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Describing and monitoring quality in value-based palliative and end-of-life care at a population level in Wales: achievements and future direction

Katherine E Woolley [1], Sarah Puntoni,[2] Kathleen Withers [1], Sally Cox [3], Idris Baker,[4] Anthony Byrne [5]

[1]CEDAR, Cardiff and Vale University Health Board, Cardiff, UK
[2]Value in Health, Value Transformation, NHS Wales Performance and Improvement, Cardiff, UK
[3]NHS Digital Health and Care Wales, Cardiff, UK
[4]Swansea Bay University Health Board, Swansea, UK
[5]Velindre University NHS Trust, Cardiff, UK

Correspondence to
Dr Katherine E Woolley; Katherine.Woolley2@wales.nhs.uk

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ABSTRACT

Improving and monitoring quality of palliative and end-of-life care is well documented within current and historic literature. However, there is a paucity of evidence around national data-informed approaches to ensure healthcare services are delivering high-quality, equitable care that meets the needs of the population within the last year of life. Wales has a legal 'Duty of Quality' obligation and has taken on the challenge to measure and monitor quality within the healthcare system at a population level within the last year of life, creating a dashboard using nationally held routine data. This manuscript aims to document the progress made in Wales to describe and monitor quality in care for people within the last year of life at a population level against the six domains of quality and discusses requirements and challenges of the approach and its future direction.

WHAT WAS ALREADY KNOWN

⇒ Quality indicators help underpin care delivery.
⇒ Evidence of at-scale clinical application of data-driven approaches to support care quality is limited.

WHAT ARE THE NEW FINDINGS

⇒ Systems-level approaches to whole population data analysis are feasible in last year of life care.
⇒ A National Health Service workforce accessible dataset provides opportunity for data-driven improvements and assessment of impacts in the last year of life.

WHAT IS THEIR SIGNIFICANCE

⇒ Clinical: Standardised data-informed approaches allow decision-makers to improve care quality.
⇒ Research: Demonstrate innovation through multisector collaborations.

INTRODUCTION

In Wales, a major shift is occurring in the strategic and operational delivery of health and care. The organisational structure, featuring integrated health boards, is capable of supporting a 'whole systems' model. *'A Healthier Wales: Our Plan for Health and Social Care'*[1] reflects a commitment to the principles of value-based health and care to deliver better population health through fairer access to higher quality care, and the power of digital technologies and data to drive transformative integration. A similar model is also present within England through the *NHS Long Term Plan*[2] and the *Health and Care Act 2022*.[3]

The broader plan for Wales encompasses the ambitions for palliative and end-of-life care (PEoLC).[4] The challenges of implementing and sustaining multisector, coordinated place-based systems of care in progressive life-shortening illness include: lack of detailed understanding of how complex systems currently operate; inconsistent approaches to assessing systems integration; and challenges to moving beyond process measures to an integrated multiperspective, multidimensional assessment of the quality of care.

Quality in healthcare can be split into six domains of care: safe, effective, person centred, timely, efficient and equitable.[5] In Wales, quality standards are part of a legal

obligation for health and social care around quality, as outlined in the 'Duty of Quality'. Quality should be embedded into clinical practice and ensure accountability, guide quality improvements, inform patient and programme-level clinical decisions and support generation of new knowledge through research.[6] Therefore, quality indicators should be explicitly defined, and where possible, evidence based, to provide valid and reliable measurements of care quality.[7]

Wales is pioneering initiatives and opportunities to ensure there is a multiperspective understanding of quality. To ensure equitable and safe care at the end of life across the whole of Wales using a person-centric rather than provider-centric approach, a population-based data-informed approach is proposed. This uses routine data sources to monitor and document care experience and quality indicators both at national and local levels.

The programme integrates expertise across strategic, policy, academic and clinical domains to support delivery of a robust value-based health and care approach to PEoLC as part of the work of NHS Wales Performance and Improvement.

The strategic approach encompasses outcomes and experience measurement, a service specification, a competency framework for staff and a new approach to commissioning palliative care services. A core outcome set to measure intervention effectiveness has been developed in Wales, as described elsewhere, designed to capture patient-reported and clinical outcomes in adults receiving PEoLC. Its digital implementation, alongside other data and digital products, will be used to drive data-informed decision-making at all levels of the care delivery (micro, meso and macro levels). Linkage of data from complementary sources is used to reflect the interconnected and unpredictable elements of a complex system to underpin this work.

THE LAST YEAR OF LIFE DASHBOARD

The approach uses data and data linkage infrastructure to develop a population, systems-level understanding of care delivery in the last year of life. As strategic imperatives demand a move towards more integrated, systems-level approaches to care delivery, in order to develop our understanding of data integration within our chosen population—residents in Wales in the last year of life—we placed a boundary on the system of interest, defining it as the unscheduled care system. This allows for a more manageable and iterative understanding of complexity with identification of the services relevant to a defined system, overexposure to which might be considered less than ideal in the last year of life. The population dataset of interest resides within the Wales Population Dashboard for the Last Year of Life, developed by Digital Health and Care Wales (DHCW).

The dashboard currently contains data on all individuals who have died in Wales between 1 January 2018 and 31 December 2024, representing a cohort of approximately 238 000 people. Data relate to the period of 12 months prior to the date of death for each individual dying within a calendar year and can be analysed at population and individual health board levels.

The study cohort includes Welsh residents (adults and children) dying within the specified period, excluding those with external causes of death (such as road traffic accidents, poisonings, death by suicide). Underlying cause of death and comorbid conditions are determined according to the International Classification of Diseases 10th Revision codes as indicated on the death certificate and reported by the Office for National Statistics. A Charlson Comorbidity Index is derived from secondary care data with a 5-year recall period.

The cohort is described by demographic variables including age, sex and geographical location with socioeconomic status derived from indices of deprivation.

Within the dashboard, interactions with unscheduled care services are captured for the 12 months prior to the date of death and include 111 calls, out-of-hours general practitioner contacts, Welsh Ambulance Service University NHS Trust (WAST) call-outs, emergency department (ED) attendances and admitted patient care (APC) episodes —with both emergency and elective APCs captured. First point of contact with specialist palliative care in the last year, along with service type (eg, hospital, community), is additionally captured. The data can be analysed by locality and across conditions, allowing for both national and locality-based interpretation.

HOW DOES THE LAST YEAR OF LIFE DASHBOARD INFORM CLINICIANS AND DECISION-MAKERS ABOUT QUALITY OF CARE?

Safe, effective and efficient care

Healthcare contacts (NHS 111, WAST, EDs, APC, specialist palliative) over time are shown on the dashboard. The dashboard is being iteratively developed and is accessible to all healthcare professionals within NHS Wales environments. Visualisation provides aggregated data on interaction with the unscheduled care services indicated above and can be interrogated by diagnosis, geographical (health board) area, comorbidity status and other demographic variables including age and gender (figures 1 and 2). In addition to allowing aggregated assessment of the impact of comorbidities, geographical (rural/urban) and socioeconomic factors on unscheduled care interactions, the visualisation has already improved understanding of the extent of unscheduled care interactions, the high level of emergency bed day use in the last year—particularly the last 3 months of life—and the potential impact of specialist palliative care service referral on use. Detailed analyses are being prepared for publication. Further projects are in progress to understand

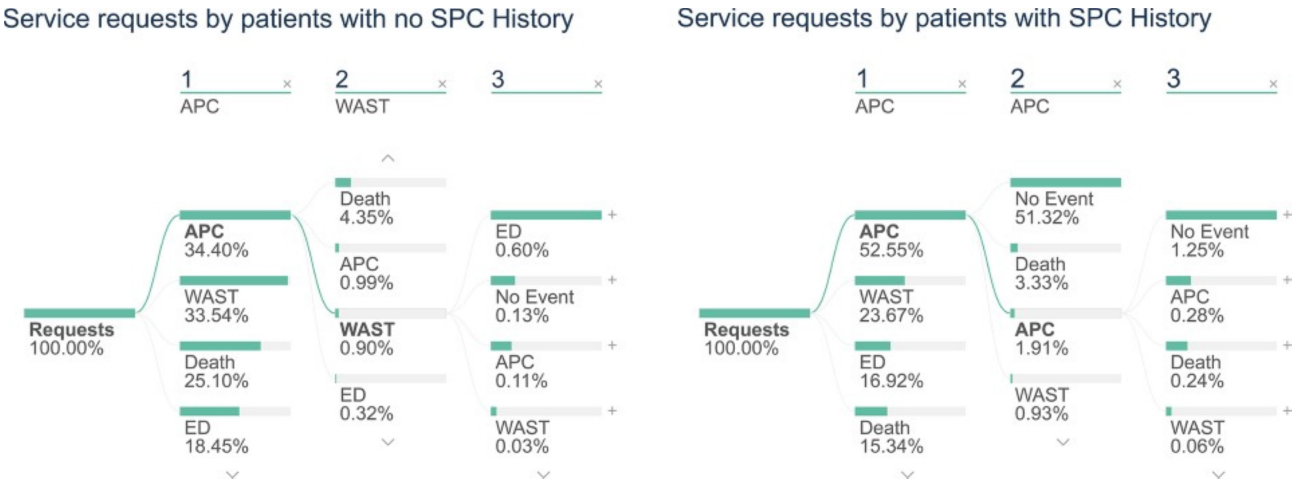

Figure 1 Decomposition tree showing how patients move between unscheduled NHS care services with a 7-day period separated by patients with and without an SPC history. ED, emergency department; NHS, National Health Service; SPC, specialist palliative care; WAST, Welsh Ambulance Service NHS Trust; APC, Admitted Patient Care. Visual developed and owned by Digital Health and Care Wales.

the nature of multiple service interactions per episode of care (including gaps in service access) and potential models for assessing capacity and demand based on real-world, population-level data. Observations can be at locality or national level, with the ambition to demonstrate patterns of service use that underpin improved care delivery.

Timely

The concept of timely referral to specialist palliative care remains challenging in terms of definition and triggers for referral. First receipt of specialist palliative care in the last 12 months of life is visible via the dashboard. The visualisation indicates that across this population as a whole, first access in the last year occurs late (median time before death of 35 days), with significant variation across conditions—particularly in cancer versus non-cancer cohorts. Referral to specialist palliative care appears often to occur at the peak of unscheduled care interactions, with a reduction in unscheduled care use thereafter. Further analyses and additional datasets will improve understanding of the true nature of any impact, taking account of confounding factors, and will allow consideration of potential triggers for earlier palliative care intervention. The dataset also allows consideration of how interactions with non-specialist services may influence the likelihood of exposure to unscheduled care. Ongoing analysis aims to identify patterns of care, which may reduce exposure and therefore influence the design and timing of future interventions—such as rapid access to healthcare-funded care packages.

By definition, the dashboard uses data on the population that is already deceased and hence is retrospective—currently updating the dataset at the beginning of each new calendar year using the data of those who have died in the previous year.

This limits how up to date the visualisations can be when they are refreshed, which is especially pertinent as the delay in reporting varies between the different data sources. Even with this reporting delay, using a dashboard provides useful aggregate feedback much faster than traditional, time-intensive, often one-off 'data dives' previously undertaken; makes information available to a wide range of stakeholders; and tracks system-wide effects of service delivery changes. It also provides the opportunity in future to undertake interrupted time series to assess the impact of a service development/innovation with consistent reporting of relevant datasets over time.

Person centred

Data reflecting the timing and nature of system interactions allow an understanding of 'what' is happening and an indication of how efficiently the system is operating as a whole. It supports hypothesis generation for more granular understanding of 'why' interactions are occurring and may underpin multimethod approaches to understand the complex sociotechnical interactions driving aspects of care. Using a population-level approach also aligns with NHS Wales' commitment to a value-based, value transformation approach to palliative care delivery. Population value-based healthcare may be considered at odds with individual person-centred approaches,[8] with natural tensions between societal and individual lenses on care. Our concept of creating an 'atlas' of care quality aims to address this by incorporating data from a patient-reported outcome set of effectiveness measures alongside the unscheduled care dashboard. This outcome set was developed using consensus methodology and mapped onto outcome measures. Data collection has commenced within the NHS Wales Clinical Portal having been adopted by the Value in Health, Value Transformation

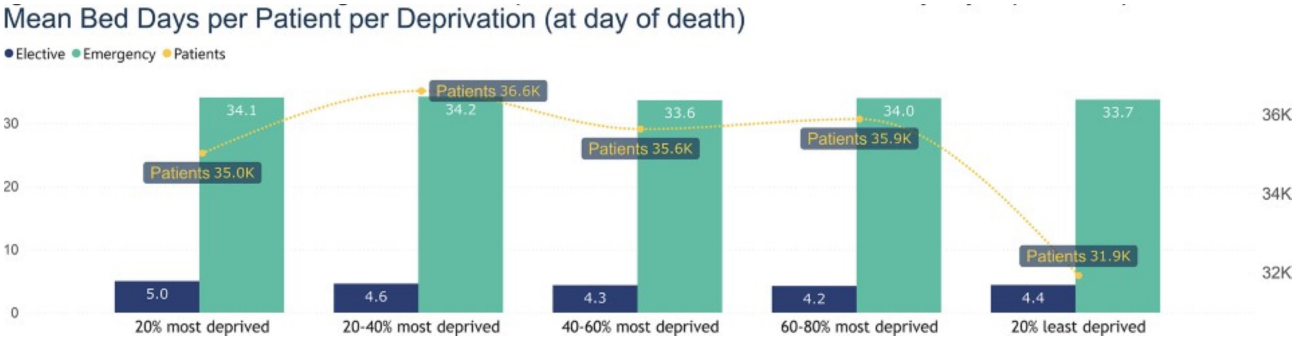

Figure 2 Illustration of the change in number of patients and mean number of bed days by deprivation quintile. Mean bed days per patient per deprivation (at day of death). Mean bed days—the mean number of bed days a patient has had over the 365 days prior to their death (the calculation will adjust based on days to death selected in the slicer at the left side of the page). Calculation=sum(length of stay)/all unique patients (regardless of whether they have had a stay in hospital in the last number of days to death). Visual developed and owned by Digital Health and Care Wales.

Team's patient-reported outcome measures (PROMs) work programme (to be reported elsewhere[9]). The outcomes are linked to an NHS number identifier. How quality outcomes may inform interpretation of systems data remains challenging, but in the context of this NHS Wales programme of work, it creates opportunity for exploration of innovative approaches to data integration including the generation of perspective through patient stories linked to unscheduled care events. Furthermore, where significant gaps exist, the dashboard could be used as a leverage for change and support the development of mandates to provide access to appropriate person-centred care.

Equitable

Certain visualisations within the dashboard can be disaggregated by health status/condition, deprivation, health board of residence, rural/urban location, age, sex and diagnosis, thus facilitating the interrogation of variation of care between different elements of equity (figure 2). By being able to identify possible inequities in care within the last year of life across Wales, directed interventions can be developed and planned. This knowledge can empower clinicians and managers to make changes to their services to ensure they meet the needs of their local population.

DISCUSSION

Data-informed systems approaches can help address uncertainties within care delivery by systematically illustrating the complexities within a healthcare system, by using validated quality indicators[7 10] and by operating within a framework that has clear strategic and operational goals. This paper describes such an approach in Wales to integrate data-informed intelligence in underpinning improvements to PEoLC. The Wales Population Dashboard for the Last Year of Life uses routine data from the NHS Wales data warehouse, working within the data governance and disclosure control rules of DHCW, to provide aggregated description of patterns of service use and care trajectories for people approaching the end of life. In aiming to work within a framework of manageable complexity, we have adopted complex systems principles[11] of clarity of population (including those in the last year of life and having clarity of system boundaries), unscheduled care and clarity of context with a strategic framework of value-based, quality-driven end-of-life care.

Already visible to clinicians within NHS Wales, this dashboard has successfully provided a wider population perspective and understanding of how parts of the unscheduled care system are operating. It gives descriptive insights into potential drivers of admission, the extent of emergency bed day use over time, pathways into and patient flow within the unscheduled care system and the timing of first specialist palliative care involvement. Rather than disease-focused or provider-centric approaches, the attention to population-level interactions potentiates the ability to pursue wider systems understanding of leverage points for care delivery. This observation is mirrored by findings of a recent review by Hurley *et al*,[12] which found that data sources or databases relating to end-of-life care mostly include only data for specialist palliative care or disease-specific pathways rather than at the whole population or system level. It also aligns with findings that although delivering and monitoring of quality at a system level is challenging, success is achievable with mandated support[10 11] and recognition of the real-world challenges at local level.[13] By developing a collaborative, skill-mixed leadership team across clinical–academic–digital–strategic boundaries, we have sought a sustainable platform for ongoing delivery against these challenges.

Data access across the healthcare system, and the level of digital literacy within the clinical workforce at both local and national levels, have been major barriers to routine access of and frontline engagement with data historically.[14] The dashboard represents an achievement in drawing multiple data sources together. The collaborative environment and early engagement

across clinical, digital, strategic and academic partners using prototypes and iterative development of the dashboard enable individuals to access informative aggregated data. Additionally, early involvement promoted engagement with the clinical workforce and supports opportunities to improve data literacy among healthcare professionals. Exposure to the early iterations of the dashboard allows healthcare professionals to explore the value of data that they collect and the primacy of accurate documentation and curation of data. The integration of this project within the wider strategic programme for PEoLC in Wales also allows the clinical and non-clinical workforce a voice in shaping ongoing development and ongoing strategic fit.

In undertaking this work, the limitations and challenges of working with routine data are acknowledged, including incomplete data, clinical coding definitions and access, coding errors, mixture of standardised and non-standardised collecting and data governance and disclosure control principles. We continue to purposefully engage with all stakeholders on the basis that we are in the earlier stages of iterative development, and the limitations of the dataset are clearly translated and communicated. However, we regard this iterative and engaged approach as a clear opportunity to mandate for access to wider datasets through the clarity and robustness of our operational and strategic vision, and to promote data literacy—all of which impact on the barriers described above.

FUTURE DIRECTION

The foundational achievements of the Wales Population Dashboard for the Last Year of Life also help clarify the nature of the challenges for the future. We continue to work with strategic and digital health partners to ensure that we develop analytical capabilities that satisfy the service innovation and assessment of impact needs of clinical services, while operating within secure NHS digital environments and to the highest standards of data governance and statistical disclosure control.

In pursuit of a wider atlas of care quality and practice (eg, benchmarking,[15] quality improvement interventions[16]), we understand the need to align the data from the current dashboard with quality indicators of care effectiveness and safety. To that end, the implementation of patient-reported outcome collection on service effectiveness underpins the opportunity to explore novel ways of interpreting and combining the population-level data with PROMS data, combining value-based and person-centric approaches. Current pilot work focuses on the ability of patient narrative to inform observed patterns of care use and their impact. We are also collaborating with academic colleagues on the development of a harm indicator tool for end-of-life care which would allow alignment with a quality indicator of safety and further underpin a multiperspective consideration of care quality. Further work is also required to understand and map the impact of non-commissioned informal or non-profit community service interventions. To this end, we have undertaken an initial participatory mapping exercise to identify such additional assets and to consider the types of data that might be accessible in reflecting their role in the system of care.

CONCLUDING STATEMENT

The rhetoric of care integration and a complex systems approach to assessing impact is commonplace, but very difficult to operationalise.[17] This project suggests that developing data-informed approaches to monitor activity within a complex system is achievable, as demonstrated through setting clear bounds on the population and system of interest, encouraging strategic and operational engagement, and iterative delivery within the confines and constraints described. Creating a collaborative environment that tolerates iterative, stepwise change provides clarity of purpose and direction which in turn can mandate for wider access to relevant data, access to innovative and secure environments to test and implement, and opportunities to improve data literacy at the clinical interface. Combining population-level data on service use with indicators of care quality offers the promise of a unique multiperspective analysis of care quality and value transformation.

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ORCID iDs
Katherine E Woolley https://orcid.org/0000-0003-3743-9925
Kathleen Withers https://orcid.org/0000-0001-9514-2025
Sally Cox https://orcid.org/0009-0008-7851-4817
Anthony Byrne https://orcid.org/0000-0002-1413-1496

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