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Briefing: assessing the impact of COVID-19 on the clinically extremely vulnerable population.

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Briefing: Assessing the impact of COVID-19 on the clinically extremely vulnerable population

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Key points

- In March 2020, the government took emergency action to slow the spread of COVID-19 in the UK and save lives. There was recognition early on that some people would be extremely vulnerable to the virus. This group was rapidly identified, advised of the risk posed to them by the virus, and provided with additional support to enable them to isolate at home. Ultimately, there were several periods lasting over 10 months in total when over 3 million people identified as clinically extremely vulnerable (CEV) were advised to stay at home, and were unable to take part in usual activities, such as shopping for food, exercise or seeing friends and family. This group was among the first to be offered a vaccine and will also be offered a booster vaccination. However, infection from the virus still poses a risk to their health, and many of these people have not yet fully resumed their usual way of life.
- In this briefing, we present analysis from the Networked Data Lab on the impact the pandemic has had on the clinically extremely vulnerable population. The Networked Data Lab is a partnership, led by the Health Foundation, of five analytical teams that are embedded in local health and care systems across the UK. This unique approach allows the Networked Data Lab to access complex linked datasets that remain on secure local systems, and are not nationally available, while benefiting from a full understanding of the local context.

The Health Foundation

- Over 2 million people were identified in March and April 2020 as being clinically extremely vulnerable and contacted and asked to stay at home. In an unprecedented use of NHS data systems, clinically extremely vulnerable people were identified using an algorithm that was applied centrally to electronic health records, alongside local clinical input. This was achieved over a very challenging timescale, using incomplete and inconsistent data and within an uncertain environment when scientific understanding of the impact of the virus was rapidly changing. As scientific understanding improved, the number of people identified as clinically extremely vulnerable increased and by February 2021 over 4 million people had been identified.
- Approximately one-third of people identified as clinically extremely vulnerable between March and August 2020 were of working age. The advice to shield had a significant impact on this age group and their ability to work. Almost two-thirds of people identified as clinically extremely vulnerable between March and August 2020 were aged 60 or older and around 1 in 20 (5.7%) were aged below 30. Just over half (52.2%) were female. People were most commonly classified as clinically extremely vulnerable because of respiratory conditions, rare diseases and cancer.
- There was substantial variation in the number of people added to the shielded patient list via central or local methods. In Wales, most people were added to the shielded patient list via the Welsh central methodology (87.9%), while in Leeds, people were most often added to the shielded patient list via local additions (61.3%).
- Between March and August 2020, a total of 50,635 people identified as clinically extremely vulnerable died in England from any cause. At the peak of the first wave of the pandemic (2 April 2020), the all-cause mortality rate among the clinically extremely vulnerable population was 1 in 2,500 (0.039%). Due to the way that the clinically extremely vulnerable population was defined, we cannot robustly compare this rate of mortality to the period before the pandemic. However, the peak age-matched mortality rate in the general population was comparatively lower at 1 in 7,000 (0.014%).
- The Networked Data Lab (NDL) partners used primary care records to examine the health care needs of their clinically extremely vulnerable populations, going beyond the clinical reason for shielding. We found that between 17% and 40% of the clinically extremely vulnerable population in NDL partner sites had a diagnosis of a common mental health disorder.
- NDL partners showed that the clinically extremely vulnerable population experienced worsening mental health during the pandemic. NDL Wales found that after adjusting for age, sex, deprivation and history of mental ill health, clinically extremely vulnerable individuals in Wales were at increased risk of diagnosed depression and/or anxiety compared with the general population during the pandemic. In Liverpool and Wirral, they found that compared with the general population, rates of antidepressant prescriptions were approximately 50% higher for the clinically extremely vulnerable cohort and that the increases in prescribing rates were also steeper.
- To create capacity to care for COVID-19 patients and to reduce the risk of infection in health care settings, NHS care was rapidly reorganised at the start of the pandemic. By April 2020, in comparison to April 2019, elective admissions for the clinically extremely vulnerable population had decreased by 51%, while outpatient appointments decreased by 48%. Although there was no intentional reorganisation of emergency care, emergency admissions for the clinically extremely vulnerable decreased by 32% from April 2019 to April 2020, while A&E attendances decreased by 42%.
- Our analysis across NDL partners shows that the most common reason for elective admissions between March and July 2019 for the clinically extremely vulnerable population was neoplasm (tumour) diagnoses. These admissions fell by 34.7% between March–July 2019 and March–July 2020. Over the same period, emergency admissions for people with neoplasm diagnoses, although much less common, increased by 42.5%. There was some geographic variation in these trends. For example, NDL partners in Grampian and Aberdeen found a significant protection of scheduled care: across outpatient appointments (where appointments fell by 35% for the clinically extremely vulnerable compared to 49% for the broader population) and elective admissions (which fell by 46% compared to 81% for the broader population).

- In absolute terms, NDL partners found that the clinically extremely vulnerable population experienced larger decreases in health care use compared with the general population. For example, in North West London the emergency admission rate (per 100 people per month) fell from 0.38 to 0.18 admissions in the general population and from 4.3 to 2.4 admissions within the clinically extremely vulnerable population. These reductions are concerning because clinically extremely vulnerable people have a high level of health need and people in this group may require additional support compared to the general population.
- There are limitations to an algorithm-driven approach to identifying the clinically extremely vulnerable population which were exacerbated by poor availability of high-quality data. Approaches taken to identifying people resulted in significant variation across local areas in terms of when people were identified and, as a result, what services and support they had access to. Experience from NDL partners showed that access to data from general practice and better data sharing aided the identification of clinically extremely vulnerable people. Further investment in data sharing and improving data quality is essential to ensure that those who might be most vulnerable can be readily and consistently identified. This is so they can be identified for any subsequent vaccination campaigns or provided with adequate support if they wish, or are again required, to limit their social contact.
- In conclusion, our analysis shows that the COVID-19 pandemic resulted in a substantial burden of severe infection and mortality among the clinically extremely vulnerable population. They were also profoundly impacted by major reorganisation of the NHS in the early part of the pandemic. Action is now needed by those planning the recovery at local and national level to address the unmet need for NHS care and worsening mental health. Alongside this immediate support, further work is needed to understand the longer-term consequences for the clinically extremely vulnerable population both in terms of long-term health care needs but also in terms of their ability to resume work and other daily activities.

Introduction

The pandemic has taken a profound toll on the nation's health. By September 2021, the total number of deaths related to COVID-19 had passed 116,800 in England, 8,100 in Scotland, 5,600 in Wales and 2,300 in Northern Ireland.[1] Most social distancing restrictions have been relaxed or ended across the UK and the shielding programme has formally ended.[2] Although the coronavirus is becoming endemic, the benefits of the vaccination campaign are being felt with fewer deaths and serious illness from COVID-19. Health and social care services now face the long-term challenges arising from the pandemic, including growing NHS waiting lists[3] and concerns around mental health among both staff[4] and the public.[5] There is still a need to plan for potential future waves of infection.[6]

Identifying the most vulnerable to COVID-19

Early in the pandemic, it was recognised that some clinical conditions place people at greater risk of being severely ill or dying from the virus. Therefore, efforts were made as early as March 2020 to identify people with these conditions, using a combination of an algorithm that was applied to electronic health records centrally and clinical input that was sourced locally (Box 1). This group of people was rapidly identified and asked to stay at home and avoid all contact with others to protect them from the virus.[7,8,9,10] They became known as the clinically extremely vulnerable (CEV) or shielding population.

Just over 850,000 people in England were identified using the central algorithm by mid-April 2020.[11] By the following month, the number had grown to over 2 million people as the method was developed and individuals were added through local adjustments.[11] As understanding of the virus and its impact grew, so did the number of people who were considered CEV.

A significant milestone came when researchers were able to build a population risk assessment tool (QCOVID), based on an improved understanding of the risk factors of COVID-19 and using primary care records from England linked to data on COVID-19 tests, hospital use, deaths, and contextual factors such as deprivation and ethnicity.[12] In February 2021, this tool was rolled out across England to identify more people at risk. By 20 March 2021, a total of 3.8 million people in England had been identified and advised to shield.[13,14,15,16] This was just under 6.8% of the population.[11]

Box 1: How the CEV population was identified in March 2020

In March 2020, patients were added to the shielded list through two methods:

1. **An algorithm which was applied to electronic health care records centrally** the four Chief Medical Officers across the UK developed criteria for defining the medical conditions associated with greatest risk of severe illness from COVID-19.[7] NHS Digital then translated this list of medical conditions into code lists that could be applied via an algorithm to health care records, with some modifications within the devolved nations.[12] At first, only secondary care, prescribing and maternity records were available.[17] Primary care records were not immediately available but incorporated into the process for producing the second iteration of the shielded patient list.
2. **Clinical input sourced locally** local health care organisations (including hospitals and GPs) could adjust the shielded patient list, and GPs were asked to assess individuals who had registered themselves as being CEV.[18]

People considered clinically extremely vulnerable, as per UK CMO criteria*

- Solid organ transplant recipients
- People with specific cancers
- People with severe respiratory conditions
- People with rare diseases and inborn errors of metabolism that significantly increase the risk of infections
- People on immunosuppression therapies that significantly increase risk of infection, and people who have had their spleens removed
- People who are pregnant with significant heart disease, congenital or acquired.

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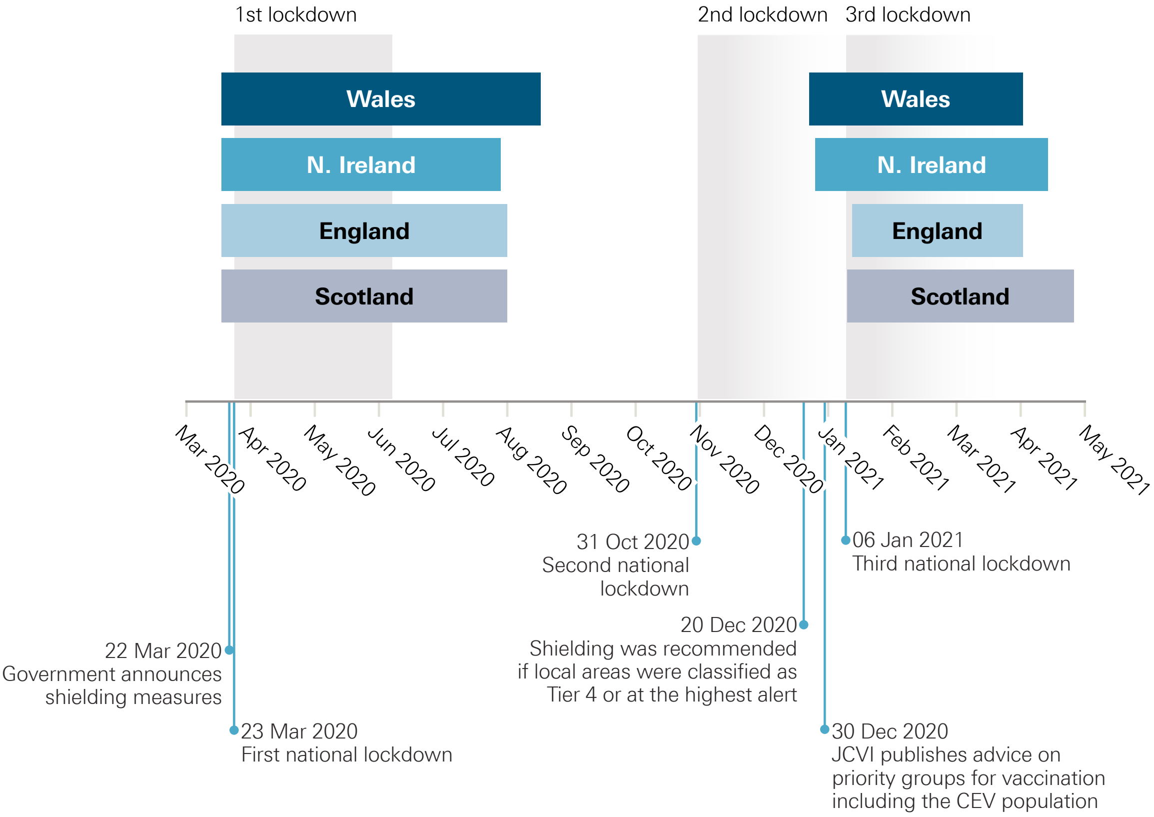
* These criteria have been updated over the pandemic – see Technical appendix for details of the version used in analyses across partners.

Implications of the shielding programme for the people concerned

The shielding guidance placed profound restrictions on peoples' lives. People identified as being CEV were asked to stay at home at all times, except when seeking medical care, and to avoid contact with anyone outside their household. Several measures were introduced to support people to stay at home as much as possible. They were advised not to go to work if they could not work from home and were eligible for Statutory Sick Pay or Employment and Support Allowance.[7,17] A website and telephone helpline were established to share information on the support available to CEV people, which included[7,17] food parcels that were delivered to homes, priority delivery slots for online grocery shopping, and a medicine delivery service. While many of these services were organised nationally, local authorities were responsible for providing basic care to CEV people who requested it and were also responsible for helping to tailor services and support to the needs of their local population. The action of the voluntary sector was also vital. Local groups formed to provide help and support within local communities.

Although shielding was implemented in March 2020, it has not been in place throughout the pandemic. Rather there have been two periods during which shielding was advised, as shown in Figure 1.

Figure 1: The timeline for the shielding programme



Motivation for this analysis

Despite the scale of the shielding programme and the high burden it placed on individuals, scant attention has been paid to the impact of the pandemic on the CEV group in terms of the management of their health needs, as well as the impact of shielding on their ability to work and participate in daily activities. A particular problem has been the poor availability of linked national data, which has hampered the ability of analysts to produce evidence about the impact the pandemic was having.[17]

In this briefing, we present analysis from the Networked Data Lab (NDL). Led by the Health Foundation, the NDL is a collaborative network of analytical teams from across the UK, which use local linked datasets to produce fresh insights regarding major challenges in health and care. The approach allows the lab to access complex datasets that would not otherwise be available, while understanding the local context. The NDL analytical partners are from Wales, Grampian, Leeds, Liverpool and Wirral, and North West London.

NDL analysis has already helped decision makers in the local health systems to mount their pandemic response. Our partners have had a key role to play throughout the pandemic, by identifying CEV people, working to understand their needs, and informing local decisions about how best to support them. In this briefing, we focus on drawing out some of the trends we have seen across multiple sites, with a view to ensuring that national health care leaders learn the lessons from the pandemic and understand how they can best support CEV people going forward. The more detailed local analysis produced by each of the partners is available online.[*]

In part 1, we explore who was identified as being CEV and quantify the impact of the pandemic on their health. We show that there was substantial mortality among this population, and that they experienced approximately three times the rate of emergency admissions related to COVID-19 as the general population. We show that a high proportion of this group had mental health conditions prior to the pandemic and in some cases mental health needs then increased.

In part 2, we describe the impact of the pandemic on health care pathways and how often CEV people have accessed services. We show that, like the rest of the population, the use of secondary care by CEV people was severely limited.

In part 3, we explore the consequences of using a new and evolving algorithm to determine who was deemed CEV to COVID-19. Using unique linked data, we show that inclusion and exclusion depended on the quality of the data available and clinician behaviour. These factors varied across areas and between types of illness, and have implications for the use of data-driven approaches in future.

Finally, we identify the implications of our analysis for policymakers and the priorities for the next phase of the pandemic.

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[*] Detailed analysis by each of the NDL partners can be found here: www.health.org.uk/funding-and-partnerships/the-networked-data-lab/local-analyses-on-covid19-clinically-extremely-vulnerable

Methods

Description of the Networked Data Lab

The Networked Data Lab is a collaborative network of analytical teams across the UK which is led by the Health Foundation and comprises the following partners:

- The Aberdeen Centre for Health Data Science (ACHDS) which includes NHS Grampian and the University of Aberdeen
- Public Health Wales, Digital Health and Care Wales (DHCW), Swansea University (SAIL Databank) and Social Care Wales (SCW)
- Imperial College Health Partners (ICHP), Institute of Global Health Innovation (IGHI), Imperial College London (ICL), and North West London CCGs
- Liverpool CCG and Healthy Wirral Partnership
- Leeds CCG and Leeds City Council.

The Networked Data Lab carries out data stewardship activities and creates open-source tools for the wider analytics community to use. The first national network of its kind, we work closely with patients and the public to refine our research priorities and interpret our findings, as well as to ensure that the data is used in a legitimate and transparent way. The Networked Data Lab provides local and national health system leaders with fresh insights that equip them to act to improve the UK's health and care systems, including addressing COVID-19 and widening health and care inequalities.

Analytical approach

The NDL uses a federated analytics approach. This means that the same analysis is performed locally on each dataset: patient data does not leave the secure local systems. There are multiple advantages to this approach. The NDL benefits from the understanding of the local context that analysts, clinicians and patients bring, while using rich linked data that is not available nationally. By synthesising findings across multiple partners, we can generate novel insights that can be used to aid decision making at a national scale.

A full description of the methods used in this briefing can be found in the accompanying technical appendix*. In brief, each partner used individual-level data from their local shielded patient list and linked this to demographic and secondary health care data. Where available, these data were supplemented with additional data from primary care and adult social care. A consensus data model was developed across the analytical partners, meaning that variables within datasets were defined in a consistent manner to ensure that results were comparable across partners. Each partner then conducted the same analyses within their own local secure data environment. The results and insights from the analyses were then shared across the network and synthesised. Partners also undertook independent analysis on specific topics. The NDL published statistical analysis plans prior to beginning our work and the code used for this analysis is available

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* The technical appendix can be viewed at https://doi.org/10.37829/HF-2021-NDL01

on GitHub.[19,20] The time period used in the analysis was 1 March to 31 August 2020, covering the first wave of the pandemic and the following summer. One caveat to the results is that the CEV population changed over time, and therefore we cannot extrapolate our findings to later waves of the pandemic.

Where it adds to our understanding of national trends, in this briefing we supplement NDL analysis with analysis of open datasets published by the Office for National Statistics and NHS Digital.[11,21,22]

Part 1: What was the impact of the pandemic on the health of people asked to shield?

The shielding programme was designed to protect the CEV population from the risk of death due to the virus – the direct effect of the pandemic. In this section, we show that despite the additional protection and support, people asked to shield suffered from very high rates of infection, hospital admission and mortality in the first wave of the pandemic.

Despite its known vulnerability, there has been sparse information from national health and care datasets describing the impact of the pandemic on this population's health, including common mental disorders like clinically diagnosed anxiety and depression. This is due to the lack of linkage between GP and mental health records at a national level. The rich linked data from the NDL allows us to examine these aspects in detail. We show that CEV people were more likely to be diagnosed with a mental health condition than the general population before the pandemic and in some cases this need increased.

Description of the CEV cohort

This briefing analyses data for people identified as CEV by our NDL partners between March and August 2020. Table 1 shows the demographic and clinical characteristics for this cohort. Most shielding people were aged over 60 and in all areas apart from Liverpool and Wirral, they were more likely to be female than male. Respiratory illness was the most common reason for shielding. There is substantial variation across regions in the proportion of the CEV population living in areas of high deprivation. In Liverpool and Wirral, 60% of the CEV population were living in the most deprived areas in England, but by contrast, in North West London only 18% were living in the most deprived areas of England. These differences reflect the characteristics of each area.

Table 1: Demographic and clinical characteristics of people identified as clinically extremely vulnerable across the five partners

	Grampian		Leeds		Liverpool and Wirral		North West London		Wales	
	N	%*	N	%*	N	%*	N	%*	N	%*
CEV cohort	16,025	100%	62,851	100%	69,293	100%	112,134	100%	128,690	100%
Age bands										
0–29	1,024	6%	5,767	9%	4,648	7%	7,160	6%	9,368	7%
30–59	4,999	31%	20,751	33%	19,854	29%	30,117	27%	38,534	30%
60+	10,002	62%	36,333	58%	44,673	64%	62,807	56%	80,788	63%
Unknown					118	0%	12,050	11%		

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* Percentages may not sum to 100% due to rounding

	Grampian		**Leeds**		**Liverpool and Wirral**		**North West London**		**Wales**	
	N	%[*]	N	%[*]	N	%[*]	N	%[*]	N	%[*]
Deprivation										
1 (Most deprived)	1,226	8%	23,042	37%	39,221	57%	16,985	15%	27,887	22%
2	3,066	19%	7,501	12%	9,809	14%	33,030	29%	27,303	21%
3	3,687	23%	9,796	16%	6,043	9%	26,873	24%	26,173	20%
4	4,353	27%	10,639	17%	7,196	10%	13,388	12%	23,633	18%
5 (Least deprived)	3,514	22%	8,324	13%	2,933	4%	6,452	6%	23,370	18%
Unknown	179	1%	3,549	6%	4,091	6%	15,406	14%	324	0%
Sex										
Male	7,428	46%	27,831	44%	33,339	48%	48,872	44%	59,954	47%
Female	8,597	54%	33,545	53%	31,899	46%	51,212	46%	68,736	53%
Other/unknown			1,475	2%	4,055	6%	12,050	11%		
Reason for shielding[†]										
Cancer	2,792	17%	5,051	8%	5,125[‡]	7%	6,575	6%	23,184	18%
Rare disease	1,221	8%	6,126	10%	7,782	11%	10,716	10%	13,647	11%
Respiratory	6,786	42%	10,218	16%	16,823	24%	12,085	11%	40,927	32%
Immunosuppressants	4,497	28%							30,550	24%
Unknown			41,941	67%	9,645	14%	84,155	75%	701	1%

The shielded list was updated periodically in response to new evidence about who was most vulnerable to the virus. We were not able to repeat analysis over time to identify how the cohort will have changed in each partner area and this is a limitation of our approach. However, the pattern in Table 1 is broadly consistent with national data from England at a

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[*] Percentages may not sum to 100% due to rounding.

[†] Many people will be shielding for multiple reasons and as a result may be counted twice across different groups. As a result, totals in this category do not sum to the total number of people in the cohort. Different areas had access to slightly different information and these groups are an aggregate of the most common conditions. In most areas, for patients added locally by GPs or hospitals there was no given reason for shielding.

[‡] In Liverpool and Wirral, the number of people asked to shield because of cancer is the sum of those with (a) haematological cancers and (b) undergoing chemo/radiotherapy. However, some patients may fall under both of those categories. Therefore, due to double-counting, this figure may be an over-estimate of the real number.

later point in time, suggesting some stability in the characteristics of the CEV population. Indeed, analysis of national data held by NHS Digital shows that, as of August 2021, approximately one-third of people on the shielded patient list in England were of working age. Almost two-thirds of people on the shielded patient list in England were aged 60 or older, while 5.7% were younger than age 30.[11] This age distribution reflects the fact that older people are more likely to have the conditions that are associated with particularly high risk of death from COVID-19. There are small differences across gender groups, with 52.3% of CEV people being female.[11]

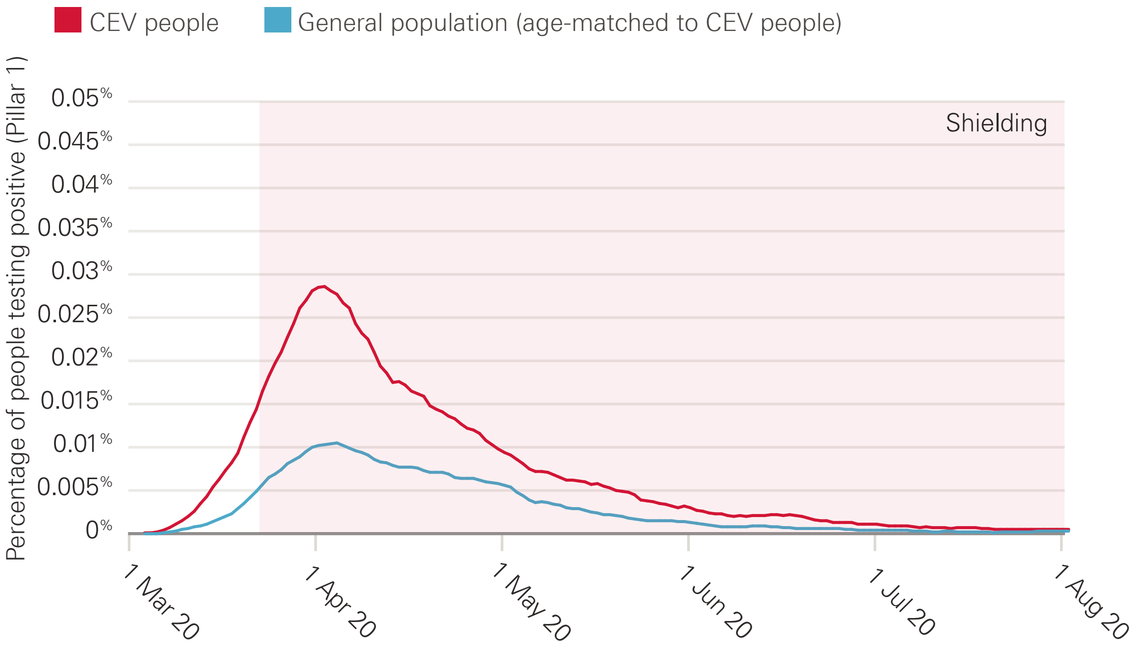
Cases during the first wave of the pandemic

NHS Digital published data on the number of positive COVID-19 tests for the shielding population in England. Focusing on those tests that were conducted in hospital, the peak number of daily positive COVID-19 tests occurred in early April 2020 and was 1 in 3,500 or 0.03% for CEV individuals and 1 in 9,500 or 0.01% for the general population. This pattern, with more positive tests per head among the CEV population than the general population, persisted throughout the first wave of the pandemic – see Figure 2.[23]

Unfortunately, these figures tell us little about rates of infection in the community, as testing was not widely available in the community during the first months of the pandemic.[24] As the CEV group were, by definition, more likely to suffer from severe disease than the general population, they were more likely require a hospital admission and to be tested for COVID-19 in the first place.

Figure 2: Positive COVID-19 test rates among the CEV population in the first wave

During the first wave of the pandemic the shielded patient group had a higher rate of reported positive COVID-19 tests than the general population



Hospital admissions during the first wave of the pandemic

Hospital admissions were also higher amongst the CEV group than the general population during the first wave of the pandemic. Data published by NHS Digital show that the rate of emergency hospital admissions related to COVID-19 was more than double in the CEV population than the general population.[23]

Using data from the NDL partners, we found that between March and July 2020, 3,920 CEV people had a hospital admission where COVID-19 was recorded, which is 3.9% of the total number of CEV people who were admitted during that period (ranging between 1.4% and 5.5% across partners[*]). It is important to note that this is likely an underestimate of the number of CEV people who had COVID-19-related hospital admissions. During the early stages of the pandemic, testing was heavily restricted due to the limited availability of tests, which means it is likely that many cases were undetected. In addition, while new ICD-10 codes for suspected or confirmed COVID-19 were rapidly defined, it will have taken time before these codes were used routinely to record COVID-19 admissions within electronic health records. Both factors mean that data quality is likely to be varied, making it challenging to identify all COVID-19 admissions effectively within electronic health records during the first few months of the pandemic.

Mortality rates

Using data from NHS Digital, we compared all-cause mortality rates for the CEV population with an age-matched sample from the general population. As seen in Figure 3, the daily mortality rate among the CEV population peaked on 2 April 2020, when 1 in 2,500 of all CEV people died, or 0.039%. The daily mortality rate was much lower for our age-matched sample from the general population, which peaked at 1 in 7,000 (0.014%).[23]

Further analysis of NHS Digital data shows that a total of 50,635 CEV people died in England between March and August 2020.[23] Data from the NDL shows that over the first national shielding period (from 23 March 2020 to 31 July 2020), 2.2% of the CEV population died within the NDL partner sites.

The higher mortality rates among the CEV population reflects the nature of their health conditions. They would have been at greater risk of death than the general population even without the pandemic. However, they also show the impact of their increased clinical vulnerability to COVID-19 and the practical difficulties of fully isolating from the general community to prevent infection from the virus.

There are some limitations to our analysis, which are due to how the CEV population was defined. As the patient list was constructed through a combination of clinician input and analysis of electronic health records, we cannot determine who was CEV in years preceding the pandemic. As a result, we cannot estimate the excess mortality among the CEV group compared with previous years, which would have been the ideal way to study the impact of the pandemic on deaths. Nevertheless, our analysis shows the impact that the first wave of the COVID-19 pandemic had on the CEV population.

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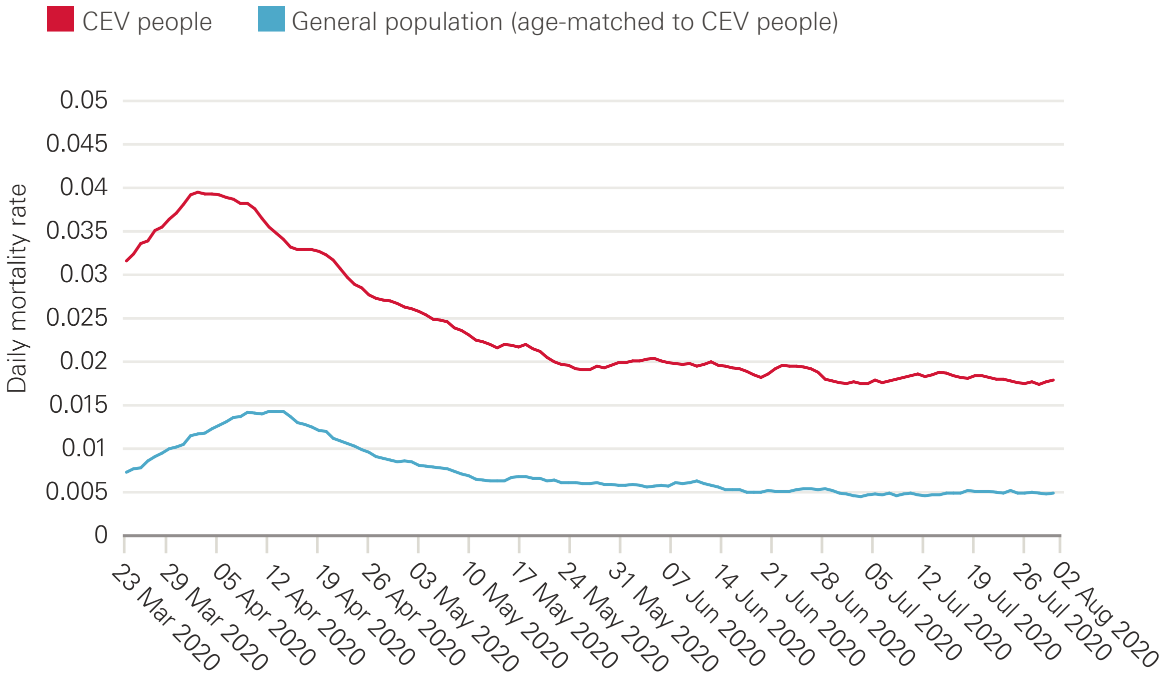
[*] If a patient was admitted more than once and in different months, they would be counted multiple times in these statistics.

Figure 3: Mortality rate for CEV people compared with general population

The mortality rate for CEV people was higher and peaked sooner than for an age-matched general population



The impact of the pandemic on the mental health and wellbeing of the CEV population

The impact of the pandemic on mental health and wellbeing has been a particular concern. The guidance to stay indoors may have led to increased loneliness and isolation. Clinical extremely vulnerable people may have had increased health anxiety due to their risk of infection and severe illness. Additionally, people shielding may not have been able to work, leading to increased stress due to reduced earnings. These and other factors may have affected the mental health of the CEV population.[25,26] Several of the medical conditions included within the CEV criteria are known to be associated with an increased likelihood of mental health conditions even in normal times.[27,28,29]

At a national level, the only published longitudinal data on the mental health of the shielding population have been the ONS shielding behavioural survey and the COVID High Risk Group Insights Study.[21,22] Both of these show that around a third of respondents reported worsening mental health and wellbeing during the first and second period of shielding.[30,31] However, other studies have suggested a protective effect from the guidance, and 41% of respondents to a survey in Scotland said that their mental health had worsened following the ending of shielding.[32]

While immensely valuable, these surveys do not allow us to examine the clinical presentation of mental health conditions, or to make comparisons against the general population.

Using data from the NDL partners, we examined the past and current prevalence of mental ill health among the CEV population. Across all the partners, a substantial proportion of the CEV population had an existing diagnosis of mental ill health in their primary care records before the pandemic. In North West London, 17.5% of the CEV population had anxiety, 21.8% had depression and 3.5% had serious mental illness recorded in their primary care records.[33] In Wales, around 40% of the CEV population had a diagnosis of depression or anxiety recorded in their primary care records. Women, people broadly of working age, and people with a previous history of mental ill health were more often affected.[34,35]

During the pandemic, people asked to shield had a greater chance of being newly diagnosed with a mental health condition or starting mental health treatment than the general population. NDL Wales found that after adjusting for age, sex, deprivation and past history of mental ill health, CEV individuals were at higher risk of diagnosed depression and/or anxiety during the pandemic than the general population (further details in Box 2).[34,35] The Liverpool and Wirral team found that rates of antidepressant prescriptions were approximately 50% higher for the CEV population than the general population (in line with findings from Wales), and that prescribing rates were increasing at a faster rate amongst the CEV from 2018 onwards.[*36] All this evidence together, it is clear that the CEV population were more likely to receive NHS care for mental health conditions than the general population both before and during the pandemic.

Box 2: Local analysis of mental health within the CEV population in Wales[†]

In Wales, 127,787 people (4.1% of the Welsh population) were identified as being CEV and advised to shield. Recent qualitative studies among shielding patients, or stakeholders from charities supporting people affected by shielding in Wales, have shown the impact on mental wellbeing for some.[34,35]

In NDL Wales, we wanted to examine mental health among the CEV population in more detail using linked primary care data (covering approximately 80% of all general practices in Wales) in the SAIL Databank trusted research environment.[37] We were able to identify almost 90% of the CEV population in primary care. Clinically recorded depression or anxiety (diagnosis, symptoms, prescription) were identified using READ codes. Past history and newly recorded depression or anxiety were examined.

We found that from March to September 2020:

- 1 in 50 of CEV individuals were clinically recorded with depression and/or anxiety during shielding.
- Of those 1 in 5 had no previous history of depression and/or anxiety.
- Women (2.8% vs 1.6% in men), people of middle age (15–55 (4.1%); 45–64 (2.7%)) and people living in urban areas (2.4% vs 2.0% in rural areas) were at increased risk of experiencing depression and/or anxiety during shielding.
- After adjusting for age, sex, deprivation and past history of mental ill health, CEV individuals were more likely to be diagnosed with depression and/or anxiety than the general population.

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[*] NDL Liverpool and Wirral focused specifically on patterns in monthly antidepressant prescribing rates across the local population, from January 2018. They observed consistently higher levels of antidepressant prescribing during the COVID-19 pandemic for the whole population. However, this increase reflects a longer term trend in increased prescribing of antidepressants from 2018 onwards, rather than any pattern that suggests a change in prescribing rates during the pandemic.

[†] NDL Wales includes Public Health Wales, Population Data Science Swansea University, SAIL Databank, Digital Health and Care Wales and Social Care Wales

What next?

This is one of the first explorations of routine population-scale electronic health record (EHR) data into the mental health of the CEV population in Wales during the first part of the pandemic. The findings suggest that the incidence of depression and anxiety for CEV individuals was higher than would be expected for the general population. However, this rapid study is likely to underestimate the incidence of depression and anxiety as it only captures presentation to primary care at a time when we know there were marked reductions in people accessing these services, and it does not take into account mental health diagnosis in other health settings. There will be many more in-depth studies to come, but this pragmatic initial insight does suggest that the self-reported impact on mental health in smaller qualitative studies is reflected in clinical presentation during the pandemic, and can help to inform targeted support to CEV individuals at increased risk of experiencing poor mental health outcomes.

It is worth noting that this analysis could still be an underestimate of the impact of shielding and the pandemic on mental health. For one reason, the impact of the pandemic may only emerge over the longer term, as highlighted by mental health experts.[38] Also, previous studies have suggested that 75% of people with mental disorders do not receive treatment.[39] As will become evident in the the second part of this briefing, the shielded population was particularly affected by changes in health care service delivery during the pandemic. Therefore, the full chronic and acute mental health needs of the CEV population may not yet have become evident to the NHS.

Vaccination of the CEV population

The CEV population was identified as a priority group for vaccination.[40] In England, they were part of the fourth priority group identified by the JCVI and invited to receive the vaccine along with people over 70 from 18 January 2021.[41,42] Similar approaches were taken across the devolved nations. Uptake of the vaccine within the CEV group has been very high. By 12 September 2021, 92.3% of CEV people had received both doses of the vaccine and 94.5% had received at least one dose (excluding CEV people identified using the QCOVID algorithm).[43]

While there were early fears that not all groups within the CEV group would develop strong antibody responses to the vaccine (meaning that they would remain CEV to COVID-19) more recent evidence is mixed, suggesting that it varies depending on an individual's underlying condition.[44,45,46,47,48,49] However, vaccination reduces rather than eliminates the risk of severe infection in this group, and there has been evidence of breakthrough severe infections, particularly from new variants such as delta.[47] The immune response is also likely to wane over time, particularly for those who are immunocompromised. The CEV group, alongside those over the age of 50 and health and social care workers, is being offered a booster vaccine to reduce mortality, morbidity and hospitalisations from COVID-19 over the 2021–22 winter period.[50,51] This is particularly important in the context of high levels of community transmission. The most recent data from the ONS COVID High Risk Group Insights study suggests that while many of the CEV group are still continuing to take precautions to reduce the risk of transmission, 90% of those asked to shield had left their home in the previous 7 days for activities including work, going to the shops or pharmacy, exercise and to socialise.[22]

2. Did changes to NHS care pathways result in a backlog of unmet need among the CEV population?

Patterns of health care service use changed markedly across the whole population during the pandemic, with the postponement of all non-urgent elective operations in the initial phases and changes in treatment-seeking behaviour from the public.[52,53] In turn, this led to substantial levels of unmet need and pent-up demand for NHS care, translating into historically long waits for NHS treatment.

Until now, there has been scant information about how patterns of health care use changed amongst the CEV population during the pandemic. In this section, we present new analysis from the NDL to fill this gap. We show that health care was severely disrupted for this cohort. For some specialties, hospital admissions and outpatient appointments were somewhat protected compared with the general population, with a smaller proportional decrease seen for the CEV than for the general population. However, the absolute reduction in activity was much greater amongst the CEV population.

The impact of the pandemic on the health care use of the CEV population

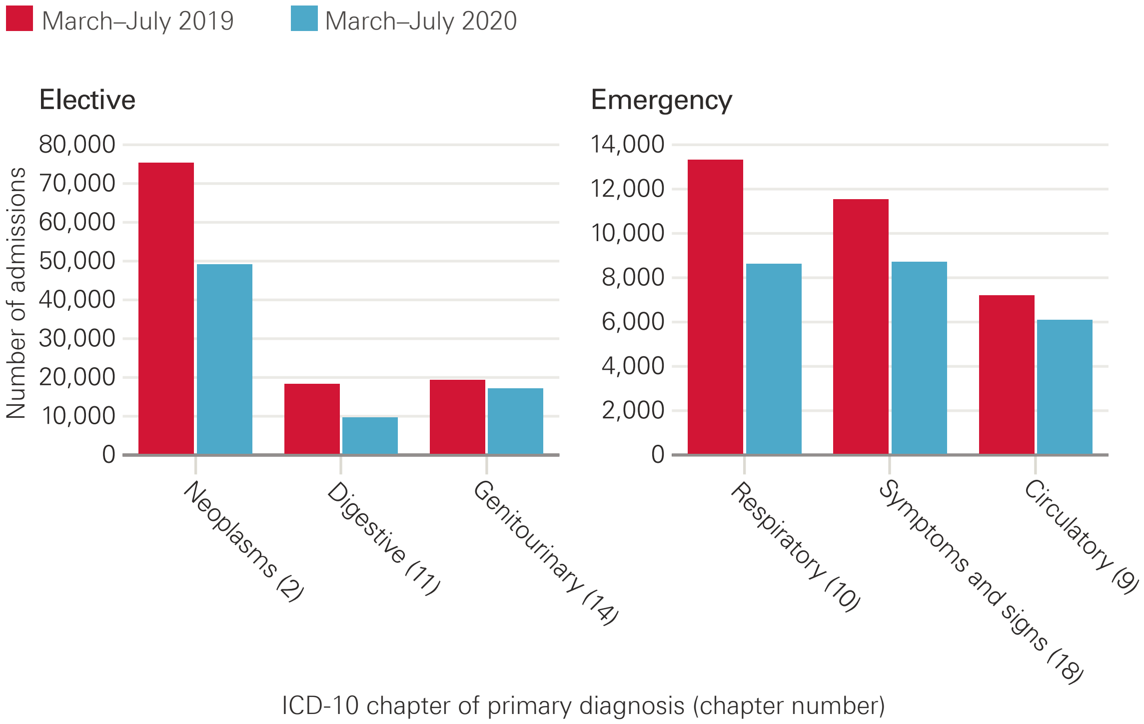
Among the CEV population, rates of hospital use were rising in the two years prior to the pandemic,[54] but dropped rapidly in April 2020.[54]

Across the NDL partners, elective admissions for the CEV population were 51% lower in April 2020 compared with April 2019, while outpatient appointments were 48% lower (a decrease of 16,270 and 72,618 admissions and appointments respectively).

Emergency admissions for the CEV population were 32% lower in April 2020 than April 2019, while A&E attendances were 42% lower (a decrease of 4,302 and 9,200 admissions and attendances respectively). These reductions happened even though there was no intentional national reorganisation of emergency care during the pandemic.

Figure 4: Trends in hospital admissions for the CEV population varied by diagnosis

Patterns of admission for the CEV population across five NDL partners, March-July 2019 vs 2020



Our analysis shows that across the NDL partners for the period from March to July 2019, the most common reason for elective admission among the CEV was neoplasms (tumours) (ICD-10 chapter 2), as shown in Figure 4. Notwithstanding the general pattern of rising hospital use among the CEV prior to the pandemic, the number of elective admissions with neoplasm as a primary diagnosis fell by 34.7% between March–July 2019 and March–July 2020, from 75,380 to 49,218 admissions. Over the same period, emergency admissions for CEV people with neoplasm diagnoses, although much less common, increased by 42.5%, from 2,517 to 3,586 admissions. These patterns are worrying as they suggest a shift from planned to unplanned cancer treatment, which is associated with worse outcomes for patients.[55] We did not see increases in emergency admissions associated with other diagnoses besides neoplasm.

For emergency admissions occurring between March and July 2019 for CEV people, the most recorded diagnostic category was diseases of the respiratory system (ICD-10 chapter 10; 13,337 admissions), as shown in Figure 4. The number of emergency admissions associated with these diagnoses fell by 35.3% between March and July 2020 to 8,632 admissions. Admissions with a primary diagnosis of suspected or confirmed COVID-19 are not included within this category.

To better understand the extent to which the CEV population was protected from changes in access to care, NDL North West London used their linked datasets to plot trends in secondary care use in the CEV (112,134 people) and non-CEV (over 2.5 million people) local populations – see Figure 5. The rate of hospital admission among the CEV population was more than 10 times greater than in the general population, as would be expected for a group with complex health care needs.*

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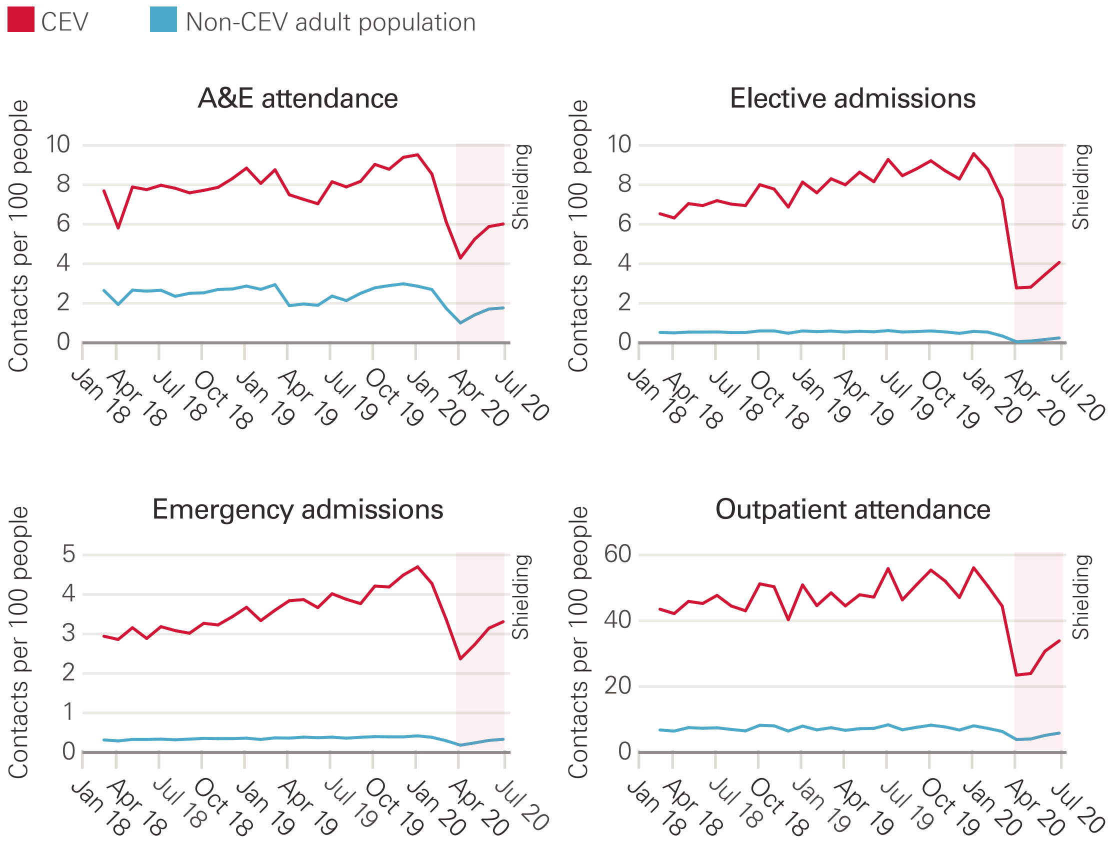
* The CEV population is older, with 36.9% over the age of 70 compared with 6.2% of the general population.

The same analysis found that, between February and April 2020, the monthly rate of emergency admission fell by 52.1% among the general population and by 44.6% among the CEV population. While the percentage fall was smaller for the CEV population, there were substantial baseline differences between these two groups. In absolute terms, the CEV population experienced larger decreases in health care use than the general population. The emergency admission rate (number of admissions per 100 people per month) fell from 0.38 to 0.18 among the general population (a reduction of 0.2) and from 4.3 to 2.4 among the CEV population (a reduction of 1.9), as shown in Figure 5. Similar trends were seen across elective admissions and A&E attendances.

Outpatient attendances show a different pattern, with a larger percentage fall for the CEV population in North West London than the general population. The rate of outpatient attendances fell by 53.5% for the CEV population (from 50.5 to 23.5 attendances per 100 people per month) compared with a smaller reduction of 46.2% for the general population (a drop from 7.3 to 3.9 attendances per 100 people per month). These reductions in routine care are very significant for both the general population and the CEV population. However, unlike other health care services, the CEV population was less protected from changes to outpatient care.

Figure 5: CEV health care service use in North West London

In North West London, CEV people had higher rates of service use and this dropped sharply during the pandemic



NDL Grampian also did in-depth statistical work to characterise the patterns within their local health system. They found that, proportionately, access to planned secondary care reduced to a lesser extent among the CEV population than the broader Grampian population during the pandemic.[56] However, unlike in North West London, outpatient appointments fell by a smaller proportion for the CEV population than the general population (35% compared with 49%). For elective admissions, the difference was very marked, with a 46% fall for the CEV compared with 81% for the general Grampian population. They also found that reductions in planned care were smaller for people who were shielding due to cancer and for younger shielding people than for the CEV population as a whole.

Support for the CEV population beyond the health care system

As a group with complex needs, the CEV population relied on support not only from the health care system, but also from local authority and voluntary sector services. NDL Leeds examined the support provided by Leeds City Council Adult Social Care services,[57] and found that 7.7% (4,084) of their CEV population received adult social care support in the two years prior to the pandemic. Moreover, an analysis of primary care data showed that 23.1% of the CEV population in Leeds (12,285) had moderate or severe frailty, underscoring the complex needs of this group. Adult social care support was more common among older CEV people, and for people living in more deprived areas.

Given the heavy impact of the pandemic on the social care system,[58] including on people receiving care in their own homes,[59] it is critical to understanding how shielding affected people who use social care services. This is only feasible with access to linked datasets that span organisational boundaries.

3. What were the consequences of using an algorithmic approach to identifying the CEV population?

Throughout the pandemic, our NDL partners played a key role within their local systems, helping to identify CEV people and understand their needs. The experience shows how important it is that analysts can access data from general practice and across the health and care system.

In this section, we describe in more detail how a centralised algorithmic approach was used at scale to identify CEV people and how it was supplemented by local clinical judgement. We also show that this approach resulted in significant variation across the country in terms of who was identified as CEV, which raises questions about whether everyone had access to the support they required throughout the pandemic.

How did the number of individuals identified as clinically extremely vulnerable vary across local areas?

As described in the introduction, during the first national shielding period, the CEV population was identified using a centralised algorithmic sweep of electronic health care records combined with local clinically led methods.

In their report on supporting vulnerable people during lockdown, the House of Commons Public Accounts Committee discussed variation in the use of local additions to the shielded patient list, highlighting the possible issues that it might pose in terms of equity of access to support.[17] However, until now, there have been no publicly available data on geographical differences in the numbers of people who were added to the shielded patient list through central and local additions.

The NDL has been able to use partner data from the first national shielding period to show there was substantial variation in the number of people added to the shielded patient list via central or local methods across the UK.[60] In Wales, the majority of CEV people were added to the shielded patient list via the Welsh central methodology (87.9%), while in Leeds, CEV people were most often added to the shielded patient list via local additions (61.3%). Across all the sites, local analytics teams played a vital role in identifying people who may otherwise have been missed by the national methods. The approach taken in Grampian to identify people is described in Box 3.

The significant variation in local additions demonstrates the challenge of relying exclusively on algorithms, particularly when the data available is incomplete or inaccurate. It highlights the need for further investment in data quality, and data sharing to improve the accuracy of health datasets. Whilst further investment in high quality linked data is essential, without the centralised approach adopted to identifying people, there may have been larger differences in how and when people were identified as CEV across local areas.

Box 3: The role of local analysis in identifying CEV people in Grampian

How were the clinically extremely vulnerable identified?

The process of identifying people who were CEV to a novel disease was not easy – it required rapid clinical consultation, the creation of algorithms to search electronic health care records and linking databases from diverse NHS services. After the Scottish government released the first version of the shielding register, clinicians and data analysts at every local NHS board worked intensely to be sure the most vulnerable people had been correctly identified – adding those who had been missed and removing those who did not need to shield.

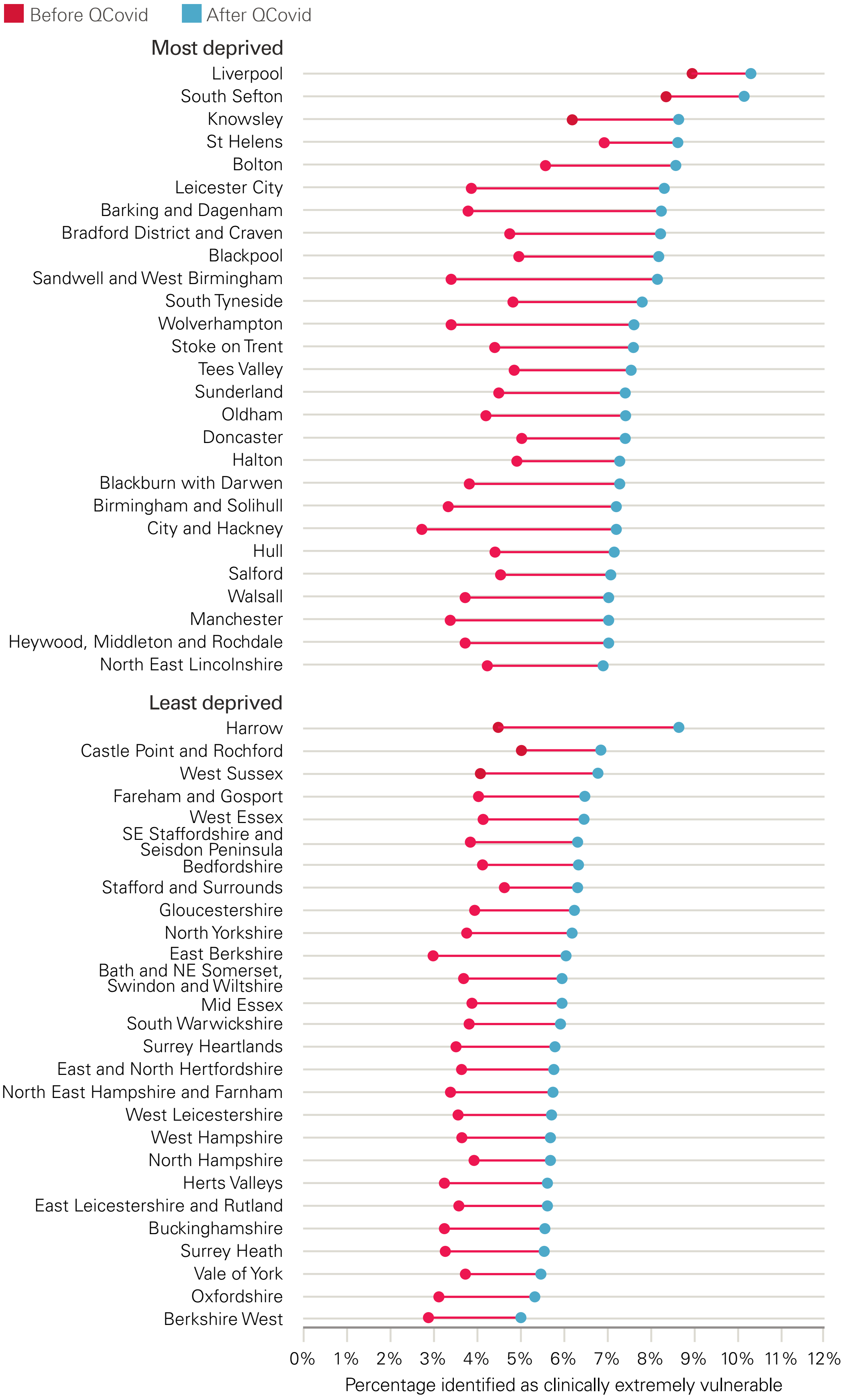
In Grampian, the NDL team was particularly interested in the differences between people who were identified in the initial health record search versus people who were missed and added locally later. NHS Grampian local experts added thousands of people to the shielding register, comprising 42% of the total shielding population there. Clinically, the national record search successfully identified more transplant patients and people with respiratory disease (97% and 85% respectively), but fewer cancer and immunosuppressed patients (25% and 43% respectively). Demographically, the national record search identified less than half of the children deemed vulnerable in Grampian (46%) but did better identifying people living in deprived areas (identifying 66% of the most deprived vs 50% of the least).

Improving identification and care for the clinically extremely vulnerable population

Rapid and reliable identification of the vulnerable will continue to be vitally important and the NDL team in Grampian outlines two ways this could be improved. First, sharing primary care records. In Scotland, primary care records are not shared nationally, limiting who could be identified quickly as being CEV and supported. Second, improving demographic data collection, including ethnicity. COVID hospital admissions and deaths have made it very clear that sociodemographic characteristics affect vulnerability to COVID-19 infection. But in Scotland, these data are not well recorded and were not used to identify those who should shield. Collecting these data during primary care visits and sharing them nationally would be a powerful way to improve care of the most vulnerable.

The initial approach to identifying the CEV population was adapted as evidence emerged during the first year of the pandemic that individuals from certain ethnic backgrounds or living in deprived areas were more at risk of COVID-19 infection. In response, using information on age, sex, body mass index, ethnicity and other factors to model an individual's combined risk of COVID-19, the QCOVID tool was developed and implemented in England in February 2021.[12] The impact of this new algorithm varied greatly: by March 2021 the percentage of the shielded patient list identified via the QCOVID algorithm ranged from 13.4% to 68.4% across English CCGs (Figure 6).[13]

Figure 6: Impact of QCOVID tool on CEV identification in most vs least deprived CCGs in England



As the QCOVID algorithm was intended to capture contextual risk factors including deprivation, a greater impact on areas of higher deprivation was to be expected. However, the substantial differences between areas in the percentage of the population already identified as CEV (as described above), which is likely to be dependent on availability of suitable data, will also have determined the additional local impact of QCOVID. The available data indicate that, across the most deprived 20% of areas in England, the implementation of QCOVID led to increases in the average percentage of people shielding from 4.5% to 7.8%. For the least deprived 20% of places in England, the average percentage of people identified as CEV rose from 3.7% to 6.0%.

This variation in how people were identified as CEV, particularly within the more deprived areas of England, had consequences not only for who was advised to follow shielding guidance, but also when they received this information and what support they had access to. QCOVID was implemented 11 months after shielding guidance was first issued. With the data available we were unable to quantify the impact of this delay in identifying so many at high risk of infection.

Implications of the analysis

Despite rapid action to identify and support the clinically extremely vulnerable population, the COVID-19 pandemic resulted in extremely high rates of infection, hospital admission and death in this group. The development of shielding guidance and the rapid identification of those who were at greatest risk of severe illness from COVID-19 infection were an urgent response to rising COVID-19 cases across the UK. Despite this intervention, the CEV population experienced an all-cause mortality rate comparatively higher than the all-cause mortality rate of an age-matched sample of the general population. This reflects their ill health and clinical vulnerability to the virus. However, it also reflects the impracticality of isolating from the wider community and the extent of COVID-19 transmission in the UK.

The pandemic led to deteriorations in the mental health of the CEV population, and additional support is now needed to prevent any long-term impacts on their health and wellbeing. People asked to shield were more likely to suffer from mental health conditions than the general population and more likely to seek help from the NHS during the pandemic. Some people in this group will continue to require additional support for mental health conditions, as well as their other health conditions including the reason for shielding, as we emerge from lockdown.

The CEV population was particularly affected by changes to NHS services during the pandemic and there is a strong argument for now prioritising its care to prevent poor outcomes. In absolute terms, the CEV population was more profoundly impacted than the rest of the population by the widescale disruption to NHS care that occurred during the pandemic. The emergency admission rate fell from 0.38 to 0.18 admissions per person per month in the general population. In comparison, it fell from 4.3 to 2.4 admissions for the CEV population. Outpatient appointments fell by 48% for the CEV population. The reductions were particularly large for people with certain conditions, and elective admissions related to tumour diagnoses fell by 34.7%. Worryingly, over the same period, emergency admissions for people with these diagnoses increased by 42.5%. These changes point to significant unmet health needs and potential long-term health impacts concentrated within the CEV population. Furthermore, this is a group of individuals with a range of clinically complex conditions who are likely to have had emerging additional care needs during this period.

There are limitations to the use of an algorithm-driven approach to identifying the CEV population which were exacerbated by poor availability of high-quality data. Not all CEV individuals were identified through the centrally developed algorithm due to lack of linked data or incomplete medical records, and many people would have been missed had they not been added to the shielded patient list by local clinicians. These approaches taken to identifying people resulted in significant variation across local areas in terms of when people were identified and, as a result, what services and support they had access to. Further investment in data sharing and improving data quality is essential to ensure that in the event of a future health emergency, it is possible to identify individuals quickly, accurately and consistently, and to enable rapid planning and delivery of relevant support.

Conclusion

By April 2021, the shielding programme had identified more than 4 million people across the UK who were at highest risk of severe illness from COVID-19. The impacts of the pandemic and the shielding guidance for this population have been felt in the risks not only to people's health, but also to their wellbeing as a result of having to limit their interactions for significant periods over 2020–21. Further work is needed to understand the impact of the pandemic on the implications for resuming employment and other daily activities.

By using the linked datasets that our NDL partners have invested in and developed over time, it has been possible to demonstrate some of the valuable and actionable insights that can be gathered when a more complete picture of the local population is available. Local health and care systems in the NDL partner sites relied on such analysis to guide their response to the pandemic. Our examination of linked health care data demonstrates the variation in clinical needs, the increased burden of mental health, and the impact of reduced access to care during the peaks of the pandemic, as well as the wider social context and need for support and resources across the CEV population. However, the data we have drawn together here do not allow us to disentangle the specific impacts of shielding policy from the wider impacts of the pandemic on the CEV population.

Our briefing shows the scale of the challenge of ensuring that the most clinically vulnerable to COVID-19 are kept safe, and in providing high-quality health and social care during the pandemic. It also indicates that there are substantial unmet needs that should be prioritised to ensure that the mental and physical health of this group does not deteriorate further. As the UK moves into the next phase of the response to the pandemic, it is critical that the issues highlighted here are urgently addressed to prevent further harm.

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Contributions page

This briefing has been written by the Networked Data Lab. This is a Health Foundation-funded collaboration of advanced analytical teams across the UK working together on shared challenges and promoting the use of analytics in improving health and social care. The other contributing authors from each of the partner organisations are listed below.

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