National Audit of Care at the End of Life

Svenska palliativ REGISTRET

A report from the United Kingdom's National Audit of Care at the End of Life and the Swedish Register of Palliative Care

Measure to improve

- A comparison of two national approaches to benchmarking at the end of life

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Abstract

Background: The Swedish Register of Palliative Care (SRPC) and the United Kingdom's National Audit of Care at the End of Life (NACEL) are currently the only national level data sources on the quality of care at the end of life.

Methods and results: In this paper we describe two national benchmarking approaches, multi-year, individual-level, retrospective clinical data, to measure the quality of care delivered to individuals who died. This paper may offer guidance to countries, regions or healthcare providers seeking to start or develop end of life care benchmarking. The study draws from two data sources and was devised and written by an international working party of experts from the UK and Sweden together with international partners.

We found that the aims and objectives of both benchmarking approaches are similar with evolving design towards many common features. Strengths of the audit include the random selection of patients for review, which significantly reduces the risk of bias, and the mandate to identify outliers. Strengths of register are the inclusion of all deaths, regardless of place of death, age or diagnosis and the possibility for individual-level linkage to other data sources.

Conclusions: Several approaches to the collection of data for benchmarking are feasible, each with strengths and weaknesses. Understanding these and designing an approach that fits with the local / national healthcare setting where it will be used is likely to be the key to being able to 'Measure to Improve Care at the End of Life'.

Bakground

Benchmarking is common in many sectors of healthcare (1). It identifies strengths and weaknesses by comparing metrics across settings, aiming to improve the quality of care by measuring against standards and learning from best practice. The data affords opportunity for local quality improvement and large datasets for research.

Systematic benchmarking in palliative care is in the early stages of development, with relatively few established initiatives to date. The World Health Organization developed global standardised indicators (1), but these indicators concern healthcare structure, rather than patient outcomes. The WHO argue patient outcomes are essential for decision making though difficult to collect.

The aim of this paper is to describe two national benchmarking approaches, multi-year, individual-level, retrospective clinical data, to measure the quality of care delivered to individuals who died: the Swedish Register of Palliative Care (SRPC) and the United Kingdom's National Audit of Care at the End of Life (NACEL). Registers aim to routinely collect information on all individuals of the study population and can be a valuable tool for improving patient care, informing healthcare policy and for research. Clinical audit is a cyclical quality improvement process where current practice is assessed against established standards and criteria.

We describe and consider the strengths and weaknesses of both approaches and give practical advice on implementation based on our learning, which may provide guidance for countries/regions/healthcare providers that wish to develop their own systems and processes for benchmarking in end-of-life care. A country developing benchmarking may choose aspects of both models, adapting to their unique healthcare context with its individual restrictions and opportunities.

Construction and content

An international working party was convened to develop this paper. Experts from NACEL and the SRPC provided expertise and oversight of the process. Core descriptive elements were reviewed at a dedicated workshop during the 2025 Summer School of the International Collaborative for Best Care of the Dying Person.

Ten headings (Table 1) were chosen to succinctly describe both national systems of benchmarking and support colleagues to consider benchmarking in their healthcare setting.

1. History, governance and legal issues: A brief story of the evolution of the register and audit, governance, lines of reporting and oversight
2. Aim and objectives
3. Scope: Deaths included in SRPC and NACEL
4. Inclusion and exclusion criteria
5. Data sources: Data streams collected by SRPC and NACEL
6. 2024 data
7. Data reporting, analysis and dissemination
8. Data validity
9. Impact
10. Cost and funding

Table 1: Description of both national approaches to benchmarking

	Swedish Register of Palliative Care (SRPC)	UK National Audit of Care at the End of Life (NACEL)
1. History, governance, legal issues	SRPC started in 2005, one of many registers of care quality started during this period by committed professionals. The legal responsibility for each register rests with a designated county council, while logistic and technical support is provided by one of five, national healthcare regions. The legal framework governing quality registers is Act 2008/355 (the Patient Data Act). The county council responsible for SRPC delegates most issues to the executive board, a seven-person multiprofessional group representing different aspects and settings of palliative care (e.g. general and specialised)	The End of Life Care Strategy, published by the Department of Health in July 2008, set out a commitment to promote high quality care for all adults at the end of life. The UK adopted a top-down approach to benchmarking. NACEL was preceded by two audits led by the Royal College of Physicians, London and Marie Curie Cancer Care (2014,2016) and is now in its sixth cycle (2018, 2019, 2021, 2022, 2024 and 2025). The National Institute for Health and Care Excellence (NICE; NG31) published its guidelines on 'Care of the dying adult' in December 2015. NACEL adopts the standards specified in the NICE guidance. National Health Service (NHS) England, the Governments of Wales and Jersey, via Healthcare Quality Improvement

	The committee provides day to day leadership, independently deciding on allocation of budget, data to collect, data sharing, validation, coverage and research etc. The registry is led from the ground up, the steering committee sits on national working groups e.g. the national care program and the national guidelines group for palliative care. IT solutions for data input and outputs are delivered by an external company, a small, specialised, agile company that has developed specifications with the steering committee, and has a deep understanding of the data. This has proven important, e.g. during the Covid-19 pandemic when the SRPC could provide timely descriptive data.	Partnership commissions NHS Benchmarking Network to undertake NACEL in England, Wales and Jersey as part of the National Clinical Audit and Patient Outcomes Programme. The Public Health Agency separately commissions NHS benchmarking network to deliver NACEL in Northern Ireland. This audit runs alongside the main NACEL audit. Hospitals are encouraged to engage with the audit as every hospital is required by the government to publish a Quality Account annually. Care at the end of life is a required element of the quality report. Nonparticipation in the audit is reported to the government and to the care quality regulator. NACEL reports to its commissioners, palliative care leads in England, Wales, and Jersey, and the Care Quality

		Commission, that regulates and inspects health and social care providers in England. Day to day leadership is provided by the NHSBN team. Final decisions rest with Healthcare Quality Improvement Partnership and the commissioners. The steering and advisory groups help staff consider the data, present the findings and disseminate learning. A patient and public involvement and engagement group help review the audit questions and consider how to present the findings. NHS Benchmarking have developed the digital tools to analyse and present data.
2. Aim and objectives	Aim: To improve end-of-life care.	Aim:

	Objectives: By collecting and analysing data, the register intends to: • Increase knowledge about the effect of palliative care, to achieve equality of care for all those dying in Sweden. • Develop process and outcome measures based on relevant evidence-based practice. • Provide information about methodology, business development and clinical improvement work. 64 academic publications are available (2)	To improve the quality of care of adults at the end of life in NHS-funded hospital inpatient settings in England, Wales, and Jersey. Objectives: • Improve quality of care by identifying areas for action in relation to delivery and outcomes, adapting quality improvement priorities in line with evidence and guidance. • Reduce unwarranted variation in care through benchmarking of outcome measures as well as identifying and managing outliers. • Share and adopt best practice including quality improvement examples, and signpost to resources available in the wider End of Life landscape.

		Research is not a core aim. Two academic publications are available. (3,4)
3. Scope	The SRPC is available to every healthcare region, municipality and healthcare provider. All regions and municipalities contribute data to the register, even though not all healthcare providers in each region/municipality will report their data. The aim of the SRPC is to collect data about all deaths in Sweden, regardless of age, underlying diagnosis, geographical location or healthcare setting. From 2005-2021, a limited dataset was collected for unexpected deaths compared to that for expected deaths. From 2022, the same information is collected for every death.	NACEL 2025 is open to NHS providers of adult care in acute and community hospitals in England, Wales, and Jersey. Scotland does not participate. Community (home and care home deaths) and hospice deaths are excluded. Deaths reviewed are usually taking place in non-specialist settings. NACEL collects data on expected deaths and the proportion of deaths expected by staff.

4. Inclusion and exclusion criteria	SRPC includes all deaths in Sweden, including non-citizens if they have a permanent or provisional national identification number. From 2021, both expected and unexpected deaths are included.	NACEL includes acute, community and mental health hospital deaths. Exclusion criteria for the audit are: Age <18, Deaths in the emergency department, sudden death, suicide, maternal death, death within 4 hours of admission to hospital
5. Data streams	SRPC collects data from four sources: 1. End-of-life questionnaire (6) This is an online questionnaire, to be answered after the death of the patient by the healthcare personnel caring for the patient. Most, though not all, questions concern the last week of life. 2. Bereavement Survey (7)	NACEL collects data from four sources: (5) 1. Case Note Review Healthcare staff collect data from patient notes about the care they received during their final admission to hospital. Audit questions are focussed across 10 indicators of care. Anonymised data is sent to NHS benchmarking network staff who curate and analyse the data. 2. Bereavement Survey

	All reporting units are invited to administer an online questionnaire to relatives, carers and those important to the person who died 2 to 3 months after the patient's death. These data reflect the experience of those at the bedside but also enable validation of the End-of-life questionnaire, by linking the two data sources at an individual level, using the patient's Swedish personal identification number. 3. Site Overview Healthcare units report annually on questions including resources available, training of the staff etc. The site overview questionnaire was paused between 2015-2023. 4. Linkage to cause-of-death registry All reported deaths are linked to the Swedish Cause of death registry (8) annually. This provides the ICD 10	Formerly known as the Quality Survey, this is an online survey completed by relatives, carers and those important to the person who died in hospital. Hospitals offer the questionnaire to those important to the patient, asking for feedback of their experiences of the care and support received at the end of life. It is not possible to link the bereavement survey to the patient who died. 3. Hospital/Site Overview This survey contains questions about the availability and size of the specialist palliative care workforce, staff training, and quality and outcomes within the hospital/site. It is completed by the NACEL audit lead in the hospital/site. 4. Staff Reported Measure This survey is completed by staff who are most likely to come into contact with dying patients and their loved ones. The

	(international Classification of Diseases) codes of cause, underlying cause and contributing cause of death as diagnosed by the physician responsible for the patient.	survey asks questions about staff confidence and experience in delivering care at the end of life, the support they receive and the culture of their workplace. This is not a staff satisfaction survey. This audit element is being paused in 2025 for acute and community providers and will resume in 2026.
6. 2024 data	SRPC received data on 60% of deaths in Sweden (n= 55,003). Reporting varies depending on place of death: • >90% in specialised palliative care (n= 11,711) • 71% in nursing homes (n= 24,947) • 49% in hospitals (n= 13,647) • 36% in private homes (n= 4,698) There are very low levels of missing data in the samples.	NACEL achieved its largest sample size in 2024; • 99.5% of eligible organisations participate in the annual audit. • 8% of inpatient deaths included (n = 20,954) • 3% of bereaved families (n= 7,354) • Staff feedback (n = 14,406) There are very low levels of missing data in the samples.

7. Data reporting, analysis and dissemination	SRPC publishes an annual report (in Swedish) with a specific area of focus each year. Increasingly, the focus has shifted to the real-time data reporting on the interactive data platform. Data are available minutes after the Healthcare practitioner reports it, this is uncommon among the Swedish quality registers. Aggregated data is openly available. Data for each individual unit is only available to them. Data on all quality indicators over time are presented as the default view. It is possible to modify the data displayed to compare across regions, municipalities and nationally and to filter on certain characteristics of the patients or care. The SRPC Executive Board do not check whether units are reviewing and using their data.	A high-level report is published for each audit cycle and includes national recommendations. Reports are published on the NHS Benchmarking Network and Healthcare Quality Improvement Partnership websites, including a report for the public. From 2024, data are reported on an interactive tool. All data is available all participating hospitals, enabling comparison with local hospitals, similar types of hospitals (acute, community and mental health hospitals) at regional healthcare commissioning level and at national level. Filters can be applied to the data to gain insights e.g. by age and ethnicity. The audit lead for each hospital site is responsible for giving permission for access when requested. Data is available continuously, but is curated for errors, missing data and is validated quarterly.

	Staff involved in quality improvement, the Swedish Board of Health and Welfare and the public e.g. journalists may access aggregated data, beyond what is available online, for more detailed analysis. Use by bereaved people is not known. Academic researchers may apply for access to individual level data. The Executive Board review the application and grant permission. Data is usually shared within 6 weeks and is free of charge.	A time series analysis is available. The seasonal effect (if any) on the quality of care is likely to be statistically valid by 2027. A compendium of good practice is published annually by the NACEL team. It offers ideas for quality improvement and identifies units who are undertaking quality improvement work. From 2025, data will be available for the public in a more easily accessible report. The Patient and Public Involvement and Engagement panel supported development. Data for research is available at two levels, from the publicly available summary reports and by application to the data controller (Healthcare Quality Improvement Partnership). The repository of data has not been exploited as fully as possible.

8. Data validity	The validity of the EoL-questionnaire has been investigated in two academic studies (9,10), validity being moderate/very good for most items. From 2026, the registry will automate re-registration of a random selection of EoL-questionnaires from each user (e.g. 5%) to assess validity on a quarterly basis. Furthermore, a medical record review of a random sample of deceased patients whose deaths are *not* registered is ongoing. By assessing the quality of care in the population not covered (comparable to a non-responder bias analysis), important information on the generalizability of conclusions from the registry will be gained.	Face validity of the audit is ensured through its clinical leadership, steering and advisory groups who hold expertise in care at the end of life, ensure that the audit questions are relevant and applicable, and that the reporting is meaningful. The Healthcare Quality Improvement Partnership has a governance and supporting role for NACEL, sharing expertise from the large audit programme it runs (>40).
9. Impact	SRPC provides data for local quality improvement but has no mandate to require improvement work or use of data. Recently, the default data presentation was	Feedback on the impact of the audit is gathered through the NACEL MAILBOX, Quality Improvement webinars and huddles (drop-in sessions), compendium of good practice (11) and outlier analysis (12). In 2025, an impact

	switched to show the unit's data as a time series, which will hopefully nudge reflection and improvement work. SRPC has been successful in influencing policy, contributing data to national reports and enquiries both in palliative care and in allied healthcare fields, e.g. primary care and care for the elderly. Improvement in outcomes are reported in the scientific literature, though a direct causal link is not possible to prove.	compendium was created, reporting and sharing evidence of impact on care in hospitals based on NACEL data. Recommendations in the annual report are signed off by the audit funder and key governmental leaders, ensuring that the goals are recognised at a senior level and can be fed into healthcare policy. The audit's healthcare improvement plan and the annual report's recommendations set out a plan for healthcare organisations and the public. Recommendations are tracked over time to identify areas of improvement.
10. Cost and funding	Funding of SRPC has varied over time. Currently the registry receives funding from three sources: the regions and municipalities, (through the Swedish Association of Local Authorities and Regions), the central governmental	NACEL is funded from a central healthcare budget. The cost is not in the public domain.

	budget, (through the National Board of Health and Welfare) and from the Swedish municipalities. SRPC employs one full time and three part-time employees (75%, 50%, 20%). The budget includes office infrastructure, IT, creation and dissemination of resource materials to support practice, dissemination of results and information about the register. The office supports 4,760 different care units and more than 23,000 registrants who report data. Healthcare staff time for data collection, between 5 and 10 minutes for the end-of-life questionnaire, is not included in budget, it is met by providers.	The contract is awarded by competitive tender for 5 years. NHS Benchmarking Network secured both contracts (2018 - 2027). NACEL employs 2 part-time staff for clinical leadership, 1 part-time employee for quality improvement and 2 part-time roles for project management. The budget includes data analytical, statistical and online developer support to enable online data collection and reporting. Staff time for data collection is not included in the budget. Costs are supported by the National Health Service (NHS) and will often be incurred by frontline clinical staff undertaking the notes review. On average, staff spend 20 minutes assessing a patient's record (1600 minutes - 27 hours per annum per hospital to collect the recommended minimum case note data).

Utility and discussion

This paper describes two national approaches to benchmarking the quality of care delivered to dying patients. We find in this paper that the two approaches may evolve toward each other. The aims and objectives of both countries are similar; however, each approach has advantages and disadvantages. Furthermore, the authors note challenges that remain unresolved in both countries and shared aspirations for the future. The discussion describes the views and opinions of the authors.

A strength of NACEL is the random selection of patients for review reducing the risk of bias, whereas the SRPC asks the patient's team to voluntarily submit data. Therefore, NACEL results are more likely to be representative of and generalizable to all adult hospital deaths at local level. Secondly, NACEL has a mandate to identify outliers (11), i.e. units falling within the lowest 2.5% against two metrics, recognising dying and use of an individual plan of care. Those units identified as an outlier are asked to re-check their results to rule out any data entry errors, and are offered support to develop an action plan for quality improvement and follow a mandated reporting procedure. Finally, NACEL has in-depth data about the included sites, available resources and training, and the staff's confidence and experience in delivering care at the end of life. Insights can be gained by comparing and contrasting patient and family data with organisational and staff data.

A strength of the SRPC is the inclusion of all deaths, regardless of place of death, age or diagnosis. This enables comparison and follow-up of care quality across all care settings, including deaths that occur at home. Secondly, the steering committee of SRPC has control over the operation of the registry, which leads to agility, both in collecting and reporting data, this is important for contingency preparedness (e.g. Covid) and opportunistic development. Finally, the SRPC, like all Swedish registers and databases, uses a personal identification number to uniquely identify each patient, enabling data linkage within the SRPC, such as connecting with the patient record with the bereaved relative questionnaire, as well as with national health registers (e.g. registration of death and cause of death),

and other healthcare databases or registers that collect data research purposes (e.g. on cancer or heart disease).

There are limitations that are common to both approaches, although these may be inherent to benchmarking initiatives more widely. For example, it is difficult to envisage that any country would have sufficient resources to collect comprehensive data for every patient death, therefore focused data selection seems unavoidable. In this regard, NACEL and SRPC have made different choices with different consequences. As well as breadth of coverage there is the question of the amount, depth and detail of data collected. For example, the more concise the dataset the less resources are required to collect it, but too concise a dataset will be limited in its application. NACEL and SRPC are comparable in data depth, but others might make a different choice when setting up benchmarking. Another potential limitation is data literacy. Both SRPC and NACEL have transitioned from static reports released annually to interactive results portals, where the user can filter, subdivide and compare the data. To exploit the data and interpret the results generated requires digital literacy and some statistical understanding e.g. proportions. Finally, expertise about the conduct of NACEL and SRPC is nested in a small group of people, both the technical and clinical teams, leading the benchmarking, which is a vulnerability.

Both Sweden and the UK aspire to understand and develop the direct impact of benchmarking for dying patients in their population. Work with other countries may develop opportunities for using routinely recorded data, international standards and comparison of core outcome sets. We support international partners in the collection and use of data to drive improvement. Countries, regions or healthcare providers looking to start benchmarking are welcome to contact the authors for discussion and support.

Conclusion

Several approaches to the collection of data for benchmarking are feasible, each with strengths and weaknesses. Understanding these and designing an approach that fits with the local / national

healthcare setting where it will be used is likely to be the key to being able to 'Measure to Improve Care at the End of Life'.

Availability of data and materials

NACEL data is freely available online:

SRPC data is freely available online: https://utdata.palliativregistret.org/sv/home

Individual data for research etc. is available after application: https://palliativregistret.se/forskare/in-english/

Competing interests

The author group consists in part of the executive group of SRPC (S.L., M.A., M.D., I.G., C.Ö., MECS.) and experts from NACEL (M.M., R.B., J.B., J.M.), neither of these or any other co-authors have financial interests in a potential increased use of either data source, or the creation of similar data bases elsewhere.

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