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Sinéad McMurray

Global Perspectives: How Other Countries Fund and Deliver Palliative Care.

NIAR-55-2025

Date 18/03/2024

This briefing is the fourth in a series of papers on palliative and end-of-life care in Northern Ireland. It examines how other countries fund and deliver palliative care services, with the aim of providing insights to inform and enhance Northern Ireland's approach.

Contents

Other papers in the series

Other research briefing papers in this series:

Paper 1: Introduction to palliative and end of life care

Paper 2: Palliative and end of life care provision in Northern Ireland

Paper 3: The economics of palliative and end of life care and sustainable funding mechanisms

Paper 4: Global Perspectives: How other countries fund and deliver palliative care

Paper 5: Equity, access, coordination and integration of palliative and end of life care

Paper 6: Future planning and need for palliative and end of life care services

Key facts

Taken together, the case studies in this paper suggest that comprehensive palliative care can be supported through a combination of data-driven planning, appropriate funding mechanisms, and inclusive, locally tailored approaches. These examples provide valuable insights for regions seeking to implement similar reforms.

However, these enablers cannot deliver sustainable change in isolation. Achieving meaningful and equitable access to palliative care requires coordinated action across all parts of the system—including governance, workforce capacity, service delivery, and education, among other key areas. A holistic approach is essential if palliative care is to be fully embedded within the broader health system reform.

Viewing palliative care through the lens of integrated care

As health systems worldwide grapple with rising costs, ageing populations, and increasingly complex care needs, integrated care has emerged as a guiding framework for reform—emphasising coordination, personalisation, and outcomes that matter to individuals and families.

For palliative care, integrated care offers a valuable lens through which to reconsider how services are planned, funded, and delivered. The core principles of integrated care—collaboration across settings, person-centred design, and a focus on quality rather than volume—are highly relevant to supporting people with serious, life-limiting illness.

The Role of Data in enabling integrated palliative care

Data is not only a technical resource but also a key enabler of accountability, service improvement, and quality in end-of-life care. For Integrated Care Systems (ICSs) in the UK, the ability to access, share, and use data in a standardised and meaningful way is widely seen as essential to delivering coordinated and person-centred care.

Across the case studies reviewed—from Germany to Wales and Sweden—data has played a central role in service planning, care delivery, and outcome measurement.

However, in the absence of high-quality, standardised data that is accessible to those involved in planning and delivering services, progress toward integrated care becomes more challenging. This is particularly relevant in palliative care, where needs are often complex and outcomes more difficult to define using conventional metrics.

Aligning funding approaches to support integrated palliative care

Traditional funding mechanisms—such as activity-based payments for acute care or block contracts for community services—may not fully support the holistic, anticipatory, and multidisciplinary nature of palliative care. These approaches can sometimes create challenges for early intervention and coordinated care planning, particularly when incentives are not aligned across care settings.

Alternative funding models that reflect integrated care principles—such as pooled budgets, pathway-based payments, or shared savings arrangements—may offer more supportive structures. These approaches can facilitate earlier identification of need, more seamless transitions between care settings, and delivery of care that is better aligned with individual goals and preferences.

Rethinking financing to enable sustainable integration

Adapting palliative care services to meet the aims of integrated care requires more than simply adding new models onto existing funding arrangements. Traditional financing structures may not provide the flexibility or incentives needed to support joined-up, person-centred care—particularly for people with complex or evolving needs.

International experience suggests that sustainable integration is more likely when financial frameworks are designed to encourage collaboration across services and focus on delivering outcomes that matter to individuals

Enabling local flexibility and joined-up funding for palliative care

Local systems are often best placed to design and deliver care that reflects the needs and preferences of their populations. Providing greater flexibility in how funding is used—alongside clear accountability for outcomes—can help ensure that resources are directed where they will have the greatest impact.

While the case studies in this paper are delivered by both public and independent providers, it is the principles underpinning service design—such as collaboration, coordination, and a focus on person-centred outcomes—that are most critical to success. The emphasis is not on the setting, but on the structures and approaches that support integrated, responsive care.

This is particularly important for palliative and end-of-life care, which often spans multiple sectors and can be overlooked in conventional funding frameworks. Integrated Care Systems provide a valuable opportunity to embed palliative care more fully within broader system planning—provided financial arrangements enable collaborative working, investment in community-based care, and attention to outcomes aligned with the values of palliative care: quality of life, dignity, and the ability to remain at home where appropriate.

Linking funding to outcomes can support prevention and sustainability

There is growing interest in aligning payments with the outcomes of care—rather than simply the volume of activity delivered. Done well, this can improve both quality and efficiency. However, outcome-based models are not without risk, especially in areas like palliative care where success is complex to define and not easily captured by standard metrics.

Nevertheless, carefully structured approaches—such as Germany's OptiMedis model and Stockholm's PROMs-linked bundled payments—demonstrate that it is possible to align incentives with prevention, coordination, and reinvestment in community services.

Value-Based Healthcare offers a broader lens for reform

Even where funding is not directly tied to outcomes, the principles of Value-Based Healthcare (VBHC)—focusing on outcomes that matter to patients relative to the cost of delivering them—can help guide more sustainable, person-centred systems. PROMs (Patient-Reported Outcome Measures) are central to this approach, offering valuable insight into patients' experiences, quality of life, and wellbeing.

When used alongside clinical and financial data, PROMs has the potential to support better service design, more informed decision-making, and continuous improvement. Case studies from Wales highlight how these tools can enhance personalisation, accountability, and value in care delivery. For palliative care, where patient priorities and quality of life are especially important, this approach is particularly relevant.

Case studies summary table

Table 1: This table presents a summary of international case studies of integrated and value-based care models included in this paper.

Case study	Key Takeaway
England: Data challenges in palliative care commissioning in palliative care	The case study explores how limitations in standardised, transparent data affect commissioning palliative care at home in England. This is a trend that is reflected internationally. Innovations like the My Care Choices Register in North East Essex demonstrate the benefits of capturing key information about individuals' care preferences and advance care plans which can support effective commissioning.
Australia's PCOC: Embedding outcome measurement in palliative care	Australia's Palliative Care Outcomes Collaboration (PCOC) shows how routine outcome measurement improves palliative care quality, responsiveness, and benchmarking. It highlights the value of structured data systems and tools for continuous improvement. While services show consistent progress, gaps remain—especially for disadvantaged and culturally diverse groups—underscoring the need to turn data into meaningful action.
Portugal's integrated dialysis care model	Portugal's integrated approach to dialysis care demonstrates how aligning funding, service delivery, and care coordination can improve outcomes while reducing costs. It offers insight into the benefits of system-wide integration—emphasizing the potential of coordinated, person-centred models to deliver both clinical and economic value.
Stockholm's bundled payment and PROMs-based reform	Stockholm's introduction of bundled payments and the use of patient-reported outcome measures (PROMs) aimed to improve quality and cost-effectiveness in planned care. The reform highlights how payment models aligned with outcomes can incentivise integrated, patient-centred care. The experience also underscores the need for careful implementation, ongoing evaluation, and alignment with broader system structures to ensure impact.

Germany's OptiMedis integrated care model	Germany's OptiMedis model integrates care delivery with data analytics, preventive services, and shared savings to improve population health and system efficiency. It demonstrates how local partnerships, aligned incentives, and data-driven planning can support more proactive, coordinated, and sustainable care models. It also points to the importance of long-term commitment and tailored local implementation.
United Kingdom: shifting approaches to measuring quality in primary care	Northern Ireland's shift from the Quality Outcomes Framework to the NI Contract Assurance Framework (NICAF) in primary care, reflects a UK-wide move toward simpler, outcomes-focused models in primary care. This creates an opportunity to support more integrated, patient-centred care — especially for those with complex needs.
Wales' approach to improving COPD outcomes: surveillance and service redesign	Aneurin Bevan University Health Board in Wales used prescribing and service-use data to identify inefficiencies in COPD care, reduce low-value interventions, and reinvest savings into evidence-based services. The initiative highlights how surveillance and targeted value-based changes can support more effective care. For Northern Ireland, it demonstrates the importance of data-led improvement and collaborative clinical-financial planning.
Wales: proms-driven insights in myeloma care	The use of patient-reported outcome measures (PROMs) in Welsh myeloma care supports more personalised and responsive treatment. PROMs, integrated with clinical data via a national dashboard, enable better understanding of treatment impact and inform quality improvement. This case shows the potential of PROMs to enhance cancer care by aligning services with patients' lived experiences and wellbeing.

A global shift towards integrated care

Globally, healthcare systems are facing increasing pressure as demand for services continues to grow while financial resources remain constrained. Despite significant investment, many developed nations are struggling to balance costs with improving patient outcomes. Ageing populations, the rising prevalence of chronic conditions, and evolving public expectations are further intensifying these challenges. While investment in healthcare remains essential, there is broad recognition that simply increasing expenditure is not a sustainable solution. Instead, a shift towards more integrated, efficient, and patient-centred models of care is required to enhance both financial sustainability and health outcomes.[1]

Historically, healthcare systems have operated within distinct silos, with hospitals, primary care, and social care functioning as largely separate entities. This fragmented model is increasingly unsuitable for the reasons outlined above.[2]

Many countries are recognising that fragmented, hospital-centric healthcare models are inefficient and unsustainable**,** leading to reforms that promote integration across primary, secondary, and community care**.** For example, in Ontario, Canada, Ontario Health Teams are being developed to integrate services across different care settings.[3] Likewise, Australia is focusing on Primary Health Networks (PHNs) to strengthen community-based care and reduce hospital dependence.[4]

More locally, the development of Integrated Care Systems (ICS) across the UK reflects efforts to address these challenges by promoting collaboration across services and enabling more coordinated, person-centred care closer to home.[5] Northern Ireland is progressing toward this model with the continued development of Integrated Care System Northern Ireland (ICS NI).[6]

A similar approach is underway in Republic of Ireland through the development of ‘Healthcare Regions’—a central component of the 10-year Sláintecare reform programme.[7]

The transition to integrated care in Northern Ireland

To improve efficiency and address the wider determinants of health, the DoH is transitioning to an Integrated Care System for Northern Ireland (ICS NI). This new model moves away from individual provider-based commissioning towards a whole-systems approach that integrates health and social care professionals, the voluntary and community sector, local councils, and statutory partners. The goal is to deliver more flexible and patient-focused care, ensuring resources are allocated to where they will best improve health outcomes.

Northern Ireland should be well-positioned for this transition compared to other UK regions implementing ICS models, as health and social care services are already structurally integrated. However, it is widely recognised that the system as it is currently configured has not reached its full potential due to siloed working, fragmented service commissioning, and a lack of transparency in funding allocation.[8] [9]

How will this transition affect palliative care?

The global shift toward integrated care aligns with the evolving role of palliative care, which is increasingly recognised as a holistic, person-centred approach that supports individuals with serious or life-limiting illness throughout the course of their condition—not solely at the end of life. There is growing emphasis on delivering care in community settings, supporting patient choice, and enabling end-of-life care at home where appropriate.[10] This reflects both patient preferences and the need to make effective use of health and social care resources.

The development of Integrated Care System Northern Ireland (ICS NI) provides an opportunity to strengthen the role of palliative care within a more coordinated system. Integration can support more consistent access to care that meets people’s physical, emotional, social, and spiritual needs.

Achieving this will require clear care pathways, improved communication and coordination between service providers, and appropriate, sustained funding.

In Northern Ireland, under the Palliative Care in Partnership Programme (PCIP), Palliative Care Locality Boards (PCLBs) have been established to implement regional palliative and end-of-life care priorities at the local level. These boards are co-chaired by the Health and Social Care (HSC) Trust Director responsible for palliative care and a nominated member from the local Integrated Care Partnership (ICP) Committee or Local Commissioning Group (LCG). This co-chairing arrangement is designed to ensure collaborative leadership and effective implementation of palliative care strategies within communities.[11]

As part of the broader transformation under ICS NI, ICPs and LCGs are being phased out and replaced by Area Integrated Partnership Boards (AIPBs), The AIPBs are expected to build upon the foundations laid by the previous structures.[12]

Aligning funding models with integrated care

Policymakers increasingly recognise that meaningful transformation of palliative care—and the wider health and social care system in Northern Ireland—requires changes to how services are funded and commissioned. Financial frameworks must evolve in parallel with new models of care to enable more joined-up, person-centred services.[13]

At present, many funding and commissioning arrangements still reflect siloed systems. Organisations often focus on individual priorities, with limited mechanisms to share responsibility or align resources across the system. This can make coordinated care difficult to deliver, particularly for individuals with complex or long-term needs.[14]

Traditional funding models, such as block payments or payments by activity, have been useful in improving access or controlling budgets, but are often less suited to integrated care, which depends on continuity, collaboration, and shared outcomes.

Traditional funding models

Table 2: Description of traditional funding models.

Payment type	Key Features and Considerations
Block funding	Fixed sums of funding to deliver a defined set of services over a specified period, regardless of the volume of activity. Offers greater budget certainty and can support service planning but may reduce incentives to increase activity or respond to changes in demand.[15]
Payment by activity and fee for service	Reimburses providers based on the number and type of treatments or services delivered. While this model can incentivise increased activity and reduce waiting times, it may also lead to fragmented care and a focus on volume over outcomes.[16]

To support integrated care—particularly in cross-cutting services like palliative care—there is a need for funding models that encourage collaboration between primary, community, and hospital-based services. Approaches that reflect patient outcomes and experiences, rather than just service volume, are better aligned with the goals of high-quality, person-centred care.[17]

Evolving approaches to funding integrated care

Across health systems internationally, alternative funding models are emerging to support integrated care:

Table 4: Description of evolving funding models

Payment type	Key features and considerations
Bundled payments	Provide a single, fixed payment for all the care a patient receives for a specific condition or treatment pathway over a defined period. Encourages coordination between providers and can support better outcomes and efficiency but depends on clear pathways and shared responsibility.[18]
Capitation and risk payments	A fixed amount paid per person to cover a defined set of services, adjusted for factors such as age or health status. This model promotes early intervention, prevention, and financial flexibility—particularly when savings are shared and additional payments are linked to improved outcomes.[19][20]

These models show how financial mechanisms can be restructured to support system goals while maintaining focus on patient-centred care.

Funding palliative care within ICS NI

Palliative care in Northern Ireland currently lacks clear categorisation within existing funding structures. This makes it difficult to track spending, monitor equity, or ensure adequate investment. Yet it aligns closely with the aims of ICS NI—providing holistic, community-based care for people with complex needs.

A core principle of integrated care systems (ICS) internationally is delegated financial authority, giving local areas greater control over how funding is allocated and used. This approach is intended to:

- Increase transparency in funding flows;

- Support flexibility to meet local needs;
- Enable more effective budget management; and
- Promote collaboration through pooled resources where appropriate.[21]

In Northern Ireland, the Department of Health has acknowledged that developing a new financial structure is a complex, long-term process. The introduction of ICS NI does not bring immediate changes to funding arrangements. However, organisations are encouraged to explore models that better align with integration goals, and a dedicated workstream has been established to help design a fit-for-purpose funding framework.[22]

While funding models alone cannot drive transformation, they are a vital enabler of change. Well-designed financial structures can support earlier intervention, improve outcomes, and reduce reliance on hospital-based services—making their development a strategic priority.[23]

The Hewitt Review, which assessed the progress of ICS implementation in England, identified funding as a key area requiring improvement for systems to realise their full potential. It found that current arrangements often limit flexibility and coordination, and recommended several reforms, including:

- Multi-year funding settlements to support long-term planning;
- Greater financial flexibility for local systems; and
- Reduced bureaucracy to improve efficiency.[24]

These recommendations highlight the broader need for financial frameworks that enable, rather than constrain, integrated service delivery—including in areas like palliative care.

The role of data in strengthening palliative care

High-quality data plays a central role in improving the effectiveness, efficiency, and responsiveness of healthcare systems. In palliative and end-of-life care, data is essential to understanding patient needs, evaluating service quality, tracking resource use, and planning care delivery. It supports both operational improvement and longer-term system transformation.[25]

Currently, much of the available research on palliative care funding focuses on service costs, with less attention given to patient outcomes, experience, or quality of care. While service-level data such as activity counts and referral volumes are useful, they are not enough on their own. Palliative care is fundamentally about meeting the individual, often complex needs of people with serious illness—so outcome measurement must also capture:

- Quality of life and symptom control
- Emotional and psychological wellbeing
- Patient and family experience
- Ability to remain at home if preferred.[26]

These indicators are essential to assessing whether services are delivering value, particularly as pressure grows to use limited resources wisely. There is an increasing requirement across health systems for services to demonstrate their effectiveness using a combination of patient, carer, clinical, and financial data—not just activity metrics.[27]

Value-based healthcare and the role of outcomes

The move toward Value-Based Healthcare (VBHC) offers a framework for aligning investment with patient outcomes. VBHC focuses on achieving the best possible outcomes for patients relative to the cost of care. It shifts the emphasis away from service volume and towards person-centred results—such as improved quality of life, symptom relief, and care aligned with patient preferences.[28] [29]

In palliative care, tools like Patient-Reported Outcome Measures (PROMs) are increasingly important. PROMs can capture how individuals experience pain, fatigue, anxiety, or dignity in care—providing insights that traditional clinical metrics may miss. However, PROMs alone are not enough. To build a complete picture, they must be used alongside costing, clinical, and population data.[30]

In England, the Getting It Right First Time (GIRFT) programme illustrates how structured data can drive quality and efficiency. GIRFT combines clinical, operational, and financial data to reduce unwarranted variation, promote best practice, and inform commissioning decisions. Although it does not focus exclusively on palliative care, its principles—particularly the focus on outcomes and resource use—can inform future data strategies in this area.[31]

Towards a more informed, responsive palliative care system in Northern Ireland

Northern Ireland currently lacks a consistent, standardised approach to collecting and using data in palliative care. There is no national or population-level dataset that captures palliative care activity, outcomes, or patient experience in a uniform way. This limits the ability to assess service effectiveness, plan equitably, or ensure funding is aligned with need.

However, there are a number of challenges in developing such a dataset, including:

- The diversity of settings in which palliative care is delivered (hospitals, hospices, care homes, and at home)
- The difficulty of defining consistent outcome measures in a highly individualised area of care
- Limited validation of many current outcome tools for palliative populations
- Variability in digital infrastructure and recording systems across services
- The need to capture data on patients who could benefit from palliative care but are not currently receiving it.[32]

Despite these challenges, there are valuable examples of progress internationally. In Australia, the Palliative Care Outcomes Collaborative (PCOC) has developed a national system of routinely collected outcome data, co-designed with clinicians and used for quality improvement, service planning, and benchmarking. Similar efforts in Scandinavia include national population-level registers in Denmark and Sweden.[33]

In Northern Ireland, improving data use is already recognised as a broader system priority. The Getting It Right First Time Efficiency Review for Northern Ireland (GIRFT) found little evidence of data being used consistently within or across organisations to support clinical and operational improvement. Tools such as CHKS (a benchmarking and performance analysis tool) and SEDIT (a financial efficiency and productivity tool) are available to all Trusts, but are underused in day-to-day planning and decision-making.[34]

The report noted there is scope to improve how existing tools and data are used to support both operational efficiency and long-term planning. For example:

- CHKS provides data to benchmark performance across trusts and identify variation in outcomes or productivity
- SEDIT helps analyse workforce productivity, costs, and resource use to support better financial planning

The GIRFT report recommended greater use of these and other tools—alongside learning from systems such as England’s GIRFT metrics—to support a more informed, efficient, and outcomes-focused approach across services.[35]

In palliative care, this would mean strengthening the use of data not only around cost and activity, but also patient outcomes, experience, and equity. As Northern Ireland moves toward integrated models of care, developing a palliative care dataset—embedded within broader data systems could provide a supportive foundation for delivering more responsive, accountable, and patient-centred care across the region.

England: Data challenges in commissioning end-of-life care at home

Key takeaway for Northern Ireland

The experience in England underscores the importance of structured data systems in commissioning effective home-based end-of-life care. Challenges such as inconsistent data collection and limited understanding of patient experiences have hindered service planning and delivery. Innovations like the My Care Choices Register in North East Essex demonstrate the benefits of capturing key information about individuals' care preferences and advance care plans, supporting coordinated care and informed decision-making.

For Northern Ireland, these insights emphasise the necessity of developing standardised, transparent, and timely data collection methods to inform commissioning decisions.

Background to commissioning at home end of life care in England[36]

Across the UK, the health and care system is increasingly focused on enabling people to die at home or in the community, where that is possible and desired. This shift reflects not only most people’s stated preferences but also policy ambitions to deliver more person-centred care, reduce hospital use in the final days of life, and support better coordination between services. Within England’s Integrated Care Systems (ICSs), this direction of travel is clear: high-quality, community-based end-of-life care is a national priority.

However, achieving this goal is being held back by serious and persistent gaps in data—especially around the care delivered in people’s homes by generalist providers like GPs, district nurses, and homecare teams. While specialist palliative care services (e.g., hospices, hospital-based teams) often have more structured reporting and quality frameworks, generalist services—who provide most end-of-life care at home—remain largely invisible in national data.

Integrated Care board Commissioners are expected to:

- Take a system-wide view of end-of-life care needs;
- Proactively address gaps and inequalities;
- Ensure data and intelligence drive decision-making.

However, recent research by The King’s Fund shows that many ICBs are struggling to meet this ambition—largely due to significant limitations in the availability, quality, and use of data. Commissioners and system leaders are often left planning services with:

- No consistent view of what care is being delivered in the home
- Little understanding of whether care aligns with people’s wishes
- No real-time information on quality or patient experience
- And limited ability to track inequalities in access or outcomes.

This lack of standardised, transparent, and timely data undermines efforts to plan, commission, and improve services. It also limits accountability and hinders progress towards integrated, equitable, and person-centred care at the end of life.

Core data challenges and examples

Table 5: Core Data Challenges and Examples in Palliative Care Commissioning

Data Challenge	Example & Impact
Lack of formal quality measures	• Commissioners often rely on hospital admission data and other process proxies, with little insight into patient experiences or outcomes. • For instance, many commissioners had no insight into whether people had adequate pain relief at home, or if care was aligned with patients' preferences.
Fragmented and inconsistent provider data	• Different providers collect data in various ways, with no shared standard. • One commissioner had to manually compile data from hospices and community providers just to assess place of death.
Invisibility of generalist care	• Most end-of-life care at home is delivered by GPs and district nurses, yet commissioners reported virtually no quality or activity data from these services.
Limited understanding of population needs	• Few commissioners used data analytics to identify people approaching end of life. One stated: "We're nowhere near where we should be" regarding end-of-life registers.
Absence of data on inequalities	• Most commissioners did not collect or analyse data on ethnicity, deprivation, or rurality, limiting the ability to target services equitably.
No national data on lived experience	• Since the VOICES survey ended in 2015, there is no national data on people's or families' end-of-life experiences. • Commissioners found this a major gap.

Emerging innovations in England

North East Essex has developed a structured approach to improving end-of-life care through the use of the My Care Choices Register, a local Electronic Palliative Care Co-ordination System (EPaCCS) introduced in 2013. The register is designed to capture key information about individuals' care preferences, advance care plans, and the conversations they have had with professionals regarding their end-of-life wishes. It is currently used in relation to approximately 50 per cent of all deaths in the area, providing a meaningful source of information for coordinating care.

The register is accessible to a wide range of professionals, including GPs, hospices, hospitals, and community services, supporting more consistent and coordinated care delivery. It enables services to tailor care in line with people's stated preferences, such as avoiding hospital admissions or remaining at home where possible and appropriate.

Monitoring quality through a co-produced dashboard

Information recorded in the register contributes to a co-produced quality dashboard, which was developed with input from patients and carers. The dashboard monitors performance across ten key domains, including pain control, hospital admissions, early identification, advance care planning, and patient feedback.

The dashboard draws on both clinical and process data, and incorporates real-time feedback through SMS surveys sent to patients and carers. This enables the collection of timely, experience-based insights. The data can also be disaggregated by diagnosis, neighbourhood, ethnicity, and deprivation, supporting more detailed analysis of care variation and potential inequalities across the local population.

Observed impact

This approach has supported local commissioners and providers in their efforts to monitor service quality, identify areas for improvement, and allocate resources more effectively. The availability of structured data has also contributed to the development of business cases and supported targeted service redesign. Having a clearer view of where care is working well—and where there may be challenges—has enabled more informed planning and decision-making.

Conditions supporting implementation

Several enabling factors have contributed to the implementation and use of the register and dashboard. These include a long-standing focus on end-of-life care within primary care, which provided a foundation for engagement; financial support for data entry, helping to offset administrative burdens; and a clear commissioning commitment to using data for service improvement rather than solely for performance monitoring.

Additionally, the system benefited from a culture of collaboration among providers, commissioners, and patients, which helped ensure the tools developed were practical, relevant, and widely adopted.

EPaCCS in Northern Ireland

Electronic palliative care coordination systems (EPaCCS) – or key information systems (KIS) in Scotland and Northern Ireland – have been shown to benefit patients as they approach the end of life, as well as providing reassurance to their loved ones and those who care for them.[37]

In Northern Ireland, the Emergency Care Summary (ECS) is an electronic record that enables healthcare professionals to access essential patient information, such as medications and allergies, during urgent situations where they might not have access to the full GP record. This system is particularly beneficial in settings like Out of Hours services and Accident & Emergency departments.

Building upon the ECS, the Key Information Summary (KIS) was introduced to provide a more comprehensive overview for patients with long-term conditions or those with an advanced care plan. Created by GPs with patient consent, the KIS includes critical details about the patient's health status, care preferences, and special requirements. This information is accessible to healthcare providers across various services.[38]

The integration of ECS and KIS facilitated better coordination among healthcare providers, ensuring that patients received consistent and informed care across different settings. The Northern Ireland Electronic Care Record (NIECR) further enhanced this by consolidating information from various sources, providing a unified view of a patient's health record to authorised clinicians.

The Encompass program is replacing the Northern Ireland Electronic Care Record (NIECR). While the NIECR has been instrumental in allowing healthcare professionals to view patient information from multiple systems, it still relies heavily on paper records and lacks certain functionalities like electronic prescribing and telemonitoring. Encompass aims to address these limitations by introducing a comprehensive electronic health and care record that enables clinicians to document, prescribe, request, schedule, and communicate more effectively, thereby enhancing patient care across Northern Ireland.[39]

General practice and Primary Care are currently not within the scope of the Encompass programme. GP led teams will have access to Encompass via EpicCare Link. EpicCare Link is an online read-only view of a person’s electronic health record. Primary Care and Non-Trust clinicians can view patient records, place referrals and radiology orders.[40]

It is not explicitly stated in the available sources about how the Key Information Summary (KIS) and Emergency Care Summary (ECS) will be incorporated into Encompass.

Australian Palliative Care Outcomes Collaboration (PCOC)

Key takeaway for Northern Ireland

Australia's Palliative Care Outcomes Collaboration (PCOC) demonstrates how routine outcome measurement can enhance the quality, responsiveness, and benchmarking of palliative care. For Northern Ireland, it underscores the importance of structured data systems and clinical tools in driving continuous improvement. Services participating in PCOC have shown consistent improvements across many measures, including those that matter most to patients and families.

However, data from PCOC also highlights significant gaps in service delivery. In particular, access to palliative care remains limited for people who are socio-economically disadvantaged or from culturally diverse backgrounds. Stakeholders suggest that having best-in-class data is not enough—what matters equally is how that data is used to inform action and drive meaningful change.

The Palliative Care Outcomes Collaboration (PCOC) is a national program that aims to improve the quality and outcomes of palliative care in Australia. Established in 2005, PCOC is a unique collaboration between three Australian universities and a wide range of participating specialist palliative care services both in hospital and community based.

Since its inception, the program has grown significantly—from just 8 pilot sites to over 220 participating services in 2025. Participation in PCOC is voluntary and contribution to the collection is sought from all palliative care service providers in public and private health sectors, across all regions, and across inpatient and community settings. However, not all services participate in PCOC. Today, PCOC supports care for more than 60,000 patients annually. PCOC is funded by the Australian Government through the Department of Health and Aged Care. [44]

The data plays a central role in shaping specialist palliative care delivery across the country by helping services collect, analyse, and interpret clinical data to drive continuous quality improvement.

How Does PCOC work?

Participating services collect a prescribed set of clinical data at every episode of care. This data is submitted to the PCOC through a secure online portal, allowing for efficient entry, submission, and review. Once services begin collecting data, they have access to tools that allow them to check data completeness, identify errors, and ensure quality before submitting their data to the PCOC. The PCOC then analyses this data and provides each service with a set of detailed reports every six months. These include outcome reports, data summaries, benchmarking dashboards, and comparisons with national averages from other participating services.[45]

A range of challenges have been recognised with setting up a palliative care register including:

- The diversity of settings in which palliative care is delivered (hospitals, hospices, care homes, and at home)
- The difficulty of defining consistent outcome measures in a highly individualised area of care
- Limited validation of many current outcome tools for palliative populations
- Variability in digital infrastructure and recording systems across services
- The need to capture data on patients who could benefit from palliative care but are not currently receiving it.

To overcome administrative challenges, the PCOC offers a comprehensive support system for participating services throughout every stage of implementation, data collection, and quality improvement. During the implementation phase, PCOC provides guidance and resources to help integrate the framework into the service's day-to-day clinical and administrative practices. This support also assists services with meeting accreditation and quality standards.

Given that system interoperability can be a significant stumbling block in the development of palliative care registers, for services that don't have a system that is compatible with the portal, the PCOC provide them with a free, purpose-built data entry system so that they can still participate.

A key strength of PCOC is its commitment to education and continuous improvement. Services have access to PCOC Improvement Facilitators who provide personalised support. This includes guidance on data collection processes, help with interpreting reports, and assistance in planning and implementing quality improvement initiatives.

Additionally, services are encouraged to take part in 'Communities of Practice' which offer opportunities to network with peers, benchmark outcomes, and share ideas on how to improve care delivery.[46]

Outcome indicators and national benchmarks

One of the most significant aspects of PCOC's work is the development and monitoring of outcome indicators. These benchmarks provide an evidence-based way to measure how well palliative care services are performing. PCOC runs education sessions for clinical staff, focused on using the five PCOC tools effectively and interpreting outcome data.[47]

The tools used in PCOC to measure outcomes are clinically sound and based on strong evidence. They have been developed and tested through research to ensure they are reliable (producing consistent results) and valid (measuring what truly matters).

One example is the Symptom Assessment Scale (SAS), which is used to record how patients rate the severity of common symptoms like pain, breathlessness, and fatigue. It is a simple tool completed by the patient themselves, giving them a direct voice in their care. Research has shown that the SAS is a valid and responsive measure of symptom burden in palliative care, supporting timely clinical decision-making.

These tools are used alongside others such as the Palliative Care Phase and the Palliative Care Problem Severity Score (PCPSS), which have also undergone validation and are shown to help standardise care and improve outcomes across services. By using standardised and tested tools like these, services can confidently use the data to improve care, compare outcomes, and focus on what matters most to patients and families.

The PCOC tools are not only used to assess individual patient outcomes—they also serve as benchmarks that allow services to compare their performance over time and against others. By collecting standardised data at the point of care, services can track patterns and outcomes across key areas such as symptom management, functional status, and phase of illness.

For example, time in unstable phase measures the number of days the patient spent in an unstable phase. An unstable phase alerts clinical staff to the need for urgent or emergency intervention requiring an associated change in the existing care plan. Once assigned, and with the new care plan in place, the clinical team monitor for improvements in the patient and/or family/carer condition.[48] Under this measure, the benchmark for care is that 90% of cases in the unstable phase should be resolved within three days.

In 2023, the data on 90,800 palliative care episodes and 203,600 palliative care phases recorded in PCOC revealed that almost 9 in 10 (86%) unstable phases lasted for 3 days or less – 91% in inpatient settings and 80% in community settings.[49]

Similarly, when patients begin a phase of care with absent or mild symptoms, the clinical goal is to maintain that low level of distress. PCOC sets a benchmark that at least 90% of these phases should end with symptoms remaining in the absent-to-mild range. Services can use this benchmark to assess how effectively they are managing symptoms and where improvements might be needed.

About 9 in 10 palliative care phases that started with absent/mild symptom/problem remained absent/mild at the end of the palliative care phase – 88% each for pain severity, distress related to pain, fatigue, and family/carer problems. For distress related to breathing problems a higher proportion remained in the absent/mild phase (94%).[50]

This kind of benchmarking, grounded in validated tools and large-scale data, supports continuous quality improvement and helps ensure more consistent care across settings.[51]

Impact and broader use of PCOC data

PCOC data has a broad impact, not just at the service level but also at the national level. Services use their six-monthly reports to understand trends, identify areas for improvement, and adjust clinical practices accordingly. Researchers and policymakers also use PCOC's comprehensive dataset to inform studies and guide the development of national standards and policies for palliative care.

Final Thoughts

Despite improvements by participating services across various measures, the PCOC has revealed significant disparities in service delivery, particularly for individuals who are socio-economically disadvantaged or from culturally and linguistically diverse backgrounds. For example, access to services for those facing the greatest socio-economic disadvantage has declined over the past decade. Moreover, only a relatively small number of culturally and linguistically diverse older adults with Alzheimer's and other forms of dementia have accessed specialist palliative care, despite a substantial proportion of such individuals living in Australia. Stakeholders emphasise that while high-quality data is essential, it is not enough on its own; it must be translated into informed, equity-focused action to address these disparities and drive meaningful change.[52]

Portugal's integrated dialysis care model: Improving outcomes and reducing costs

Key takeaway for Northern Ireland

Portugal's integrated dialysis care model may offer useful insights for the development of palliative care services in Northern Ireland. While the clinical context is different, both areas involve caring for people with complex, long-term conditions where coordinated, patient-centred approaches are essential.

The Portuguese experience suggests that aligning funding with quality indicators, improving coordination through multidisciplinary teams, and investing in data systems can support better outcomes while managing costs. These features may have relevance for palliative care, particularly in efforts to reduce variation in care quality, improve access, and support more consistent service delivery across settings.

Background [53] [54] [55]

Portugal has one of the highest incidences and prevalence rates of Stage 5 Chronic Kidney Disease (CKD) in Europe, leading to End-Stage Renal Disease and the need for dialysis. CKD is a complex condition, primarily affecting elderly patients with multiple comorbidities, requiring a strict dialysis regimen of three treatments per week (four hours each).

In 2008, Portugal's Ministry of Health (MoH) identified that rising dialysis patient numbers and inefficiencies in the reimbursement system were making renal care financially unsustainable. The government sought to transition towards a more cost-effective system that could support quality improvement while maintaining financial efficiency.

Pre-2008 dialysis care model: fee-for-service structure

Before 2008, dialysis care in Portugal operated under a fee-for-service reimbursement model:

- Private dialysis providers were reimbursed per dialysis session administered
- The public sector managed vascular access surgeries, medication, and laboratory services.

This system created incentives based on treatment volume, which may have contributed to inefficiencies and limited focus on patient outcomes.

Transition to a capitation-based reimbursement model

To address these issues, the MoH introduced a capitation-based reimbursement model, which provided a fixed weekly payment per patient covering:

- Dialysis treatment.
- Laboratory and imaging tests.
- Medication (excluding vascular access surgeries).

A key characteristic of this model was that payment was linked to specific quality and performance indicators aligned with national and international dialysis care standards, including:

- Adequacy of dialysis (measured via Kt/V ratios).
- Hemoglobin level targets
- Bone metabolism and phosphate control
- Water quality used in dialysis
- Patient outcome measures such as mortality and hospitalisation rates.

Private providers failing to meet these indicators faced financial penalties, including reduced reimbursement rates, warnings, payment suspensions, or license revocation.

Provider adaptations to the new model show road map for integrated care

To comply with the capitation payment regulations, private providers implemented a number of operational changes:

- Optimised clinical practices: Dialysis prescriptions were refined to balance treatment quality and efficiency
- Internal Pay-for-Performance (P4P) systems: Incentives were introduced to reward clinics that exceeded efficiency and quality targets
- Enhanced auditing and monitoring: Introduced a centralised audit system to monitor compliance with performance indicators
- Upgraded IT systems: Automated data reporting tools helped improve transparency and support government compliance efforts.

Private providers assumed greater responsibility for medication and testing management, which contributed to efficiency improvements, including:

- Standardised procurement: Bulk purchasing, price negotiations, and increased use of generic medicines helped reduce costs.
- Integrated pharmacy services: On-site pharmacies enabled closer monitoring of prescriptions and adherence to treatment guidelines.
- Medication reconciliation: Pharmacists helped ensure accurate and efficient medication use, reducing waste and supporting patient safety.

Further refinements as part of 2011 economic reforms

During the 2011 economic downturn, the MoH sought a 6% reduction in dialysis reimbursement rates. Industry negotiations led to a compromise of a 2% reduction, with vascular access surgeries included in the capitation package.

- Some providers, like NephroCare, established specialised surgical centres for vascular access to improve outcomes and reduce complications.

- Others, like Diaverum, outsourced vascular access surgeries under capitated agreements with external partners.

Introduction of Patient Care Coordination in 2014

To enhance care integration further, Diaverum launched the Patient Care Coordination (PCC) initiative in 2014, which included:

- Interdisciplinary care teams: Nephrologists, nurses, social workers, pharmacists, and nutritionists collaborated to develop personalised care plans.
- Patient education programmes: Structured training aimed to improve patient understanding and adherence to treatment.
- Vascular access optimisation: Emphasis was placed on increasing the use of arteriovenous (AV) fistulas for more stable outcomes.
- Advanced IT integration: Improved patient monitoring and compliance reporting supported ongoing quality assurance.

Observed Outcomes

Clinical quality

A review of the capitation model two years after its introduction found improvements across key clinical quality indicators, suggesting that care standards remained stable or improved under the new payment model.

Between 2008 and 2019, despite an ageing dialysis population with increasing comorbidities, mortality and hospitalisation rates either remained stable or showed signs of improvement.

Anaemia management also improved: the average weekly dose of erythropoietin (EPO) medication fell by 40% between 2008 and 2019. This suggests clinics may have become more consistent in using the appropriate amount of medication, contributing to safer and more effective anaemia care.

Patient experience

Patient satisfaction scores remained high throughout the reform period, increasing from 90.8 in 2013 to 94.6 in 2018. These gains have been linked to improved communication, more personalised care, and higher trust in services.

Following the launch of the PCC initiative in 2014, satisfaction scores improved in five of the six subsequent years.

Efficiency gains

Several areas saw reductions in cost and improved efficiency:

- Pharmaceutical costs decreased by 31% due to centralised procurement and more consistent prescribing practices.
- Laboratory costs fell by 21% through the elimination of redundant testing.
- Total cost of care dropped from EUR 35,000 per patient in 2010 to EUR 30,000 in 2011—a reduction of approximately 10.5%.
- Procurement efficiencies were achieved through standardised purchasing agreements.

Accountability and transparency

The capitation model also supported greater transparency and accountability through the use of key performance indicators (KPIs), which helped monitor provider performance in a consistent way.

Private providers took on broader responsibility for overall service provision, and the simplified reimbursement structure helped reduce administrative burden. More predictable healthcare spending was another reported benefit, with capitation supporting better budget forecasting and planning.

Stockholm’s bundled payment and proms-based care reform

Key takeaway for Northern Ireland

Stockholm County’s shift to bundled payments for joint and spine surgery demonstrates how aligning funding with outcomes can support better resource use, reduce complications, and incentivise quality improvement. PROMs were central to evaluating patient experience and guiding provider accountability.

For palliative care in Northern Ireland, this model offers potential insights into how value-based approaches, when supported by robust data and multidisciplinary care pathways, may help improve consistency, promote person-centred outcomes, and support more efficient use of resources. The Swedish experience also highlights the need for appropriate outcome measures and fair benchmarking to ensure such models are both clinically meaningful and equitable.

Background: Sweden’s health data infrastructure

Sweden has a long tradition of using national quality registries to support the evaluation and improvement of healthcare services. These registries, developed in collaboration with healthcare providers and the Swedish Association of Local Authorities and Regions (SALAR), cover a wide range of clinical areas and have been used to track outcomes, support clinical research, and inform system-level improvements. Around 50 of the country’s approximately 100 national quality registries contribute data to *Vården i siffror* (Healthcare in Numbers), a publicly accessible platform for reporting health quality indicators.

While there have been issues with regional variation and data completeness in some areas, the overall infrastructure for health data in Sweden is considered strong.

Many registries have achieved high levels of coverage and are used to inform quality improvement and policy decisions at both local and national levels.[56]

The Swedish Register of Palliative Care (SRPC) was established in 2005 with the aim of improving end-of-life care across all settings, regardless of diagnosis or location. It collects data on key aspects of palliative care delivery, including symptom management, communication, and care planning. Over time, the register has expanded to include indicators related to emotional well-being, caregiver burden, and the preservation of patient dignity at the end of life.

The SRPC contributes to Sweden's broader efforts to support patient-centred care and continuous improvement. By linking outcome data with clinical practice, the register enables healthcare providers to identify areas for development and to benchmark care delivery across settings. The SRPC plays an important role in supporting equitable and consistent palliative care services.[57]

Stockholm's Orthochoice payment model

The Swedish health care system is mainly government-funded, universal for all citizens and decentralised. Regional responsibility for financing and providing health care is decentralised to the 21 county councils.[58]

Prior to reform in 2009, more than 18,000 primary hip replacement surgeries were performed annually across Sweden in approximately 75 orthopaedic providers, including region-owned local, central, and university hospitals, as well as some private specialised centres. These providers were generally reimbursed through a fee-for-service structure.

In 2009 Stockholm County Council (SCC) introduced a bundled payment model in 2009 for hip and knee replacements for lower risk patients. The reform aimed to move away from this fee-for-service structure towards value-based care, while reducing lengthy surgical waiting times, which had reached up to two years.

Providers received fixed payments to cover all aspects of the care pathway, diagnostics, surgery, rehabilitation, and follow-up, with responsibility for complications extending up to two years post-surgery. Bonus or penalty payments of up to 3% were linked to the achievement of defined health outcome thresholds.[59]

Reform design and early outcomes

The reforms included patient choice of provider and open entry for new providers through accreditation. Before the reform, patient choice was limited to primary and outpatient care. While patients were covered by the national healthcare guarantee—which entitled them to care elsewhere if waiting times were exceeded—they had no influence over where care would be provided.

To become accredited, providers had to meet specific criteria, including reporting requirements for quality indicators and a minimum of 50 surgeries per year for each operating surgeon. Data used to monitor performance came from local patient administrative systems and national quality registries.

Within two years of implementation, the programme was associated with an 18% reduction in complications, 23% fewer reoperations, and a 19% decrease in revision surgeries. For the county, the total cost of primary hip and knee replacement surgery fell by three percent, even though total volumes increased by 21 percent. Patient flow also shifted, with more individuals choosing efficient specialist clinics over high-cost acute hospitals.[60]

Despite strong overall clinical outcomes, specific patient-reported outcome measures (PROMs) collected via the Swedish Hip Arthroplasty Register (SHAR) showed no significant improvement in quality-of-life metrics such as EQ-5D and VAS pain scales. The EQ-5D is a standardised tool used to measure health-related quality of life across five dimensions, while the Visual Analogue Scale (VAS) assesses a patient's self-rated pain intensity.

Researchers reported that may reflect high baseline PROM scores pre-intervention or limited sensitivity of the tools to detect marginal gains.[61]

Expansion to spine surgery

In 2013, Stockholm County Council (SCC) expanded its bundled payment model to include spine surgeries, focusing on lumbar spinal stenosis. Due to the complexity of these cases, the model incorporated advanced analytics and predictive modelling to adjust payments according to patient risk.

The financial structure of this model featured performance-based adjustments, with potential bonuses up to 6% and penalties, depending on patient-reported outcomes measured one-year post-surgery. These outcomes were assessed using the Global Assessment (GA) metric, where patients reported changes in their pain levels compared to pre-surgery. [62]

Over a three-year period, clinics participating in this program observed significant improvements:

- Reoperation rates: A 28% reduction in reoperations was noted, contrasting with a 44% increase at non-participating clinics within Stockholm County and an 18% increase in other Swedish counties without a bundled payment program during the same timeframe
- Hospital length of stay: The total length of stay for lumbar spinal stenosis patients decreased by 28% at participating clinics, compared to a 1% reduction at non-participating clinics
- Cost efficiency: The average cost per episode declined by 9%, and the average cost per surgery decreased by 7%.

These findings suggest that the bundled payment approach in spine surgery within Stockholm County led to enhanced patient outcomes and operational efficiencies.

Germany’s OptiMedis integrated care model

Key takeaway for Northern Ireland

Regional, accountable care models such as OptiMedis suggest that it is possible to better align financial incentives with prevention, community-based services, and improved care coordination. These models have been associated with improved health outcomes and more efficient system performance. For Northern Ireland, this may highlight the potential value of exploring shared savings mechanisms, investing in integrated data infrastructure, and supporting local partnerships to strengthen person-centred, preventative care.

Background and context

Germany operates a universal healthcare system primarily funded through a mandatory social health insurance (SHI) model, in which both employers and employees contribute to sickness funds that provide healthcare coverage. This system ensures access to comprehensive services for the entire population.[1]

Despite its strong coverage, Germany’s healthcare system has historically struggled with fragmentation, service duplication, and avoidable hospital admissions due to poor coordination across care sectors.[63]

In response to these challenges, OptiMedis, a Hamburg-based social enterprise, developed a population-based integrated care model in 2005. The model focuses on shifting the system from reactive treatment to proactive, preventative, and value-driven care. OptiMedis acts as a regional integrator, supporting collaboration among healthcare providers, sickness funds, and community stakeholders to deliver more coordinated, effective care. Their approach uses data to manage population health,

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supports shared goals across sectors, and reinvests system savings into improving local health services.[64]

Though based in Germany, OptiMedis has influenced health reform internationally. It has worked with NHS England and Integrated Care Systems in the UK on population-based commissioning pilots, advised health systems in the Netherlands, and supported reforms in France and Belgium. The organisation also contributes regularly to global health policy forums such as the OECD, WHO Europe, and the European Union.[65]

How the model works: Shared savings in action

The core of the OptiMedis model is a shared savings contract between the integrated care network and the sickness funds. Together, they set an expected level of healthcare costs for a defined population, based on risk-adjusted forecasts. Providers then work together to reduce avoidable care costs by improving prevention, early intervention, and coordination across services.

If actual costs come in lower than expected, the savings are shared. A portion goes to the integrated care network to fund further integration efforts, performance bonuses, and innovation. The remaining savings are retained by the insurer. This creates a direct financial incentive to improve outcomes and reduce inefficiencies.

To prevent cost-cutting that harms care, the model includes mandatory quality standards, continuous monitoring, and safeguards to ensure patient access is maintained or improved.[66]

Financing and reinvestment

The model applies to a clearly defined patient population, preventing “cherry-picking” of easier-to-treat cases. Shared savings are reinvested locally into digital tools, staff development, and service redesign. In doing so, the model creates a positive feedback loop: improved outcomes lead to savings, which are then used to further strengthen the system.

Performance is continuously measured against agreed benchmarks to ensure care remains safe, accessible, and equitable.[67]

Outcomes and impact

Independent evaluations and projections by the OECD suggest the OptiMedis model could have major long-term impacts:

- 146,000 additional life years could be gained by 2050
- Over 97,000 disability-adjusted life years could be avoided
- Estimated €3,470 saved per person in healthcare spending
- Significant reductions in hospital admissions in pilot regions
- Improved care quality without limiting access to services.

These results demonstrate that integrated care can deliver both better health and better value.

Table 6: OptiMedis payment model - timeline of development

Year	Milestone
2005	OptiMedis model launched with pilot regional networks
2008–2012	Refinement of the shared savings model and introduction of quality safeguards
2014–2018	Expansion to more regions and introduction of digital health tools
2019–2023	Independent evaluations confirm long-term cost savings and quality gains
2024+	Continued scaling and international adaptation efforts

Challenges and considerations

While the model has shown strong results, several challenges remain:

- Scalability**:** Adapting the model to new regions with different systems and structures is complex and requires local tailoring[68]
- Data integration**:** Achieving secure, interoperable data sharing is essential for effective population health management[69]
- Stakeholder alignment: Sustained collaboration is crucial, especially in sectors like mental health or social care where coordination can be more difficult.
- Financial sustainability**:** The shared savings approach must remain viable and equitable over the long term, with transparent reinvestment processes.[70]

United Kingdom: shifting approaches to measuring quality in primary care

Key takeaway for Northern Ireland

As Northern Ireland transitions from QOF to the NI Contract Assurance Framework (NICAF), there is an opportunity to rethink how quality is defined and measured across general practice and wider primary care. This shift reflects a broader trend across the UK toward simplifying payment models for general practice and moving away from complex, indicator-heavy frameworks. Embedding outcomes that reflect what matters most to patients — alongside more integrated approaches to service delivery — could support improved coordination and continuity of care, particularly for people with complex or ongoing needs.

Overview[71]

Across the UK, the Quality and Outcomes Framework (QOF) has played a central role in measuring and incentivising the quality of primary care since its introduction in 2004. As a national pay-for-performance scheme, QOF financially rewarded general practices for achieving a wide range of clinical and organisational targets. In 2023/24, these covered four domains: maintaining disease registers; clinical care (including chronic disease management); public health (e.g. vaccination uptake and risk factor reduction); and quality improvement initiatives (such as workforce wellbeing and addressing capacity issues).

Evidence suggests that QOF has had a significant impact on embedding structured care processes in general practice, particularly in relation to chronic disease management. Evaluations have also shown that it encouraged a more systematic approach to care and incentivised some secondary prevention efforts. However, the framework has also attracted sustained critique. There is limited evidence that QOF has driven meaningful improvements in primary prevention or broader public health outcomes. Some GPs have expressed concerns about increased administrative burden, and a tendency toward a mechanistic or transactional style of care focused on process measures rather than patient-centred outcomes.

Furthermore, QOF’s evolution over time—alongside the introduction of additional payment mechanisms like the Impact Investment Fund (IIF) and Primary Care Network (PCN) Directed Enhanced Services (DES)—has added complexity and bureaucracy. Indicators have often shifted away from strong evidence-based foundations, and the cumulative reporting requirements have made the system increasingly difficult to navigate.

Evolving approaches

Recognising these challenges, devolved nations have begun to diverge in their approach:

- Scotland abolished QOF in 2016, replacing it with a more collaborative and qualitative system focused on quality circles and continuous improvement within GP clusters. However, research found that the removal of QOF was followed by reductions in recorded quality of care across many indicators, underscoring the need for careful design and implementation of alternatives.

- Northern Ireland has now opted to replace QOF with a new approach known as the NI Contract Assurance Framework (NICAF). This marks a substantial change in how quality will be monitored and incentivised going forward. NICAF consists of six domains—including one for Access—with the intention that these will evolve to provide enhanced assurance over service quality across each area. In the 2024/25 contract agreement, QOF funding totalling £38.9 million was repurposed to support core services and indemnity cover for GPs.

Key features of this transition include:

  - The Clinical Care Domain will replace QOF, with expectations that practices deliver these services as clinically appropriate
  - Several Enhanced Services (e.g. for amber drug monitoring, alcohol interventions, and chronic respiratory care) will also be incorporated into this core Clinical Care Domain
  - A portion (£5 million) of the repurposed funding will support GP indemnity on an interim basis
  - The remaining £33.9 million will be distributed to practices via the Global Sum, based on patient list sizes as of April 2024.

While the full workings of NICAF are still being finalised, the Department of Health has stated that assurance over the required level of care will be provided through this framework.[72] [73]

Wales: harnessing data and outcomes to drive value-based care

Overview

Wales has emerged as a leader in adopting data-driven, value-based healthcare approaches. This effort is part of broader initiatives led by the Welsh Value in Healthcare Centre, which collaborates with international organisations such as the World Economic Forum and the OECD to enhance outcome-focused care.

A key feature of this approach is the integration of Patient-Reported Outcome Measures (PROMs) across clinical pathways. PROMs provide insight into patients' quality of life, symptom burden, and treatment experiences—offering a more holistic view of care that goes beyond traditional clinical metrics. Wales has developed 47 PROMs pathways across a range of specialties, allowing outcomes to be linked with costing data to inform targeted interventions and optimise the use of resources.

This case study presents two examples that illustrate how the strategic use of data and patient-reported outcomes can inform and improve care delivery:

How Aneurin Bevan University Health Board used prescribing and service data to reallocate resources and improve COPD management.

How Cardiff and Vale University Health Board is embedding PROMs in myeloma care to support personalised treatment decisions and enhance patient-clinician communication.

Together, these initiatives show how combining clinical and financial data with patient-reported outcomes can support the development of more responsive, equitable, and sustainable health services—offering valuable insights for healthcare systems across the UK, including Northern Ireland.

Improving COPD care through data-driven decision-making

Key Takeaway for Northern Ireland

The ABUHB (Aneurin Bevan University Health Board) example illustrates how a value-based, data-informed approach can support improved outcomes and more efficient use of resources by reducing low-value care and prioritising interventions with greater impact. For Northern Ireland, it highlights the potential benefits of investing in data analytics to identify inefficiencies, optimise prescribing practices, and inform more effective resource allocation.

The approach also emphasises the importance of collaboration between clinical and financial teams, and the opportunity to reinvest savings into preventative and community-based services. These principles are particularly relevant to palliative care, where proactive planning, integrated working, and targeted investment can improve patient experience while supporting more sustainable system performance.

Overview[74]

Aneurin Bevan University Health Board (ABUHB) in South Wales has adopted a value-based healthcare approach to improve the management of chronic obstructive pulmonary disease (COPD). By redirecting resources from lower-value interventions to those with greater clinical impact, the initiative achieved cost reductions alongside improvements in patient outcomes. The use of data was central to the process, helping to identify inefficiencies, support informed decision-making, and assess the effectiveness of the changes introduced.

Insights from prescribing and service use data

An analysis of prescribing patterns and hospital admissions in Gwent during 2014/15 highlighted high levels of spending on respiratory medications. Of the £17.3 million spent, approximately £16 million was allocated to inhaled therapies for asthma and

COPD. However, despite this investment, hospital admissions for COPD remained the highest in Wales—raising questions about the effectiveness of current treatment strategies in improving patient outcomes.

Further examination revealed that 61% of patients with mild-to-moderate COPD were receiving triple therapy (ICS/LABA), despite NICE guidelines advising against its use in this group. In addition, 45% of inhaled corticosteroid (ICS) prescriptions were for high-strength formulations, exceeding recommended dosing levels. These findings raised concerns about potential over-prescribing without corresponding clinical benefit. The absence of standardised prescribing practices across primary and secondary care settings contributed to this variation and inefficiency.

The analysis also identified significant variation in access to pulmonary rehabilitation, a well-evidenced intervention known to improve outcomes for people with COPD. Meanwhile, many asthma patients were found to be missing their annual reviews, potentially increasing the risk of poorly managed symptoms and inappropriate medication use.

Implementing data-driven solutions

Drawing on these insights, Aneurin Bevan University Health Board (ABUHB) developed a strategic intervention plan aimed at reducing low-value prescribing and reinvesting savings into evidence-based care. Key components of the approach included:

- Optimising prescribing practices by aligning treatment decisions with national guidelines, reducing the use of high-strength inhaled corticosteroids (ICS), and promoting more cost-effective medication choices
- Improving medication adherence by simplifying inhaler options and enhancing inhaler technique through "train the trainer" programmes delivered to healthcare professionals
- Addressing underuse of asthma reviews through a community pharmacy pilot, which helped identify and support patients who had missed routine appointments

- Expanding pulmonary rehabilitation services, using savings achieved through medicines optimisation to improve access for patients most likely to benefit
- Enhancing collaboration between finance and clinical teams to support more flexible allocation of resources based on patient need, rather than traditional budgetary silos

Measuring success and impact

Ongoing data monitoring indicated notable improvements following the implementation of ABUHB's value-based interventions. Between 2014 and 2017, the health board reported the following outcomes:

- A £1.3 million reduction in respiratory prescribing costs, primarily achieved through more appropriate and targeted medication use
- A 9.2% decrease in the average cost per respiratory medication item, reflecting improved cost-efficiency
- A 16% reduction in high-strength inhaled corticosteroid (ICS) prescriptions, better aligning with clinical best practice
- A decline in short-acting beta agonist (SABA) prescriptions, suggesting improved long-term disease control and reduced reliance on reliever medications

These findings reinforced the value of a data-driven approach in supporting more effective resource allocation. Rather than focusing solely on cost reduction, the strategy aimed to redirect funding towards interventions that improve patient outcomes—such as pulmonary rehabilitation and enhanced medicines management.

Looking ahead, the next phase of work will involve the systematic collection of patient-reported outcomes to ensure that improvements in care continue to reflect patient needs and experiences. This initiative illustrates how aligning financial decision-making with clinical priorities can support the delivery of sustainable, high-quality care—a model that may have relevance for other chronic disease areas, including palliative care.

Improving myeloma care with PROMs

Key takeaway for Northern Ireland

The integration of patient-reported outcome measures (PROMs) into myeloma care is helping to strengthen understanding of patient needs and improve the responsiveness of clinical care. In Wales, PROMs are being embedded into routine decision-making, quality of life clinics, and national data dashboards, supporting a more evidence-informed, person-centred approach to cancer care. Future developments in digital communication are expected to further enhance this work, with the aim of not only extending survival but also improving quality of life for patients living with myeloma.

The role of PROMs in myeloma care[75]

Patient-reported outcome measures (PROMs) play an important role in monitoring and improving the quality of care for individuals living with myeloma—a condition characterised by complex clinical needs and a wide range of treatment options. Unlike many other cancers, myeloma is currently incurable; however, treatment can substantially extend life and alleviate symptoms. This places particular importance on ensuring that care aligns with patients' individual needs, preferences, and quality of life goals.

Patients with myeloma often face challenging treatment decisions. While many therapies can be highly effective, they may also carry a risk of significant toxicity and side effects. Given that many patients are older or living with frailty, it is vital to balance clinical benefit with the potential impact on day-to-day life. PROMs offer meaningful insights into the lived experience of treatment, going beyond clinical indicators to assess how care is affecting patients' overall wellbeing.

Dr. Ceri Bygrave, Clinical lead for Myeloma at Cardiff and Vale University Health Board (CAV UHB), explains

> “PROMs help answer the critical question: Is this treatment actually making a difference? If chemotherapy leaves someone too fatigued to enjoy life outside their home, is it truly beneficial? Without PROMs, we risk overlooking what really matters to patients.”
>
> — Dr Ceri Bygrave, Clinical Lead for Myeloma, Cardiff and Vale University

Addressing challenges in symptom reporting

One recognised challenge in using PROMs is that patients may underreport their symptoms during face-to-face consultations, sometimes due to concerns that disclosing discomfort could result in changes to or withdrawal of treatment. In contrast, completing PROMs in private may provide a more comfortable setting for patients to report issues such as fatigue, pain, or emotional distress.

To help address this, patients who consistently report low PROM scores are now offered a review at a specialist Quality of Life Clinic. These clinics provide additional support for managing side effects, psychological wellbeing, and social concerns—ensuring that care remains responsive to the full range of patient needs.

Bringing PROMs and clinical data together

Patient-reported outcome measures (PROMs) become even more valuable when combined with clinical and demographic data. In Wales, this integrated approach is being implemented through the Welsh National Myeloma Dashboard, which brings together information on:

- Survival rates and treatment responses
- Quality of life indicators
- Patient demographics, including age, gender, and geographic location

By combining real-world clinical outcomes with patient-reported experiences, the dashboard offers a more comprehensive understanding of how different treatments affect patients—at individual, regional, and national levels. This supports the identification of trends, helps to highlight potential inequalities in care, and enables the refinement of treatment approaches.

Next steps: enhancing communication

Looking ahead, the development of a two-way digital communication system between patients and clinicians is seen as an important next step in improving myeloma care. Such a system would allow:

- Patients to report symptoms or side effects in real time
- Clinicians to monitor patient wellbeing between appointments
- More timely and personalised adjustments to care plans

Dr Bygrave envisions a digital application where patients can log side effects, track treatment cycles, and receive automated guidance for common concerns. This could help reduce delays in care and improve the overall patient experience.

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