Winter Discharges—Designated Setting' [70]
Second lockdown in England begins [71]	05-Nov	Nov 20	23-Nov	'COVID-19 Winter Plan' [72]
			27-Nov	PHE publishes COVID-19 vaccination programme [73]
Second lockdown ends, returns to three tier system [74]	02-Dec	Dec 20	01-Dec	CQC publish information on regulating 'designated care settings' [75]
			01-Dec	Government rolls out lateral flow testing to enable indoor visiting in all LTCFs [76]
Regulatory approval of Pfizer/BioNTech vaccine [77]	02-Dec		04-Dec	Vaccinations in LTCFs programme launched [78]
COVID-19 vaccination delivered in England [79]	08-Dec		14-Dec	'COVID-19: our action plan for adult social care' – updated [31]
			16-Dec	'Discharge into care homes: designated settings'[a] [80]
Fourth tier of restrictions introduced in England [81]	19-Dec		20-Dec	NHS issue guidance on staffing to support vaccination in LTCFs [82]
England enters third national lockdown [83]	06-Jan	Jan 21	11-Jan	'UK COVID-19 vaccines delivery plan' [84]
Moderna vaccine approved [85]	08-Jan		15-Jan	'Adult Social Care Rapid Testing Fund: guidance'[a] [86]
			17-Jan	Social care sector to receive £269 million boost staffing and testing [87]
AstraZeneca/Oxford vaccine approved [88]	30-Jan		22-Jan	'Your care home during winter'[a] [89]
			29-Jan	Workforce Capacity Fund for adult social care [90]
Roadmap to ease lockdown restrictions announced [91]	22-Feb	Feb 21	01-Feb	Every older LTCF resident in England offered a COVID-19 vaccine [92]
			09-Feb	'Care for Others. Make a Difference' recruitment campaign launched [93]
			25-Feb	COVID-19 vaccine: one of UK's largest LTCF firms introduces 'no jab, no job' policy [94]
Step 1 of lockdown easing begins in England [95]	08-Mar	Mar 21	01-Mar	'Restricting workforce movement between care homes and other care settings'[a] [96]
Gatherings of six people allowed in England [91]	29-Mar		24-Mar	'Coronavirus (COVID-19) testing available for adult social care in England'[a] [97]
			29-Mar	'Adult Social Care Infection Control and Testing Fund'[a] [98]
Twice weekly rapid testing available in England [99]	09-Apr	Apr 21	12-Apr	LTCF residents in England allowed two visitors [100]
Step 2 of lockdown easing begins in England [91]	12-Apr		14-Apr	Consultation launched on COVID-19 vaccines among LTCF staff [101]
Further easing of COVID-19 restrictions announced [91]	17-May	May 21	04-May	LTCF residents can go on outdoor trips without isolating [102]
			17-May	LTCF residents allowed five named visitors [103]
Janssen vaccine approved [104]	28-May		20-May	'Testing for professionals visiting care homes'[a] [105]
		Jun 21	16-Jun	LTCF staff to be fully vaccinated under new law, to be implemented in October 2021 [106]

Table 1 (continued)

Further easing of COVID-19 restrictions announced [107]	19-Jul	Jul 21	02-Jul	'Adult social care extension to Infection Control and Testing Fund 2021'[a] [108]
			19-Jul	Frontline health and care staff can work rather than self-isolate [109]
Self-isolation removed for double-jabbed contacts	16-Aug	Aug 21	04-Aug	'Coronavirus (COVID-19) vaccination of people working or deployed in care homes: operational guidance'[a] [110]
		Sep 21	07-Sep	Record £36 billion investment to reform NHS and Social Care [111]
			14-Sep	JCVI issues updated advice on COVID-19 booster vaccination [112]
			15-Sep	Temporary medical exemptions for COVID-19 vaccination of LTCF staff [113]
		Oct 21	21-Oct	'Adult Social Care Infection Control and Testing Fund: round 3'[a] [114]
			29-Oct	Guidance updated to allow flexibility in booster programme for LTCF residents [115]
		Nov 21	03-Nov	Workforce Recruitment and Retention Fund[a] [116]
			11-Nov	COVID-19 vaccination introduced as a condition of deployment for all frontline social care workers [117, 118]
			24-Nov	Lift COVID-19 ban on staff working in more than one LTCF [96]
Plan B implemented in England [119]	08-Dec	Dec 21	10-Dec	Support package to protect care sector this winter [120]
			10-Dec	'People at the Heart of Care: adult social care reform' [121]
Self-isolation for COVID-19 cases reduced from 10 to 7 days following negative LFD tests [122]	22-Dec		16-Dec	Workforce Recruitment and Retention Fund for adult social care, round 2[a] [123]
			24-Dec	Health and Care Visa scheme expanded [124]
Positive LFT no longer required to take PCR test [125]	11-Jan	Jan 22	10-Jan	Adult Social Care Omicron Support Fund [126]
			13-Jan	Free PPE for frontline extended for another year [127]
Self-isolation can end after 5 days following 2 negative LFD tests [128]	17-Jan		27-Jan	Government eases social care restrictions after booster success, including unlimited visitors [129]
England to return to Plan A [130]	19-Jan		31-Jan	Consultation on removing vaccination as a condition of employment for social care staff announced [131]
Plan for living with COVID-19 announced [132]	24-Feb	Feb 22		
UK COVID-19 inquiry draft terms of reference set out [133]	11-Mar	Mar 22	01-Mar	Regulations making COVID-19 vaccination a condition of deployment to end [134]
			03-Mar	'A guide to the spring booster for those aged 75 years and older and older residents in care homes'[a] [135]
			31-Mar	'Infection prevention and control in adult social care: COVID-19 supplement'[a] [136]
Mass free testing stops [137]	01-Apr	Apr 22	05-Apr	'Bereavement resources for the social care workforce'[a] [138]
			06-Apr	Health and Social Care Levy to raise billions for NHS and social care [139]
		May 22	19-May	JCVI provides interim advice on an autumn COVID-19 booster programme [140]

Events marked with an [a]refer to guidance documents included in the review

Acronyms: *ADASS* Association of Directors of Adult Social Services, *CQC* Care Quality Commission, *IPC* Infection Prevention and Control, *JCVI* Joint Committee on Vaccination and Immunisation, *LFD* Lateral flow device, *LGA* Local Government Association, *NHS* National Health Service, *PCR* Polymerase chain reaction, *PHE* Public Health England, *PPE* Personal protective equipment, *WHO* World Health Organisation

resource was used to access the original publications if no longer available online [156].

Study selection

Guidance documents were included if they met the inclusion criteria shown in Table 2. In stage one, titles and executive summaries were reviewed for potential inclusion, and if suitable a full document was sourced for review in stage two. A randomly selected subset of 20% of the documents were reviewed by a second reviewer (AG).

Charting the data

Five areas of data were extracted; publication data, including author, date and central theme; the stated aim of the guidance, the main recommendations, implementation of the recommendation, and intended outcome,

Table 2 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
• Guidance, recommendations, or policy issued by a UK national governing body, relating to England • Guidance related predominantly to the management of COVID-19 or providing care during the COVID-19 pandemic either in LTCFs for older adults, or among older adult LTCF residents. Guidance related to adult social care, which does not specifically exclude LTCFs for older adults, would be included • An LTCF is operationally defined as a long-term care setting where several older people live, with access to on-site care services. It may be either CQC or non CQC registered • Guidance related to LTCFs in England • Published online between 1st January 2020 and 1st June 2022 • Original publication accessible online as of October 2022	• Guidance, recommendations, or policy issued by non-government bodies • Documentation reporting data only, press releases or that contained no guidance, recommendations, or policy • Content unrelated to the management of COVID-19 either in LTCFs, or among LTCF residents, such as infection control in general, or managing COVID-19 in the community, acute settings, sheltered accommodation etc. Guidance related to LTCFs for any group other than older adults, such as children or those with learning disabilities, were excluded • Guidance related to Northern Ireland, Scotland and Wales, or countries outside of the United Kingdom • Guidance related to a specific region or locality within England, such as local government guidance

where stated. A randomly selected subset of 20% of the included documents were discussed with a second reviewer (AG), who independently checked the data extracted. If disagreements arose between reviewers, these were discussed openly and if necessary, a third reviewer was included to make a final decision (NP). At this stage, included documents were added to a narrative timeline of key international, national and LTCF related events.

Collating, summarizing and reporting of results

Finally, the extracted data was analysed using thematic synthesis, starting with coding the text, grouping the codes into descriptive themes, and developing analytical themes (DCM/AG) [157]. Thematic synthesis was used as the approach transparently connects the data collected to the conclusions interpreted from the analytical themes [157].

The analytical themes generated were then discussed by the research team, re-applied to the data, and subsequently refined, using NVivo v12 [158]. The Enhancing Transparency in Reporting the synthesis of Qualitative research (ENTREQ) statement and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) were used to direct the reporting of the review [159, 160].

Results

The screening process is shown in Fig. 1 and resulted in 33 included documents. The earliest guidance was from 25 February 2020, with the most recent guidance published 19 May 2022. Twenty-five documents were published by the Department of Health and Social Care, five by Public Health England/UK Health Security Agency and three were multi-authored, including by the Care Quality Commission (CQC) and NHS England.

The 33 documents focused on ten areas: nine focused on available funding to support LTCFs, seven provided multi-thematic guidance, such as outbreak management and controlling the spread of infection, five focused on COVID-19 testing or vaccination, and two on discharge and admission, caring for residents or staff with COVID-19, providing equitable care for residents, supporting the workforce, working safely in LTCFs and visiting/movement between LTCFs, respectively. Full data extracted is shown in the supplementary material. A timeline of key international and national events related to LTCFs in England during the pandemic is shown in Table 1, with the main funding streams shown in Table 3.

Timeline of LTCFs in England during the COVID-19 pandemic

First national lockdown (23rd March 2020 to 13th May 2020)

The first publicly issued guidance for LTCFs was published on the 25th February 2020, more than three weeks after the first cases of COVID-19 in England were confirmed. By this time, the National Health Service (NHS) England had declared the pandemic a Level 4 National Incident, implementing a nationally coordinated response [11, 12, 161]. In hindsight, the recommendations underestimated the potential impact of COVID-19 in residential settings; despite recognition that older adults were likely to experience more severe COVID-19 symptoms, the guidance stated that it remained unlikely that those receiving care in a LTCF would become infected [161]. On the 11th March 2020, COVID-19 was defined as a pandemic, and national social distancing measures were announced [16, 18]. The 'COVID-19 Action Plan' was published, with minimal reference to adult social care, as the CQC, the independent regulator of health and social care in England. announced the immediate cessation of routine inspections [15, 17].

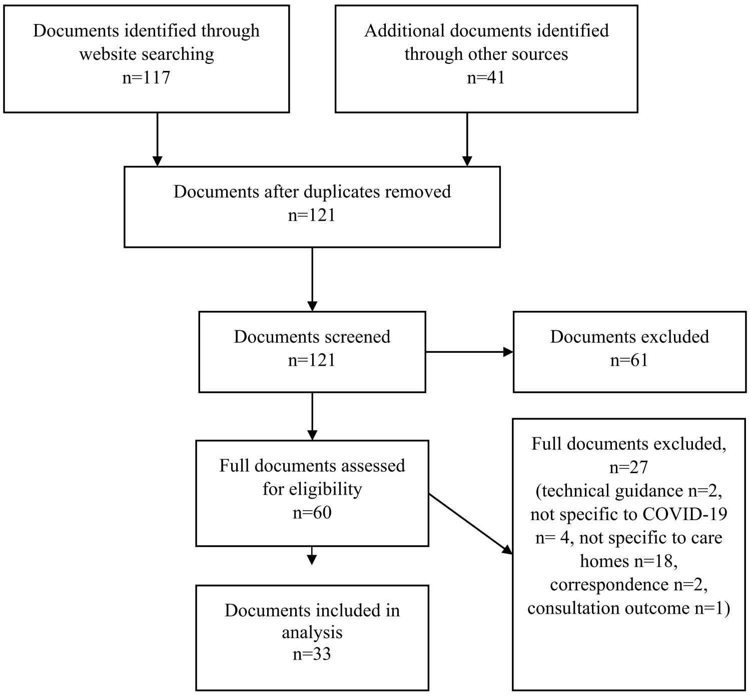

Fig. 1 PRISMA flowchart

Table 3 Main funding streams in England for either adult social care or discharge to adult social care during the COVID-19 pandemic

Funding title	Announced	Amount	Description
Hospital Discharge Funding	Mar 2020	£1.3 billion	To support NHS and local authorities to work together to fund the additional needs of people leaving hospital during the pandemic
Adult Social Care Infection Control Fund	May 2020	£600 million	To support adult social care providers to reduce the rate of COVID-19 transmission in and between care homes and support wider workforce resilience
Adult Social Care Infection Control Fund: round 2	Oct 2020	£546 million	Same as the Adult Social Care Infection Control Fund
Adult Social Care Rapid Testing Fund	Jan 2021	£149 million	To support increased LFD testing in care settings
Workforce Capacity Fund for adult social care	Jan 2021	£120 million	To enable local authorities to deliver measures to supplement and strengthen adult social care staff capacity to ensure that safe and continuous care is achieved
Adult Social Care Infection Control and Testing Fund	Mar 2021	£341 million	Consolidates the Adult Social Care Infection Control Fund and the Adult Social Care Rapid Testing Fund
Adult Social Care Infection Control and Testing Fund—extension	Jul 2021	£250 million	Extension, consolidates the Adult Social Care Infection Control Fund and the Adult Social Care Rapid Testing Fund
Adult Social Care Infection Control and Testing Fund: round 3	Oct 2021	£388 million	Same as the Adult Social Care Infection Control and Testing Fund, including vaccine funding
Workforce Recruitment and Retention Fund	Nov 2021	£162.5 million	To support local authorities to address adult social care workforce capacity pressures through recruitment and retention activity
Workforce Recruitment and Retention Fund for adult social care, round 2	Dec 2021	£300 million	Same as the Workforce Recruitment and Retention Fund
Adult Social Care Omicron Support Fund	Jan 2022	£60 million	To support the sector with measures already covered by the infection prevention and control allocation of the Infection Control and Testing Fund (round 3) to reduce the rate of COVID-19 transmission within and between care settings through effective IPC practices

On 17th March 2020, the 'Next steps on NHS response to COVID-19' was published by NHS England, which aimed to free up hospital beds through postponing all non-urgent elective operations, and urgently discharging hospital inpatients as soon as it was clinically safe to do so, anticipating 1% of which would be discharged to LTCFs [11, 19]. The only reference to testing for COVID-19 was that, where applicable, test results would be included within patient discharge documentation [19]. By 2nd April 2020, guidance reiterated that negative tests were not required prior to LTCF admission, with family and friends advised not to visit LTCFs except next of kin in exceptional situations such as end of life [27]. As England entered its first lockdown, the implications of the pandemic on adult social care, in terms of staff absences, access to PPE and concerns regarding the blanket application of advance care plans at end of life, were being recognized within government briefings [21–23, 25].

National lockdown was extended for three weeks, and on 15th April 2020, 'COVID-19: our action plan for adult social care' was published, adopting a four-pillar approach based on (a) controlling the spread of infection, (b) supporting the workforce, (c) supporting independence, people at the end of life, and responding to individual needs, and (d) supporting local authorities and the providers of care [31, 32]. The action plan committed to an emergency release of seven million PPE items, alongside a further 34 million items of PPE across local resilience forums (LRFs); local multi-agency partnerships made up of representatives from local public services. The action plan initiated testing for social care workers and their households, in line with NHS staff workforce, introduced an online reporting system for LTCFs (the 'Capacity Tracker'), implemented COVID-19 testing prior to LTCF admission, reiterated a commitment to providing appropriate end of life care to residents, and addressed increasing the social care workforce [24]. A recruitment campaign for adult social care commenced, and the CQC launched the 'Emergency Support Framework', to identify care providers that needed extra support to respond to the pandemic [34, 37].

As lockdown restrictions began to lift in May 2020, the COVID-19 recovery strategy 'Our Plan To Rebuild' re-emphasised the importance of protecting LTCFs, committing to the testing of all symptomatic LTCF residents and hospital patients discharged into LTCFs [38, 41]. It offered a polymerase chain reaction (PCR) COVID-19 test to every staff member and resident, symptomatic or asymptomatic, in LTCFs in England, by 6th June 2020. Further recommendations on reducing workforce movement between LTCFs were published, acknowledging significant asymptomatic transmission in LTCFs via both residents and staff [42]. The recommendations were supported by a £600 million Infection Control Fund [51].

Autumn and winter 2020 restrictions and second national lockdown (14 October 2020 to 4 January 2021)

On the 8th June 2020, it was confirmed that the testing target to distribute 'whole home' testing kits, for all residents and staff within any LTCF for residents over 65 or those with dementia, had been met, and by the 6th July 2020, weekly staff and monthly resident testing for all LTCFs had been implemented [55]. By mid- September, the first local lockdown was introduced in Leicester, and limitations on groups of more than six were introduced in England to curb the growing number of infections, including an increase among LTCF staff [62, 63]. These recommendations were timely, as on 24th September 2020 further restrictions were announced, pre-empting local lockdowns, prior to national lockdown on 5th November 2020 [65, 67, 71, 74, 81]. Further funding for adult social care was announced, and the CQC introduced 'designated settings', areas within LTCFs where newly admitted residents with COVID-19 could safely complete a period of isolation [64, 68, 80].

Third national lockdown (from 6 January 2021 to 8th March)

England's third national lockdown was introduced on 6th January 2021, as new variants of COVID-19 emerged and the vaccination programme was being rolled out [83, 84, 89]. LTCF residents and staff were prioritized for vaccination by the Joint Committee on Vaccination and Immunisation, and by 1st February 2021 every LTCF resident over 65 years had been offered a COVID-19 vaccine [73, 92]. By April 2021, free lateral flow device (LFD) tests were provided to everyone in England, which further supported visitation to LTCFs; and from 12th April 2021, LTCF residents were allowed two regular visitors, indoors, on the condition of providing a negative LFD test [99, 100, 105]. As further easing of COVID-19 restrictions were announced double-vaccinated staff were permitted to attend work instead of self-isolating, contingent on a negative PCR test and daily negative LFD tests [107, 109]. By September 2021, LTCF residents and staff were offered a COVID-19 booster vaccine [112, 115].

As LTCF staff became eligible for vaccination, some care providers introduced a 'no jab, no job' policy, which was widely criticised at a time of staff shortages [94]. In June 2021 it was announced that anyone working in an LTCF required two doses of a COVID-19 vaccine, unless medically exempt [101, 106, 110, 113]. In November 2021, COVID-19 vaccination became a condition of employment for all frontline social care workers, and restrictions on staff working in multiple settings were lifted to tackle staff shortages [117, 118].

Plan B (8 December—27 January 2022) and ending of restrictions

In December 2021, as COVID-19 infections again increased, England temporarily moved to 'Plan B', which recommended working from home and face coverings in public indoor venues [119]. These restrictions were subsequently removed on the 27th January 2022, which was said to be possible due to the success of the booster vaccination programme [130]. On 1st March 2022, regulations making vaccines a condition of deployment for social care staff were revoked, after widespread criticism [134]. In February 2022, the government's plan for removing the remaining legal restrictions was published, including removing the need for self-isolation after a positive test, and discontinuation of mass free testing on 1st April 2022 [132, 137]. LTCF residents and staff would still be able to access free symptomatic/ asymptomatic testing, with residents offered a second, spring booster, and a third booster in Autumn 2022 [135, 140].

Thematic analysis

The aims, main recommendations, implementation and outcomes of the documents were analysed using thematic analysis. Six areas of recommendations were identified: infection prevention and control, hospital discharge, testing , staffing, visitation and continuing routine care. In addition, seven areas of implementation were identified: funding, collaborative working, monitoring and data collection, reducing workload, decision making and leadership, training and technology and communication.

Aims and intended outcomes of the included documents

Where stated, the guidance predominantly aimed to reduce the risk of, or help prevent and control, COVID-19 transmission in LTCFs, and prevent future outbreaks, while ensuring that residents continued to receive appropriate care. As the pandemic progressed, this focus shifted to supporting care providers to reduce the rate of COVID-19 transmission in, and between, LTCFs. While the guidance consistently focused on protecting residents and staff, over time the additional need to protect vulnerable staff from COVID-19 infection was recognised. Specific aims related to hospital discharge service requirements, providing effective infection prevention and control (IPC) practices, supporting workforce resilience, capacity and health and wellbeing, reducing movement between sites, enabling visiting, and increasing testing and vaccination uptake. Seasonal guidance, such as providing care in LTCFs during winter, was also published [64, 89].

In terms of implementation, the policies aimed to disseminate guidance across services, including to local authorities, NHS organisations and care providers, at local, regional and national level. In some cases, the guidance required further dissemination, such as asking care providers to pass on advice to their staff, or to support health professionals in developing facility specific policies in line with their own professional codes of conduct and regulations [20, 29].

Overall, the intended outcomes, where explicitly stated in the guidance, reflected the aims, and focused on reducing the risk of transmitting the infection to others and avoiding exposure to COVID-19. Specific outcomes included preventing and controlling COVID-19, protecting staff, reducing the rate of transmission in and between LTCFs, increasing uptake of staff vaccination and providing funding to support these outcomes. In some cases, outcomes centred on supporting decision makers, such as in conducting risk assessments [53].

Main recommendations of the included documents

Six themes relating to recommendations were identified: infection prevention and control, hospital discharge, testing, staffing, visitation and continuing routine care. The guidance was updated throughout the pandemic, as the rate of transmission varied, and local lockdowns were introduced.

Infection prevention and control

In the early days of the pandemic, initial guidance focused on the management of those exposed to COVID-19, and was limited to residents, visitors or staff who had visited specific countries. Normal practice was recommended for LTCF staff who had come into contact with COVID-19 without PPE, on the basis that exposure would be short-lived, and LTCF closures were not required [28, 161]. In addition, if a resident or staff member was asymptomatic, no change to care was required [161]. Within days, IPC guidance was updated, with emphasis on keeping asymptomatic residents safe through daily symptom monitoring and social distancing measures amongst residents and staff [27]. General PPE use was recommended for providing personal care, regardless of whether the resident had symptoms or was known to have COVID-19, recognising that older residents often had minimal symptoms of infection [33, 60].

Arguably the central strategy to minimising COVID-19 transmission in LTCFs, and nationally, was social distancing. Care providers were advised to follow social distancing measures for everyone within the facility, with extremely vulnerable groups subject to additional shielding [27]. This included reducing contact between staff, holding team meetings and handovers remotely, staggering times of entry to collect equipment, reducing communal activities, and having a smaller number of workers dedicated to supporting residents with COVID-19 [61, 136]. Any resident showing COVID-19 symptoms was to be isolated and separated immediately in a single room, with a separate bathroom, and isolation, 'cohorting' and infection control measures strictly implemented [27]. Cohorting referred to limiting residents and staff to floors or wings, segregating COVID-19-positive and COVID-19-negative residents [61]. Cohorting and zoning recommendations were published, and included early discussions with care providers regarding the safety and feasibility of implementing these arrangements within LTCFs [64]. In Dec 2021, the CQC released guidance on 'designated settings', areas within a LTCF that had additional policies, procedures, equipment, staffing and training in place to maintain infection control to safely care for COVID-19 positive residents admitted to the LTCF [80]. Funding to support social distancing was provided, and to pay for the costs associated with implementing cohorting, recruiting and paying extra staff, paying for structural or physical changes to support cohorting, and providing accommodation for staff who proactively chose to live in the facility, therefore reducing social contact outside work [51, 96, 98, 108, 114].

Two recommendations require further exploration: staff isolation and restricting staff movement.

Guidance on staff isolation was relatively consistent across the pandemic; staff with COVID-19 symptoms were asked to notify their line manager immediately and self-isolate for seven days, later extended to 10 days [27, 28, 61]. This included staff with a symptomatic or COVID-19 positive household member, or those notified to isolate by the NHS Test and Trace system, with funding available to reimburse the wages of self-isolating staff [64, 68].

In terms of staff movement, care providers were recommended to limit all staff movement between settings unless necessary. This applied to staff working for one care provider across several facilities, staff working on a part-time basis for multiple employers in multiple facilities, and agency staff [42, 68]. Where the use of agency staff was needed, care providers were asked to use block bookings, review exclusivity arrangements with recruitment agencies and recruit additional staff over winter [42, 68]. A ten day interval between staff attending the two settings and a negative test result prior to entering the facility was also recommended [96]. Again, the Infection Control Fund could be used to meet associated costs [64].

In response to concerns over access to PPE, an emergency provision of seven million items of PPE was provided, alongside 23 million items of PPE for onward sale to social care providers and the release of a further 34 million items of PPE across LRFs [31, 42]. Three emergency routes to access PPE were developed, an online PPE Portal, LRFs and the National Supply Disruption Response system, which responded to emergency PPE requests, supported by a 24/7 helpline and an express freight service [31]. Ongoing monitoring was provided through the Capacity Tracker, which collected key adult social care data, collating daily information on bed capacity, workforce absences, PPE levels, and overall risks in LTCFs, and a CQC community care survey [61, 64]. Maintaining PPE stocks was a consistent message throughout the guidance, especially during winter, and was sustained by IPC funding [68, 89, 98, 108, 114, 136]. Support and training for LTCF staff on implementing IPC was provided through training videos on using PPE, support from infection control nurses, identification of a lead individual for IPC within the facility to ensure adherence to infection prevention guidance, and undertaking post reflective learning reviews [31, 33, 42, 60, 64].

Hospital discharge

Discharge from hospital for patients as soon as it was clinically safe to do so was implemented early on in the management of COVID-19 in England [19]. In practice, this meant that at the beginning of the pandemic older adults were discharged to LTCFs, without the requirement for a negative COVID-19 test prior to admission [27]. New residents required isolating for a 14-day period following admission, regardless of COVID-19 status. The guidance emphasised that no care provider would be forced to admit a resident if they were unable to safely cohort or isolate COVID-19 positive residents, with the responsibility on local authorities to provide alternative accommodation to quarantine and isolate residents [61].

This policy was later amended to testing all residents 48 h prior to discharge, with results communicated to the LTCF provider in advance and included in discharge documentation prior to admission [64, 80, 136]. Again, this was monitored by local health protection teams and through the Capacity Tracker [64, 136].

Testing

Available, accessible COVID-19 testing was integral to the policy response for LTCFs. For two or more possible cases of COVID-19, testing to confirm an outbreak was arranged through health protection teams, who arranged for swabbing for up to five initial possible cases, with testing of all cases not required as it would not change subsequent outbreak management [27]. In addition to testing, local health protection teams provided advice on and supported outbreak management, including on isolating cases and reinforcing infection control practices, such as PPE use, appropriate staffing, and restricting visitation [31].

By July 2020, this approach had changed to testing all symptomatic residents, with the introduction of 'whole home', repeat testing for all residents implemented in July 2020 [31, 61]. Repeat testing included weekly PCR testing of staff and testing of residents every 28 days in LTCFs without outbreaks, with access testing for all their residents and staff via a digital portal [97]. Initially, testing was available for LTCFs with a new outbreak, COVID-19 free LTCFs with over 50 beds and LTCFs referred by local authorities, before extending to LTCFs for over-65s and those with dementia [42, 61].

The funding included the costs of PCR testing, ensuring that staff who needed to attend work or another location for the purposes of being tested for COVID-19 were paid their usual wages, as were any costs associated with travel to a testing facility, and any reasonable administrative costs associated with organising and recording outcomes of COVID-19 tests [89, 108, 114]. Testing was available for LTCF staff and their households through local test centres, in line with NHS staff, albeit introduced at a later date, and also for visiting health professionals and relatives [31, 97, 105].Testing was supported by multiple funding steams, which could be used to pay for staff costs associated with training and conducting LFT testing within the LTCF 86, 98.

Staffing

Multiple policies focused on supporting adult social care staff during the COVID-19 pandemic. Firstly, staff were able to receive normal wages while self-isolating, funded through the Infection Control Fund [64, 98]. In addition, support was available in the form of increases to statutory sick pay, universal and working tax credit and the furlough scheme, whereby staff unable to work due to the pandemic were continued to be paid wages through a combination of government and employer contributions. [31, 117]. The Workforce Capacity Fund provided funding to address staff shortages, support restricted staff movement and to allow care providers to access additional staffing resources to minimise deployment of those who work in multiple settings [90]. In addition to self-isolating, staff classed as clinically vulnerable could be removed from providing direct care to symptomatic residents, with risk assessments encouraged to identify and protect potentially vulnerable workers [27, 53, 64].

Secondly, the guidance addressed recruiting and retaining staff through the launch of a national recruitment campaign to attract people to the social care workforce. Temporary arrangements to provide free, fast safety vetting checks to aid recruitment were introduced, including access to rapid online induction training for new staff, and the redeployment of existing staff into new roles [31, 90]. In addition, existing benefits NHS staff were made available to adult social care workers, including death in service benefits, designation as key workers and the establishment of the 'CARE' brand, a logo to recognise and identify the adult social care sector [31, 34, 35, 40, 45].

Thirdly, further support on managing health and wellbeing among the adult social care workforce was provided, including the extension of a crisis text messaging support service and a dedicated free-to-caller support helpline.

Visitation

Restrictions on visitation from relatives were a point of contention throughout the pandemic. Despite recognition that restricting contact with relatives would likely have a detrimental effect on residents, for the majority of the pandemic family and friends were advised not to visit LTCFs, except in exceptional situations such as at the end of life [27, 110]. Specific guidance was issued for visitors, including limiting visitors to one at a time, minimising contact with other residents and staff, enabling a booking system for visitors, keeping personal interaction with the resident to a minimum and limiting visits to one room [27, 59]. Visiting policies were largely facility specific, with visiting restrictions rapidly imposed in the event of an outbreak, if local incidence rates increased or if the LTCF was located in an 'area of intervention' [64]. As the rate of COVID-19 transmission reduced, limited visits were allowed, ensuring every resident was enabled to continue to receive one visitor [136].

The guidance provided advice for LTCFs on developing visiting policies, emphasising the need to provide regular, personalised updates on residents and the active involvement of the resident and their family or friends in making decisions regarding visitation [59]. Funding could be used to support safe visiting, including assigning staff to support and facilitate visits, putting in place additional IPC measures between visits, and alterations to the LTCF to allow safe visiting such as developing a dedicated space [68, 98, 108]. The guidance also supported alternative options to maintain social contact for residents during times of limited visitation, including the use of telephones or video calling [27].

Continuing routine care

Finally, guidance focused on maintaining routine care for LTCF residents. Early on in the pandemic, LTCF managers were required to postpone routine, non-essential appointments, including those that would involve residents visiting a hospital or other health care facilities [27]. Care providers were asked to work with NHS partners to reduce unnecessary emergency admissions, by assessing the appropriateness of hospitalisation, consulting a resident's advance or emergency care plan and through discussions with the resident and their relatives to determine if hospitalisation was the best course of action [64].

Continuing care within LTCFs was supported by primary care networks, who were responsible for delivering the 'Enhanced Health in Care Homes' framework, which provided access to clinical advice for staff and residents, including a named clinical lead and weekly multidisciplinary team support [31]. The guidance emphasised that if medical advice on routine care was needed, LTCFs should consider telemedicine consultations, delivered remotely via a phone call or video conferencing, alongside virtual rounds and multidisciplinary team meetings, unless a physical presence was clinically required [27, 31, 39, 42]. An accelerated rollout of cross-service e-mail and conferencing software was delivered to LTCFs to enhance communication with healthcare providers, allowing secure sharing of information between services [31, 61].

Early in the pandemic, concerns regarding anecdotal reports of blanket application of advance care plans led to a joint statement issued from the CQC, British Medical Association, Care Provider Alliance and Royal College of General Practitioners reiterating that any advance care plan, including Do Not Attempt Cardiopulmonary Resuscitation orders, should be person centred and made on an individual basis [25]. In particular, any advance care decision should be fully discussed with the resident and their family, and signed by the clinician responsible for their care [61, 64]. Further guidance was issued on end of life care in the context of the mental capacity act, and removing the requirement for family testing for residents at end-of-life [29, 64, 136].

Implementation of the included documents

Seven areas of recommendations were identified: funding, collaborative working, monitoring and data collection, reducing workload, decision making and leadership, training and technology and communication. These are expanded on below.

Funding

Throughout the pandemic, multiple funding streams were established to support hospital discharge, infection prevention and control, workforce capacity and later testing and vaccination, as shown in Table 3. The specific aims of the funding have been referenced in the main recommendation's discussion. In most cases, funding was provided to local authorities, who were able to pass on approximately 80% of this funding to LTCFs, with the rest of the funding allocated at the discretion of the local authority [68, 86].

Collaborative working

The need for collaborative working across services was repeatedly emphasised, specifically between the NHS and care providers. This included recommendations for timely access to clinical advice, including a named clinical lead with weekly check-ins, proactive support for residents through personalised care and support, support for residents with suspected or confirmed COVID-19 through remote monitoring, and sensitive and collaborative decisions around hospital admissions for residents [42]. Outside the NHS, local resilience forums were responsible for managing the local response to the pandemic, in addition to wider stakeholders, such as Care Provider Associations [31, 59, 161].

Monitoring and data collection

Monitoring systems were developed, namely the Capacity Tracker, which provided intelligence on adult social care for decision making [19, 31]. In addition, suspected and confirmed COVID-19 deaths were reported by care providers to the CQC, adding to data already collected by the Office for National Statistics [31]. Online systems were put in place for testing, with LTCFs required to register the results of all of LFD tests [86, 98].

Reducing workload

Several steps were made to reduce workloads during the pandemic, facilitating transfers between settings. These included CQC cessation of routine inspections and launch of the Emergency Support Framework, removing the requirement for NHS Continuing Health Care assessments and suspending the need for funding panels for hospital discharge, where required [19, 29, 36, 37].

Decision making and leadership

A key focus of implementing the guidance was on the role of leadership and decision making, including guidance for decision makers on applying ethical values and principles in urgent and uncertain circumstances for LTCF residents [20, 29]. This could be, for example, through applying a risk assessment on deciding on whether to admit a resident without a negative COVID-19 test, identification of clinically vulnerable staff or having difficult conversations, such as using the Vaccine Communications Toolkit for Adult Social Care [53, 105, 110].

Training

Much of the guidance recognised the need for further training to implement the recommendations proposed. The training available included online webinars, guidance followed up by competency assessments and annexes, with decision-making flow charts or case studies of good practice. [19, 27, 29, 31].

Technology and communication

The COVID-19 pandemic highlighted the need for secure, consistent communication and dissemination across services. Initiatives to facilitate this included implementing NHSmail in LTCFs, distributing Microsoft Teams to all care providers and offering discounted broadband deals to improve internet connectivity and to further introduce new technologies [19, 64]. Nearly all the guidance included in this review signposted to further guidance, including those produced by other agencies. In some cases, guidance was co-produced, such as using PPE in social care settings [80].

Discussion

This review has identified publicly available policy, guidance and recommendations related to LTCFs, their residents, and staff, in England issued by the UK government during the COVID-19 pandemic. In doing so, the key guidance developments within the wider pandemic are provided in a narrative timeline of the main recommendations. Six themes of recommendations and seven areas of implementation emerging from the management of COVID-19 have been identified.

Strengths and limitations

Despite widespread criticism of the management of the COVID-19 pandemic in LTCFs, academic literature on national policies is relatively scarce [162]. A strength of this review is its location of the guidance within the wider key events; the timeline illustrates how the approach to managing COVID-19 evolved over time, highlighting policies that could be implemented earlier in future pandemics. In addition, the review has focused on recommendations and their implementation, identifying how such polices were intended to be delivered and supported.

The review is timely in that it synthesises over two years of policy, providing a contextual reference for wider published outputs in the research area. Given the need for accessible, updatable guidance during the pandemic, all the documents included in this review were published online. Sourcing such data was challenging, in terms of finding the literature online and accessing original versions. In addition, not involving an academic librarian could be considered a limitation of this review. Without a clear repository of guidance, it is difficult to judge whether this review has included all the relevant documents published, despite following best practice methodological approaches [154, 155].

The pathways through which LTCFs accessed the policy recommendations and guidance discussed in this review, and subsequent updates, is an area for further research, however the need for guidance to be clear, consistent and accessible is apparent. In addition, the review focused solely on LTCFs for older adults, rather than wider adult social care, and did not extract data on updates to the guidance, however these updates mainly referred to local lockdowns and are reflected in the narrative timeline. In addition, whilst the review focused on policy in England, it may reflect practice internationally in other countries with comparative LTCFs for older adults.

Connection to wider literature

The aim of this review was to identify, collate and synthesise guidelines, policy and recommendations, and has identified four areas which require further discussion in terms of managing pandemics in LTCFs.

Firstly, in some cases policies had unintended consequences; for example, the mass discharge of hospital patients to LTCFs has been associated with COVID-19 outbreaks, however the relative risk of transmission through hospital discharge compared to that of transmission from community routes into LTCFs is unclear [163].

Secondly, the predominant focus on preventing the spread of COVID-19 may have been at the detriment of wider health and wellbeing. It is possible that the risk of COVID-19, for some residents, may have been less of a priority compared to the impact on quality of life of not having contact with relatives or the effect of social isolation, however this was acknowledged relatively little in the policies included in this review.

Thirdly, the extent to which the policies identified were effective is debatable. In the case of residents approaching end of life, during which visits from relatives were allowed, one survey found that 18% of LTCFs surveyed did not allow visitors at the end of life, and of those that did 51% experienced challenges in providing bereavement support to relatives [164, 165]. In addition, despite the introduction of mental health and wellbeing resources for adult social care staff, health care workers in LTCFs reported experiencing high levels of stress, especially among those with personal health issues, and high levels of post-traumatic stress disorder [166–168].

Finally, the extent to which the policies issued were able to be implemented in LTCFs is also questionable. For example, the ability of non-purpose built LTCFs to successfully isolate residents from one another, is unclear. Alternatively, efforts to digitise LTCFs and introduce new technologies, such as remote conferencing, while a welcome development, were dependant on the availability of training and support required to introduce, embed and sustain such interventions [169–171].

Arguably, some of the areas that policies were aimed at were longstanding challenges faced by adult social care in England, and trying to address historic issues exacerbated by the pandemic could be difficult. For example, strategies to manage COVID-19 related staff shortages were central in the policies identified, despite high staff turnover, relatively low pay and a reliance on external agency staff across multiple sites existing pre-pandemic [145]. In addition, the pandemic highlighted the need for joint working between LTCFs and wider sectors, an area of concern that has existed for years prior to COVID-19 [172, 173].

From a more positive perspective, the experience of COVID-19 in LTCFs may have improved some longstanding challenges experienced by adult social care in England. Firstly, identification as key workers and albeit delayed access to household testing repositioned adult social care staff in line with the wider healthcare workforce. Secondly, one arguably successful policy was the introduction of the Capacity Tracker to collect data on LTCFs, and the wider implementation of upgrading technology in the process. The paucity of data on adult social care has also been highlighted prior to the pandemic, supporting further calls for development of a minimum dataset [174, 175].

Implications for policy, practice and further research

From a policy perspective, this review has highlighted the need for effective, accessible, and timely guidance and recommendations on managing pandemics in LTCFs. In particular, the secondary effects of the outcomes of such policies, and how such impacts can be measured, beyond numbers of infections, outbreaks or deaths, requires further thought. For example, while hospital admissions from LTCFs declined during COVID-19; the extent to which this reflects appropriate care within the facility or unmet need is unclear [176].

The timing of such guidance also warrants further discussion, particularly in reference to asymptomatic presentation and testing availability [177]. The role of asymptomatic presentation was likely under-estimated in the early stages of the pandemic. In one study on COVID-19 symptomology within an LTCF, of 40% of residents who tested positive, 43% were asymptomatic, and 4% of staff tested positive, all of whom were asymptomatic [178]. In hindsight, had ‘whole home’ testing been available after one suspected case, asymptomatic cases could have been identified earlier, allowing more time for the updating and if necessary, implementing, of advance care plans, cohorting exposed residents and planning for potential staff shortages [179, 180].

The extent to which wider stakeholders, including LTCF staff, residents and relatives’ groups and charities such as the National Care Forum, were consulted during policy development, and how this involvement would have shaped the policy recommendations, is also unclear [181]. An example of the need for stakeholder engagement can be seen in vaccine hesitancy among LTCF staff [182]. In future, further engagement with wider stakeholders is needed to identify areas of importance to LTCF residents, relatives and staff during pandemics, and how policies can be successfully implemented on the ground.

In addition, a better understanding of the mechanisms by which LTCFs access policy recommendations could further enhance policy development in this area. Throughout the pandemic, there were repeated calls by LTCF managers for clear, consistent guidance, however the routes of dissemination through which guidance is accessed, and how these can be enhanced, needs further development [183, 184].

In terms of further research, this review has identified three areas of priority. Firstly, exploring why some LTCFs experienced the pandemic differently to others, and how this relates to the implementation of issued policies and guidance, is a priority. As of Dec 2020, 70% of all LTCFs in England had experienced a COVID-19 infection, and 33.1% of these had experienced multiple outbreaks [185]. The likelihood of outbreaks has been associated with higher bed occupancy, lower staff levels and the use of agency staff across multiples sites, however this knowledge base is far from complete [186, 187]. In comparison, in Canada 54% of resident deaths were in privately owned, profit oriented LTCFs, and in Australia COVID-19 outbreaks were associated with areas of increased community transmission and no face-to-face infection control training [188, 189]. Comparing the experiences of LTCFs internationally and understanding the mechanisms behind the differences between countries is a key area for exploration. In addition, inequalities in the number of COVID-19 infections in LTCFS in areas of higher and low deprivation require further investigation [190].

Secondly, further research is needed to explore how effective policies across the themes identified can be implemented in LTCFs, within the context of pre-existing challenges to adult social care and the immediate pressures of a pandemic. Ongoing research in some of these areas is already emerging, such as how LTCF staff can be supported in providing end of life care and delivering training on the use of PPE, however this needs expanding, with training ideally covering more than one aspect of pandemic management [168, 171, 191, 192].

Thirdly, international comparison to countries with comparable long-term care systems would support further development in this area. Initiatives such as the International Long-Term Care Policy Network are already making progress in this area, and developing an understanding of how other countries approached pandemic management in LTCFs could provide valuable learning for England [193].

In relation to changing practice, further research is needed to explore the extent to which policies were implemented, and the barriers, facilitators and challenges to doing so. Understanding how current approaches to providing care in this setting can be 'pandemic proofed', and whether there are preventative measures that could be addressed to avoid repeating the mistakes of the COVID-19 pandemic in the future could be beneficial. This could include sustaining a system to ensure equitable access to PPE supplies and testing facilities, or maintaining procedures limiting staff movement between sites.

There is also potential for wider discussion on how residents with dementia and those lacking mental capacity can be cared for [194]. While the policies issued referred to the specific care needs of older adults in managing COVID-19, further guidance on practical approaches to prognostic trajectory, advance care planning and recovery from COVID-19 could be useful [168, 195]. Recognising COVID-19 in residents with dementia can be especially problematic, often presenting atypically; with residents more likely to experience delirium and deteriorate relatively fast. These residents may be less able to understand social distancing or handwashing requirements, and experience the mental and emotional impact of isolation and decreased socialisation more severely [196].

Finally, managing the impact of COVID-19 on residents who are not infected is also an area of interest. As discussed by Burton et al., excess deaths, both COVID-19-related and non-COVID-19-related, were concentrated in LTCFs with a confirmed outbreak of COVID-19 [197], indicating that the extra burden of caring for residents with COVID-19 had a detrimental indirect impact on residents not infected. Again, how to ensure appropriate care is maintained during outbreaks for all residents requires further exploration.

Conclusion

The impact of the COVID-19 pandemic on LTCFs in England should not be forgotten, and the opportunity to learn from the experience not missed. This review has provided an overview of key themes within the policy, guidance and recomendations issued, and identified areas for further development in terms of pandemic preparedness. As the ageing population continues to grow across the world and the long-term care needs of older adults increases, developing effective responses for managing future pandemics in LTCFs should remain a priority, in England and internationally.

Abbreviations

CQC	Care Quality Commission
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
ENTREQ	Enhancing Transparency in Reporting the synthesis of Qualitative research
HPT	Health protection team
IPC	Infection prevention and control
LFD	Lateral flow device
LRF	Local resilience forum
NHS	National Health Service
NSDR	National Supply Disruption Response
PPE	Personal protective equipment
PCR	Polymerase chain reaction
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
UK	United Kingdom

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12877-024-04867-9.

Supplementary Material 1.

Authors' contributions

DCM conceived the study and conducted the review search, inclusion criteria, data extraction and synthesis. AG contributed to data extraction and synthesis. NC, AH and NP contributed to overall writing of the paper.

Funding

The research was funded by the Dowager Countess Eleanor Peel Trust, as part of the Sir Robert Boyd Fellowship. The views expressed are those of the authors and not necessarily those of the Dowager Countess Eleanor Peel Trust.

Availability of data and materials

All data generated or analyzed during this study are included in this published article and its supplementary information files.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Author details

[1]Division of Health Research, Lancaster University, Lancaster, UK. [2]Lancaster Medical School, Lancaster University, Lancaster, UK.

Received: 1 August 2023 Accepted: 4 March 2024
Published online: 03 May 2024

References

1. Adelina Comas-Herrera JZ, Elizabeth Lemmon, David Henderson, Charles Litwin, Amy T. Hsu, Andrea E. Schmidt, Greg Arling, Florien Kruse and Jose-Luis Fernández. Mortality associated with COVID-19 outbreaks in care homes: international evidence. 2020.
2. Burki T. England and Wales see 20,000 excess deaths in care homes. Lancet. 2020;395(10237):1602.
3. Bone AE, Finucane AM, Leniz J, Higginson IJ, Sleeman KE. Changing patterns of mortality during the COVID-19 pandemic: population-based modelling to understand palliative care implications. Palliat Med. 2020;34(9):1193–201.
4. Office for National Statistics. Care homes and estimating the self-funding population, England: 2021 to 2022 2022. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/carehomesandestimatingtheselffundingpopulationengland/2021to2022.
5. Akhtar-Danesh N, Baumann A, Crea-Arsenio M, Antonipillai V. COVID-19 excess mortality among long-term care residents in Ontario, Canada. PLoS One. 2022;17(1):e0262807.
6. Krzyzaniak NSA, Bakhit M, Bryant A, Taylor M, Del Mar C. Impact of the COVID-19 pandemic on the Australian residential aged care facility (RACF) workforce. Aust J Adv Nurs. 2021;38(3):47–58.
7. Snyder RLAL, White KA, Tavitian S, Fike LV, Jones HN, Jacobs-Slifka KM, Stone ND, Sinkowitz-Cochran RL. A qualitative assessment of factors affecting nursing home caregiving staff experiences during the COVID-19 pandemic. PLoS One. 2021;16(11):e0260055.
8. Reitinger E, Froggatt K, Brazil K, Heimerl K, Hockley J, Kunz R, et al. Palliative care in long-term care settings for older people: findings from an EAPC taskforce. Eur J Palliat Care. 2013;20(5):251–3.
9. Froggatt K, Payne S, Morbey H, Edwards M, Finne-Soveri H, Gambassi G, et al. Palliative care development in European care homes and nursing homes: application of a typology of implementation. J Am Med Direct Assoc. 2017;18(6):550. e7-e14.
10. World Health Organization. Timeline: WHO's COVID-19 response 2022. Available from: https://www.who.int/emergencies/diseases/novel-coronavirus-2019/interactive-timeline#!
11. NHS England and NHS Improvement. Letter: Important and urgent -Next steps on NHS Response to COVID-19. 2020. Published 17 March 2020. Available from: https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/urgent-next-steps-on-nhs-response-to-covid-19-letter-simon-stevens.pdf.
12. Department of Health and Social Care. CMO confirms cases of coronavirus in England 2020. Published 31 January 2020. Available from: https://www.gov.uk/government/news/cmo-confirms-cases-of-coronavirus-in-england.
13. Public Health England. Guidance for social or community care and residential settings on COVID-19 2020. Published 25 February 2020. Available from: https://www.gov.uk/government/publications/guidance-for-social-or-community-care-and-residential-settings-on-covid-19/guidance-for-social-or-community-care-and-residential-settings-on-covid-19.
14. Department of Health and Social Care. CMO for England announces first death of patient with COVID-19 2020. Published 05 March 2020. Available from: https://www.gov.uk/government/news/cmo-for-england-announces-first-death-of-patient-with-covid-19.
15. Department of Health and Social Care. Coronavirus (COVID-19) action plan 2020. Published 03 March 2020. Available from: https://www.gov.uk/government/publications/coronavirus-action-plan.
16. World Health Organization. Tweet - "We have therefore made the assessment that #COVID19 can be characterized as a pandemic" 2020. Published 11 March 2020. Available from: https://twitter.com/WHO/status/1237777021742338049?s=20.
17. Care Quality Commission. Routine inspections suspended in response to coronavirus outbreak 2020. Published 16 March 2020. Available from: https://www.cqc.org.uk/news/stories/routine-inspections-suspended-response-coronavirus-outbreak.
18. Prime Minister's Office, 10 Downing Street, The Rt Hon Boris Johnson MP. Prime Minister's statement on coronavirus (COVID-19): 16 March 2020 2020. Published 16 March 2020. Available from: https://www.gov.uk/government/speeches/pm-statement-on-coronavirus-16-march-2020.
19. Department of Health and Social Care. Coronavirus (COVID-19): hospital discharge service requirements 2020. Published 19 March 2020. Available from: https://www.gov.uk/government/publications/coronavirus-covid-19-hospital-discharge-service-requirements.
20. Department of Health and Social Care. Responding to COVID-19: the ethical framework for adult social care 2020. Published 19 March 2020. Available from: https://www.gov.uk/government/publications/covid-19-ethical-framework-for-adult-social-care/responding-to-covid-19-the-ethical-framework-for-adult-social-care.
21. Prime Minister's Office, 10 Downing Street, The Rt Hon Boris Johnson MP. Prime Minister's statement on coronavirus (COVID-19): 23 March 2020 2020. Published 23 March 2020. Available from: https://www.gov.uk/government/speeches/pm-address-to-the-nation-on-coronavirus-23-march-2020.
22. Department of Health and Social Care. Letter from the Minister of State for Care to recruitment agencies 2020. Published 23 March 2020 Available from: https://assets.publishing.service.gov.uk/media/5e78e86fe90e073e3502c221/Letter_from_Helen_Whately.pdf.
23. Local Government Association, Association of Directors of Adult Social Services. Letter to Secretary of State Matt Hancock from the LGA and ADASS 2020. Published 27 March 2020. Available from: https://www.local.gov.uk/letter-secretary-state-matt-hancock-lga-and-adass.
24. NHS England. COVID-19 testing to support retention of NHS staff 2020. Published 29 March 2020. Available from: https://www.england.nhs.uk/coronavirus/publication/letter-covid-19-testing-to-support-retention-of-nhs-staff/.
25. Care Quality Commission. Joint statement on advance care planning 2020. Published 03 April 2020. Available from: https://www.cqc.org.uk/news/stories/joint-statement-advance-care-planning.
26. Wolrd Health Organisation. Transmission of SARS-CoV-2: implications for infection prevention precautions 2020. Available from: https://www.who.int/news-room/commentaries/detail/transmission-of-sars-cov-2-implications-for-infection-prevention-precautions.
27. Department of Health and Social Care, Care Quality Commission, Public Health England, NHS England. Coronavirus (COVID-19): admission and care of people in care homes 2020. Published 02 April 2020. Available from: https://www.gov.uk/government/publications/coronavirus-covid-19-admission-and-care-of-people-in-care-homes.
28. Public Health England. COVID-19: management of exposed health care workers and patients in hospital settings 2020. Published 04 April 2020. Available from: https://www.gov.uk/government/publications/covid-19-management-of-exposed-healthcare-workers-and-patients-in-hospital-settings.
29. Department of Health and Social Care. Coronavirus (COVID-19): looking after people who lack mental capacity 2020. Published 09 April 2020. Available from: https://www.gov.uk/government/publications/coronavirus-covid-19-looking-after-people-who-lack-mental-capacity.
30. Office for National Statistics. Publication of statistics on deaths involving COVID-19 in care homes in England: transparency statement 2020. Published 28 April 2020. Available from: https://www.ons.gov.uk/news/statementsandletters/publicationofstatisticsondeathsinvolvingcovid19incarehomesinenglandtransparencystatement.
31. Department of Health and Social Care. COVID-19: our action plan for adult social care 2020. Published 14 December 2020. Available from: https://www.gov.uk/government/publications/coronavirus-covid-19-adult-social-care-action-plan/covid-19-our-action-plan-for-adult-social-care.
32. Foreign and Commonwealth Office, Prime Minister's Office, 10 Downing Street, The Rt Hon Dominic Raab MP. Foreign Secretary's statement on coronavirus (COVID-19): 16 April 2020 2020. Published 16 April 2020. Available from: https://www.gov.uk/government/speeches/foreign-secretarys-statement-on-coronavirus-covid-19-16-april-2020.
33. Public Health England. COVID-19: how to work safely in care homes 2020. Published 17 April 2020. Available from: https://www.gov.uk/government/publications/covid-19-how-to-work-safely-in-care-homes.
34. Department of Health and Social Care. Adult social care recruitment care campaign launched to boost workforce 2020. Published 23 April 2020. Available from: https://www.gov.uk/government/news/adult-social-care-recruitment-care-campaign-launched-to-boost-workforce.
35. Department of Health and Social Care. New guarantee on death in service benefits for frontline health and care staff during pandemic 2020.

Published 27 April 2020. Available from: https://www.gov.uk/government/news/new-guarantee-on-death-in-service-benefits-for-frontline-health-and-care-staff-during-pandemic.
36. Department of Health and Social Care, The Rt Hon Matt Hancock MP. Health and Social Care Secretary's statement on coronavirus (COVID-19): 28 April 2020 2020. Published 30 April 2020. Available from: https://www.gov.uk/government/speeches/health-and-social-care-secretarys-statement-on-coronavirus-covid-19-28-april-2020.
37. Care Quality Commission. CQC launches emergency support framework 2020. Published 01 May 2020. Available from: https://www.cqc.org.uk/news/stories/cqc-launches-emergency-support-framework.
38. Prime Minister's Office, 10 Downing Street, The Rt Hon Boris Johnson MP. Prime Minister's statement on coronavirus (COVID-19): 10 May 2020 2020. Published 10 May 2020. Available from: https://www.gov.uk/government/speeches/pm-address-to-the-nation-on-coronavirus-10-may-2020.
39. NHS England and NHS Improvement. COVID-19 response: Primary care and community health support care home residents, 2020. Published 01 May 2020. Available from: https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/COVID-19-response-primary-care-and-community-health-support-care-home-residents.pdf.
40. Department of Health and Social Care. Dedicated app for social care workers launched 2020. Published 06 May 2020. Available from: https://www.gov.uk/government/news/dedicated-app-for-social-care-workers-launched.
41. Cabinet Office. Our plan to rebuild: The UK Government's COVID-19 recovery strategy 2020. Published 11 May 2020. Available from: https://www.gov.uk/government/publications/our-plan-to-rebuild-the-uk-governments-covid-19-recovery-strategy.
42. Department of Health and Social Care. Coronavirus (COVID-19): care home support package 2020. Published 15 May 2020. Available from: https://www.gov.uk/government/publications/coronavirus-covid-19-support-for-care-homes.
43. Department of Health and Social Care. Health and wellbeing of the adult social care workforce 2020. Published 19 May 2022. Available from: https://www.gov.uk/government/publications/health-and-wellbeing-of-the-adult-social-care-workforce.
44. Department of Health and Social Care, UK Visas and Immigration, and The Rt Hon Priti Patel MP. Home Office extends bereavement scheme to NHS support staff and social care workers 2020. Published 20 May 2020. Available from: https://www.gov.uk/government/news/home-office-extends-bereavement-scheme-to-nhs-support-staff-and-social-care-workers.
45. Care Management Matters. Join Social Care recruitment platform 2020. Published 26 May 2020. Available from: https://www.caremanagementmatters.co.uk/join-social-care-recruitment-platform/.
46. Department of Health and Social Care, The Rt Hon Matt Hancock MP. Health and Social Care Secretary's statement on coronavirus (COVID-19): 1 June 2020 2020. Published 02 June 2020. Available from: https://www.gov.uk/government/speeches/health-and-social-care-secretarys-statement-on-coronavirus-covid-19-1-june-2020.
47. Department of Health and Social Care. NHS volunteers extend support to frontline health and social care staff 2020. Published 06 June 2020. Available from: https://www.gov.uk/government/news/nhs-volunteers-extend-support-to-frontline-health-and-social-care-staff.
48. Department of Health and Social Care. Coronavirus (COVID-19) testing in care homes: statistics to 8 July 2020 2020. Published 16 July 2020. Available from: https://www.gov.uk/government/publications/coronavirus-covid-19-testing-in-care-homes-statistics-to-8-july-2020/coronavirus-covid-19-testing-in-care-homes-statistics-to-8-july-2020.
49. Department of Health and Social Care. Social Care Sector COVID-19 Support Taskforce 2020. Published 08 June 2020. Available from: https://www.gov.uk/government/groups/social-care-sector-covid-19-support-taskforce.
50. Foreign and Commonwealth Office, Prime Minister's Office, 10 Downing Street, The Rt Hon Dominic Raab MP. Foreign Secretary's statement on coronavirus (COVID-19): 15 June 2020 2020. Published 15 June 2020. Available from: https://www.gov.uk/government/speeches/foreign-secretarys-statement-on-coronavirus-covid-19-15-june-2020.
51. Department of Health and Social Care. About the Adult Social Care Infection Control Fund 2020. Published 15 June 2021. Available from: https://www.gov.uk/government/publications/adult-social-care-infection-control-fund/about-the-adult-social-care-infection-control-fund.
52. Department of Health and Social Care, The Rt Hon Matt Hancock MP. Plans for managing the coronavirus (COVID-19) outbreak in Leicester 2020. Published 29 June 2020. Available from: https://www.gov.uk/government/speeches/local-action-to-tackle-coronavirus.
53. Department of Health and Social Care. Coronavirus (COVID-19): reducing risk in adult social care 2020. Published 19 June 2020. Available from: https://www.gov.uk/government/publications/coronavirus-covid-19-reducing-risk-in-adult-social-care.
54. UK Health Security Agency. Staying alert and staying safe from 4 July 2020. Published 03 July 2020. Available from: https://ukhsa.blog.gov.uk/2020/07/03/staying-alert-and-staying-safe-from-4-july/.
55. Department of Health and Social Care, The Rt Hon Matt Hancock MP, Helen Whately MP. Regular retesting rolled out for care home staff and residents 2020. Published 03 July 2020. Available from: https://www.gov.uk/government/news/regular-retesting-rolled-out-for-care-home-staff-and-residents.
56. Cabinet Office. The next chapter in our plan to rebuild: The UK Government's COVID-19 recovery strategy 2020. Published 24 July 2020. Available from: https://www.gov.uk/government/publications/our-plan-to-rebuild-the-uk-governments-covid-19-recovery-strategy/the-next-chapter-in-our-plan-to-rebuild-the-uk-governments-covid-19-recovery-strategy--2.
57. Wolrd Health Organisation. Preventing and managing COVID-19 across long-term care services: Policy brief, 24 July 2020. 2020. Available from: https://www.who.int/publications/i/item/WHO-2019-nCoV-Policy_Brief-Long-term_Care-2020.1.
58. Department of Health and Social Care. COVID-19 supplement to the infection prevention and control resource for adult social care. 2020. Published 24 August 2022. Available from: https://www.gov.uk/government/publications/infection-prevention-and-control-in-adult-social-care-covid-19-supplement/covid-19-supplement-to-the-infection-prevention-and-control-resource-for-adult-social-care.
59. Department of Health and Social Care. Update on policies for visiting arrangements in care homes 2020. Published 22 July 2020. Available from: https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus.
60. Public Health England. PPE guide for community and social care settings 2020. Published 31 July 2020. Available from: https://www.gov.uk/government/publications/personal-protective-equipment-ppe-illustrated-guide-for-community-and-social-care-settings.
61. Department of Health and Social Care. Overview of adult social care guidance on coronavirus (COVID-19) 2020. Published 25 August 2020. Available from: https://www.gov.uk/guidance/overview-of-adult-social-care-guidance-on-coronavirus-covid-19.
62. Cabinet Office. Coronavirus (COVID-19): What has changed – 9 September 2020. Published 09 September 2020. Available from: https://www.gov.uk/government/news/coronavirus-covid-19-what-has-changed-9-september.
63. Department of Health and Social Care. COVID-19 infection rises: letter to care providers from Director of Adult Social Care Delivery 2020. Published 11 September 2020. Available from: https://www.gov.uk/government/publications/covid-19-infection-rises-letter-to-care-providers-from-director-of-adult-social-care-delivery/covid-19-infection-rises-letter-to-care-providers-from-director-of-adult-social-care-delivery.
64. Department of Health and Social Care. Adult social care: our COVID-19 winter plan 2020 to 2021 2020. Published 18 September 2020. Available from: https://www.gov.uk/government/publications/adult-social-care-coronavirus-covid-19-winter-plan-2020-to-2021/adult-social-care-our-covid-19-winter-plan-2020-to-2021.
65. BBC News. Covid: Pubs and restaurants in England to have 10pm closing times 2020. Published 22 September 2020. Available from: https://www.bbc.co.uk/news/uk-54242634.
66. Department of Health and Social Care. Social Care Sector COVID-19 Support Taskforce: final report, advice and recommendations 2020. Published 12 October 2020. Available from: https://www.gov.uk/government/publications/social-care-sector-covid-19-support-taskforce-report-on-first-phase-of-covid-19-pandemic/social-care-sector-covid-19-support-taskforce-final-report-advice-and-recommendations.

67. BBC News. Covid-19: New three-tier restrictions come into force in England 2020. Published 14 October 2020. Available from: https://www.bbc.co.uk/news/uk-54533924.
68. Department of Health and Social Care. Adult Social Care Infection Control Fund – round 2: guidance 2020. Published 01 July 2022. Available from: https://www.gov.uk/government/publications/adult-social-care-infection-control-fund-round-2/adult-social-care-infection-control-fund-round-2-guidance.
69. Care Quality Commission. Joint statement from CQC's Chief Inspectors, and Deputy Chief Inspector and lead for mental health services 2020. Published 16 September 2020. Available from: https://www.cqc.org.uk/news/stories/joint-statement-cqcs-chief-inspectors-deputy-chief-inspector-lead-mental-health.
70. Department of Health and Social Care. Winter Discharges - Designated Settings 2020. Published 13 October 2020. Available from: https://www.nationalcareforum.org.uk/wp-content/uploads/2020/10/DHSC-Letter-_-Designated-Settings-13Oct20.pdf.
71. Prime Minister's Office, 10 Downing Street, The Rt Hon Boris Johnson MP. Prime Minister's statement on coronavirus (COVID-19): 31 October 2020 2020. Published 31 October 2020. Available from: https://www.gov.uk/government/speeches/prime-ministers-statement-on-coronavirus-covid-19-31-october-2020.
72. Cabinet Office. COVID-19 Winter Plan 2020. Published 23 November 2020. Available from: https://www.gov.uk/government/publications/covid-19-winter-plan.
73. UK Health Security Agency. COVID-19: the green book, chapter 14a 2022. Published 17 August 2022. Available from: https://www.gov.uk/government/publications/covid-19-the-green-book-chapter-14a.
74. Prime Minister's Office, 10 Downing Street, The Rt Hon Boris Johnson MP. Prime Minister's statement on coronavirus (COVID-19): 2 December 2020 2020. Published 02 December 2020. Available from: https://www.gov.uk/government/speeches/prime-ministers-statement-on-coronavirus-covid-19-2-december-2020.
75. Care Quality Commission. Designated settings for people with COVID-19 leaving hospital 2020. Published 28 April 2021. Available from: https://www.cqc.org.uk/news/stories/designated-settings-people-covid-19-leaving-hospital.
76. Department of Health and Social Care. Care home residents to be reunited with families by Christmas 2020. Published 1 December 2020. Available from: https://www.gov.uk/government/news/care-home-residents-to-be-reunited-with-families-by-christmas.
77. Medicines and Healthcare products Regulatory Agency. Regulatory approval of Pfizer/BioNTech vaccine for COVID-19 2020. Published 02 December 2020. Available from: https://www.gov.uk/government/publications/regulatory-approval-of-pfizer-biontech-vaccine-for-covid-19#:~:text=Updated%20the%20Public%20Assessment%20report,announced%20on%204%20June%202021.
78. Department of Health and Social Care. COVID-19 vaccinations and care homes: programme launch 2020. Published 04 December 2020. Available from: https://www.gov.uk/government/publications/covid-19-vaccinations-and-care-homes-programme-launch/covid-19-vaccinations-and-care-homes-programme-launch.
79. NHS England. Landmark moment as first NHS patient receives COVID-19 vaccination 2020. Published 08 December 2020. Available from: https://www.england.nhs.uk/2020/12/landmark-moment-as-first-nhs-patient-receives-covid-19-vaccination/.
80. Care Quality Commission, Department of Health and Social Care, NHS England, Public Health England. Discharge into care homes: designated settings 2020. Published 11 February 2022. Available from: https://www.gov.uk/government/publications/designated-settings-for-people-discharged-to-a-care-home/discharge-into-care-homes-designated-settings.
81. Prime Minister's Office, 10 Downing Street, The Rt Hon Boris Johnson MP. Prime Minister announces Tier 4: 'Stay At Home' Alert Level in response to new COVID variant 2020. Published 19 December 2020. Available from: https://www.gov.uk/government/news/prime-minister-announces-tier-4-stay-at-home-alert-level-in-response-to-new-covid-variant.
82. NHS England. Staffing support to deliver the COVID-19 vaccine to care home residents and staff 2020. Published 20 December 2020. Available from: https://www.england.nhs.uk/coronavirus/documents/staffing-support-to-deliver-the-covid-19-vaccine-to-care-home-residents-and-staff/.
83. Prime Minister's Office, 10 Downing Street, The Rt Hon Boris Johnson MP. Prime Minister announces national lockdown 2020. Published 04 January 2021. Available from: https://www.gov.uk/government/news/prime-minister-announces-national-lockdown.
84. Department of Health and Social Care. UK COVID-19 vaccines delivery plan 2020. Published 11 January 2021. Available from: https://www.gov.uk/government/publications/uk-covid-19-vaccines-delivery-plan.
85. Department of Health and Social Care, Department for Business E, Industrial Strategy. Moderna COVID-19 vaccine authorised by UK medicines regulator 2021. Published 08 January 2021. Available from: https://www.gov.uk/government/news/moderna-covid-19-vaccine-authorised-by-uk-medicines-regulator.
86. Department of Health and Social Care. Adult Social Care Rapid Testing Fund: guidance 2020. Published 01 July 2022. Available from: https://www.gov.uk/government/publications/adult-social-care-rapid-testing-fund/adult-social-care-rapid-testing-fund-guidance#background.
87. Department of Health and Social Care, Helen Whately MP, The Rt Hon Matt Hancock MP. Social care sector to receive £269 million to boost staffing levels and testing 2020. Updated 17 January 2021. Available from: https://www.gov.uk/government/news/social-care-to-receive-269-million-to-boost-staff-levels-and-testing.
88. Medicines and Healthcare products Regulatory Agency. Oxford University/AstraZeneca COVID-19 vaccine approved 2021. Published 30 December 2020. Available from: https://www.gov.uk/government/news/oxford-universityastrazeneca-covid-19-vaccine-approved.
89. Department of Health and Social Care. Your care home during winter 2021. Published 01 April 2021. Available from: https://www.gov.uk/government/publications/coronavirus-covid-19-support-for-care-homes/your-care-home-during-winter.
90. Department of Health and Social Care. Workforce Capacity Fund for adult social care 2021. Published 29 January 2021. Available from: https://www.gov.uk/government/publications/workforce-capacity-fund-for-adult-social-care.
91. Cabinet Office. COVID-19 Response - Spring 2021 (Summary) 2021. Published 22 February 2021. Available from: https://www.gov.uk/government/publications/covid-19-response-spring-2021/covid-19-response-spring-2021-summary.
92. NHS England. NHS confirms COVID jab now offered at every eligible care home in England 2021. Published 01 February 2021. Available from: https://www.england.nhs.uk/2021/02/nhs-confirms-covid-jab-now-offered-at-every-eligible-care-home-in-england/.
93. Department of Health and Social Care. Public urged to consider work in adult social care 2021. Published 09 February 2021. Available from: https://www.gov.uk/government/news/public-urged-to-consider-work-in-adult-social-care.
94. Booth R, Sample I. Coronavirus vaccine: one of UK's largest care home firms introduces 'no jab, no job' policy. The Guardian. 2021 25 February 2021. Available from: https://www.theguardian.com/society/2021/feb/25/one-of-uks-largest-care-home-firms-introduces-no-jab-no-job-policy.
95. Prime Minister's Office, 10 Downing Street, Department for Education, Public Health England, The Rt Hon Boris Johnson MP, The Rt Hon Gavin Williamson CBE MP. Schools and colleges to reopen from tomorrow as part of Step One of the roadmap 2021. Published 07 March 2021. Available from: https://www.gov.uk/government/news/schools-and-colleges-to-reopen-from-tomorrow-as-part-of-step-one-of-the-roadmap.
96. Department of Health and Social Care. Restricting workforce movement between care homes and other care settings 2021. Published 01 March 2021. Available from: https://www.gov.uk/government/publications/restricting-workforce-movement-between-care-homes-and-other-care-settings.
97. UK Health Security Agency. Coronavirus (COVID-19) testing for adult social care services 2021. Published 24 March 2021. Available from: https://www.gov.uk/government/publications/coronavirus-covid-19-testing-for-adult-social-care-settings.
98. Department of Health and Social Care. Adult Social Care Infection Control and Testing Fund ring-fenced grant 2021: guidance 2021. Published 21 October 2021. Available from: https://www.gov.uk/gover

nment/publications/adult-social-care-infection-control-and-testing-fund-round-3.
99. Department of Health and Social Care, The Rt Hon Boris Johnson MP, The Rt Hon Matt Hancock MP. Twice weekly rapid testing to be available to everyone in England 2021. Published 05 April 2021. Available from: https://www.gov.uk/government/news/twice-weekly-rapid-testing-to-be-available-to-everyone-in-england.
100. Prime Minister's Office, 10 Downing Street. Further easing of Covid restrictions confirmed for 12 April 2021. Published 05 April 2021. Available from: https://www.gov.uk/government/news/further-easing-of-covid-restrictions-confirmed-for-12-april.
101. Department of Health and Social Care. Consultation launched on staff COVID-19 vaccines in care homes with older adult residents 2021. Published 14 April 2021. Available from: https://www.gov.uk/government/news/consultation-launched-on-staff-covid-19-vaccines-in-care-homes-with-older-adult-residents.
102. Department of Health and Social Care. Care homes residents allowed more out-of-home visits 2021. Published 01 May 2021. Available from: https://www.gov.uk/government/news/care-homes-residents-allowed-more-out-of-home-visits.
103. Department of Health and Social Care. More restrictions eased for care homes 2021. Published 10 May 2021. Available from: https://www.gov.uk/government/news/more-restrictions-eased-for-care-homes.
104. Department of Health and Social Care. Janssen coronavirus (COVID-19) vaccine authorised by UK medicines regulator 2021. Published 28 May 2021. Available from: https://www.gov.uk/government/news/janssen-coronavirus-covid-19-vaccine-authorised-by-uk-medicines-regulator.
105. Department of Health and Social Care. Testing for professionals visiting care homes 2021. Published 01 April 2022. Available from: https://www.gov.uk/government/publications/coronavirus-covid-19-testing-in-adult-care-homes/testing-for-professionals-visiting-care-homes.
106. Department of Health and Social Care. Everyone working in care homes to be fully vaccinated under new law to protect residents 2021. Published 16 June 2021. Available from: https://www.gov.uk/government/news/everyone-working-in-care-homes-to-be-fully-vaccinated-under-new-law-to-protect-residents.
107. Shearing H, Lee J. England Covid restrictions ease as PM urges caution. BBC News. 2021 19 July 2021. Available from: https://www.bbc.co.uk/news/uk-57882029.
108. Department of Health and Social Care. Adult Social Care Extension to Infection Control and Testing Fund Ring-Fenced Grant 2021 2021. Published 02 July 2021. Available from: https://www.gov.uk/government/publications/adult-social-care-extension-to-infection-control-and-testing-fund-2021.
109. Department of Health and Social Care. Frontline health and care staff can work rather than self-isolate 2021. Published 19 July 2021. Available from: https://www.gov.uk/government/news/frontline-health-and-care-staff-can-work-rather-than-self-isolate.
110. Department of Health and Social Care. COVID-19 vaccination of people working or deployed in care homes: operational guidance 2021. Published 04 August 2021. Available from: https://www.gov.uk/government/publications/vaccination-of-people-working-or-deployed-in-care-homes-operational-guidance.
111. Prime Minister's Office, 10 Downing Street, Department of Health and Social Care, HM Treasury, The Rt Hon Sajid Javid MP, The Rt Hon Rishi Sunak MP, et al. Record £36 billion investment to reform NHS and Social Care 2021. Published 07 September 2021. Available from: https://www.gov.uk/government/news/record-36-billion-investment-to-reform-nhs-and-social-care.
112. Department of Health and Social Care. Most vulnerable to be offered COVID-19 booster vaccines from next week 2021. Published 14 September 2021. Available from: https://www.gov.uk/government/news/most-vulnerable-to-be-offered-covid-19-booster-vaccines-from-next-week.
113. Department of Health and Social Care. Temporary medical exemptions for COVID-19 vaccination of people working or deployed in care homes 2021. Published 15 September 2021. Available from: https://www.gov.uk/government/publications/temporary-medical-exemptions-for-covid-19-vaccination-of-people-working-or-deployed-in-care-homes.
114. Department of Health and Social Care. Adult Social Care Infection Control and Testing Fund, round 3: guidance 2021. Published 21 October 2021. Available from: https://www.gov.uk/government/publications/adult-social-care-infection-control-and-testing-fund-round-3.
115. Department of Health and Social Care. Guidance updated to allow flexibility in booster programme for most vulnerable 2021. Published 29 October 2021. Available from: https://www.gov.uk/government/news/guidance-updated-to-allow-flexibility-in-booster-programme-for-most-vulnerable.
116. Department of Health & Social Care. Workforce Recruitment and Retention Fund for adult social care 2021. Updated 3 November 2021. Available from: https://www.gov.uk/government/publications/workforce-recruitment-and-retention-fund-for-adult-social-care.
117. Department of Health and Social Care. Making vaccination a condition of deployment in older adult care homes 2021. Published 09 November 2021. Available from: https://www.gov.uk/government/consultations/making-vaccination-a-condition-of-deployment-in-older-adult-care-homes/making-vaccination-a-condition-of-deployment-in-older-adult-care-homes.
118. Department of Health and Social Care, NHS England, The Rt Hon Sajid Javid MP. Government to introduce COVID-19 vaccination as a condition of deployment for all frontline health and social care workers 2021. Published 09 November 2021. Available from: https://www.gov.uk/government/news/government-to-introduce-covid-19-vaccination-as-a-condition-of-deployment-for-all-frontline-health-and-social-care-workers.
119. Prime Minister's Office, 10 Downing Street, The Rt Hon Boris Johnson MP. Prime Minister confirms move to Plan B in England 2021. Published 08 December 2021. Available from: https://www.gov.uk/government/news/prime-minister-confirms-move-to-plan-b-in-england.
120. Department of Health and Social Care. Support package to protect care sector this winter 2021. Published 10 December 2021. Available from: https://www.gov.uk/government/news/support-package-to-protect-care-sector-this-winter.
121. Department of Health and Social Care. People at the Heart of Care: adult social care reform 2021. Published 10 December 2021. Available from: https://www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper/people-at-the-heart-of-care-adult-social-care-reform.
122. UK Health Security Agency. Self-isolation for COVID-19 cases reduced from 10 to 7 days following negative LFD tests 2021. Published 22 December 2021. Available from: https://www.gov.uk/government/news/self-isolation-for-covid-19-cases-reduced-from-10-to-7-days-following-negative-lfd-tests.
123. Department of Health & Social Care. Workforce recruitment and retention fund for adult social care, round 2 2021. Updated 16 December 2021. Available from: https://www.gov.uk/government/publications/workforce-recruitment-and-retention-fund-for-adult-social-care-round-2.
124. Department of Health and Social Care, Home Office, Gillian Keegan MP, The Rt Hon Sajid Javid MP, The Rt Hon Priti Patel MP. Biggest visa boost for social care as Health and Care Visa scheme expanded 2021. Published 24 December 2021. Available from: https://www.gov.uk/government/news/biggest-visa-boost-for-social-care-as-health-and-care-visa-scheme-expanded.
125. UK Health Security Agency. People with a positive lateral flow test no longer required to take confirmatory PCR test 2022. Published 11 January 2022. Available from: https://www.gov.uk/government/news/people-with-a-positive-lateral-flow-test-no-longer-required-to-take-confirmatory-pcr-test.
126. Department of Health & Social Care. Adult Social Care Omicron Support Fund: guidance 2022. Updated 10 January 2022. Available from: https://www.gov.uk/government/publications/adult-social-care-omicron-support-fund.
127. Department of Health and Social Care. Free PPE for frontline extended for another year 2022. Published 13 January 2022. Available from: https://www.gov.uk/government/news/free-ppe-for-frontline-extended-for-another-year.

128. Department of Health and Social Care, The Rt Hon Sajid Javid MP. Self-isolation for those with COVID-19 can end after 5 full days following 2 negative LFD tests 2022. Published 13 January 2022. Available from: https://www.gov.uk/government/news/self-isolation-for-those-with-covid-19-can-end-after-five-full-days-following-two-negative-lfd-tests.
129. Department of Health and Social Care. Government eases social care restrictions after booster success 2022. Published 27 January 2022. Available from: https://www.gov.uk/government/news/government-eases-social-care-restrictions-after-booster-success.
130. Department of Health and Social Care, The Rt Hon Sajid Javid MP. England to return to Plan A following the success of the booster programme 2022. Published 19 January 2022. Available from: https://www.gov.uk/government/news/england-to-return-to-plan-a-following-the-success-of-the-booster-programme.
131. Department of Health and Social Care. Consultation on removing vaccination as a condition of deployment for health and social care staff 2022. Published 31 January 2022. Available from: https://www.gov.uk/government/news/consultation-on-removing-vaccination-as-a-condition-of-deployment-for-health-and-social-care-staff.
132. Cabinet Office. COVID-19 Response: Living with COVID-19 2022. Published dated 21 February 2022. Available from: https://www.gov.uk/government/publications/covid-19-response-living-with-covid-19.
133. Cabinet Office. UK COVID-19 Inquiry: draft terms of reference 2022. Published 10 March 2022. Available from: https://www.gov.uk/government/publications/uk-covid-19-inquiry-draft-terms-of-reference.
134. Department of Health and Social Care. Regulations making COVID-19 vaccination a condition of deployment to end 2022. Published 01 March 2022. Available from: https://www.gov.uk/government/news/regulations-making-covid-19-vaccination-a-condition-of-deployment-to-end.
135. UK Health Security Agency. A guide to the spring booster for those aged 75 years and older and older residents in care homes 2022. Published 24 March 2022. Available from: https://www.gov.uk/government/publications/covid-19-vaccination-spring-booster-resources/a-guide-to-the-spring-booster-for-those-aged-75-years-and-older-residents-in-care-homes.
136. Department of Health and Social Care. Infection prevention and control in adult social care: COVID-19 supplement 2022. Published 31 March 2022. Available from: https://www.gov.uk/government/publications/infection-prevention-and-control-in-adult-social-care-covid-19-supplement.
137. Department of Health and Social Care. Government sets out next steps for living with COVID 2022. Published 29 March 2022. Available from: https://www.gov.uk/government/news/government-sets-out-next-steps-for-living-with-covid.
138. Department of Health and Social Care. Bereavement resources for the social care workforce 2022. Published 05 April 2022. Available from: https://www.gov.uk/government/publications/bereavement-resources-for-the-social-care-workforce.
139. Department of Health and Social Care, The Rt Hon Sajid Javid MP, The Rt Hon Rishi Sunak MP, The Rt Hon Boris Johnson MP. Health and Social Care Levy to raise billions for NHS and social care 2022. Published 06 April 2022. Available from: https://www.gov.uk/government/news/health-and-social-care-levy-to-raise-billions-for-nhs-and-social-care.
140. UK Health Security Agency. JCVI provides interim advice on an autumn COVID-19 booster programme 2022. Published 19 May 2022. Available from: https://www.gov.uk/government/news/jcvi-provides-interim-advice-on-an-autumn-covid-19-booster-programme.
141. Honinx E, Van Dop N, Smets T, Deliens L, Van Den Noortgate N, Froggatt K, et al. Dying in long-term care facilities in Europe: the PACE epidemiological study of deceased residents in six countries. BMC Public Health. 2019;19(1):1–12.
142. Onder G, Carpenter I, Finne-Soveri H, Gindin J, Frijters D, Henrard JC, et al. Assessment of nursing home residents in Europe: the Services and Health for Elderly in Long TERm care (SHELTER) study. BMC Health Serv Res. 2012;12:1–10.
143. Booth A, Reed AB, Ponzo S, Yassaee A, Aral M, Plans D, et al. Population risk factors for severe disease and mortality in COVID-19: a global systematic review and meta-analysis. PLoS One. 2021;16(3):e0247461.
144. Pineles L, Perencevich EN, Roghmann M-C, Gupta K, Cadena J, Baracco G, et al. Frequency of nursing home resident contact with staff, other residents, and the environment outside resident rooms. Infect Control Hosp Epidemiol. 2019;40(7):815–6.
145. Devi R, Goodman C, Dalkin S, Bate A, Wright J, Jones L, et al. Attracting, recruiting and retaining nurses and care workers working in care homes: the need for a nuanced understanding informed by evidence and theory. Age Ageing. 2021;50(1):65–7.
146. Brainard J, Rushton S, Winters T, Hunter PR. Introduction to and spread of COVID-19-like illness in care homes in Norfolk UK. J Public Health (Oxf). 2021;43(2):228–35.
147. Edwards N, Curry N. Deaths in care homes: what do the numbers tell us? Nuffield Trust comment. London: Nuffield Trust; 2020.
148. Van Houtven CH, Boucher NA, Dawson WD (2020) The Impact of COVID-19 Outbreak on Long Term Care in the United States. Country report in LTCcovid.org, International Long-Term Care Policy Network, CPEC-LSE, 24th April 2020.
149. Chu CH, Wang J, Fukui C, Staudacher SA, Wachholz P, Wu B. The impact of COVID-19 on social isolation in long-term care homes: perspectives of policies and strategies from six countries. J Aging Soc Policy. 2021;33(4–5):459–73.
150. Savage A, Young S, Titley HK, Thorne TE, Spiers J, Estabrooks CA. This was my crimean war: COVID-19 experiences of nursing home leaders. J Am Med Dir Assoc. 2022;23(11):1827–32.
151. Cooney C, Morton B. Matt Hancock disputes claim he rejected care home Covid advice. 2022. BBC News. Available from: https://www.bbc.co.uk/news/uk-politics-64807127.
152. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol. 2005;8(1):19–32.
153. GOV.UK. Search GOV.UK 2022. Available from: https://www.gov.uk/search.
154. Pivodic L, Smets T, Gott M, Sleeman KE, Arrue B, Cardenas Turanzas M, et al. Inclusion of palliative care in health care policy for older people: a directed documentary analysis in 13 of the most rapidly ageing countries worldwide. Palliat Med. 2021;35(2):369–88.
155. Godin K, Stapleton J, Kirkpatrick SI, Hanning RM, Leatherdale ST. Applying systematic review search methods to the grey literature: a case study examining guidelines for school-based breakfast programs in Canada. Syst Rev. 2015;4(1):138.
156. Way Back Machine. Way back machine internet archive; 2023. Available from: https://archive.org/web/.
157. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med Res Methodol. 2008;8(1):45.
158. Lumivero (2017) NVivo (Version 12) www.lumivero.com.
159. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med. 2018;169(7):467–73.
160. Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Med Res Methodol. 2012;12(1):181.
161. Public Health England. Guidance for social or community care and residential settings on COVID-19; 2020. Published 25 February 2020. Available from: https://www.gov.uk/government/publications/guidance-for-social-or-community-care-and-residential-settings-on-covid-19/guidance-for-social-or-community-care-and-residential-settings-on-covid-19.
162. Chan DKY, McLaws ML, Forsyth DR. COVID-19 in aged care homes: a comparison of effects initial government policies had in the UK (primarily focussing on England) and Australia during the first wave. Int J Qual Health C. 2021;33(1)::mzab033.
163. Hollinghurst J, North L, Emmerson C, Akbari A, Torabi F, Williams C, et al. Intensity of COVID-19 in care homes following hospital discharge in the early stages of the UK epidemic. Age Ageing. 2022;51(5):afac072.
164. Hanna K, Cannon J, Gabbay M, Marlow P, Mason S, Rajagopal M, et al. End of life care in UK care homes during the COVID-19 pandemic: a qualitative study. BMC Palliat Care. 2022;21(1):91.
165. Batkovskyte I, Bourke L, Ellis-Smith C, Bone A, Goodman C, Barclay S, et al. Care home staff experiences of palliative and end-of-life care in care homes during Covid-19. BMJ Supp Palliat Care. 2021;11(Supplement 2):A80–1.

166. Maben J, Conolly A, Abrams R, Rowland E, Harris R, Kelly D, et al. 'You can't walk through water without getting wet' UK nurses' distress and psychological health needs during the Covid-19 pandemic: a longitudinal interview study. Int J Nurs Stud. 2022;131:104242.
167. Beattie M, Carolan C, Macaden L, Maciver A, Dingwall L, Macgilleeathain R, et al. Care home workers experiences of stress and coping during COVID-19 pandemic: a mixed methods study. Nurs Open. 2023;10(2):687–703.
168. Cousins E, Preston N, Doherty J, Varey S, Harding A, McCann A, et al. Implementing and evaluating online advance care planning training in UK nursing homes during COVID-19: findings from the Necessary Discussions multi-site case study project. BMC Geriatr. 2022;22(1):419.
169. Johns G, Khalil S, Williams J, Lees M, Hockey L, Ogonovsky M, et al. Connecting and connectivity: providing video consulting in care homes in Wales. J R Coll Phys Edinb. 2021;51(3):283–7.
170. Johnston L, Koikkalainen H, Anderson L, Lapok P, Lawson A, Shenkin SD. 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):16.
171. Russell S, Stocker R, Cockshott Z, Mason S, Knight J, Hanratty B, et al. Use of a digital application to enhance communication and triage between care homes and National Health Service community services in the United Kingdom: a qualitative evaluation. medRxiv. 2023:2023.03.02.23286669.
172. Victor C, Davies S, Dickinson A, Morbey H, Masey H, Gage H, et al. "It just happens". Care home residents' experiences and expectations of accessing GP care. Arch Gerontol Geriatr. 2018;79:97–103.
173. Coles T, Crawley S, Martin F, Diem P, Patel J, Masterton J, et al. Reflections of a care home provider on the COVID-19 pandemic: a catalyst for integrated care. Eur Geriatr Med. 2020;11(SUPPL 1):S63–4.
174. Hanratty B, Burton JK, Goodman C, Gordon AL, Spilsbury K. Covid-19 and lack of linked datasets for care homes: the pandemic has shed harsh light on the need for a live minimum dataset. BMJ. 2020;369:m2463. no pagination.
175. Burton JK, Wolters AT, Towers AM, Jones L, Meyer J, Gordon AL, et al. Developing a minimum data set for older adult care homes in the UK: exploring the concept and defining early core principles. Lancet Healthy Longev. 2022;3(3):e186–93.
176. Grimm F, Hodgson K, Brine R, Deeny SR. Hospital admissions from care homes in England during the COVID-19 pandemic: a retrospective, cross-sectional analysis using linked administrative data. Int J Popul Data Sci. 2020;5(4):1663.
177. Graziadio S, Urwin SG, Cocco P, Micocci M, Winter A, Yang Y, et al. Unmet clinical needs for COVID-19 tests in UK health and social care settings. PLoS One. 2020;15(11):e0242125.
178. Graham NSN, Junghans C, Downes R, Sendall C, Lai H, McKirdy A, et al. SARS-CoV-2 infection, clinical features and outcome of COVID-19 in United Kingdom nursing homes. J Infect. 2020;81(3):411–9.
179. Barker RO, Astle A, Spilsbury K, Hanratty B. COVID-19 testing during care home outbreaks: the more the better? Age Ageing. 2021;50(5):1433–5.
180. Tang S, Sanchez Perez M, Saavedra-Campos M, Paranthaman K, Myers R, Fok J, et al. Mass testing after a single suspected or confirmed case of COVID-19 in London care homes, April-May 2020: implications for policy and practice. Age Ageing. 2021;50(3):649–56.
181. National Care Forum. National Care Forum 2023. Available from: https://www.nationalcareforum.org.uk/.
182. Dennis A, Robin C, Jones LF, Carter H. Exploring vaccine hesitancy in care home employees in North West England: a qualitative study. BMJ Open. 2022;12(5):e055239.
183. Gilissen J, Pivodic L, Unroe KT, Van den Block L. International COVID-19 palliative care guidance for nursing homes leaves key themes unaddressed. Palliat Care Soc Pract. 2021;15:11.
184. Amnesty International. As if expendable: The UK government's failure to protect older people in care homes during the COVID-19 pandemic. London: Amnesty International Ltd.
185. Chudasama DY, Milbourn H, Nsonwu O, Senyah F, Florence I, Cook B, et al. Penetration and impact of COVID-19 in long term care facilities in England: population surveillance study. Int J Epidemiol. 2022;50(6):1804–13.
186. Office for National Statistics. Impact of Coronavirus in Care Homes in England: 26 May to 19 June 2020. 2020. Available from:https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/impactofcoronavirusincarehomesinenglandvivaldi/26mayto19june2020.
187. Dutey-Magni PF, Williams H, Jhass A, Rait G, Lorencatto F, Hemingway H, et al. COVID-19 infection and attributable mortality in UK care homes: cohort study using active surveillance and electronic records (March-June 2020). Age Ageing. 2021;50(4):1019–28.
188. Stall NM, Jones A, Brown KA, Rochon PA, Costa AP. For-profit long-term care homes and the risk of COVID-19 outbreaks and resident deaths. CMAJ. 2020;192(33):E946–55.
189. Gilbert GL, Smith J, Cvejic E, Lilly A, McCaffery K. Characteristics and preparedness for COVID-19 outbreaks of australian residential aged care facilities: a cross-sectional survey. medRxiv. 2022:2022.02.05.22270416.
190. Bach-Mortensen AM, Degli EM. Is area deprivation associated with greater impacts of COVID-19 in care homes across England? A preliminary analysis of COVID-19 outbreaks and deaths. J Epidemiol Community Health. 2021;75(7):624–7.
191. Evett-Towner F. End of life education and training to social care professionals in a response to an urgent need in the a crisis situation as an effect of the Covid-19 pandemic. BMJ Supp Palliat Care. 2022;12(Supplement 3):A17–8.
192. Garner A, Preston N, Caiado C, Stubington E, Hanratty B, Limb J, et al. Understanding health service utilisation patterns for care home residents during the covid-19 pandemic using routinely collected healthcare data. medRxiv. 2023:2023.07.11.23292499.
193. London School of Economics and Political Science. International Long Term Care Policy Network; 2023. Available from: https://ltccovid.org/.
194. Kuylen M, Wyllie A, Bhatt V, Fitton E, Michalowski S, Martin W. COVID-19 and the mental capacity act in care homes: perspectives from capacity professionals. Health Soc Care Community. 2022;30(5):e3018–28.
195. Devi R, Daffu-O'Reilly A, Haunch K, Griffiths A, Jones L, Meyer J, et al. A qualitative exploration of the clinical presentation, trajectory, management and recovery of COVID-19 in older people: learning from frontline staff experiences. Health Soc Care Community. 2022;30(6):e5223–33.
196. Burns A, Lobo A, OldeRikkert M, Robert P, Sartorius N, Semrau M, et al. COVID-19 and dementia: experience from six European countries. Int J Geriatr Psychiatry. 2021;36(6):943–9.
197. Burton JK, Bayne G, Evans C, Garbe F, Gorman D, Honhold N, et al. Evolution and effects of COVID-19 outbreaks in care homes: a population analysis in 189 care homes in one geographical region of the UK. Lancet Healthy Longev. 2020;1(1):e21–31.

Publisher's Note

Appendix B

Impact of the HOPE initiative on hospital admission for self-harm across Liverpool: A longitudinal synthetic control study

Unpublished Draft

Pooja Saini[1], **Alex Garner**[2], Rachael Mountain[2], Konstantinos Daras[3], Catherine Mills[4], Cecil Kullu[5] and Benjamin Barr[3]

[1] School of Psychology, Liverpool John Moores University

[2] Lancaster Medical School, Lancaster University

[3] Institute for Population Health, University of Liverpool

[4] Mersey Care NHS Foundation Trust

[5] Greater Manchester Mental Health NHS Foundation Trust

Abstract

Objective: To examine the effects of a nurse-led, hospital outpatient psychotherapy engagement (HOPE) service on emergency hospital admissions.

Design: A longitudinal synthetic control study to compare the change in outcomes in the intervention population to a similar synthetic comparison group, five years before and three years after implementation.

Setting: A deprived city in the North West of England between 2012 and 2020.

Intervention: A hospital based, outpatient service providing psychotherapy for people who attended for self-harm from 2017–2020.

Main outcome measures: Emergency hospital attendances (admissions or accident and emergency attendance), emergency hospital admissions and emergency re-admissions for self-harm.

Results: The intervention was associated with 64% (95% CI: 43%-77%, $p<0.001$) fewer in self-harm related emergency attendances per 100,000 population in the treated area compared to the synthetic control group. No marked effects were observed for the admissions and reattendances outcomes.

Conclusion: We found some evidence that suggests there were fewer self-harm related emergency for treated areas. However, these results look to be due to an increase in the control areas rather than a reduction in the treated area and were not seen across other outcomes. The results of the additional sensitivity analysis also indicate that the results should be interpreted with caution.

Introduction

Self-harm is a national and global public health priority.[1,2] Self-harm (defined as *"any intentional act of self-injury or self-poisoning regardless of motivation or suicidal intent"*) is associated with personal and social difficulties, as well as increased risk of suicide and premature death by other causes.[3] The number of presentations for suicidal crisis at Emergency departments (ED) is unknown, however the increasing impact of those visits is evident through the increasing number of community crisis resolution/home treatment/ ‘first response’ schemes and more recently the 24-hour response.[4] There are over 200,000 presentations to hospital emergency departments for self-harm annually,[3,5] however, many people do not present to the hospital and these figures substantially underestimate the true prevalence of self-harm.[6] Self-harm is the most important risk factor for suicide, and the risk increases markedly with age.[7]

In a national survey in the United Kingdom (UK), it was reported that between 4.6 and 6.6% of the population self-harm at some point in their lives[8] making it a significant health issue, which often needs to be dealt with by staff in emergency departments. Guidelines from the National Institute for Health and Care Excellence (NICE) on self-harm management have emphasised the important role played by emergency departments and the majority of research conducted on self-harm has been undertaken in secondary healthcare settings.[9,10] An estimated 220,000 emergency department presentations of self-harm occur annually in England,[4,5] which places considerable pressure on hospital services.[11] However, because self-harm is the strongest risk factor for subsequent suicide,[7] these episodes also represent an important opportunity for prevention.[11] To date, limited studies have been reported on the treatment outcomes for patients who attend hospital for self-harm.[12]

The burden of self-harm disproportionally effects disadvantaged socioeconomic groups with rates in the most deprived areas of the population twice as high as in the least deprived.[13,14] The prevalence of self-harm has increased by three times over the last decade[15] and the burden on health services is increasing, particularly in young people[16] and girls with a suspected diagnosis of autism.[17] The costs of self-harm to the National Health Service (NHS) annually in England is estimated at £162 million, with an additional costs in lost productivity.[18] These costs to the NHS are unsustainable especially as self-harm is one of the main risk factors for death by suicide which has a significant economic cost to society.[19] Improving the identification and treatment of self-harm, whilst reducing emergency admissions and length of inpatient stay, has been highlighted as a priority for the NHS in its Five-Year Forward View.[20] The NHS Long Term Plan[20] also aims to tackle health inequalities between the most and least deprived, and highlights that cause of death from suicide is the second largest contributor to the life expectancy gap between these groups. There is, therefore, an urgent need for evidence of effective interventions that improve the management of self-harm and reduce unplanned emergency admissions, particularly in disadvantaged populations.

Self-harm may be preventable by rapid access to brief psychological interventions, particularly within deprived communities where there is a higher prevalence of self-harm.[13,14] However access to brief psychological interventions for self-harm is limited.[12] Existing evidence shows that rapid access to talking therapies is efficient and effective for self-harm.[21-25] There are examples to indicate that rapid access to brief psychological intervention may be underutilised by those in poorer socioeconomic circumstances.[13] This could potentially be due to problems with access, however there is limited published evidence investigating the provision for self-harm treatment in hospital outpatient settings.[12] Community-based self-harm services have been suggested to improve access and reduce emergency admissions,[26] however further research is needed to measure cost-effective of these services. Feasibility of delivering community-based self-harm services has been shown but this has yet to be associated with reduced length of hospital stay, reduced mortality rates and improved health-related quality of life for patients who recently self-harmed.[27] Although there is evidence for community-based approaches to reduce hospital admissions for physical health issues such as cardiovascular disease[28] and respiratory conditions,[29] there is a lack of evidence for integrated self-harm services in deprived areas.

To address these gaps in the evidence-base we investigated the impact on emergency hospital admissions of a hospital outpatient psychotherapy engagement (HOPE) service implemented in a deprived area in the North West of England.[30] The service brought together diagnostic, treatment, management and outpatient services for self-harm, offering a rapid response psychotherapy service within 48 hours that would usually be provided after a longer period of time (up to weeks and months). The aim of this study was to examine the impact of this service on emergency admissions, length of inpatient stay and readmissions for self-harm.

Method

Setting

The intervention discussed in this paper was implemented in The Royal Liverpool University Hospital in 2017. The Liverpool city region was the location with the highest proportion of neighborhoods in the 10% most deprived areas of the UK, according to the 2015 Indices of Multiple Deprivation (IMD).[31] In Liverpool, 7.4% of adults were in contact with mental health, learning disability and autism services 2021-22.[31] Liverpool is in the ten worst areas in the UK for all three post-mental health treatment outcomes measured by Improving Access to Psychological Therapies 2021-2022.[32]

The Hospital Outpatient Psychotherapy Engagement (HOPE) Service

The HOPE service was set up in a busy inner-city hospital ED to provide brief psychological therapy (four sessions plus one follow-up) to those people presenting to ED following self-harm. To be eligible to be referred into the HOPE service, a person needed to have attended at the ED for self-harm. The HOPE service used an integrative approach that combined Psychodynamic Interpersonal Therapy (PIT)[25] with elements of cognitive-analytic therapy (CAT),[33] based on preliminary evidence that such approaches may be helpful for people who self-harm.[25,34] HOPE was developed in response to the growing prevalence of self-harm within the area,[12,30] and a recognition of the need for prompt access to psychological treatment. HOPE is delivered by nursing and psychiatric liaison staff and includes a therapeutic conversation with patients with a focus on attending to, describing and elaborating the patient's feelings, both within the room with the therapist and in their wider lives.[12] The therapy focuses on identifying and understanding possible links between feelings, relationships, and experiences (e.g., noting a common pattern of avoiding conflict with others that occurs across various relationships). Both CAT and PIT have a relational focus, considering the patient's relationships with others and the way they relate to themselves (e.g., self-critical, supportive, dismissive) as important processes underlying problems like self-harm.

Therapists received one day focused training on the HOPE therapy approach delivered by a Clinical Psychologist, and a further five-day training course on PIT. HOPE therapists received ongoing weekly supervision from a qualified clinical psychologist. Therapy sessions took place in a private room connected to the main hospital ED. Sessions were scheduled to last approximately 50 minutes. The therapy does not follow a pre-determined structure across the four sessions. The initial focus of the therapy is on a process of exploring and mapping out the connections between the patients experiences of self-harm, feeling states (including avoided or ignored feelings), and experiences with themselves and others. There is an emphasis on staying with emotions, helping the patient to recognise and label these feelings and understand how they connect with their difficulties around self-harm. The therapist may use diagrams to help capture connections between experiences and feelings, and explore the antecedents and consequences of instances of self-harm or suicidal thinking.[33,35] Later in therapy, there is a shift to focus on discussing alternatives to self-harm, and, given the shared understanding that has been formed about what drives the self-harm, what preventive strategies may be helpful. Given the brief nature of the therapy, the therapy ending, and how this may affect the client, is also discussed. Patients are invited to a fifth, follow-up session, a month after they complete therapy, to review progress and reflections following therapy.

From 2016/2017 to 2021/2022 (financial year), the clinic has provided care to almost 350 patients. Initially, the service was contracted for four years, at an approximate value of £160,000.

Data Sources and Measures

This study used anonymized Hospital Episode Statistics (HES) and Office for National Statistics (ONS) data to construct the variables for analysis. The primary outcome variable was emergency attendances for self-harm per 100,000 population. This is defined as the number of emergency admissions (ICD-10 codes X60*–X84*, Y10*–Y34* but excluding Y33.9*, and Y87*) OR A&E attendances for self harm (AEPATGROUP=30) divided by the ONS mid year population estimate. This outcome reflects potential effects of the intervention on less severe episodes of self-harm that do not lead to admission and is also less sensitive to changes in admission thresholds. We considered two additional outcome variables. Firstly, self-harm emergency hospital admissions per 100,000 population defined as above.[36] Secondly readmissions to for self-harm, defined as the number of admissions of people who had previously been admitted for self-harm in the past 30 days, divided by the population. Variables were defined for each lower super output area (LSOA) in the North West of England for each year in the study period, 2011-2019.

Study Design

This study is a longitudinal synthetic control study using LSOAs as the unit of analysis. LSOAs are small geographical regions created by the UK's Office for National Statistics for the output of census estimates.[37] Since the intervention was implemented at Royal Liverpool hospital, the 'treatment' group of LSOAs were defined as LSOAs where at least 50% of emergency attendances for all causes to any hospital are to Royal Liverpool Hospital, resulting in a treatment group of 59 LSOAs.[38]

A synthetic control group was produced for each outcome investigation using the synthetic control method for microdata that was developed by Robbins et al.[39] The *donor pool* (set of possible LSOAs to use in the synthetic controls) consisted of the remaining LSOAs in the North West of England. To minimize the impact of the intervention on the control group, LSOAs with over 30% of emergency admissions going to Royal Liverpool University Hospital were excluded from the control group. We checked that no other similar intervention was implemented in the North West of England during the time frame and, therefore, the control populations would not have experienced a similar intervention.

The synthetic control group for each outcome consisted of a weighted group of LSOAs from the donor pool based on similarity of several pre-intervention characteristics, as well as the pre-intervention outcome measure, to those of the treatment group (2011-2017). The following variables were used to generate the weights of the LSOAs in the control group; mean distance to an emergency department, mean distance to a GP Index of Multiple Deprivation decile,[38] the age distribution of residents (% <24, 25-44, 45-64, 65+), , proportion of female residents, the annual depression prevalence rate and proportion of population claiming jobseekers' allowance or universal credit and the outcome measure in the pre-intervention time periods The weights were calculated using the raking method [1] so that the weighted averages for all the variables outlined above in the synthetic control group were the same as for the intervention.

The estimated effect of the intervention was then calculated as the difference between the intervention and the (weighted) synthetic control cohorts in the outcome during the post intervention period. To estimate the sampling distribution of the treatment effect, and the permuted p-values and 95% confidence intervals, the sampling distribution was approximated by generating 250 permutations of a placebo group, a group of untreated LSOAs which act as the treatment group for testing purposes. A new synthetic control group is generated for each placebo group and a treatment effect is generated. This demonstrates how the actual set of treated LSOAs have been impacted compared to a random, ‘null’, group from the donor pool. Jackknife replication groups are also generated to calculate a standard error on the treatment effect.[39]

Patient involvement

The research question was developed through a collaboration involving local health service providers, public advisors and researchers. Public advisors are members of the public and/or service users who have knowledge of HOPE and the locality in which it is delivered. The public advisors were involved in a series of meetings agreeing the focus for the research and the planned analysis. A public advisor (CM) is a coauthor of this paper and has contributed to the drafting of the paper and the interpretation of the results.

Results

In total, there were 59 LSOAs classed as the treatment group and 4,302 LSOAs we included in the donor pool. This number excludes any LSOAs that were found to have 30% or more of the emergency attendances to Royal Liverpool Hospital. Each of the synthetic control groups were produced separately for each of the three defined outcomes.

We use the main outcome, number of self-harm related emergency attendances per 100,000 of the population, in each LSOA to demonstrate the results of the analysis. Results from the other outcomes are presented and discussed further in the supplementary materials. In total 281 LSOAs from the donor pool had a non-zero weight in this analysis. The distribution of weights of LSOAs from the donor pool (the North West of England) for the attendances outcome can be seen in Figure 1, the red area is the intervention area, the grey area is the donor pool of

LSOAs in the North West. Table 1 shows the calculated mean of each of the characteristics of the intervention area, and the corresponded weighted average of the synthetic control group.

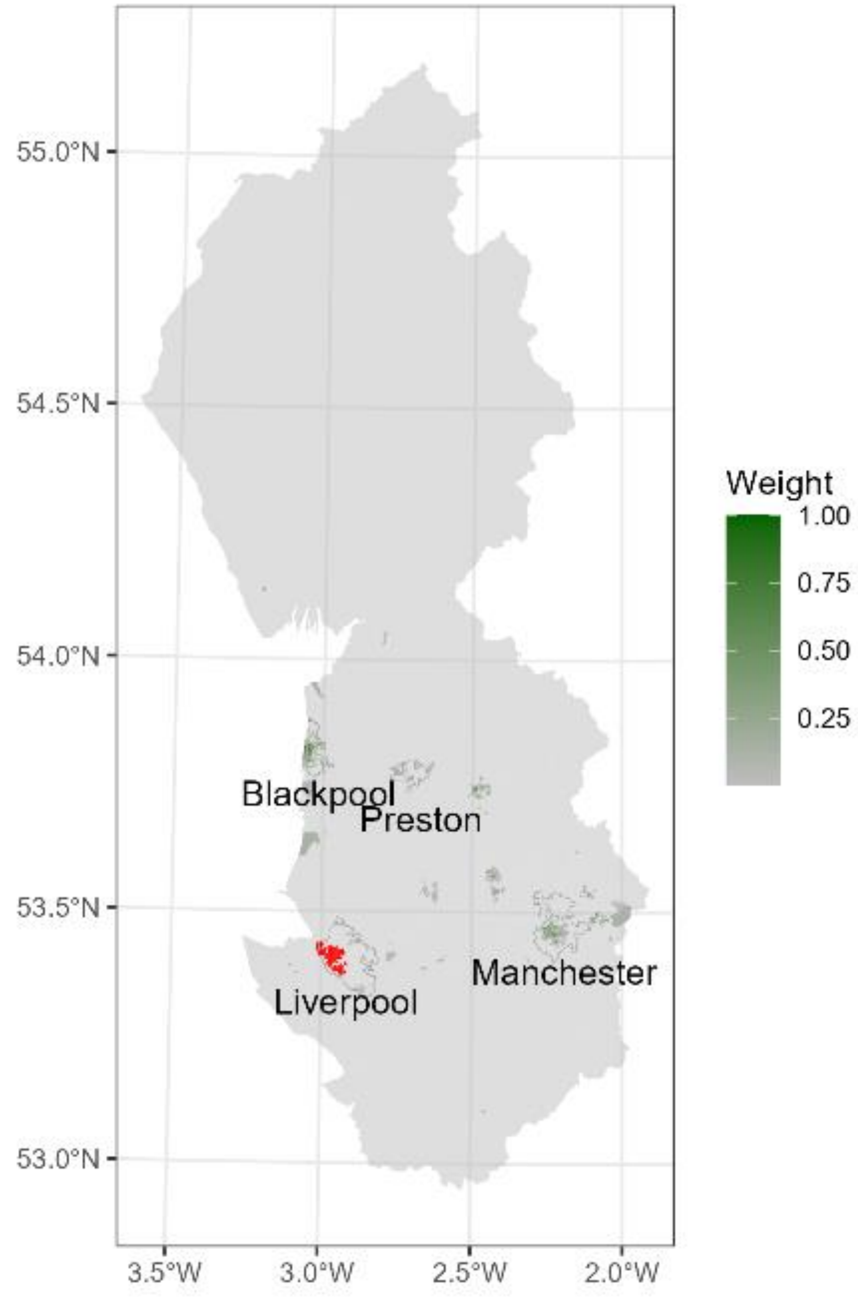

Figure 1: Map of the North West of England. The grey area demonstrates the LSOAs in the donor pool. The red area represents the areas defined as treated by the intervention. The green-ness of an LSOA signifies its weight in the synthetic control group.

Table 1: Weighted means of matching characteristics of the intervention area and the matched control area.

Variable/Outcome	Treated Area Mean	Synthetic Control Group Weighted Mean
Distance to nearest ED	3.13	3.44
Distance to nearest GP	0.643	0.656
Depression	8.51	8.76
IMD Decile 2015	1.78	2.09
Total population	1950	1850
Population <24	586	365
Population 25-44	575	548
Population 45-64	335	358
Population > 65	215	220
Proportion of population female	0.483	0.490
Proportion using jobseekers' allowance (or equivalent)	0.164	0.162

The exact outcome matching is visible in the outcome plot in Figure 2, showing there is no difference in weighted attendance rates in the pre-intervention period. The attendance rates for both groups increase in the post-implementation period, with the increase for the synthetic control group being much sharp than the intervention group.

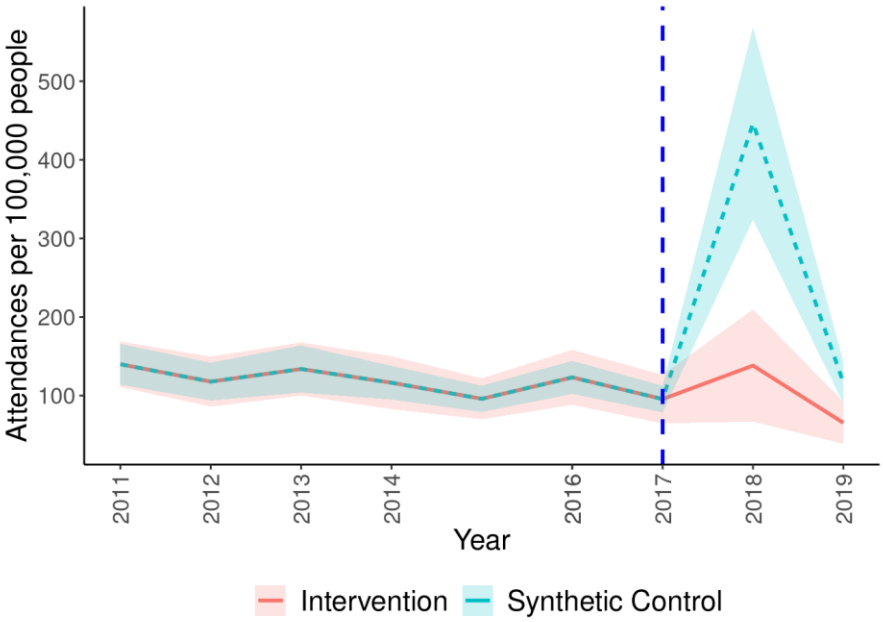

Figure 2: The attendance rates across the study period for the intervention and synthetic control group. Pre-intervention the synthetic control group is matched to the intervention group.

The results for each of the outcomes can be found in Table 2. Evaluating the difference between the during the we see that fewer attendances per 100,000 population are expected for the treated group compared to the synthetic control group, after the intervention. The self-harm related attendances per 100,000 in the treatment group 64% (95% CI: 77% - 43%, p<0.001) lower than the synthetic control group. This appears to be due to a greater increase in self-harm related attendances in the synthetic control group rather than a decrease in the treated group.

Table 2: The calculated change in outcomes at the end of the study period, 95% confidence interval, and associated p-value.

Outcome/Model	Percentage change (2019)	95% CI	P-value
Attendances	-63.8	(-77.0, -43.1)	>0.001
Admissions	-3.2	(-18.9, 15.4)	0.719
Readmissions	-15.7	(-42.2, 22.8)	0.495

When conducting this analysis for the other two outcomes, we find that there is no detectable change in the self-harm related emergency admissions, or readmissions per 100,000 due to the intervention. The details of the analysis for these outcomes can be found in the supplementary material. These null results are reflected in the sensitivity analysis in the supplementary materials.

In the sensitivity analysis using matched controls in a difference-in-difference methodology (details included in supplementary materials), we find the change in self-harm related emergency attendances is not markedly different in the intervention group following the intervention compared to the intervention group. However, the groups in this analysis are not well matched and have diverging trend in outcomes pre-intervention, suggesting they do not meet the parallel trends assumptions required for inferring a causal effect.

Discussion

Principle findings

We found that a hospital-based self-harm psychotherapy engagement service was associated with lower emergency admissions for self-harm, relative to a similar control group. However, this should be interpreted with caution since this effect was not found to be significant in the sensitivity analysis. The attendance rate increased in both groups in the post-implementation period, however the increase was much higher in the synthetic control group. There was also a small decline in both admissions and readmissions to hospital in the intervention group compared to the control following intervention, but these were not statistically significant.

Comparison to previous literature

The term 'self-harm' encompasses a range of methods with varying degrees of intent.[5] Most of the evidence on self-harm and attempted suicide has arisen solely through data collected in hospital settings. There is a dearth of evidence on service implementation for self-harm in the UK and other countries. This is due to the lack of service provision, and the limited treatment options for patients visiting A&E for self-harm, and is highlighted in recent NICE guidelines on the longer term management of self-harm.[10] The guideline report includes a section that highlights the importance of providing appropriate services for managing self-harm, such as talking therapies, but the recommendations of providing psychological talking therapies prior to pharmacological medication is not usually fulfilled due to lack of specialised services or long waiting times.

The results of the attendances analysis reflected a spike in attendances in 2018 which was much higher in the control group. This was also reflected in the sensitivity analysis. One reason for this observed sudden rise in self-harm for both intervention and matched areas could be the release of the Netflix series *'13 Reasons Why'* (released in March 2017) which shows explicit scenes of self-harm. A few months after the release there was a petition to remove those scenes as it was increasing self-harm urges and behaviours worldwide.[41] The HOPE initiative could have led to a lesser increase in the intervention area, but we cannot make a definite link from these findings. Previous research[42] has highlighted a marked increase in self-harm-related emergency department visits (+6.4%) in the three months after the series was released, particularly in females.

Strengths and limitations

Our study has a number of strengths. Firstly, we evaluated the HOPE service in its real-life implementation setting, which makes our findings potentially more externally valid than those set in a trial context. Secondly, we use the synthetic control methodology to produce a control group that matches the chosen characteristics of the treated group as closely as possible. Our approach provides a reasonably large effective sample size of a control group consisting of 281 LSOAs in the North West, and a treatment group consisting of 59 LSOAs in Liverpool providing reasonable power to identify relatively small effects. This methodology is robust compared to other causal inference methods such as difference in difference, which relies on parallel trends before the intervention.

However, some limitations remain. Firstly, comprehensive ascertainment of all self-harm episodes among this hospital patient cohort was reliant on patient disclosure of self-harming behaviour to the hospital staff, the consistency of clinical coding practice among hospital staff in hospital emergency departments. Validation of self-harm case definition, by chart review of medical records, is not possible when using data from HES. A comprehensive self-harm database does not currently exist in the UK, but this is true of all other countries worldwide, except for the Republic of Ireland, which has established a national registry of hospital presentations.[43] Multicentre monitoring of secondary care presentations has been undertaken, with the purpose of characterising the epidemiology of self-harm at a population level beyond reports from single centres.[6] While these studies provide useful data, they report findings from just three cities and therefore do not provide a comprehensive national picture. Hospital Episodes Statistics (HES) linked to national mortality records have recently been used to examine self-harm in England.[44] This dataset captures the more medically serious cases that require admission, however it does not provide a broadly representative UK-wide sample with overall distributions of age and gender corresponding to those of the whole population.

We cannot rule out the possibility that different trends in unobserved confounding factors between the two groups may have influenced the results. Although there are clear differences between the intervention and control groups, time invariant differences between the two groups could not bias the results due to the synthetic control methodology.[45] The results of the analysis are still susceptible to unobserved confounders in the post-intervention period such as changes to health service admission thresholds or health provider financial incentives that could have driven differences in outcome after the study period. We used an additional sensitivity analysis using matched controls and difference in difference analysis to assess our results.

Secondly, the service has been in operation for only three years giving a short follow-up period of two years that could be included in this study. Therefore, further work would be needed in a few years’ time to allow us to look at whether effects were sustained. We did not have access to data on other outcomes such as thoughts of self-harm or out of hours calls for self-harm, and were only able to assess the impact of the intervention on emergency self-harm hospital admissions, length of stay and emergency self-harm readmission rates. Whilst these outcomes may not fully reflect health benefits to the users of these services, they were the planned outcomes of the intervention agreed by the commissioner in their contract with the service provider. Finally, the ecological nature of this study limits the conclusions that can be drawn about individual-level factors, and the results reflect the population-level impact of the HOPE service.

Ethics approval and consent to participate

No ethical approval was needed.

Acknowledgements

The authors would like to thank the Public and Patient Involvement representative, Mersey Care Foundation Trust, and The Applied Research Collaboration North West Coast.

Consent for publication

Not required.

Availability of data and materials

Data may be obtained from a third party and are not publicly available. All data relevant to the study are included in the article or uploaded as online supplementary information. The manuscript's guarantor (BB) affirms that the manuscript is an honest, accurate and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

Competing interests

The authors declare that they have no competing interests.

Funding

KD and BB are part funded by the National Institute for Health and Care Research Applied Research Collaboration North West Coast (ARC NWC). The views expressed herein are those of the authors, not necessarily the Institute for Health and Care Research nor the Department for Health and Social Care.

AG is funded by an EPSRC doctoral training partnership (grant number: EP/R513076/1).

Authors' contributions

PS and BB conceived the study. PS, BB, KD, CM and CK participated in the design of the study. RM, AG and KD completed the analysis. PS, RM and AG drafted the manuscript and PS, BB, KD, AG, CM and CK revised the manuscript. All authors read and approved the final manuscript.

References

1. World Health Organisation. Preventing suicide: A global imperative. Geneva: World Health Organization; 2014.
2. The University of Manchester. *National Confidential Inquiry into Suicide and Safety for Mental Health [NCISH].* Annual report 2022: UK patient and general population data 2009-2019, and real-time surveillance data. University of Manchester; 2023.
3. Hawton K, Bergen H, Casey D, Simkin S, Palmer B, Cooper J, et al. Self-harm in England: A tale of three cities. Multicentre study of self-harm. Social psychiatry and psychiatric epidemiology. 2007; 42(7): 513-21.
4. NHS England, National Collaborating Centre for Mental Health, National Institute for Health and Care Excellence. *Achieving better access to 24/7 urgent and emergency*

mental health care – part 2: implementing the evidence-based treatment pathway for urgent and emergency liaison mental health services for adults and older adults – guidance. 2016

5. Hawton K, Harriss L, Hall S, Simkin, S., Bale, E., Bond, A. Deliberate self-harm in Oxford, 1990–2000: a time of change in patient characteristics. *Psychol Med*; 2003; 33(6):987–995.
6. Geulayov G, Kapur N, Turnbull P, Clements, C., Waters, K., Ness, J., et al. Epidemiology and trends in non-fatal self-harm in three centres in England, 2000–2012: findings from the Multicentre Study of Self-harm in England. *BMJ Open.* 2016; 6: e010538.
7. Geulayov, G., Casey, D., McDonald, K.C., Foster, P., Pritchard, K., Wells, C., et al. Incidence of suicide, hospital-presenting non-fatal self-harm, and community-occurring non-fatal self-harm in adolescents in England (the iceberg model of self-harm): a retrospective study. *Lancet Psychiatry.* 2018; 5 (2):167–174.
8. The University of Manchester. *National Confidential Inquiry into Suicide and Safety for Mental Health [NCISH]. Annual report 2019: England, Northern Ireland, Scotland and Wales.* University of Manchester; 2020.
9. National Institute for Health and Care Excellence. Self-harm: Longer-term management. London: Institute for Health and Care Excellence (NICE); 2011.
10. National Institute for Health and Care Excellence. Self-harm: Longer-term management. London: Institute for Health and Care Excellence (NICE); 2011.
11. Saini P, Kullu C, Mullin E, Boland J, Taylor P. Rapid access to brief psychological treatments for self-harm and suicidal crisis. British Journal of General Practice. 2020; 70(695): 274-5.

12. Taylor, P.J., Fine, K., Mulholland, H., Duarte, R., Dickson, J.M., Kullu, C. Pilot service evaluation of a brief psychological therapy for self-harm in an emergency department: Hospital Outpatient Psychotherapy Engagement Service. Psychology and Psychotherapy: Theory, Research and Practice. 2021; 94(S1): e12277.
13. Lin, C.Y., Bickley, H., Clements, C., Webb, R.T., Gunnell, D., Hsu, C.Y., et al. Spatial patterning and correlates of self-harm in Manchester, England. Epidemiol Psychiatr Sci. 2019 Nov 19;29:e72.
14. Geulayov, G., Casey, D., Bale, E., Brand, F., Clements, C., Farooq, B., et al. Socio-economic disparities in patients who present to hospital for self-harm: Patients' characteristics and problems in the multicentre study of self-harm in England. *Journal of Affective Disorders*, 2022, *318*, 238–245.
15. McManus, S., Gunnell, D., Cooper, C., Bebbington, P.E., Howard, L.M., Brugha, T., et al. Prevalence of non-suicidal self-harm and service contact in England, 2000-14: repeated cross-sectional surveys of the general population. Lancet Psychiatry 2019; 6: 573–81.
16. Mars, B., Heron, J., Crane, C., Hawton, K., Lewis, G., Macleod, J., et al. Clinical and social outcomes of adolescent self harm: population based birth cohort study. *BMJ*. 2014; 349:g5954.
17. Ashworth, E., Provazza, S., McCarthy, M., Saini, P. Children and Young People Presenting in a Pediatric Emergency Department in North-West England in Suicidal Crisis: An Exploratory Case Series Study. *Front Psychiatry*; 2022; 25;13:892939.
18. Tsiachristas, A., McDaid, D., Casey, D., Brand, F., Leal, J., Park, A.L., et al. General hospital costs in England of medical and psychiatric care for patients who self-harm: A retrospective analysis. *The Lancet Psychiatry*. 2017; 4(10): 759-67.

19. Tsiachristas, A., Geulayov, G., Casey, D., Ness, J., Waters, K., Clements, C., et al. Incidence and general hospital costs of self-harm across England: estimates based on the multicentre study of self-harm. Epidemiol Psychiatr Sci. 2020 Mar 12;29:e108.
20. NHS England. The NHS Long Term Plan. www.longtermplan.nhs.uk/publication/nhs-long-term-plan (accessed on 28 March 2024). NHS Improvement (2019).
21. Hawton, K., Witt, K.G., Taylor Salisbury, T.L., Arensman, E., Gunnell, D., Hazell, P., et al. Psychosocial interventions for self-harm in adults. *Cochrane Database Syst Rev*. 2016; 12(5): CD012189.
22. Cuijpers, P., de Beurs, D.P., van Spijker, B.A.J., Berking, M., Andersson, G., Kerkhof, A.J.F.M. The effects of psychotherapy for adult depression on suicidality and hopelessness: A systematic review and meta-analysis. *Journal of Affective Disorders*. 2013; 144(3):183-90.
23. Tarrier, N., Taylor, K., Gooding, P. Cognitive-behavioral interventions to reduce suicide behavior: A systematic review and meta-analysis. *Behavior modification*. 2008;32(1):77-108.
24. Christensen, H., Batterham, P.J., O'Dea, B. E-health interventions for suicide prevention. *Int J Environ Res Public Health*. 2014; 12;11(8):8193-212.
25. Guthrie, E., Moghavemi, A. Psychodynamic-Interpersonal Therapy: An overview of the treatment approach and evidence base. *Psychodynamic Psychiatry*. 2013; 41(4):619-35.
26. Saini, P., Hunt, A., Taylor, P., Mills, C., Clements, C., Mulholland, H., et al. Community Outpatient Psychotherapy Engagement Service for Self-harm (COPESS): A feasibility trial protocol. *Pilot Feasibility Stud*. 2021;7(1):165.

27. Saini, P., Hunt, A., Taylor, P., Mills, C., Clements, C., Mulholland, H., et al. *Community Outpatient Psychotherapy Engagement Service for Self-harm (COPESS): A feasibility trial.* NIHR Report. 2023.

28. Downing, J., Rose, T.C., Saini, P., Matata, B., McIntosh, Z., Comerford, T., *et al*. Impact of a community-based cardiovascular service in an area of high deprivation. *Heart* 2020; 106(5):374-379.

29. Saini, P., Rose, T., Downing, J., Matata, B., Pilsworth, S., Pemberton, A., *et al*. Impact of community-based chronic obstructive pulmonary disease service, a multidisciplinary intervention in an area of high deprivation: a longitudinal matched controlled study. *BMJ Open* 2020; 10**:** e032931.

30. Brizell, J., Russell, S., Whitfield, M. The Trauma and Injury Intelligence Group Merseyside and Cheshire Themed Report. Deliberate Self-Harm across Merseyside and Cheshire April 2011 to March 2014. Injury Surveillance in the North West of England, 2015. http://allcatsrgrey.org.uk/wp/download/public_health/mental_health/MC-DSHThemed-Report-Apr-11-to-Mar-14.pdf

31. Lewis, C., Ubido, J., Jones, L. Vulnerable Individuals and Groups Profile Liverpool City Region. Public Health Institute, Liverpool John Moores University, 2021. https://www.ljmu.ac.uk/~/media/phi-reports/pdf/2021-03-vulnerable-groups-profile-liverpool-city-region (accessed on 12th February 2024)

32. Higgins, A. *An overview of health across the Liverpool city region:* Towards a Spatial Development Strategy for the Liverpool City Region. Liverpool City Region Combined Authority, 2022. https://api.liverpoolcityregion-ca.gov.uk/wp-content/uploads/2023/11/LCR-SDS-Health-Overview-of-the-Liverpool-City-Region-May-2022.pdf (accessed on 12th February 2024)

33. Ryle, A., Kerr, I.B. *Introducing Cognitive Analytic Therapy: Principles and practice of a relational approach to mental health*. 2nd ed. Chichester, West Sussex: Wiley; 2020.

34. Guthrie, E., Patton, G.C., Kapur, N., Mackway-Jones, K., Chew-Graham, C., Moorey, J., et al. Randomised controlled trial of brief psychological intervention after deliberate self poisoning. *BMJ*. 2001; 323:135.

35. Hallam, C., Simmonds-Buckley, M., Kellett, S., Greenhill, B., Jones, A. The acceptability, effectiveness, and durability of cognitive analytic therapy: Systematic review and meta-analysis. *Psychology and Psychotherapy: Theory, Research and Practice*. 2021; 94(S1): 8-35.

36. NHS digital. NHS digital, 2021. *Available:* https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics/hospital-episode-statistics-data-changes-in-2021

37. Office for National Statistics. Lower layer super output area population estimates (supporting information), 2018. *Available:* https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/lowersuperoutputareamidyearpopulationestimates

38. Department for Communities and Local Government. The English Indices of Deprivation 2015: Statistical Release, 2015. *Available:* https://www.gov.uk/government/statistics/english-indices-of-deprivation-2015 *[Accessed* 01 Sep 23*]*.

39. Robbins, M.W., Saunders, J., Kilmer, B. (2017). “A Framework for Synthetic Control Meth-ods with High-Dimensional, Micro-Level Data: Evaluating a Neighborhood-

Specific CrimeIntervention." *Journal of the American Statistical Association*, 112(517), 109–126.

40. Dimick, J.B., Ryan, A.M. Methods for evaluating changes in health care policy: the difference-in-differences approach. *JAMA* 2014*;* 312*:* 2401–2402.
41. Hong, V., Ewell Foster, C.J., Magness, C.S., McGuire, T.C., Smith, P.K, King, C.A. 13 Reasons why: Viewing patterns and perceived impact among youths at risk of suicide. *Psychiatric Services*; 2019; 70: 107–114.
42. Sinyor, M., Mallia, E., Oliveira, C.D., Schaffer, A., Niederkrotenthaler, T., Zaheer, J., et al. Emergency department visits for self-harm in adolescents after release of the Netflix series '13 Reasons Why'. *Australian New Zealand Journal of Psychiatry*; 2021, 56(11):1434-1442.
43. Joyce, M., Chakraborty, S., Hursztyn, P., O'Sullivan., G., McGuinnan, J.C., Nicholson, S., Arensman, E., et al. *National Self-Harm Registery Ireland: Annual report 2021*. National Suicide Research Foundation, 2022. https://www.nsrf.ie/wp-content/uploads/2024/02/NSRF-National-Self-Harm-Registry-Ireland-annual-report-2021.pdf (accessed on 12th February 2024)
44. Clements, C., Turnbull, P., Hawton, K., Geulayov, G., Waters, K., Ness, J., et al. Rates of self-harm presenting to general hospitals: a comparison of data from the Multicentre Study of Self-Harm in England and Hospital Episode Statistics. *BMJ Open* 2016; 6**:** e009749.
45. Abadie, A., Diamond, A., & Hainmueller, J. (2015). Comparative politics and the synthetic control method. *American Journal of Political Science*, 59(2), 495–510.

Supplementary Materials

Methods

The primary analysis is as outlined in the main text. This analysis is conducted for three outcomes, *Attendances*, *Admissions*, and *Readmissions*. Detailed results of the *Attendances* analysis can be found in the main paper. Detailed results of the other two outcomes are found in the results section below.

Results

The analysis uses the synthetic control method as outlined in the main manuscript on the different outcomes. A different synthetic control group is created for each outcome. The characteristics of the synthetic control group are described here, and results of the analysis are show. Additionally, results of the sensitivity analysis using matched controls are described.

Admissions

The first additional outcome is self-harm related emergency admissions to hospital per 100,000 of the population. The characteristics of the synthetic control group produced for this outcome are shown in Table S 1.

Table S 1: Weighted means of matching characteristics of the intervention area and the matched control area for the admissions outcome.

Variable/Outcome	Treated Area Mean	Synthetic Control Group Weighted Mean
Distance to nearest ED	3.13	3.16
Distance to nearest GP	0.643	0.675
Deprivation Prevalence Rate	8.51	8.49
IMD Decile 2015	1.78	2.20
Total population	1950	1820
Population <24	586	331
Population 25-44	575	529
Population 45-64	335	373
Population > 65	215	234
Proportion of population female	0.483	0.494
Proportion using jobseekers' allowance (or equivalent)	0.164	0.153

A map of the distribution of the control group across the North West can be seen in Figure S 1.

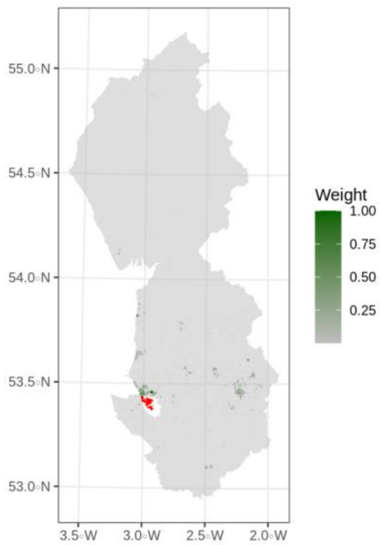

Figure S 1: Distribution of the LSOAs that make up the synthetic control group for the admissions outcome. The red area represents the areas defined as treated by the intervention. The green-ness of an LSOA signifies its weight in the synthetic control group. The gap in LSOAs around Liverpool demonstrates the LSOAs that were excluded due to their significant – but minority – use of Liverpool hospital.

The number of admissions per 100,000 over the study period can be seen in Figure S 2. The scores of the two groups remain similar in the post-intervention period, indicating no significant impact on the self-harm related admissions.

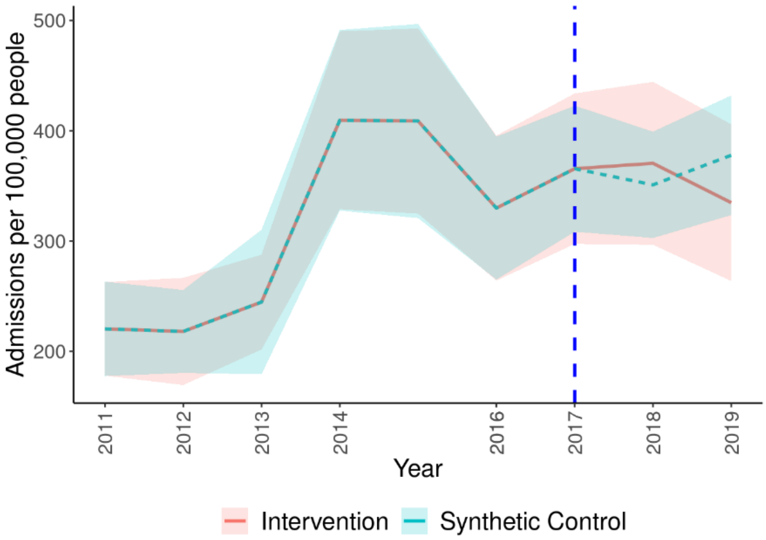

Figure S 2: The admission scores across the study period for the intervention and synthetic control group. Pre-intervention the synthetic control group is matched to the intervention group.

Readmissions

The second additional outcome is self-harm related 28-day readmissions to hospital per 100,000 of the population. The characteristics for the synthetic control group for this analysis are shown in Table S 2.

Table S 2: Weighted means of matching characteristics of the intervention area and the matched control area for the readmissions outcome.

Variable/Outcome	Treated Area Mean	Synthetic Control Group Weighted Mean
Distance to nearest ED	3.13	3.31
Distance to nearest GP	0.643	0.677
Deprivation Prevalence Rate	8.51	8.89
IMD Decile 2015	1.78	1.98
Total population	1950	1810
Population <24	586	324

Population 25-44	575	540
Population 45-64	335	370
Population > 65	215	224
Proportion of population female	0.483	0.492
Proportion using jobseekers' allowance (or equivalent)	0.164	0.158

A map of the distribution of the control groups across the North West can be seen in Figure S 3.

The number of self-harm related readmissions per 100,000 in the study period in Figure S 4. The scores of the two groups remain similar in the post-intervention period, indicating no significant impact on the self-harm related admissions.

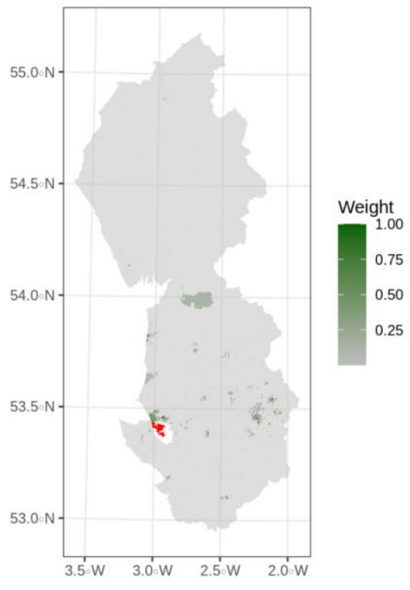

Figure S 3: Distribution of the LSOAs that make up the synthetic control group for the admissions outcome. The red area represents the areas defined as treated by the intervention. The green-ness of an LSOA signifies its weight in the synthetic control group.

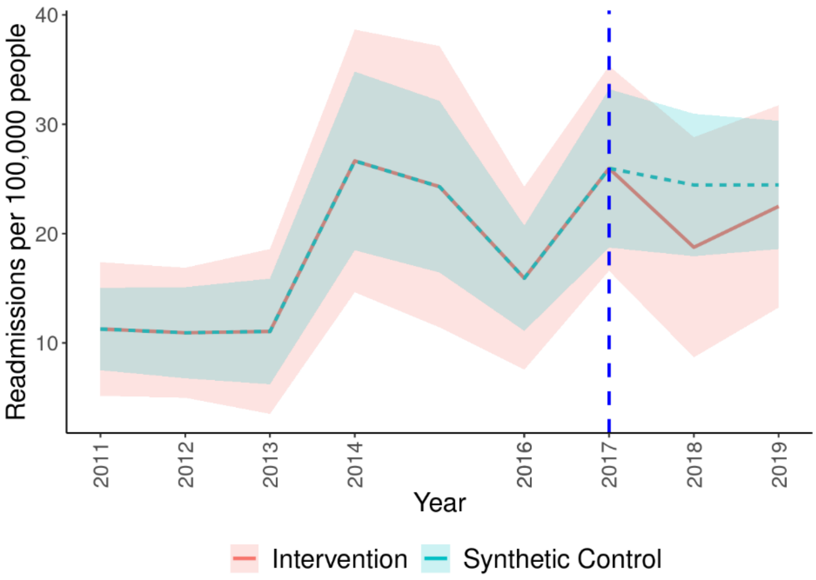

Figure S 4: The readmission scores across the study period for the intervention and synthetic control group. Pre-intervention the synthetic control group is matched to the intervention group.

Sensitivity Analysis– Matched Controls

Methodology

We provide an additional sensitivity analysis of all of the outcomes. The sensitivity analysis uses a matched control methodology where LSOAs were matched 3:1 control to treatment group and a difference in difference analysis was conducted. The control LSOAs were matched to the LSOAs groups using propensity score matching of characteristic variables; distance from the nearest A&E department, distance from the nearest GP, IMD 2015, population groupings in 2014, proportion of females in 2014, prevalence of depression 2014, proportion of population claiming for unemployment at points 2011, 2014, 2017 and the value of the outcome 2011, 2014, 2017. The matching on the previous values of the outcome is hence why we need a separate control group for each outcome.

We then perform a difference in difference analysis, using a longitudinal linear regression over the study period. Consisting of an LSOA level random intercept, a temporal spline, proportions of age ranges, proportion of females, proportion claiming for unemployment and the estimate for the effect size.

Matched controls are less complex, since they are a typical study design with a control group and an intervention group. However, they are also less robust. They don't have the same weighting flexibility that is in the synthetic control design, and therefore are less likely to meet the parallel trends assumption in the pre-intervention period. If this assumption is not met, results may be confounded by temporal variation between the two groups.

Sensitivity Analysis – Methods.

In this matched control analysis LSOAs are displayed as either Control, Intervention, or Unused. This is a categorisation rather than a weighting as per the main analysis.

The parallel trends assumption was generally not met by the control and treatment groups in the pre-intervention period, so results in the sensitivity analysis should be interpreted with caution.

Attendances

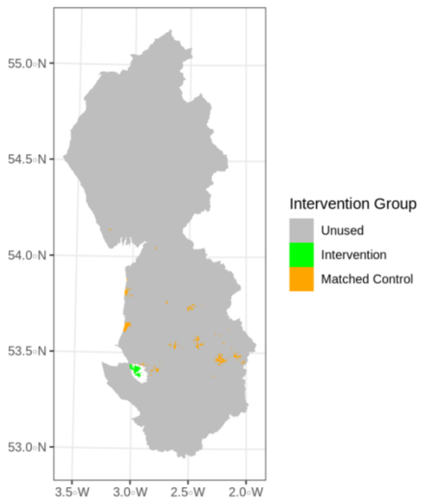

Figure S 5: Map of the North West showing the intervention area and the matched control LSOAs for the attendances outcome.

A map of the control group LSOAs can be found in Figure S 5.

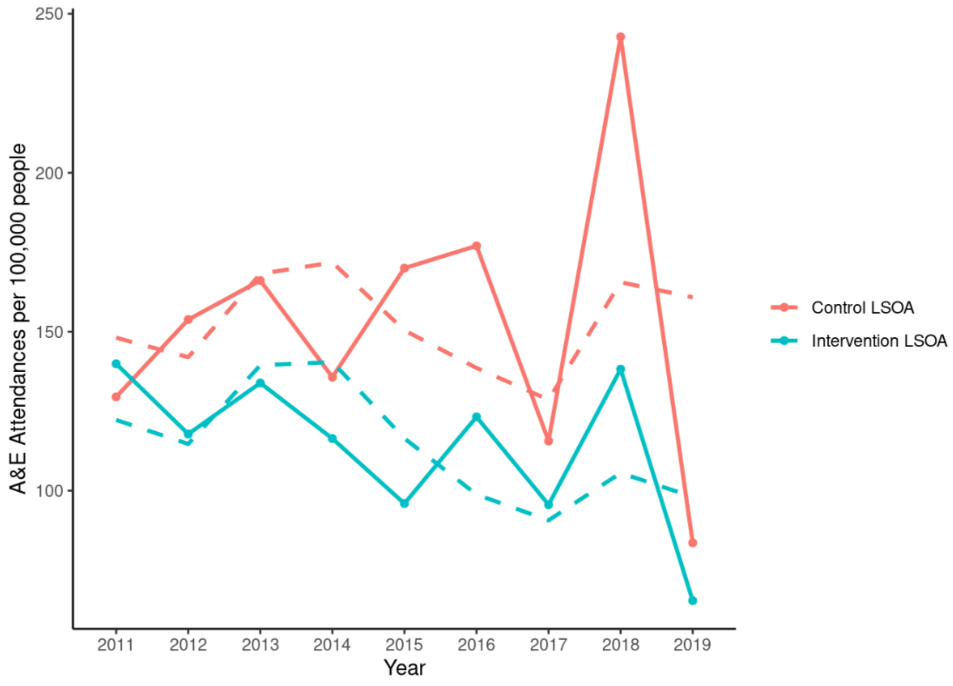

Figure S 6: Actual (solid) and fitted (dotted) numbers of self-harm related attendances per 100,000 in each LSOA in the control and intervention groups.

The number of attendances per 100,000 over the study period can be seen in Figure S 6. The actual values (solid lines) appear cross over one another in the pre-intervention period. This does not meet the parallel trends assumption, hence results for this outcome in this sensitivity analysis are likely not valid.

We see no significant divergence post-intervention between the two groups. We see an effect size of -19 attendances per 100,000 per year in the intervention group compared to the control group, which is not found to be significant in the linear model with a p-value of 0.36.

Admissions

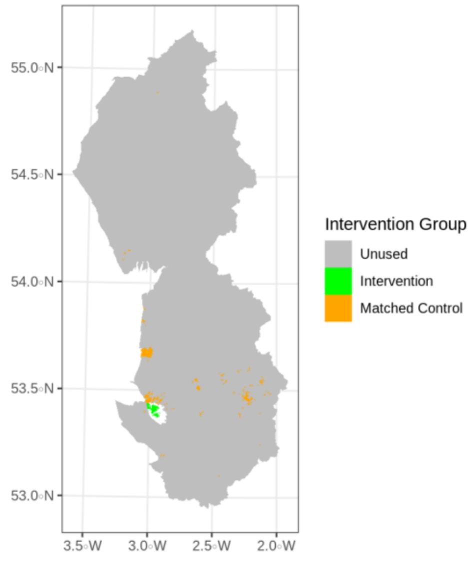

Figure S 7: Map of the North West showing the intervention area and the matched control LSOAs for the admissions outcome.

A map of the control group LSOAs can be found in Figure S 7.

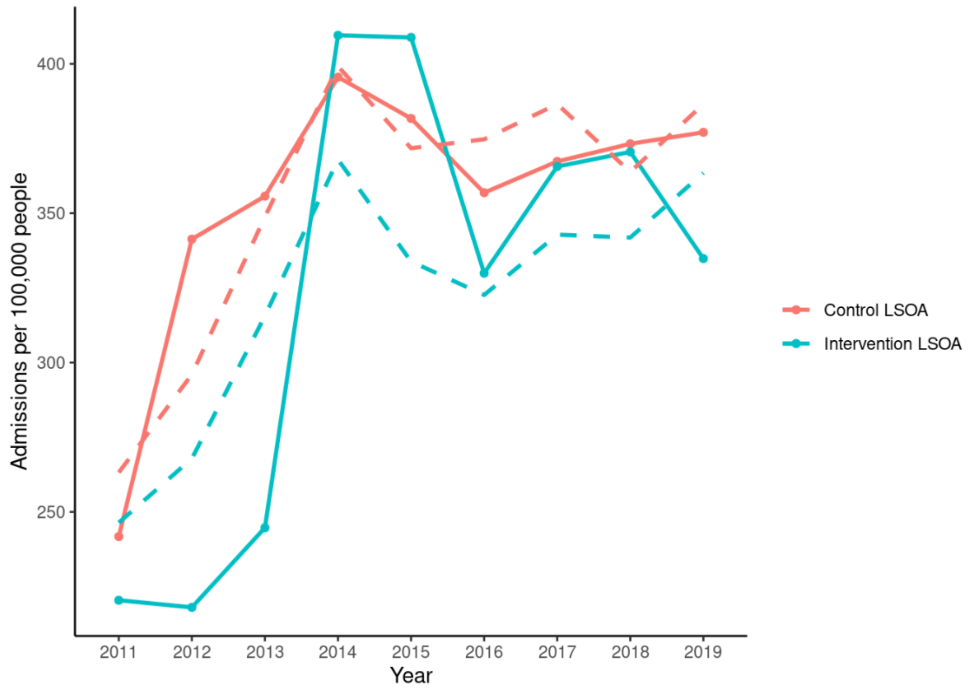

Figure S 8: Actual (solid) and fitted (dotted) numbers of self-harm related admissions per 100,000 in each LSOA in the control and intervention groups.

The number of admissions per 100,000 over the study period can be seen in Figure S 8. The actual values (solid lines) appear to be approximately parallel over this time, indicating this method is valid for this outcome.

We see no significant divergence post-intervention between the two groups. We see an effect size of 25 per 100,000 admissions per year in the intervention group compared to the control group, which is not found to be significant in the linear model with a p-value of 0.36.

Readmissions

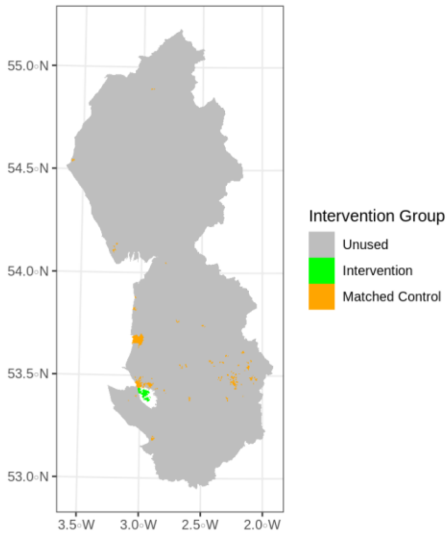

Figure S 9: Map of the North West showing the intervention area and the matched control LSOAs for the readmissions outcome.

A map of the control group LSOAs can be found in Figure S 9.

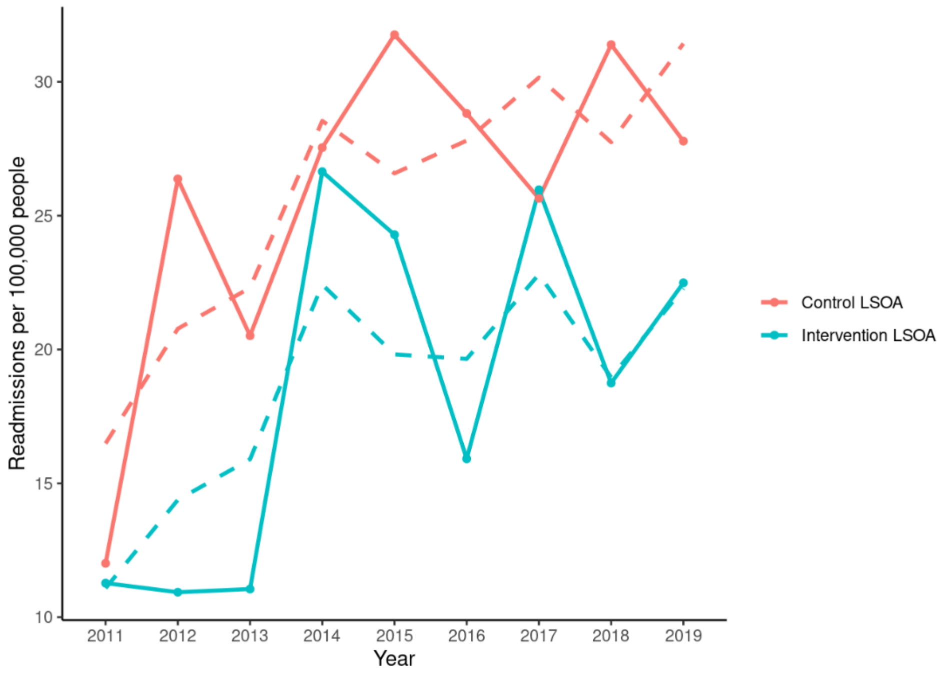

Figure S 10: Actual (solid) and fitted (dotted) numbers of self-harm related readmissions per 100,000 in each LSOA in the control and intervention groups.

The number of readmissions per 100,000 over the study period can be seen in Figure S 10. The actual values (solid lines) do not follow a similar pattern in the pre-intervention period. This does not meet the parallel trends assumption, hence results for this outcome in this sensitivity analysis are likely not valid.

We see no significant divergence post-intervention between the two groups. We see an effect size of -1 per 100,000 readmissions per year in the intervention group compared to the control group, which is not found to be significant in the linear model with a p-value of 0.83.

Appendix C

Estimating the number of children with palliative and end-of-life care needs who are currently receiving care in North West England

A commissioned report for the Integrated Care Boards of NHS Cheshire and Merseyside, NHS Greater Manchester and NHS Lancashire and South Cumbira.

This report is not available in the public version of this thesis.

Catherine Walshe[1], **Alex Garner**[2] and Maddy French[1]

[1] Division of Health Research, Lancaster University
[2]Lancaster Medical School, Lancaster University