Caring for older patients with complex needs

How does England compare with 11 OECD countries?

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Key points

• How the NHS performs compared to health care systems in other countries is the subject of ongoing public debate. But international comparisons can be methodologically limited and often raise more questions than answers.

• Launched in 2018, the International Collaborative on Costs, Outcomes and Needs in Care (ICCONIC) aims to advance international comparisons research by using patient-level data. This enables comparison across whole pathways of care – essential in order to identify areas for improvement for the most complex patients.

• The first publications from the collaborative, which appear in a special issue of Health Services Research, focus on two groups of high-need patients. First, patients aged 65 and older admitted to hospital for hip fracture surgery. Second, patients aged 65–90 hospitalised with heart failure and with a comorbidity of diabetes. These groups were chosen to represent older people living with frailty and living with complex multiple conditions, respectively, and have been identified as high priority by the NHS.

• ICCONIC includes research partners from 11 OECD countries. These have used electronic medical records securely to conduct comparable analysis examining how health care use, spending and outcomes differ between countries. The Health Foundation provided the analysis for England based on data from 2014/15 to 2017/18.

• In this long read we set out to examine the results for England, reflect on whether these are part of a wider trend, and consider the implications for clinicians and policymakers in the context of the COVID-19 recovery.

• Based on pre-pandemic data, the analysis is further evidence that the NHS in England remains a relatively low-cost health care system. For both patient groups, England had among the lowest spending across both primary and acute health care settings.

• The findings support previously stated concerns that the mortality rate in England among older patients with high needs is higher than average among comparable countries. For both patient groups, England had the highest mortality at 30, 90 and 365 days.

• England is performing relatively well in acute care according to the measures available (time to surgery and readmission rates), which suggests further scrutiny and investment may be needed to improve the availability and quality of post-acute care. Unfortunately, our ability to look at the details of post-acute care in England is hampered by data availability.

• The results also highlight potential opportunities to improve productivity – and free up additional capacity for tackling the backlog from the pandemic – by reducing length of stay in acute care for hip fractures. Hip fracture patients in England spend on average 21.7 days in hospital after their surgery, the highest of all 11 countries.

• Analysis was adjusted for the age and sex of patients. It was not possible to adjust statistically for differences in comorbidities between countries, but we compared the number of
comorbidities. England was towards the middle, so while case-mix adjustment may have reduced some of the differences we saw, it is unlikely to have eliminated them.

- With integrated care systems (ICSs) to be established as statutory bodies from April 2022, there is a clear opportunity to make a step change in terms of linking up patient data and using the insights generated to reduce delays in discharge and improve quality of care and patient experience.
Introduction

What can international comparisons tell us about the NHS?

From the inception of the NHS, its performance relative to health care systems in other countries has been the subject of public debate. Such comparisons have often shown the NHS performs neither as well as its supporters sometimes claim, nor as poorly as its critics often allege.

In the Commonwealth Fund’s ranking of health care system performance across 11 OECD countries, performance varies considerably across the different domains of the assessment. While the NHS performs well on measures of access, equity and administrative efficiency, health outcomes remain an area of relative weakness – with the UK ranked only 9 out of 11. A 2018 review of the NHS’s performance by the Health Foundation, Institute for Fiscal Studies, The King’s Fund and the Nuffield Trust found that although the gap is closing, the mortality rate in the UK among people treated for some of the biggest causes of death, including cancer and cardiovascular disease, is higher than average among comparable countries.

Although the UK spends around 10% of GDP on health – about 1 percentage point higher than the OECD average – spending on long-term care is below the OECD average. Informal carers shoulder a heavy burden, with nearly one in five (18%) of people aged 50 and older caring for a relative, the fourth highest among the 18 OECD countries with comparable data.

While important methodological progress has been made with international comparisons of quality of care and health care system performance, these comparisons often raise more questions than they answer. For example, if one country outperforms another, does that reflect differences in how health services are organised, differing levels of investment within health care systems or the impact of wider social and economic factors?

When done well, international comparisons have the potential to provide policymakers with information on how different care strategies might influence care quality and cost. Such comparisons offer the potential for mutual learning and sharing policy knowledge between countries. An example from the early 2000s is the macro-level comparison of the NHS with California’s Kaiser Permanente health system, which found that Kaiser achieved better performance at roughly the same cost as the NHS. The findings of this study were a wake-up call for the UK and have been cited as responsible for significant NHS policy changes, such as greater investments in predictive risk models and a renewed focus on integrated care.

The COVID-19 pandemic has reignited interest in international scientific endeavour and led to a massive increase in global collaboration around the use of patient-level medical record data to support rapid knowledge pipelines. An essential enabler of this work has been the development of common data models – frameworks that allow the data from across the world to be standardised in
Improving health care for patients with high needs

A key challenge facing many health care systems is how to best design services to provide care to high-need patients. This clinically diverse group of patients includes individuals with extreme functional limitations and those with multiple complex chronic illnesses. Although these patients constitute a relatively small proportion of the population, they often account for a large and growing proportion of medical expenditure across systems and are most likely to experience poor-quality care. For example, in the US it is estimated that 5% of the population accounts for over 50% of the country’s annual health care spending. Costs are similarly concentrated across other countries, such as England, Germany, the Netherlands, Spain, Switzerland, and Canada.

Despite this, there are limited data on the diverse ways in which high-need patients are managed across health care systems. Traditional comparative metrics, such as those produced by the OECD and the Commonwealth Fund and used by studies like the Kaiser Permanente comparison, are based on aggregate national data that relate to the care delivered in certain settings, for example hospitals. They do not use patient-level data that follow an individual patient through the health care system.

About the ICCONIC research

Launched in 2018, ICCONIC aims to advance international comparisons research by using patient-level data to develop metrics that allow health care systems to be compared in terms of the care delivered across the entire patient care pathway. This development is especially important for patients with complex needs, who often require services that cross many settings.

ICCONIC includes research partners from 11 OECD countries: Australia, Canada, France, England, Germany, the Netherlands, New Zealand, Spain, Sweden, Switzerland, and the United States. It is led by researchers at Harvard University and LSE, and co-funded by the Commonwealth Fund and the Health Foundation. Additionally, the Health Foundation has produced the analysis for England.

The ICCONIC partners have focused on two types of patients that represent priority groups of people with substantial and complex care needs and could be studied using data from patient-level electronic health records (EHR):

- Patients aged 65 or older who sustain a hip fracture and are admitted to hospital for surgery. This group was selected to represent a high-need population of older adults living with frailty.
• Patients between the ages of 65 and 90, hospitalised with heart failure and with a comorbidity of diabetes. This group was selected to represent a high-need population of older people who have multiple long-term health conditions.

These two groups represent priority areas for the NHS. Hip fracture is the most common reason for older people needing emergency anaesthesia and surgery, and leads to prolonged dependence for many of those who survive. The number of people living with multiple health conditions is growing. These now account for over half of NHS costs for hospital admissions and three-quarters of primary care prescriptions, a fact that is a major motivation for establishing integrated care systems (ICSs) as statutory bodies via the Health and Care Bill.

The ICCONIC findings shed light on the different ways in which health systems in countries care for older patients with complex needs. In this long read we set out to examine some of the more striking results for England, reflect on whether these can be seen as part of a wider trend and consider the implications for clinicians and policymakers in the context of the COVID-19 recovery.

Overall approach

ICCONIC has developed a novel framework and methodology for comparing health care use, spending and health outcomes across countries. This involves using a federated model of data analysis to follow comparable groups of patients beyond the acute care setting using existing linked patient-level EHRs and administrative datasets. This federated approach means that individual-level patient data remain on secure servers in each country, and teams carry out the same analysis using agreed definitions of each variable within a common data model.

Although there are differences across countries in the availability and structure of data sources, all 11 countries were able to use hospital data containing diagnostic codes to identify individuals corresponding to both patient groups. Timescales for accessing and linking different data sources to allow this type of research vary considerably between countries, but there is often a significant lag involved. For consistency, across most countries a 1-year window (2016/17) was used to identify patients, except in Australia (2012/13 to 2016/17) and England (2014/15 to 2016/17), which had smaller samples and therefore pooled more years of data. These patients were then tracked for a year after their initial hospitalisation to track health care use, spending and outcomes across different care settings.

Figure 1 shows that only Canada, France, the Netherlands and Sweden could track patients across all seven care settings. England was able to identify nationally representative data that could be linked across four settings, but data were not available for post-acute rehabilitative care, home health, and long-term care.
The primary care data used for the analysis in England came from the Clinical Practice Research Datalink (CPRD), which includes a sample of general practices that is broadly representative of the population of England. This was linked at patient level to the Hospital Episode Statistics (HES) inpatient, outpatient and emergency care datasets. Indicative unit costs were then attached to different types of health care activity from best available sources, such as national tariffs. Patients’ electronic health records were further linked to the Office for National Statistics death register to measure mortality at different time periods (30-day, 90-day and 1 year).

Figure 1

There were significant differences in the data held by different countries. Some used administrative claims data from public or private insurers, while others used national registry data or large survey data that are linked with claims data. However, a common data model was developed through many hours of discussion between the research partners with clinical input from an advisory board to limit cross-national differences and potential misclassifications.

The results are adjusted for differences in the age and sex of patients between countries. They were not adjusted for severity of illness or the presence of comorbidities due to differences between countries in the incentives to code these in the electronic health record. Countries’ spending was adjusted for differences in purchasing power using the method recommended by the OECD for economy-wide conversion of health expenditure (Actual Individual Consumption Purchasing Power Parities).

The methodology is described further in the peer-reviewed articles published in the special issue of Health Services Research. The code for the English analysis is available on Github.
How does the NHS in England compare internationally?

Taking each patient group in turn, we now explore what the available data for England tell us about how the NHS is performing and where there is room for improvement.

Hip fracture

We identified 2,738 people in England who were hospitalised with a hip fracture and had linked primary and secondary care records. The number of patients included from the other countries ranged from 1,859 in Spain to 42,849 in France. The median age of the hip fracture patients in England was 83 years and the majority (71.0%) were female, a similar age and sex profile to the other 10 countries. Patients in England had on average two comorbidities recorded in their hospital admission record and common conditions included chronic obstructive pulmonary disease (COPD) (22.0%), diabetes (15.1%) and renal failure (15.2%).

For patients admitted to hospital with a hip fracture, surgery within 48 hours is recommended as a key component of high-quality care. Here, England performed well, with over 82.4% of hip fracture patients in England having hip surgery within 48 hours of hospital admission, second only to Sweden with 86.3%.

Despite this, across all time periods, hip fracture patients in England had the highest all-cause mortality of all 11 countries (Figure 2). 1 year after their initial admission, almost a third of patients in England had died, compared with only a quarter of the Swedish patients. Among the hip fracture patients who died in the year following surgery in England, 37% died in hospital – the highest of the seven countries that could provide this data – while in New Zealand this was only 12% of patients.
Another striking finding for England was the large number of days people spent as a hospital inpatient. In England, hip fracture patients spend 29.3 days in hospital on average in the year following their admission, second only to Germany at 29.5 days. This includes the stay for the initial admission for hip fracture – known as the index admission – as well as any subsequent admissions for any reason. The total for England is nearly three times the average length of stay in the United States (11.3) and the Netherlands (11.7). Most of the days in hospital (21.7 of 29.3 days) are spent during the index hospital admission (Figure 3). In contrast, in the US patients are discharged much more quickly for rehabilitation (in a skilled nursing facility) and spend on average only 6.4 days as an inpatient following their surgery.
When it comes to spending, a relatively consistent picture emerges. Figure 4 shows that England has among the lowest spending in both primary and acute care settings for these patients. It also spends the least of all the countries on outpatient drugs. Only the Netherlands had lower overall spending. In contrast, the US and Australia spend almost twice as much caring for hip fracture patients in the acute setting, despite much shorter hospital admissions.
Heart failure and diabetes

We identified 742 older people in England who were admitted to hospital with heart failure, had a comorbidity of diabetes listed on their hospital record, and had linked primary and secondary care records. The number of patients included from the other countries ranged from 1,270 in Spain to 21,803 in the US. The median age of the patients in England was 79 years and the majority (57.5%) were male. Again, the demographic profile of patients was similar to the other countries included in the comparison. Patients had on average five comorbidities (including diabetes) recorded in their hospital admission record, with common conditions including hypertension (64.2%), renal failure (39.2%) and COPD (31.0%).

Among patients with heart failure and diabetes, again, across all time periods England had the highest mortality (Figure 2). 43.2% of patients died in the year following the index hospital admission, compared with 22.5% of patients in Australia. Figure 2 illustrates that the higher mortality at 1 year in England is largely explained by high mortality in the first 30 days (15.9%). For example, 30-day mortality in England is 7 percentage points higher than in the US (8.9%), whereas the mortality rate after 30 days is very similar in both countries.

The average number of days spent in hospital for heart failure patients ranged from 18.6 in the Netherlands to 33.5 in Germany, with England ranking in the middle at 23.5. Figure 3 shows that the average length of an index stay in England was fairly low (9.2 days). This is in contrast to the hip
fracture results, where patients in England spent 21.7 days in hospital following their surgery, more than any other country. Other countries saw more consistency between the two patient groups, with Germany having long lengths of stay and the US tending to discharge much faster.

In terms of spending, again England spends the least across three of the four domains for which we had data (inpatient, primary care and drugs), and the least overall across these four settings (Figure 5). US patients on the other hand cost the health care system over three times as much, despite spending on average 5 days less in hospital and having less than half the number of GP visits than patients in England over the course of the year.

Figure 5
Limitations of the analysis

There are some important limitations to state. First, there are differences in country datasets used for this study, but a common data model was developed to limit cross-national differences and potential misclassifications. The dataset used to produce the English results is based on a small sample of 2,738 hip fracture patients and 742 heart failure patients, collected from a sample of GPs and hospital providers. This captures around 3% of the patients who would have been eligible for this study nationally. This contrasts with countries like New Zealand and Sweden that have linked national datasets with complete population coverage, or countries like France, Spain and Canada that have large, linked regional databases. However, the CPRD dataset has several advantages, including that it:

- contains all general practice activity and detailed information on patient comorbidities
- fully captures all mortality through linkage to the ONS
- is representative of the population in England in terms of age and sex.

Second, there are important differences in national coding practices and cost accounting between countries, which may influence the results. Many countries were also missing data for particular care settings; for example, those related to the post-acute rehabilitative care setting (Figure 1).

Among the possible reasons for the differences in mortality seen between the 11 countries are different local thresholds for hospital admission, which marks the entry point for patients into the study. This is more likely to explain the variation in mortality for patients with heart failure and diabetes, where the extent to which patients are managed within the community versus hospital differs between countries, than explain the variation for hip fracture patients, where appropriate management almost always requires hospital admission for surgery.

The ICCONIC results are adjusted for age and sex but not for the baseline severity of the clinical diagnoses of heart failure or diabetes, nor for the number and severity of clinical comorbidities, which are strongly related to mortality risk in these patient populations. That said, England ranked in the middle in terms of the average number of recorded comorbidities, so while case-mix adjustment may have reduced some of the differences we saw, it is unlikely to have eliminated them. Because people’s health is affected by the wider determinants of health – not just by health care systems – it is also possible that the results could be influenced by other factors.

Another possible explanation for some of the observed difference is that the recording of mortality may differ across countries. In the data for England, health care records were linked to the ONS national death register. This means that the date of death, whether in hospital or elsewhere, was captured. In other countries, for example France and the Netherlands, the date of death is not recorded with such precision, meaning adjustments had to be made to estimate mortality within particular time windows.
Comparison with other studies

Prior work covering the same time period found lower 30-day mortality rates for hip fracture patients in England than reported by ICCONIC, by around 3 percentage points. This was produced using data reported by the National Hip Fracture Database (NHFD), which covers almost all hip fractures in England, including those in younger hip fracture patients, which could explain the differences with our findings. The NHFD analysis would still place England among the countries with the highest mortality rate. Previous reports of the National Heart Failure Audit have also found lower 1-year mortality rates than ICCONIC but included younger people and those without comorbid diabetes.

The ICCONIC data are historical and may not adequately capture substantial improvements made in recent years, nor how COVID-19 has affected mortality. The latest NHFD annual report for England and Wales, using data from 2019, found a 30-day mortality rate of 6.5% for all hip fracture patients. During the ICCONIC time period a lower rate than this was achieved by only New Zealand and Australia. However, we know that mortality for hip fracture patients in England has increased during the pandemic (to 8.2% in Dec 2020). The latest summary report from the National Heart Failure Audit suggests 30-day and 1-year mortality continued to fall up to 2018/19 (to 14/9% and 31.8% respectively), but it is not yet known how the pandemic will have affected this.

What do these results mean?

Outcomes

Previous comparative analyses have consistently identified patient outcomes as an area for improvement in the NHS. Although the gap has closed over the past decade for stroke and several forms of cancer, the mortality rate in England among people treated for some of the most common causes of death, including cancer, heart attacks and stroke, is higher than average among comparable countries. The ICCONIC findings add weight to these concerns. They highlight the need to look more widely than the quality of acute care, where England performs well using the measures available (for example time to surgery and readmission rates). The establishment of ICSs as statutory bodies might provide an opportunity to improve the quality of care along entire patient pathways, including community and post-acute care.

Though they have important caveats, the concerning findings from ICCONIC certainly warrant further investigation to fully understand the implications for the NHS in England. Several areas for improvement in care have already been identified by the national audits. Two in five hip fracture patients are not receiving best practice care across all quality domains. Particular areas for improvement include timely assessment by a geriatrician who specialises in the care of older orthopaedic inpatients, coordinated multidisciplinary care, prompt mobilisation and access to.
physiotherapy after surgery. Amid concerns that England has fallen behind other European countries as a result of neglecting the development of non-acute rehabilitation services, NHS England recently announced the appointment of its first director for rehabilitation care.

Similarly, there is still room for improvement in the assessment and diagnosis of heart failure using ECG. Rates of specialist follow up for heart failure patients are below 50%, fewer than half of patients are seen on a dedicated cardiology ward, and rates of referral for cardiac rehabilitation are very poor. This latter point is particularly concerning given that patients who received rehabilitation had higher quality of life and lower mortality. An area where the national audits are less able to shed light is how to improve care for people with multiple health conditions that span across several different audit programmes.

Efficiency

More positively, our findings add weight to previous reports that found, relative to health care systems in comparable countries, the NHS in England remains a low-cost and efficient way of providing universal health care. England has among the lowest spending on outpatient drugs, and in both primary and acute care settings for both groups – see Figure 5. This is despite the relatively long length of stay for the hip fracture patients.

However, the findings do highlight that there may be scope to reduce length of stay in acute care for hip fractures – the most common reason for emergency surgery. There is broad agreement that an acute inpatient ward is unlikely to be the right place for an older person to recover from hip fracture surgery, who may be confused and have multiple health problems. The environment is not one that is generally therapeutic or conducive to rest or rehabilitation; worse, it can lead to deteriorations in health. We know that a key objective for most older patients is to be able to spend as much time as possible back in their place of residence, be that their own home or a residential care home, particularly when it comes to the end of life.

The ICCONIC results show that countries able to provide an accessible and multidisciplinary post-acute care service for hip fracture rehabilitation, such as the Canada and the Netherlands, have much shorter average hospital stays than hip fracture patients in England. However, a contrasting picture is seen for heart failure patients, where England ranks in the middle for length of stay, suggesting that long inpatient stays are not inevitable. The hip fracture results may indicate a lack of capacity in the community and/or social care for patients recovering from surgery with high rehabilitative needs, and/or poor integration of these services.
What we still do not know

One of the key conclusions from the ICCONIC programme is that limiting comparisons to the acute setting provides a misleading picture of resource use for these patients. For example, relative hospital use for hip fracture patients in the US as compared with other countries appears low, but this is largely a displacement effect since the bulk of days are spent in rehabilitation facilities. When comparing total utilisation across both acute and rehabilitation care settings, hip fracture patients in the US have comparatively long length of stay.

Implications for the National Data Strategy

Unlike Canada, France, Sweden and the Netherlands, in England there are no nationally collected data that can be linked to hospital or primary care data in a number of significant areas. These include community, post-acute rehabilitation, long-term residential care or home care data (Figure 1). Consequently there are major gaps in the national picture of total costs and quality of care for some patients with the most complex needs. This means there is a lack of the information needed to improve care outside of hospital settings.

This problem has been recognised by the draft National Data Strategy and plans by NHS Digital to collect client-level adult social care data. According to the data strategy, this will be linkable to health care data. The same impetus is urgently needed for community care. There remains very limited research into the characteristics of people who receive care at home, what drives the demand or need for home care services and how it relates to care in other settings. This is at least partly due to the lack of linked data across different settings. Although there is now a national community services data flow, there are still significant gaps in the coverage and completeness of data. Data on patient reported outcome measures also need to be a priority; research funded by the Foundation shows it is possible to collect these at scale.

Alongside new datasets we need bigger and bolder action, in collaboration with the social care sector, to address the data challenges that ICCONIC has highlighted. In social care there are particular challenges around the variable levels of digitisation among care providers and a fragile provider landscape that produces conflicting motives when it comes to data sharing. More broadly, the strategy needs to support agreed common data models, the training of skilled informaticians and platforms to support international collaboration.

The government is now seeking to pass the biggest set of NHS reforms in the past 10 years via the Health and Care Bill, moving away from choice and competition towards a much stronger focus on collaboration and integration via ICSs. The establishment of ICSs as statutory bodies and their emphasis on population health provides an opportunity to address the care of older patients with complex needs and improve it.
Integral to this effort will be linked datasets capable of following a patient through primary and acute care, and on from hospital discharge to community care and into social care. While the creation of datasets covering the ICS geographical footprints is ongoing, there remains a gap in providing national-level data that will allow patient care to be monitored, positive and negative experiences of care to be identified and improvements tracked. There is a clear opportunity to use this reform agenda to make a step change in linking up patient data and using those insights to improve quality of care, patient experience and efficiency.

Conclusions

The analysis shows that looking across the system is essential to understand the true resource use of patients with complex needs, if policymakers are to identify areas for improvement in care. The comparatively high mortality rates for people admitted for hip fracture and for people with heart failure and diabetes in England are concerning and require scrutiny by policymakers, commissioners and providers. England performs relatively well on the quality of acute care according to the measures available, but mortality rates were higher than in other countries at 30, 90 and 365 days, which suggests there is potential to improve post-acute care. Unfortunately, our ability to examine this area in detail is hampered by lack of data.

This analysis is further evidence that the NHS in England remains a relatively low-cost health care system. But it also highlights potential opportunities to improve productivity – and free up additional capacity for tackling the backlog created by the pandemic – by reducing length of stay in acute care for the most common reason for emergency surgery. While extra funding has been announced alongside expectations that the NHS will significantly boost capacity, in reality the capacity to tackle the backlog will be constrained by longstanding (and so far unaddressed) workforce shortages. That means trying to use existing capacity more efficiently, preventing avoidable admissions and reducing delayed transfers of care from acute to post-acute settings.
Supporting information

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