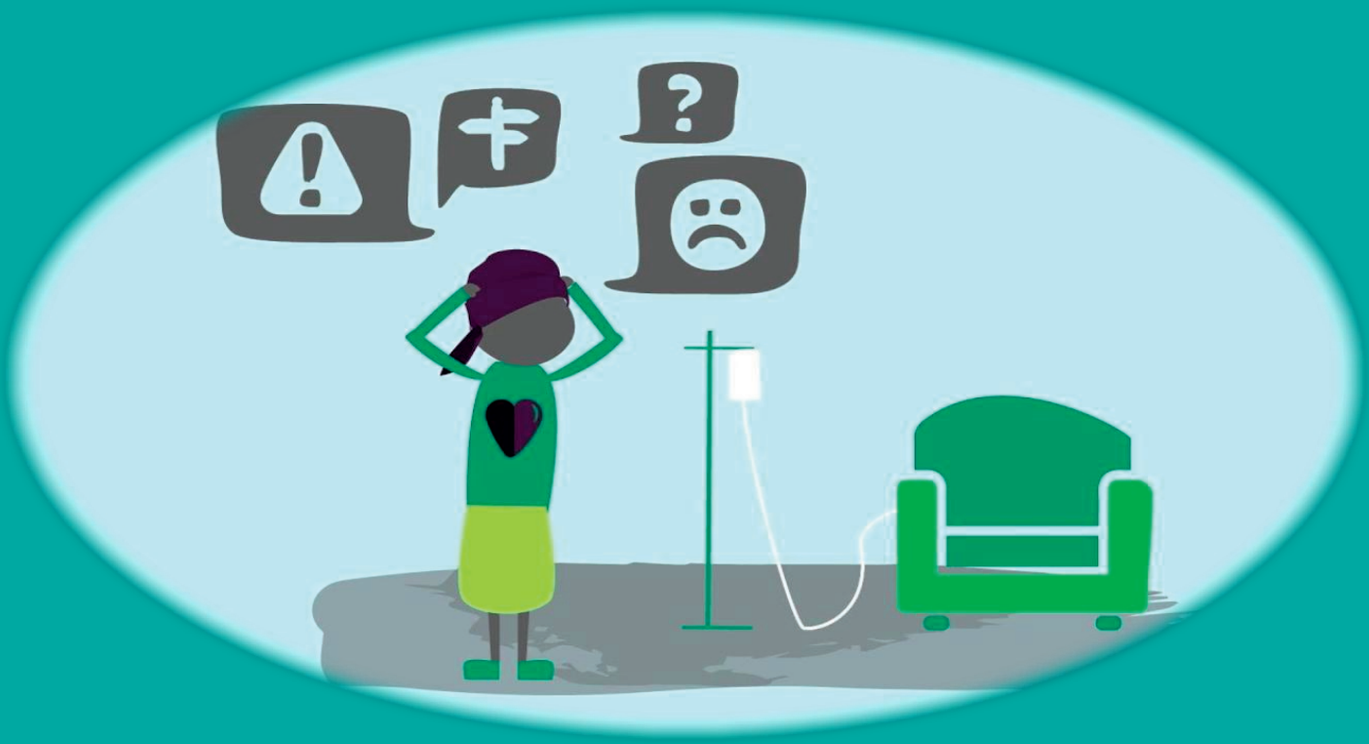
Macmillan Personalised Care Support Worker Test of Change Phase 1 Northern Ireland Evaluation Report May 2026



Strengthening the culture of person-centred care

NICaN Northern Ireland Cancer Network | HSC Public Health Agency | HSC Northern Health and Social Care Trust | HSC Southern Health and Social Care Trust | Macmillan Cancer Support

Executive Summary

The *Macmillan Personalised Care Support Worker (PCSW) Test of Change was implemented to assess the contribution of a non-clinical, personalised care role within cancer services. The evaluation demonstrated measurable impact, including improved access to **Holistic Needs Assessment (HNA), timely support, and enhanced coordination of care. The model supported earlier identification of concerns, reduced duplication across services, and released clinical capacity by addressing non-clinical needs within a structured framework. The findings indicate that the PCSW role adds value to the cancer pathway and provides a scalable, evidence-based model for wider implementation.

Key points:

Macmillan Cancer Support funded the Test of Change project in Northern Ireland.

The pilot project provided funding for 3.2 WTE Band 4 Personalised Care Support Workers (PCSW).

Northern Health & Social Care Trust (NHSCT) and Southern Health & Social Care Trust (SHSCT) were chosen as pilot sites representing 2 of the 5 Health & Social Care Trusts.

Timescales

January 2025 and February 2026 (14 months).

Outcomes

The Test of Change demonstrated measurable impact:

- Increased delivery of holistic needs assessments
- A strengthened culture of person-centred care
- Improved identification and escalation of concerns
- Release of CNS time for complex clinical care

As a result of the evidence generated through this Test of Change, Macmillan Cancer Support has committed a further £1.6 million for three years to support regional roll-out of this PCSW model, strengthening equity of access to person-centred care and supporting more effective use of Cancer Clinical Nurse Specialist (CNS) expertise.

* *The Macmillan Personalised Care Support Worker role will be abbreviated to PCSW for the remainder of this document.*

***A Holistic Needs Assessment (HNA) is a structured conversation used to identify and address a patient's physical, emotional, social, and spiritual needs to create a personalised care plan.*

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Background and Rationale

1. Strategic and Policy Drivers for Person-Centred Care

The value of person-centred care is consistently recognised across key policies and strategic priorities in Northern Ireland and by Macmillan Cancer Support. These frameworks collectively provide a strong rationale for workforce roles that enhance continuity of care, personalised support, and effective coordination across the cancer pathway.

- **The Cancer Strategy for Northern Ireland 2022- 2032,** Department of Health (DoH, 2022) sets out a clear ambition to support people to live well and die well following a diagnosis of cancer. It recognises that individuals require coordinated care and support throughout all stages of the cancer pathway – from diagnosis, through treatment, living with and beyond cancer. Central to this ambition is the delivery of high- quality, holistic, and person-centred care that responds to individuals' physical, emotional, social, and practical needs, exemplified within:

Action 39, which mandates that every person diagnosed with cancer has a CNS as their key worker.

Action 36, which requires that all patients are offered Holistic Needs Assessment (HNA) and a personalised care plan.

- **Delivering Together: Health and Wellbeing 2026** (DoH 2016): further emphasises person-centred care, multidisciplinary collaboration, and workforce sustainability. It supports service models that empower individuals, improve continuity, and enable workforce transformation – providing a clear policy context for support worker roles within cancer services.
- **The Living With and Beyond Cancer** (LWBC) approach, endorsed through the NI Cancer Strategy and the Northern Ireland Cancer Network, promotes holistic needs assessment, personalised care and support planning, supported self-management and stratified follow-up. PCSW roles directly enable delivery of these components, particularly for people with ongoing physical, psychological or social needs following active treatment.
- **The HSC Reset Plan 2025** reinforces a system-wide commitment to stabilising services, reforming delivery, and accelerating transformation, with a strong emphasis on sustainability, workforce wellbeing, and person-centred care.
- **Digital transformation** also plays a critical enabling role. The introduction of Encompass supports integrated, person-centred care through a shared electronic record, improving communication, continuity, and coordinated decision-making across services. Regional agreement through the NICAN Nurse Leaders Reference Group to adopt the Macmillan electronic Holistic Needs Assessment (eHNA) for adult cancer services further strengthens person-centred care delivery by providing a consistent mechanism for offering HNAs and generating actionable care plans.
- **Macmillan Cancer Support Strategy 2025-2030** reinforces these priorities through its focus on personalised care, patient empowerment, and the use of innovative workforce models to improve outcomes and experience across the cancer pathway.

Background and Rationale

2. Population Need

Projections indicate that by 2040, cancer incidence rates across the UK will rise to approximately 625 cases per 100,000 population annually. In Northern Ireland, on average more than 14,000 people are diagnosed with cancer annually, equating to approximately 30 new diagnoses each day. This increase is largely attributable to an ageing population. Around 17% of the population is currently aged over 65 and projected to increase by 25% over the coming years. As a result, cancer prevalence continues to rise, with increasing numbers of people living with and beyond cancer.

The demographic shift, combined with improved survival, places growing demand on person-centred support to address short and long-term physical, psychological, social and practical needs, and to support patient empowered self management.

3. Workforce Pressures and Capacity Constraints

The current workforce pressures within cancer nursing services limit capacity to provide assurance that every patient will be offered a Holistic Needs Assessment (HNA), as mandated by the Cancer Strategy for Northern Ireland.

NI Cancer Nursing Workforce Census (DoH, 2022) identified a number of key challenges impacting sustainability and service delivery, including:

- An ageing workforce, with 30% of Cancer Nurse Specialists (CNSs) aged 50 years and over, highlighting future sustainability risks
- Vacancy rates of 23% within the unregistered workforce, later confirmed through targeted audit
- Significant variation in regional approaches to cancer nursing job roles, limiting consistency, and effective workforce planning

Further workforce analysis identified the need for 76% increase in CNS posts to meet projected population need across Northern Ireland.

Background and Rationale

4. Value of skill mix

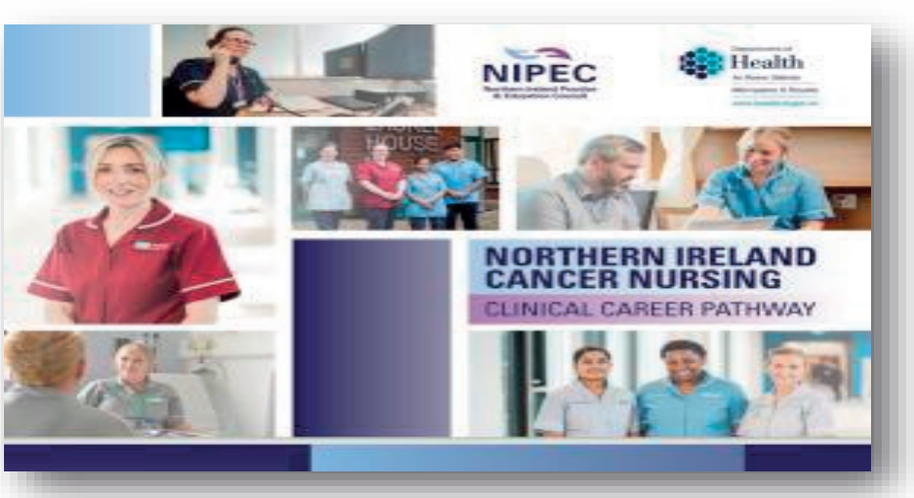
The population trends reinforce the importance of expanding and diversifying the cancer workforce. As demand increases it is imperative to consider capacity and efficiency in the cancer workforce. Optimising nursing contributions through a skill mix is essential to enable sustainable transformation within Health and Social Care Cancer Services.

The Band 3 Cancer Support Worker role has made a valued contribution to CNS teams, predominately through administrative functions such as clinic coordination, patient liaison, and data management.

Learning from the implementation of Improving the Cancer Journey (ICJ) model in Scotland provided valuable insights into the potential development of a Personalised Care Support Worker (PCSW) role. The Scottish ICJ was not intended to be replicated within Northern Ireland. Instead, it offered transferable, evidence-based insights that could be adapted to the local context.

5. Alignment to Cancer Nursing Clinical Career Pathway

The proposal to undertake a Test of Change using a structured service improvement approach was supported by the Chief Nursing Officer, Professor Maria McIlgorm and also the Northern Ireland Cancer Network (NICaN) Nurse Leader Reference Group. This furthermore provided opportunity to test alternative skill mix models and role development within the NIPEC Northern Ireland Practice and Education Council



The proposed Macmillan Personalised Care Support Worker would work alongside the CNS as an integral part of the cancer team to ensure that a holistic needs assessment would be offered to individuals diagnosed with cancer.

Testing in Partnership and Collaboration

The Test of Change approach was enabled through partnership working underpinned by shared governance and a strong commitment to co-production.

Central to this approach was the active involvement of two **Macmillan Lived Experience panel members**, whose insights and perspectives helped ensure that the design, implementation and governance of the Test of Change remained truly person- centred.

Governance and Oversight

An oversight group was established to provide strategic direction, governance, and collective accountability for the Test of Change. The group was chaired by the Public Health Agency (PHA) Nurse Consultant on behalf of the Northern Ireland Cancer Network (NICaN) Nurse Leaders Reference Group.

Core membership included:

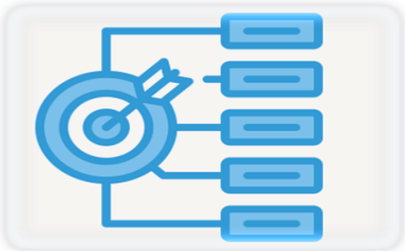
- Cancer Service Improvement Leads from the Southern Health and Social Care Trust and the Northern Health and Social Care Trust
- The PHA Macmillan Regional Nurse Project Lead
- Representatives from Macmillan Cancer Support
- Two Patient and Public Involvement (PPI) representatives, one from each participating Trust

The PPI representatives contributed actively, supporting the training and induction of the Macmillan Personalised Care Support Workers (PCSWs) and acting as named buddies throughout the Test of Change. This approach strengthened relational support for staff in post and ensured continuous engagement with lived experience throughout delivery.

The oversight group was responsible for providing guidance and assurance, supporting risk identification and mitigation, monitoring implementation progress, and facilitating learning and adaptation during the Test of Change. Clear communication and accountability mechanisms were maintained with key stakeholders, ensuring transparency and shared ownership of both the process and outcomes.

Diagram 1 Key Stakeholder Engagement

Aim and Objectives



The evaluation of the Test of Change was designed to demonstrate the extent to which the PCSW role delivered on defined aim and objectives of the role. The evaluation would also generate evidence to inform the case for wider implementation of the role across Northern Ireland and the potential for sustainable funding.

Aim

The Macmillan Personalised Care Support Worker role aims to deliver person centred care through the offer and completion of Holistic Needs Assessments, enabling coordinated access to appropriate support across the cancer pathway.

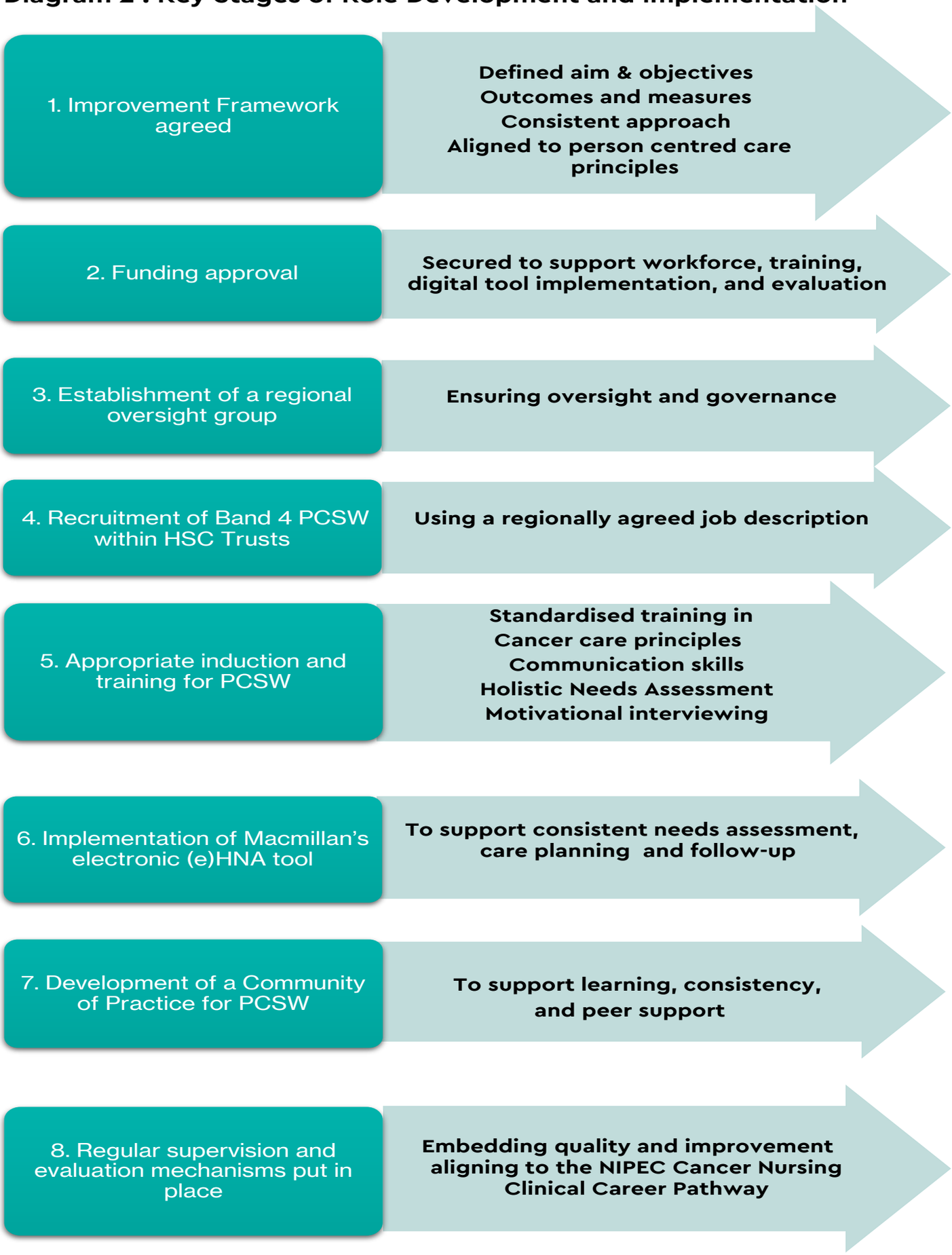
Objectives

This aim will be achieved thorough the following objectives:

- To support people affected by cancer to identify their holistic needs and articulate what matters to them
- To empower people living with cancer to access timely and appropriate support that enables them to live as well as possible
- To strengthen the delivery of person-centred care across the cancer pathway
- To increase the number of people offered and supported to complete a Holistic Needs Assessment (HNA) and personalised care plan.

Role Development and Implementation

Diagram 2 : Key Stages of Role Development and Implementation



Project Evaluation:

The oversight group developed and agreed an evaluation plan aligned to the five dimensions of the **Quintuple Aim** for Healthcare Improvement.

This framework provided a structured approach to assessing the contribution of the PCSW role to value-based cancer care, capturing impact across patient experience, population health, cost and resource use, staff wellbeing, and health equity, whilst reflecting a system-wide contribution of personalised care roles within cancer services. The following sections present evaluation assumptions under each dimension of the Quintuple Aim:

Improving Population Health

By enabling earlier identification of unmet need and more consistent delivery of holistic assessment and support, the role contributes to reducing variation in access to person-centred care and supporting improved outcomes across the cancer pathway.

Advancing Equity

Supporting people affected by any cancer type, at any stage, and across all geographies. Use of demographic and activity data helps target support in line with incidence and prevalence; areas of known deprivation and recognised inequalities. This will contribute to more equitable and efficient delivery of person-centred care across Northern Ireland.

Enhancing Safety & Experience of Care

Supporting self-management, improving quality of life, and ensuring care is responsive to individual needs. A standardised, tiered approach based on HNA supports timely escalation to Clinical Nurse Specialists where appropriate. Evidence-based pathways enable effective signposting and timely referrals, contributing to high levels of patient satisfaction and improved experience of care.

Ensure value for all

Supporting early identification of financial concerns and timely signposting to advice and support helps to mitigate the financial impact of living with cancer. By ensuring people receive the right level of support at the right time, the role enables more efficient use of resources, release of Clinical Nurse Specialist capacity, and supports workforce sustainability and value-based delivery across cancer services.

Workforce Wellbeing

Strengthening navigation of support pathways, identifying service gaps, and enabling appropriate escalation of need. PCSWs are supported through supervision and have clear role boundaries enabling confidence and developing competence and safe practice. Clinical Nurse Specialists report confidence in the contribution of the PCSW role to refer appropriately, and benefit from collaborative working that supports a more sustainable cancer workforce model.

Gathering Evidence, Activities and Outputs

Throughout the evaluation evidence drawn from the key activities and resulting outputs was used to demonstrate consistent, evidence-led delivery of person-centred care across cancer services.

Key Activities… what was done

- Analyse available data to identify priority tumour groups and inform targeted implementation
- Recruit and train PCSWs to work alongside CNSs, ensuring an appropriate skill mix to support person- centred care delivery
- Conduct Holistic Needs Assessments (HNAs) with people affected by cancer (PABC)
- Support PABC to identify needs and co-create personalised care plans through meaningful person-centred conversations
- Facilitate timely access to appropriate support services across organisational and professional boundaries
- Enhance communication between PABC and the wider multidisciplinary team (MDT)
- Monitor and evaluate the impact of the PCSW role using agreed, evidence-based measures
- Capture workforce experience through semi-structured interviews with PCSWs and CNSs

Key Outputs… what was delivered

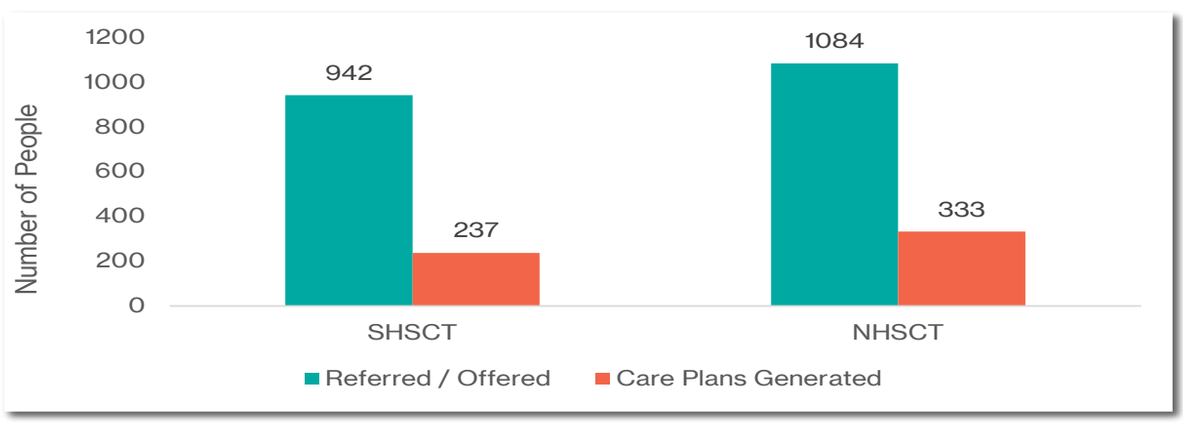
- PCSW role embedded within Health & Social Care (HSC) cancer teams
- Increased number of people affected by cancer offered and supported to complete an HNA and personalised care plan, initiated from initial diagnosis
- Increased number of appropriate referrals to support services for people affected by cancer
- Improved navigation of health, social care and third-sector services, contributing to strengthened patient support networks
- Regular evaluation and reporting on PCSW effectiveness, informed by:
    - Patient Satisfaction Surveys (PSS)
    - Staff feedback and qualitative reporting
    - Patient case studies (see example in Appendix)

Findings: Data sourced from Electronic Systems Macmillan My Care Plan & Encompass

The digitisation of the HSC system, alongside the regional standardisation of the evidence–based eHNA tool, has enabled the collection of both baseline and ongoing data. This drives real service improvement on what matters, transforming data into action including national, regional and local benchmarking.

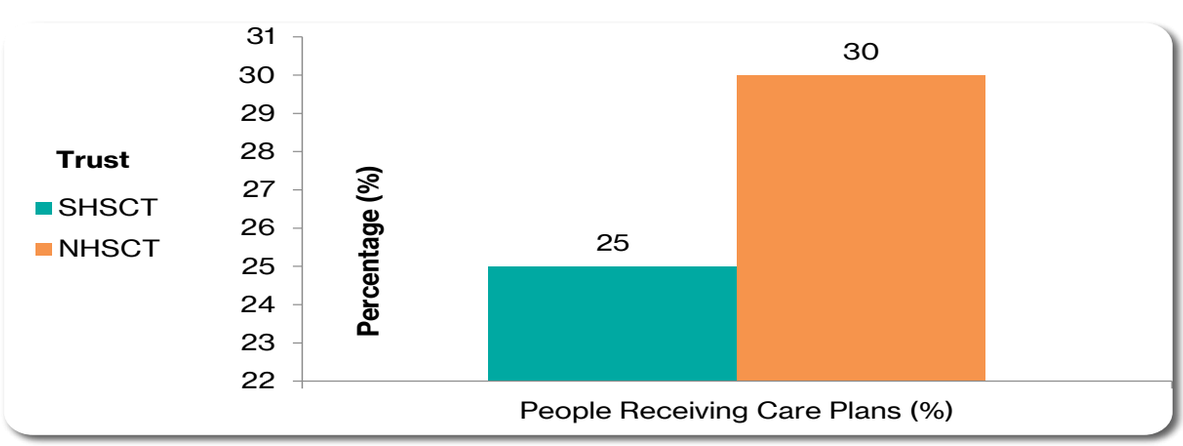
In line with Action 36 of the Cancer Strategy, two key metrics underpinning this analysis are:
- the offering of HNA
- the generation of a personalised care plan

Table 1 Number of HNAs offered by PCSW & Care Plans generated



Between January 2025 and February 2026, the variation in conversion rates between SHSCT and NHSCT is likely due to differences in local populations, case mix, timing and approach to offering support, patient readiness to engage, and how PCSW capacity and referral pathways are implemented across each Trust

Table 2 Percentage % of Patients positively impacted by completing HNAs



NHSCT had 30% and SHSCT 25% completion rates with both trusts moving towards the national average of 30-55% completion of HNAs. There is scope for improvement in converting offers to completed care planning.

Findings: Demographic Evidence

Tables 3 and 4 below present a demographic breakdown of service focusing on age and gender in both Trusts.

Most service users in both trusts are aged 50+, especially in the 50–70 age group. Very few service users are aged under 30 across either trust. SHSCT has a balanced gender distribution.

NHSCT shows a strong female predominance, reflective of the service cohort which focused on Breast cancer, with high female incidence, aged over 50 years old.

Table 3 Age Distribution of People Receiving HNA

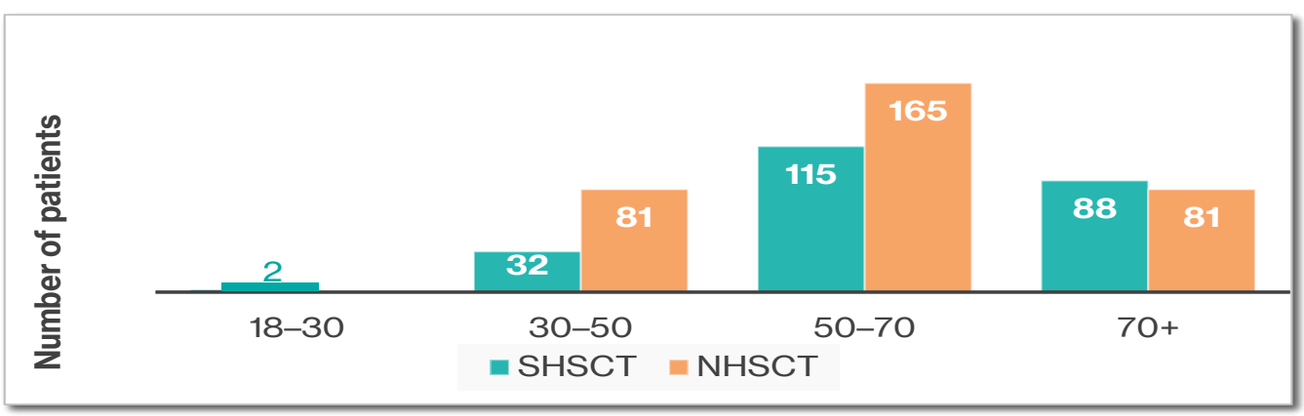
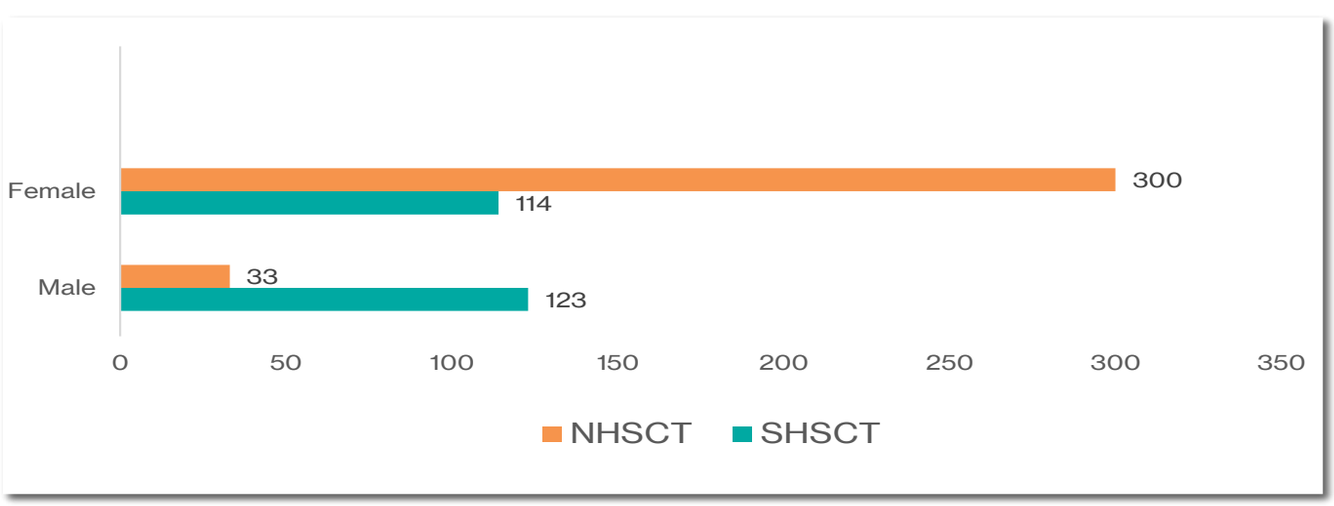


Table 4 Gender Distribution of People Receiving HNA



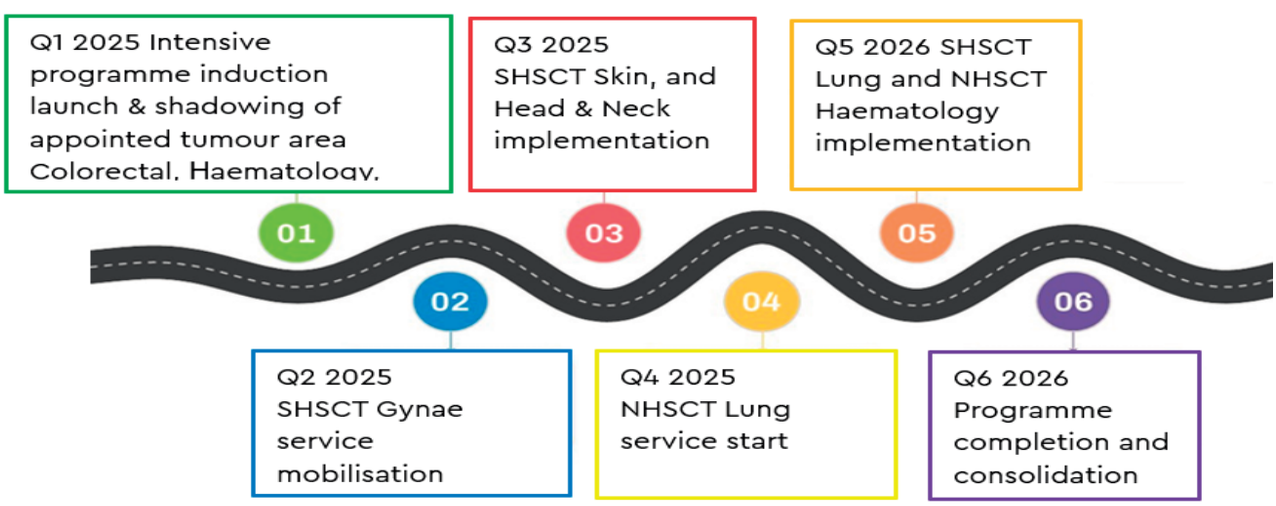
Review of postcode data shows that the largest proportion of patients with care plans generated in SHSCT were resident in the Armagh, Banbridge and Dungannon locality.

For NHSCT, the highest proportion of patients with care plans resided in Antrim, Ballymena and Newtownabbey.

Findings: Implementation Phases & Stage in Pathway

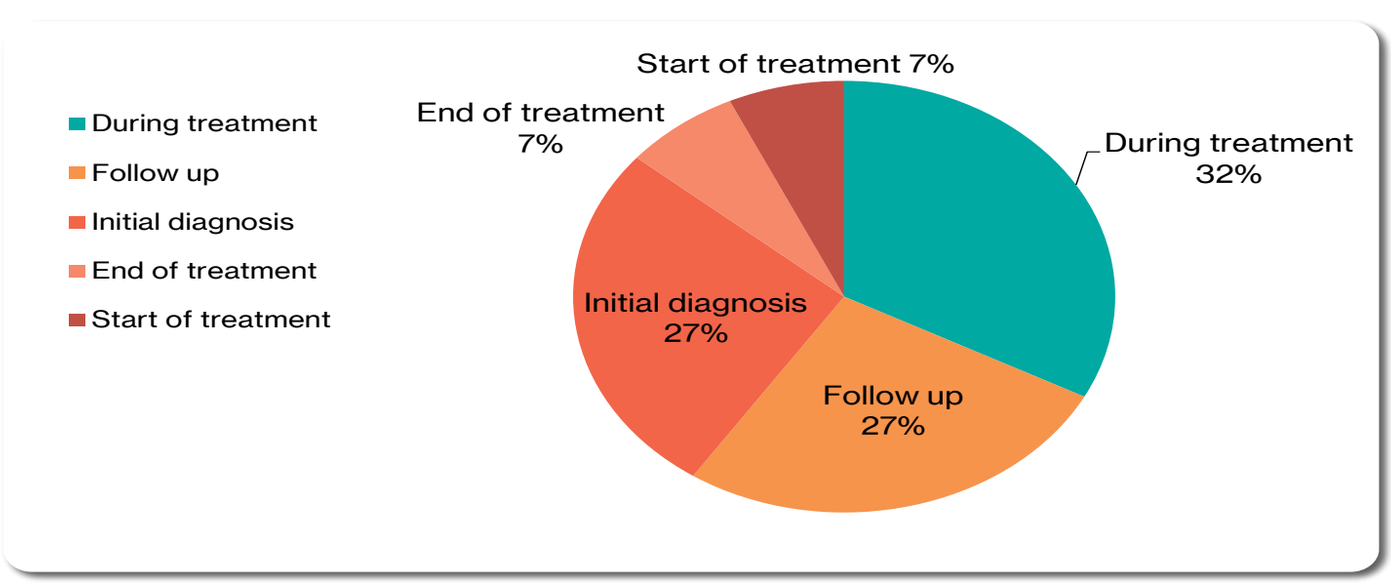
Diagram 3 demonstrates how the demand for the PCSW service increased over time across tumour sites, coinciding with greater confidence in service delivery.

Diagram 3 - Roadmap Summary by Quarter



Pathway Stage: The majority of concerns are raised during treatment, but a substantial proportion also emerge at diagnosis and follow-up, highlighting ongoing needs across the pathway.

Table 6-Distributon of PCSW contact by Pathway stage



Findings: Top Concerns

Table 7 Top 10 Reported Patient Concerns – Trust Comparison

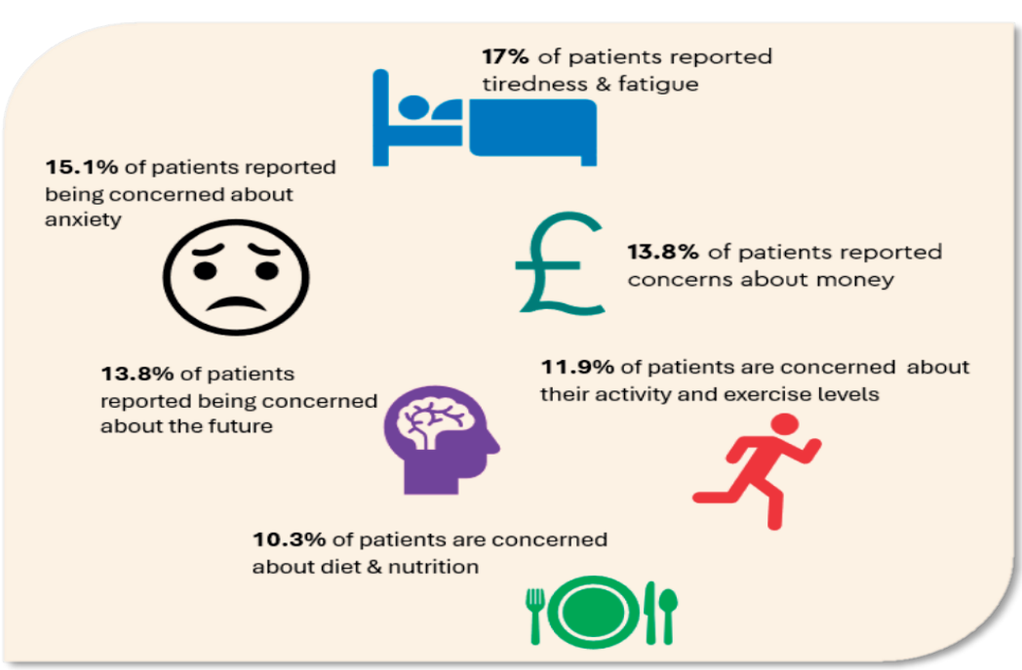
The table below presents a clear comparison of the top 10 reported concerns for patients across SHSCT and NHSCT.

Rank	SHSCT – Top Reported Concerns	NHSCT – Top Reported Concerns
1	Tired, exhausted or fatigued	Tired, exhausted or fatigued
2	Worry, fear or anxiety	Worry, fear or anxiety
3	Sleep problems	Complementary therapies
4	Pain or discomfort	Money or finance
5	Thinking about the future	Thinking about the future
6	Moving around (walking)	Sleep problems
7	Money or finance	Health and wellbeing
8	Memory or concentration	Exercise and activity
9	Exercise and activity	Uncertainty
10	Diet and nutrition	Diet and nutrition

Both SHSCT and NHSCT report fatigue and worry or anxiety as the top concerns, with overlapping themes around sleep, financial issues, lifestyle, and future planning. This highlights the need for regionally consistent, holistic support for core needs, alongside targeted Trust-specific responses.

Please note: any acute or complex clinical issues were escalated promptly to the Clinical Nurse Specialist (CNS), ensuring timely intervention while maintaining a consistent, person-centred approach across Trusts.

Diagram 4 Top Reported Patient Concerns – Percentage Comparison



Findings: Levels of Intervention

Levels of Intervention – Definitions

The levels of intervention describe a graduated approach to supporting patients following assessment, through the Holistic Needs Assessment (HNA), ensuring care is proportionate to need.

- Level 1 involving simple reassurance or signposting with no follow-up
- Level 2 where a single contact resolves a specific concern
- Level 3 provides short-term involvement to address multiple concerns through referrals and follow-up
- Level 4 interventions are required for patients with complex psychosocial needs and involve ongoing support, coordinated care, and potentially a repeat HNA, with possible escalation to appropriate clinical nurse specialist where necessary.

Table 8 Levels of Intervention – SHSCT and NHSCT

This table summarises the distribution of Levels of Intervention across both Trusts, based on combined activity recorded through Holistic Needs Assessments.

Level of Intervention	Combined Total (n)	Combined (%)
Level 1 – Simple problem solving	**58**	**12.4%**
Level 2 – Single contact intervention	**101**	**21.6%**
Level 3 – Short-term support (multiple concerns)	**172**	**36.8%**
Level 4 – Complex intervention	**136**	**29.2%**
Total	467*	100%

- Across both Trusts, the majority of activity sits at Levels 3 and 4, indicating that many patients present with multiple or complex psychosocial needs requiring coordination and follow-up.
- Acute or complex clinical concerns identified at any level are escalated to the Clinical Nurse Specialist to ensure timely and appropriate clinical management.

**The total number of patients who had a level of intervention recorded from month 3 onwards*

Findings: Time Requirements & Value for Money Analysis

Time Requirement: PCSWs across both trusts reported comparable completion times for the HNA (30 minutes to 1 hour), indicating that routine implementation is feasible within existing service structures.

Table 9 Time Requirements to complete HNA & associated Administrative Tasks

Activity	SHSCT	NHSCT
Average time using MyCarePlan	30 minutes – 1 hour	30 minutes – 1 hour
Administrative time (referrals, coordination)	30 minutes – 1 hour	1 hour or more

Value for Money

In keeping with the Quintuple Aim, the table below presents an indicative comparison of value for money. Prior to the test of change, the cost of a Clinical Nurse Specialist completing the HNA was estimated at £24, compared with approximately £13 when completed by a Personalised Cancer Support Worker.

This represents a substantial potential saving in both cost and CNS time.

The release of an estimated **570 CNS hours** This represents a significant release of Clinical Nurse Specialist capacity, enabling redeployment of specialist expertise to higher value clinical activity. The benefits identified relate primarily to opportunity cost and workforce optimisation rather than cash releasing savings, in line with value-based healthcare principles. Calculated savings equate to:

£11 per hour x 570 hours = £6,270

Figures are intended to support high-level comparison only

Table 10 Indicative staffing cost savings comparison

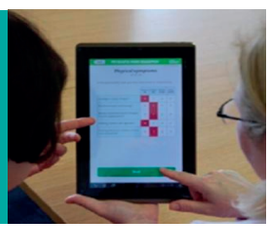
Staff Completing HNA	Approximate cost per hour	Approximate cost for 570 hrs HNA during Test of Change
PCSW	£13	£7410
Clinical Nurse Specialist	£24	£13,680

These estimates suggest that efficiency gains are achieved primarily through **role optimisation** rather than **direct cost reduction**. This reinforces the value of allocating administrative and coordination tasks to appropriately skilled staff, with clear escalation processes in place for clinical concerns, thereby enabling senior clinicians to focus on complex, high-value clinical care.

Patient Satisfaction Survey Feedback

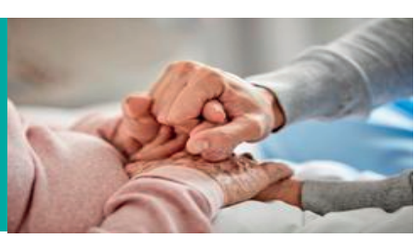
During 6 months of the project, patients received a request to share their perspective via an online or hard copy survey.

I felt as though I was a person not just a patient – PCSW got to know me first and then was able to help me talk about my concerns.



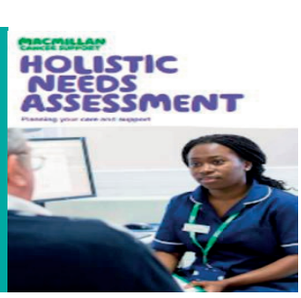
PCSW was extremely helpful, knowledgeable & professional. I felt valued and supported. My experience of the process was comforting and informative. Grateful to the Care Support Worker – thank you so much.

I would like to thank you very much for the help & advice given. It is a very anxious time & everything has been overwhelming since my diagnosis. PCSW was of great comfort and assurance.



I cannot praise the HNA team highly enough. I have been so impressed at how helpful and approachable they have been – a very big thank you to all concerned.

I wasn't sure what to expect prior to HNA but following the call and receipt of the care plan I am feeling more positive and in control. After diagnosis or end of treatment one can feel very alone – the support worker was so helpful and empathetic.



HNA – excellent service. It helps with the 'grey areas' and gives great help and direction. This is such an important link service and much needed. One of the most important calls I have received.

Clinical Nurse Specialist Feedback

Using semi-structured interviews CNS were invited to provide feedback on the role and impact of the PCSW

An additional point of contact that helps patients feel heard and supported throughout their cancer journey

Support with emotional, practical and benefits advice, enabling more personalised and co-ordinated care

PCSW provide valuable, accessible practical support and add an important supportive dimension across the pathway

PCSW know the patient group well, identify concerns early, escalate appropriately, and inspire high staff confidence

Observed Service Impact by CNS

- PCSW involvement strengthens holistic care delivered by clinical teams
- High accessibility due to co-location with nursing staff (SHSCT)
- Strong working relationships when present in CNS clinics
- Improved visibility and uptake of HNA through PCSW presence at patient Health & Wellbeing Events
- Responsive referral processes, with work queue and email used for urgent need

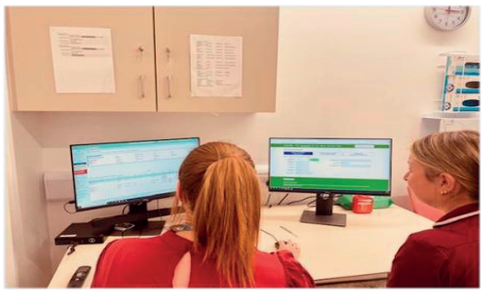
How the PCSW Role Benefited CNS Staff in Their Work?

- Freed up time for key worker responsibilities, allowing staff to focus on their core role
- Enabled more time to be present with patients at the point of need
- Allowed clinicians to focus on treatment-related discussions and specialist care
- Increased capacity for direct face-to-face clinical work
- Introduction of dedicated 'SOS' slots for improved communication between PCSW and CNS:
  - Three 30-minute slots per week available if needed
  - Used when clinical concerns needed escalated to the CNS
  - Improved management and efficiency of HNA clinics

Clinical Nurse Specialist Feedback
Learning for future service model

Theme	Key Learning / Issue Identified	Potential Risk	Mitigation / Action
Clarity of role boundaries for patients	Perceived overlap between PCSW and nursing roles resulted in uncertainty among patients about who to contact for specific concerns.	Patient confusion, delayed escalation of clinical issues, and reduced pathway efficiency.	Strengthen patient-facing communication outlining PCSW and nursing roles; provide clear written and verbal guidance during HNA discussions.
Use of correct clinical reporting channels	Physical or clinical concerns raised during HNA discussions were sometimes directed to PCSWs rather than appropriate nursing or helpline pathways	Potential delays in clinical review and pathway confusion	Reinforce escalation protocols for PCSWs; include scripted prompts within HNA training; consistently signpost patients to appropriate reporting pathways
Previous cancer service experience	PCSWs with prior cancer service experience adapted well; concerns were raised about future recruitment of staff without this background (SHSCT)	Reduced confidence in managing complex conversations and increased supervision requirements	Specify essential or desirable cancer experience in role criteria; strengthen induction, shadowing, and supervision for PCSWs without prior experience
Role scope across multiple tumour sites	Coverage across multiple tumour pathways may dilute site-specific knowledge; however, staff reported broader insight and consistency of psychosocial needs across tumour sites	Potential gaps in tumour-specific clinical knowledge	Maintain access to CNS support for tumour-specific issues; provide targeted tumour-site orientation; reinforce PCSW focus on psychosocial domains with escalation processes
Alignment with MISS services	Feedback suggested that clearer alignment may be achieved by positioning the PCSW role within the MISS structure, supporting integration and clearer pathways	Continued role overlap, fragmented referral pathways, and reduced clarity for patients accessing psychosocial and supportive services	Map PCSW, CNS and MISS contact points to reduce role overlap and improve patient navigation of support; undertake process mapping to integrate PCSW activity with MISS services; reiterate alignment with NIPEC and Nursing Management

Personalised Care Support Worker Reflections and Appraisals



The NIPEC Cancer Nursing Clinical Career Pathway includes competencies for unregistered staff. These covered all key aspects of the role, including person-centred collaborative working.

Using the NIPEC Competency Framework for self assessment and appraisal, and PCSWs were invited to provide feedback on their experiences and competency development. This was completed as part of their annual appraisal.

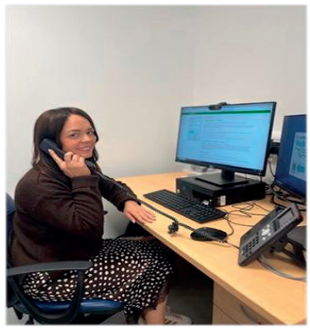
Excerpt from NIPEC Cancer Nursing Clinical Career Pathway - Competencies

Domain A: Person-centred collaborative working **1.0 & 2.0 Capabilities: Professional values and behaviours and ethical approach. The practitioner is able to:**	CSW	Achieved	Comment on Furthe development
1.1 Seek and engage with individuals' perspectives on their condition, their preferences for their care, and what is important to them and their carers in terms of treatment goals and outcomes.	√		
1.2 Demonstrate understanding of the individual and show empathy for the impact of their cancer diagnosis.	√		
1.5 Recognise the wider impact that symptoms of cancer, its treatment and progression, can have on individuals, their families and those close to them.	√		
1.12 a Demonstrate safe, effective, person centred reflective practice.	√		
1.16 Promote person-centred care to meet individuals' best interests to enhance the personal experience of care delivery.	√		
2.4 Use self-awareness to identify and act appropriately when own or others' behaviour undermines equality, diversity and human rights.	√		
2.5 Advocate and role model equality, fairness and respect for people and colleagues in day to day practice.	√		
2.7 Recognise and ensure a balance between professional and personal life that meets work commitments, maintains own health, promotes the well-being of self and others and builds resilience	√		
Domain A: Person-centred collaborative working **3.0 & 4.0 Capabilities: Communication & Consultation skills. The practitioner is able to:**	**CSW**	**Achieved**	**Comment on Furthe development**
3.1 a Consistently role model emphatic interpersonal and communication skills to engage in effective, appropriate, enabling interactions with individuals, carers and colleagues. Training: Confirm attendance and reflection following communication skills training	√		
3.3 (4.8) Select and adapt verbal and non-verbal communication styles, responsive to people's communication and language needs, via appropriate mode of media (including remote consultation such as telephone, virtual platforms and sign language, written) to facilitate empathetic and effective communication and interactions with people affected by cancer.	√		
3.4 Respond sensitively to individual preferences and needs, upholding and safeguarding the individuals' best interests.	√		
3.5 Establish and integrate individuals' specific needs, preferences, priorities and circumstances to guide care and treatment.	√		
4.2 a Optimise communication approaches appropriately using communication skills such as active listening, for example frequent clarifying, paraphrasing and picking up verbal cues such as pace, pauses and voice intonation Training: Confirm attendance and reflection following communication skills training	√		
4.5 Communicate effectively, respectfully and professionally with individuals, carers and within the multiprofessional team, at all times	√		
4.6 Convey information and address issues in ways that avoid jargon and assumptions; respond appropriately to questions and concerns to promote understanding, including use of verbal, written and digital information.	√		

- In total 76 competencies, which span across 7 domains were explored. These were reviewed through self-assessment by the PCSW providing opportunity to reflect on the skills, knowledge and competencies they developed from their induction, additional training undertaken and the mentoring from the CNS teams.

- During appraisal with their line manager PCSW could reflect on individual experiences, raise unanticipated issues, and be supported in their development and progression.

- This approach ensures safe, consistent and high-quality cancer care, while enabling exploration of perceived feasibility, time requirements, role clarity, and the impact on clinical workflow.



Personalised Care Support Worker Feedback

Qualitative feedback was sourced from semi structured interviews.

Key Findings

Role clarity & satisfaction: The PCSW role matched expectations and aligns well with day-to-day work, with high job satisfaction driven by positive patient feedback and visible impact.

Effective ways of working: Proactive introductory phone calls to patients, supportive relationship with CNS, nurses and line management enable effective delivery.

Team interface: Close working with nurses, particularly when co-located, strengthens integration. Effectiveness is reduced when this coordination and engagement are limited.

Learning:

- Occasional overlap with Macmillan Information Support Services (MISS) when patients had contact with MISS around the same time as the HNA offer by PCSW
- Concerns checklist completion acting as a barrier for some patients as they did not want to fill in a checklist however were willing to have a supportive conversation
- Variable nursing engagement across some sites highlighted the importance of a supportive working relationship with the CNS Teams

Patient feedback: Follow-up conversations provide valuable insight into patient experience and the impact of HNAs and referrals, reinforcing the value of early and ongoing contact.

Overall feedback is positive, with strong role satisfaction and impact, alongside opportunities to improve coordination and flexibility.

Outcomes

Patient Outcomes

The introduction of the PCSW role has contributed to improved access to person-centred care for people affected by cancer.

Key patient-level outcomes include:

- Increased access to HNAs, supporting earlier identification of physical, emotional, practical, and psychosocial needs
- Improved opportunities for meaningful, person-centred conversations focused on what matters most to individuals
- More timely and appropriate signposting and referral to health, social care, and third-sector support services
- Greater continuity and coordination of support across the cancer pathway

These outcomes support the delivery of Action 36 of the Cancer Strategy and align with Living With and Beyond Cancer principles.

Workforce Outcomes

The Test of Change has demonstrated clear benefits for the cancer nursing workforce, particularly Clinical Nurse Specialists (CNSs).

Key workforce outcomes include:

- Release of CNS capacity from non-complex activity, enabling greater focus on advanced clinical care and decision-making
- Improved skill-mix within cancer teams through integration of Band 4 PCSW roles
- Increased confidence and consistency in the delivery of person-centred care approaches
- Enhanced multidisciplinary working and communication within and across teams

These outcomes contribute to workforce sustainability and respond directly to challenges identified in the Cancer Nursing Workforce Census.

Service Outcomes

At a service and system level, the PCSW model has supported more consistent, efficient delivery of person-centred care.

Key system-level outcomes include:

- Improved consistency in HNA delivery and care planning across participating Trusts
- Strengthened use of digital systems (Macmillan My Care Plan and Encompass) to support assurance, reporting, and learning
- More effective navigation of services for people affected by cancer, reducing fragmentation of care
- Improved service efficiency through role optimisation, enabling CNSs to focus on complex care but with clear escalation pathways for the PCSW
- Potential to demonstrate significant value for money with wider roll out
- Early indications that the model supports scalability and regional implementation

The Test of Change indicates that the PCSW role adds measurable value across patient experience, workforce capacity, and system delivery. Outcomes demonstrate improved access to personalised care, more effective use of CNS expertise, and enhanced consistency in service delivery. These findings provide a robust platform for further qualitative exploration of patient experience and for informing decisions regarding sustainable regional implementation.

Key Learning Year 1

Targets & delivery: Year 1 activity targets were ambitious and, by month 14, recognised as unrealistic, highlighting the need for phased and proportionate target-setting.

Pathway clarity: Variation in how and when the PCSW offer is made indicates a need for clear pathway mapping and improved patient understanding of the role.

Reach & equity: Variation in uptake across tumour groups, together with high levels of "zero concern" HNAs, indicates that communication, understanding, timing and access may be influencing engagement. Further analysis is required to better understand patterns of engagement and ensure equity across population groups and those under- represented.

Patient outcomes & systems: Integrating of HNA care plans into Encompass alongside tracking of Patient Satisfaction and strengthen outcome measurement.

Workforce impact: CNS teams value the PCSW role for improving patient experience, releasing clinical capacity, and supporting equitable, responsive care. Clear role alignment with the NIPEC Cancer Nursing Clinical Career Pathway, under nursing leadership and governance, are essential. A defined interface with the Macmillan Information and Support Service (MISS) supporting integrated working, will ensure effective processes and maximise mutual impact.

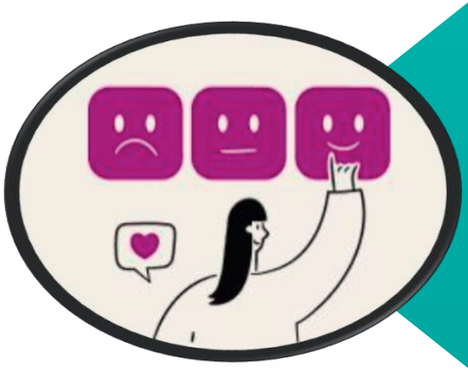
Referral impact: Timely and appropriate referrals are achieved , with scope to strengthen feedback loops from voluntary and community partners to evidence impact.

Year 1 learning confirms strong value and impact, alongside clear opportunities to improve consistency, clarity, equity and system integration in Year 2-4

Overall Impact

Increased Person-centred Care

The PCSW role has contributed to a transformed cancer care pathway in NHSCT and SHSCT ensuring more personalised, holistic support for individuals diagnosed with cancer.



Improved Patient Experience

By optimising the contribution of nursing and support staff, the project enhances patient well-being, promotes self-management, and enables the cancer care workforce to meet growing demands efficiently through a whole system approach

Future Workforce Planning

The findings have informed future workforce planning, service development, and scaling of the PCSW role across Northern Ireland, supported by three years of non-recurrent funding. This aligns with the Cancer Strategy (DoH, 2022) ambition to ensure access to tailored, person-centred care for all people affected by cancer

Next Steps & Priorities (Years 2-4)

Year 1 of the programme has demonstrated the value and impact of the PCSW role in delivering personalised, person-centred cancer care, providing a strong foundation for future development. Building on this evidence, Macmillan Cancer Support has committed an additional £1.6 million investment over the next three years to support regional scale-up and service sustainability across all Health and Social Care Trusts.

Key priorities for Years 2–4 include:

- **Regional roll-out of the PCSW model.**

The additional investment will enable a phased regional roll-out of the PCSW service, with two PCSWs appointed within each Health and Social Care Trust. Staff currently in post will be retained as part of the expanded cohort, supporting continuity and knowledge transfer.

- **Strengthened leadership and programme oversight**

A Regional Programme Lead (Band 8a) will be appointed to provide strategic leadership, consistency, and oversight across Northern Ireland. This role will support standardisation, shared learning, and continued service development.

- **Independent external evaluation**

An external evaluation will be commissioned to ensure the three-year programme is robustly and independently assessed. This will provide assurance regarding impact, effectiveness, and value, and will inform ongoing development and long-term sustainability.

- **Alignment with professional standards and workforce development**

Continued alignment with the NIPEC Cancer Nursing Clinical Career Pathway competencies will support professional standards, clarify role expectations, and strengthen workforce development for person-centred care roles.

- **Clarification of the person-centred care vision and service mapping**

The roll-out programme will include mapping of personalised care activity across services to identify gaps in provision, reduce duplication, and agree shared regional priorities for improvement.

- **Phased implementation aligned to system reform**

Learning from the Test of Change will inform a phased regional roll-out from 2026 and should look to opportunities to align with the HSC Neighbourhood Model. This will support consistent, person-centred care delivered as close to home as possible and integrated across local neighbourhood teams.

- **Engagement and shared learning**

Learning and achievements from the Test of Change will be shared through a regional engagement event scheduled for 21 May 2026. This will provide an opportunity to celebrate progress, strengthen partnerships, and engage key stakeholders — including the Department of Health Chief Nursing Officer — in shaping future development.

NEIGHBOURHOOD MODEL OF HEALTH AND WELLBEING

HSC RESET STABILISE | REFORM | DELIVER

Conclusion

The Test of Change for the Personalised Care Support Worker (PCSW) role has demonstrated clear and compelling value in strengthening person-centred, equitable, and coordinated support for people affected by cancer across Northern Ireland.

Evidence from Year 1 shows that PCSWs enhance patient experience, support empowered self-management, improve navigation of complex services, and enable more effective use of the wider cancer workforce by releasing Clinical Nurse Specialist capacity for advanced clinical care.

Crucially, the Test of Change has shown that person-centred care, a core component of CNS practice, is optimised when supported through appropriate skill mix, protected time, and clearly defined roles. It has clarified what works, identified where refinement is needed, and established a robust, evidence-informed foundation for future development. The learning generated has directly informed decisions on scale-up, workforce design, governance, and evaluation.

With continued investment, strong programme leadership, digital enablement, and alignment to the NIPEC Cancer Nursing Clinical Career Pathway, the HSC Neighbourhood Model, and Macmillan Cancer Support's Strategy 2030, the PCSW role is well positioned to deliver person-centred care at scale. This model offers a sustainable approach that supports improved outcomes for individuals, strengthens workforce wellbeing, and contributes to the long-term resilience and transformation of cancer services across Northern Ireland.

Acknowledgements

We would like to extend our sincere thanks to Avril and Jenny, who generously supported the Personalised Care Support Worker project through their invaluable contributions as a Lived Experience Panellist and Service User. Their insight, honesty, and commitment helped to shape and strengthen this work in meaningful ways.

We also wish to pay special tribute to Jenny, whose contributions continue to have a lasting impact. Her voice, compassion, and dedication will be remembered with gratitude and respect.

Our sincere thanks go to the Personalised Care Support Workers, whose dedication, hard work, and compassion were evident throughout this test of change. Taking on a newly established role, they not only delivered support but actively shaped and developed the post, helping it to grow and succeed. Their contribution has been invaluable to both the service and the people it was designed to support.

Personalised Care Support Workers

SHSCT
Stacey Leathem
Laura Daly

NHSCT
Colette Quigg
Katie Brady

Finally, our thanks are extended to the Oversight Group, made up of Nurse Leaders, Service Improvement Leads, Personalised Care Facilitators and Macmillan Leadership Team, whose guidance, insight, and support helped steer the Test of Change. Their leadership and collaborative approach provided a strong foundation for the development and delivery of this work.

Abbreviations

CNO: Chief Nursing officer

CNS: Clinical Nurse Specialists

DOH: Department of Health

HSC: Health Social Care

eHNA: Electronic Holistic Needs Assessment

HNA: Holistic Needs Assessment

NICaN: Northern Ireland Cancer network

NIPEC: Northern Ireland Practice Education Council for Nursing and Midwifery

NHSCT: Northern Health and Social Care Trust

MISS: Macmillan Information Support Service

PABC: People Affected By Cancer

PSS: Patient Satisfaction Surveys

PCSW: Personalised Care Support Worker

PHA: Public Health Agency

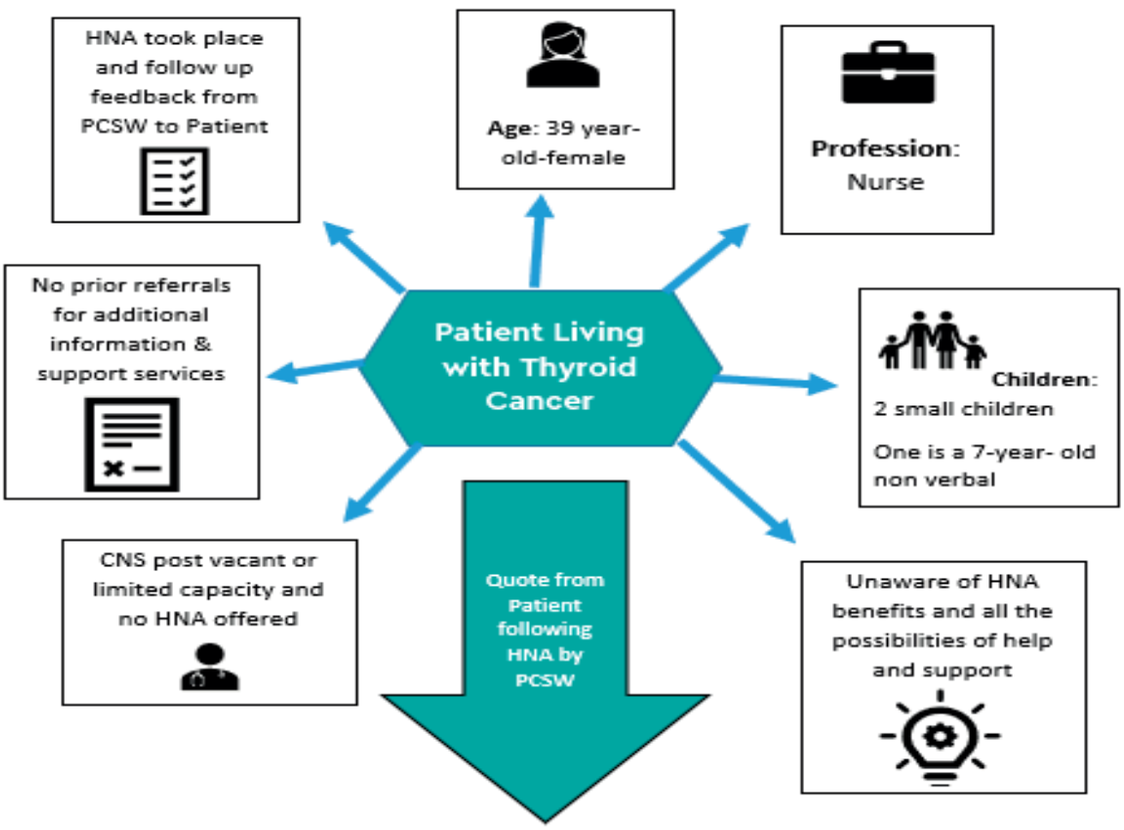
PPI: Patient and Public Involvement

SHSCT Southern Health and Social Care Trust

Appendix

How I made a difference as a PCSW

A Patient Case Study



...our world shattered into a million pieces all within a few seconds of hearing the one word - Cancer!

Having had surgery and treatment in April I was put in contact with Stacey who has supported me with guidance & opportunities that are available to me and my family. Having worked in the trust as a staff nurse for years I wasn't aware of these opportunities and I honestly, I hadn't even heard of them before.

Stacey's information and guidance has been exceptional it's allowed me to start and focus on healing myself (Charis) as well as a family retreat for us (Daisy Lodge)

She has also put is in the right direction financially to speak to people and advise us of benefits we are entitled to and what we are not aswell as putting us in contact with people who have had similar experiences to speak too.

We greatly appreciate her service at a time where you need guidance more than ever.

Only for Stacey we would never have knew about any of these.

Thank you Stacey!

References

- Evaluation of Improving the Cancer Journey: Final Report. Young, J., Snowden, A., & Savinc, J. (2020, September)

- A Cancer Strategy for Northern Ireland 2022- 2032, (DoH 2022)

- Shaping Our Future, A Vision for Nursing and Midwifery in NI 2023- 2028, (DoH 2023)

- Northern Ireland Practice and Education Council for Nursing and Midwifery Cancer Nursing Clinical Career pathway (NIPEC 2026)

- Health and Social Care Reset Plan (DoH, July 2025)

- Macmillan Cancer Support-How We're Changing Cancer Care 2025 – 2030

Additional Links

Holistic Needs Assessment (HNA) | Healthcare professionals | Macmillan Cancer Support

Improving personalised care and support planning for people living with treatable-but-not-curable cancer

Dr Clair Le Boutillier - THIS Institute - The Healthcare Improvement Studies Institute

Macmillan Personalised Care Support Worker
Test of Change Phase 1
Northern Ireland Evaluation Report
May 2026

NICaN Northern Ireland Cancer Network

HSC Public Health Agency

HSC Northern Health and Social Care Trust

HSC Southern Health and Social Care Trust
TOGETHER, IMPROVING CARE, TRANSFORMING LIVES

MACMILLAN CANCER SUPPORT