Final Evaluation Report

Cancer Connected Communities

West project

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Contents

Executive Summary

The Cancer Connected Communities West (CCCW) project is the first of its kind in Northern Ireland and was developed with funding from the National Lottery Community Fund. The initiative brought together six charities along with the Western Health and Social Care Trust to connect people affected by cancer to each other, to provide support in the community and link them to the people who deliver cancer services, so they can use their experiences to make improvements.

The CCCW project followed an original model, developed by Derry Well Women, which had never been used in a cancer context before with a dedicated Project Manager, Deirdre O'Neill, Resource Assistant, Jennifer Turner, and External Evaluator, Fiona Boyle Associates.

The project supported and engaged with 2,748 participants affected by cancer living across the entire Western Trust geography. Project participants attended workshops over the course of three years and used their lived experience to improve cancer care by negotiating change with senior representatives from the Western Health and Social Care Trust (Western Trust), Department of Health, Macmillan, the Public Health Agency, Department for Infrastructure and many other organisations. The change commitments were presented at the final conference in the Ebrington Hotel, 20 June 2024.

The commitments related to various themes including connecting rural communities, improving the health and wellbeing of the cancer workforce, addressing health inequalities, supporting informal carers, modernising pathways for patients being treated at the NW Cancer Centre, improving the completion of Holistic Needs Assessments for all WHSCT cancer patients, as well as addressing and implementing changes to improve communication and many others. Speaking at the conference, Health Minister for NI Mike Nesbitt, said the Cancer Connected Communities West project "set a benchmark" for co-production in cancer services.

Key contributing success factors to the CCCW project included:

- The Model of Engagement which involved a nurturing and empowering process, enabling those affected by cancer to share their insights and experiences in a safe, trusted space, through co-production methods. This model gained considerable interest during the project, with references to its transferability to other areas and fields.
- The bravery of the service users who engaged and participated and used their lived experiences to take the lead in developing the change agenda, and inputting how services could and should be shaped.
- The diverse and dynamic partnership with strong endorsement from Western Health & Social Care Trust and Department of Health.
- Having a dedicated Project Manager and Resource Assistant to manage the end-to-end delivery of the project, including all challenges, risks, budget streams and stakeholder relationships.

The service delivery element of the project ensured that those experiencing cancer and their wider families received individual and group support through a wide range of activities and services. This element of the project resulted in friendships amongst cancer patients, as well as enabling charitable organisations to further develop and plan their own and continuing services.

The final change commitments negotiated by service users along with cancer care providers and other service planners were publicly presented and are in the process of being drafted into a contract which will be tracked and monitored to ensure accountability.

The project was recognised at a national level and won an award at the Patient Experience Network National Awards (PENNA)[1] in October 2024, in the category of: 'Engaging and Championing the Public'.

[1] https://patientexperiencenetwork.org/awards/

Foreword from the lead partner – Derry Well Women

I know what it is to live with a cancer diagnosis. I also know what it is to lose family and friends to cancer. It was these experiences that influenced my desire and wish for cancer services for people living with cancer and for those who care for them to improve.

This unique 3-year project aimed to do exactly what its project name said: to connect communities experiencing cancer in the west of Northern Ireland - Cancer Connected Communities West (CCCW).

At its heart, the Lottery funded project sought to develop and work in partnership with a range of local community and voluntary sector groups, service users and carers to improve services and experiences for those affected by cancer. The rationale for the project centred on a lack of accessible services for those experiencing cancer in the west of the province, compounded with factors relating to transport, marginalisation and rurality.

Working through a 3-tier model of engagement and based on the principles of inclusion and co-production this project positively impacted 2,748 participants who had or were still experiencing cancer – either as individuals, or within their families or as carers.

The project far-exceeded its targets and objectives, ensuring that vital services such as reflexology, transport to hospitals, information talks and financial advice were delivered by those best placed to provide services at a local level.

CCCW led the way in terms of its methodology for ensuring that every voice was heard, every issue was listened to, and nothing was overlooked in highlighting the nature and impact of experiencing cancer in Derry/Londonderry, Omagh, Strabane, Enniskillen and all the surrounding areas.

Four Gathering Sessions were held, three Negotiating Change workshops were facilitated, culminating in the final 'Commitment to Change' Conference - which brought together all the strands of the project.

The CCCW project brought forward themes and issues around primary and secondary care, as well as associated factors in an individual's experience of cancer and cancer services.

The Board, project staff team and the six partners did an amazing job; surpassing our and their expectations.

We commend the final recommendations from the project to you.

Whilst this 3-year phase of the project has completed, there is interest and impetus to keep up the pressure to ensure that changes are made to services and support for those experiencing cancer in the west of the province.

I would like to thank Fiona Boyle for her dedication and work to developing this evaluation.

I have great pleasure and pride presenting it on behalf of Derry Well Women.

Susan Gibson, Derry Well Women

Section 1 Introduction

1.1 This Evaluation report provides a summary of the Cancer Connected Communities West project (CCCW) and evaluation findings for the three years from September 2021 to September 2024. The project was managed by the lead partner, Derry Well Women.

1.2 The agreed research methods for this evaluation are outlined in Appendix 1. This report covers background and context to the project, and then provides an analysis of available quantitative and qualitative data. This includes:

- Data and information collected by the lead partner (Derry Well Women)
- Data and information collected by the project partners
- Review of files and information held by DWW by the project evaluator
- Primary data collected by the project evaluator from interviews with the lead partner, the project partners and service users.

Section 2 Background and context to the CCCW project

2.1 Funded by the National Lottery Charities Board, the 3-year CCCW project commenced in the Western Health & Social Care Trust (WHSCT) area in September 2021. The CCCW project is an active partnership of eight partners[2] operating throughout the Trust area, who have come together to understand and improve locally based cancer care, with a specific focus of putting patients' voices and experiences at the heart of shaping any improvements. This is being done via a number of mechanisms to listen to the members, users and communities associated with each of the eight partners and also by listening to each other across the partnership. Funded to the tune of £465,000[3] the programme is aimed at people and family members affected by cancer throughout the WHSCT area. Details of the programmes and support is outlined below at section 2.10.

Aims and Objectives

2.2 The overall objective of the CCCW project is three dimensional; firstly, to closely connect people affected by cancer to each other, secondly to connect them to support in the community, and thirdly to link them to people who deliver cancer services so they can use their experiences to make improvements. Overall, the initiative is about supporting cancer patients to take the lead in creating a change agenda to integrate and improve cancer care in the WHSCT area.

The project summary in the funding application stated:
Cancer patients take the lead in creating a change agenda to integrate cancer care in the WHSCT using co-production and an engagement model to connect people living with cancer across communities to each other and organisations with the capability to improve their lives. The project will engage marginalised groups where cancer services are limited and barriers exist due to rurality, exclusion, fear; deliver support programmes; listen to cancer programme participants; set priorities for improved cancer services; directly articulate priorities to service planners to influence strategic change.

2.3 The aims of the CCCW project were to:

- Ensure that people living with cancer in this geography, especially those who have difficulty accessing services, are front and centre in the development of their cancer care provision and that their specific needs are heard and met;
- Simplify the complexity of post cancer care ensuring people find the right pathway for them to the right service at the right time;
- Create an integrated movement of organisations in this area committed to working together to secure improvement for prevention of and care for cancer.

[2] Six main partners - Derry Well Women (Lead partner), Action Cancer, Advice North West, Cancer Focus NI, Care for Cancer, Supported We Live Life (SWELL) – all funded partners, alongside external/service delivery partners of Macmillan Cancer Support and the Western Health & Social Care Trust.

[3] £460K National Lottery funding to improve cancer care across Western Trust region | Western Health & Social Care Trust (hscni.net) Including cost of living uplift in April 2023 total amount is £482,976.

2.4 As the project progressed the project aims were developed and outlined as follows[4]:

- Engage marginalised groups[5] for whom cancer services may be limited and for whom barriers to access exist;
- Deliver support programmes;
- Listen to cancer programme participants;
- Set priorities for improved cancer services;
- Directly articulate priorities to service planners to influence strategic change.

2.5 The beneficiaries of the project are the population of the Western HSCT area, individual families and communities whose lives, health and wellbeing can and are affected and compromised by cancer.

Rationale for the CCCW project

2.6 The need/rationale for the CCCW project is well documented in the funding application and initial paperwork including the Project Initiation Document. These highlighted poor service provision and difficulties in accessing services in the Western HSC Trust area for those experiencing cancer. The cancer related groups, working within the WHSC Trust area, have long recognised the levels of cancer diagnosis (see Section 3), the population coverage[6] and unequal access to community resources and support because of rurality and lack of public transport.

Prior to the CCCW project, the Cancer Locality Partnership Group (CLPG) was active for 10 years, representing the community and voluntary groups involved in cancer services, with a clear focus on the patient voice. In March 2019 the CLPG met together to discuss and develop a shared understanding and commitment to work together. This resulted in commitments to being people-led, relationship oriented, asset-based and place-based.

In 2020, over 500 service users affected by cancer from the various groups associated with the partner organisations completed a survey. Their response indicated a clear need for this project under the aims and objectives set out above. This survey highlighted the following areas which respondents said needed to be addressed:

Access to/lack of services

- Lack of access to services including screening
- Receiving diagnosis/follow up by telephone
- Cancelled surgeries/scans
- Unable to access GPS
- Lack of local community support in rural areas, especially counselling and carers support

[4] Taken from the Gathering Session 1 – Outcomes Report.
[5] Marginalised groups as referenced by Section 75 of the NI Act 1988.
[6] The Western HSC Trust serves a population of approximately 300,00 across a geography of 4,842km, including a large rural community. It covers population living in the Derry City & Strabane District Council and Fermanagh & Omagh District Council areas.

Emotional impact of cancer diagnosis

- Feelings of isolation, lack of peer/social support
- Mental/emotional health
- Increased anxiety

Wider accessibility issues

- Travel concerns
- Lack of information on specific issues e.g. finance, nutrition
- Uncomfortable with or unable to use IT platforms

The rationale for the CCCW project also sits hand-in-hand with *A Cancer Strategy for Northern Ireland 2022 – 23*[7] and its Funding Plan 2022 – 2032 which were launched in March 2022 and set the direction of travel for cancer services for the next 10 years. This strategy highlights a number of factors of significance for those living in the Western HSC Trust area as follows:

- **Early diagnosis** is a complex, multifaceted topic dependent on a range of factors including public awareness of symptoms, access to primary care, access to diagnostic services, referral guidelines and pathways. (Page 26)

- In addition, there are **challenges in ensuring equitable access** for all sections of the population, particularly seldom-heard and underrepresented sectors, e.g. LGBTQ+ people, those from ethnically diverse backgrounds, people with cognitive impairment such as those with dementia, those experiencing homelessness, people in long-term institutional care including prison care, the ageing and frail population, and those living in rural and remote areas. (Page 99)

- **Accessibility to vital services** including pharmacies, Clinical Nurse Specialists, acute Oncology Services – some of which may require people in the Western HSC Trust area to travel longer distance to access (services referenced in number of places in report)

The aim of the CCCW project is to input to the outworking of the Cancer Strategy for NI, together with other key health strategies including *Making Life Better 2013 – 2023*[8] and *Health and Wellbeing 2026 – Delivering Together*[9]

The CCCW project – Management Structure

2.7 At the outset of the project a Management and Governance Framework was established as part of the partnership to oversee and manage the project in terms of recruitment (for posts outlined below), development of the Project Board and the Project Advisory Group and the development of policies and procedures.

[7] Op cit.
[8] Making Life Better - A Whole System Framework for Public Health 2013-2023 (health-ni.gov.uk)
[9] health-and-wellbeing-2026-delivering-together (health-ni.gov.uk)

The Project Board comprises:

Organisation	Name
Derry Well Women (Lead partner)	Susan Gibson
Derry Well Women	Karen Meehan
Western HSCT	Tara Boyle
CCCW project	Deirdre O'Neill

The Project Advisory Group membership comprises:

Organisation	Name
Derry Well Women	Susan Gibson
Action Cancer	Ruth Fleming
Advice North West	Jacqueline Gallagher
SWELL	Genevieve Irvine
Care for Cancer	Laura Mills and Martina Morris
Cancer Focus NI	Anthony Stuart
Western HSCT	Una Cardin
Western HSCT	Tara Boyle
Western HSCT	Bridget Tourish

Two staff members manage the CCCW project – Deirdre O'Neill (Project Manager) and Jennifer Turner (Resource Assistant).

A menu of forms and administrative processes were established at the outset of the project. These are used for recording purposes, and for specific reasons such as obtaining consent; the data is then collated and recorded by the Project Administrator and is used for reporting purposes e.g. to the National Lottery and for evaluation purposes. The suite of forms include:

- Consent forms – including consent to attend Gathering Sessions
- Individual participant profile form – to be completed by participant
- Group programme/service form – to be completed by facilitator
- One to one services form – to be completed by facilitator

Data collection and subsequent analysis is important for the ongoing monitoring and evaluation of the project. A partnership agreement was set up with each partner, outlining the agreed level and type of activity, along with the range and nature of data to be returned to the lead partner. This included information on service delivery and attendance, plus client profile data.

The funding awarded by the National Lottery included provision for capital (laptops, software and mobile phones) as well as revenue (salaries for the two staff members, recruitment, travel and subsistence and running costs) plus partner's project delivery costs,

training and engagement costs e.g. training courses, Gathering Sessions and Negotiating Change workshops.

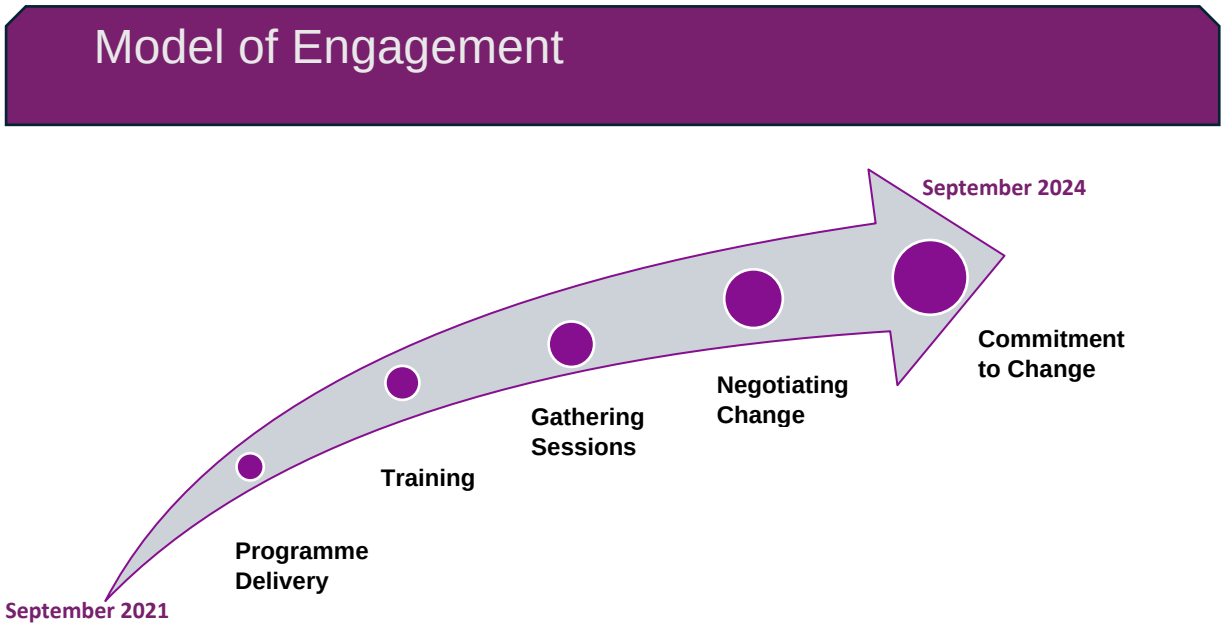
The CCCW project model

2.8 The CCCW project model aims to improve connections at three levels, as follows:

- Between patients across the WHSCT area;
- Between patients and their own communities and organisations;
- Between the people within organisations who have a role/responsibility to impact on care.

To this end, the CCCW project has developed and put in place a model of engagement at six levels with people living with a cancer diagnosis across the WHSCT area, as outlined on the next page.

The timeline of the model of engagement is outlined below.



Model of Engagement – CCCW Project

Training – Facilitators, therapists and representatives from partner organisations participated in the ELEC[10]; this was delivered in October 2022 to volunteers in all of the partner organisations. This bespoke training incorporated the use of a listening technique developed in a framework for listening to feedback from participants in community-based cancer support programmes. Other training has included Social Media Training and ABCD training. Further details are noted below.

Direct provision – Partner organisations within the CCCW Project rolled out locally based programmes tailored to suit the needs of their groups ensuring they were capturing the participants' voices through the application of the listening technique.

Consensus Building – Facilitators, group representatives and participants from across all programmes came together in four Gathering Sessions to agree a consensus and a shared agenda for change for individuals, families and communities living with cancer across the Western Trust area. Further details of the Gathering Sessions are outlined below. This structured approach enabled participants to share their story and feel empowered. Given the emotive nature of this process, the CCCW project had counselling available if required.

Negotiating Change – This element took place in Year 3 of the project. In workshops change requests were developed by programme participants in discussion with cancer care service planners and providers, including the WHSCT, the Department of Health, Macmillan, the Public Health Agency and other cross-sector bodies including the Department for Infrastructure and community and voluntary groups.

Commitment to Change – This element took place in Year 3 of the project. The 'Commitment to Change' conference focused on the change requests agreed at the negotiating change workshops. The requests were presented by those with lived experience of cancer to senior representatives from the sectors who have a responsibility in relation to health including the WHSCT, the Department for Health, and other cross sector bodies including the Department for Infrastructure and the community & voluntary sector; who addressed and made commitments to action in relation to issues raised by participants in their localities.

Accountability Loop – the process for change implementation and the accountability arrangements from service providers back to local people was continuous throughout the project where possible. The final commitments will be monitored and fed back to the service users.

[10] ELEC training – Effective Listening for effecting change.

There were four Gathering Sessions, with details noted below.

Gathering Session – Number and Date	Location	Focus	Number of participants
1 – November 2022	Silverbirch Hotel Omagh	People living with cancer	56
2 – April 2023	Waterfoot hotel, Derry	Cancer care providers - Health professionals	66
3 – June 2023	Waterfoot hotel, Derry	People living with cancer, their carers and family members	53
4 – October 2023	Killyhevlin hotel, Enniskillen	Rural voice	56

2.9 The CCCW project used a co-production and partnership model. The principles and usage of co-production are increasingly used in project delivery and in research/evaluation terminology. In research terms, with particular relevance to evaluations, *Co-production' can describe research between practitioners, policy makers and service users (aiming to improve public services), and research between academics, community organisations and residents (aiming to create new knowledge).*[11] Furthermore *co-produced research is said to create new knowledge through including the perspectives of those traditionally excluded from knowledge production, which in turn is expected to enhance research quality and impact*[12].

The CCCW project's co-production principles and a co-production approach are based on the *Co-production Guide for Northern Ireland – Connecting and Realising Value Through People*[13]. This Guide describes co-production and transformational change as follows:

Transformational change in this guide means harnessing the collective efforts of policy makers, people who use services, carers, staff, staff representatives and local communities

[11] *Conceptualising quality in co-produced research,* Marilyn Howard, Helen Thomas-Hughes. First published June 2 2020 – Research article - https://doi.org/10.1177/1468794120919092
[12] Ibid.
[13] 126493 H&SCB - Co-Production Guide.indd (health-ni.gov.uk)

who all work together in partnership to improve health and wellbeing outcomes for the people of Northern Ireland. It places people at the centre of decision making and aims to connect people together in representative networks so that they can meaningfully influence, shape and participate as real partners in the commissioning, planning, delivery and evaluation of services. (page 6)

This highlights the CCCW project's desire to use a co-production approach not only for the project delivery but also the evaluation process. This theme is explored in more detail in Section 7, with a focus on other co-production models in the fields of health and in particular cancer services.

The project partners

2.10 This sub-section now provides an overview of each of the partner organisations, the type and range of activities they were committed to provide as part of the CCCW project, and the overall and annual targets[14] that were set for each group at the outset. Each of the six delivery partners receives approximately £35,000 across the lifetime of the project for activities and individual work; itemised budgets are provided below for each partner.

In addition to the six delivery partners, the project membership includes the Western HSC Trust and the Macmillan Information and Support Service. The interactive nature of the project has created key milestones for interaction between the six delivery partners and the two associated partners, who are responsible for delivery of statutory health and cancer related services in the area.

Derry Well Women

Derry Well Women (DWW) is a Women's Health Organisation which provides women centred health services to improve the health and wellbeing of women, families and community and recognise the changing needs of women's health. Derry Well Women was the lead partner of the Cancer Connected Communities project.
Throughout the lifespan of the project, Derry Well Women delivered at three levels:
Level 1- 1:1 Services, Counselling and Complementary Therapies.
Level 2 – Therapeutic Group Work,
Level 3 – Social Support

Level 1 - 1:1 Services, Counselling and Complementary Therapies.

Within this category of work, DWW planned on delivering 90 hours of counselling sessions to 15 clients across the lifetime of the project, 30 hours each year. Due to unforeseen personal circumstances the counsellor working on the CCCW project was unavailable to continue within year 3 of the project. Within the CCCW project, 73 sessions were delivered, and 14 clients were reached. Cancer counselling services continued within the DWW centre, provided by counsellors working under different funding strands.

[14] The targets outlined are based on the reviewed targets, calculated in Year 2 of the project.

Complementary therapies provided a much-needed service for women on a cancer journey and Derry Well Women were able to increase their capacity for this service within the CCCW project through additional funding including the balance from their counselling budget.

Level 2 - Therapeutic Group Work

Derry Well Women have delivered 7 Well Programmes across the duration of the CCCW project. The programme has been delivered both inhouse and in rural areas through collaboration with the project partners SWELL, Fermanagh and Care for Cancer, Omagh.

The Mental Health & Wellbeing programme stopped in year 3 of the project due to facilitator availability. Derry Well Women reprofiled the budget amount to their Cancer Talks budget.

Derry Well Women provided 2 Carers Days and 1 Carers programme for female carers during year three of the project. The focus was self-care and mindfulness.

Level 3 - Social Support

Throughout the project, the Cancer Support group provided a fun, safe, environment where women of different ages came together in a relaxed social and supportive setting. Throughout the project the group have engaged in a range of health and wellbeing workshops.

Level 4 - Cancer Talks/Information days

21 hours have been allocated to guest speakers to provide workshop and talks to 420 clients across the life of the project. Due to Covid restrictions on group settings in Year 1 of the project and with due consideration for vulnerable clients the forecasted number of clients for the Cancer talks/information days was reduced from 20 clients to 12 per session. Within year 3 of the project, Derry Well Women reacted to the needs of cancer clients and engaged with a Nutritionist guest speaker for groups and a Specialist Cancer Dietician who provided one to one consultation and follow-up appointments for women with a cancer diagnosis who were not already assigned to a Trust dietician.

Through the CCCW project DWW planned on delivering the activities outlined below.

Table 1: DWW planned activities, Years 1 - 3

DWW planned activities and targets	Total – Year 1	Total – Year 2	Total – Year 3
1:1 service – counselling	30 hours	30 hours	30 hours
1:1 service – complementary therapy sessions	30 sessions	30 sessions	47 sessions
Therapeutic group work – Well programme	2 programmes	2 programmes	2 programmes
Mental Health & Wellbeing programme	2 programmes	2 programmes	2 programmes
Carers Support	1 programme	1 programme	1 programme
Social Support – Cancer Support group	15 sessions	15 sessions	15 sessions
Cancer talks/information days	7 sessions	7 sessions	7 sessions

The budget breakdown for DWW's project activities is outlined overleaf. As noted above readjustments were made to the original budget in relation to the SAM programme; in addition, a cost-of-living uplift was included from April 2023. In addition, DWW received an underspend from the Advice North West budget of £1,253, which was used against their Cancer Support Group and their complementary therapies.

- Cancer Talks/Information Sessions - £5,129
- Carer's Support - £2,520
- 1:1 Counselling - £2,555
- The Well Programme - £11,465
- Cancer Support Group - £3,569
- Complementary Therapies - £5,284
- The Mental Health & Wellbeing Programme - £5,611
- Stress Anxiety Management Programme - £720

Total = £36,853

Action Cancer

Action Cancer is a regional service providing support to people living with cancer and their carers throughout Northern Ireland. Within the CCCW project, Action Cancer extended their delivery to the Limavady and Derry areas. Through the CCCW project, Action Cancer delivered services at a number of levels:

Level 1 - Counselling /Life Coaching/complementary therapies

Over the life of the project Action Cancer aimed to deliver 184 Counselling and Life Coaching sessions to 18 clients living with cancer or their carers. This was a service which other partners could refer into and was delivered from the Limavady Community Development Initiative (LCDI). Action Cancer also aimed to deliver 276 Complementary Therapy sessions to 46 clients. Initially these were to be in both Limavady and Derry. However, there was low uptake in Limavady, and this element of the project was then delivered at The Yoga & Pilates Centre, Derry.

Level 2 - Positive Living Programme

Action Cancer delivered two, 2-day Positive Living programmes at the Everglades hotel in Derry, one in Year 1 (May 2022) and one in Year 2 (May 2023). This was a Life Coaching programme for people affected by cancer to help them reflect, refocus, rebuild, and re-energise and move forward following a cancer diagnosis.

Level 3 - Research

Research was undertaken in March/September 2022. This comprised an online survey (Cancer Experiences – your views matter) with 100 clients. Flyers for the survey were circulated widely amongst the CCCW partners, the WHSCT, Macmillan and various health care settings including GP practices. Over 1200 people completed the survey. Although some of these had treatment outside of NI, 1011 clients were treated regionally whose data was useable. Of these – 128 lived in the WHSCT area – 66% were cancer patients and the remaining were family members.

During the project's 3-year lifetime Action Cancer engaged with 296 clients and provided 395 complementary therapy sessions and 240 counselling sessions, as well as two Positive Living programmes and an online survey completed by over one thousand people.

Through the CCCW project Action Cancer planned to deliver the activities outlined below.

Table 2: Action Cancer planned activities, Years 1 - 3

Action Cancer planned activities and targets	Total – Year 1	Total – Year 2	Total – Year 3
1:1 Counselling/Life Coaching	69 sessions	92 sessions	23sessions
1:1 Complementary Therapy	103 sessions	138 sessions	52sessions
Positive Living Programme	2-day programme	2-day programme	-
Client interviews and survey work	30 days	-	-

The budget breakdown for Action Cancer's project activities is outlined below a cost-of-living uplift was included from April 2023. In addition, Action Cancer, received an underspend from the Advice North West budget of £1,253, which was used against their Counselling/Life Coaching sessions.

- Counselling/Life Coaching - £6,440 + £1,253 ANW reallocation = £7,693
- Complementary therapies - £10,260 including £600 cost of living uplift
- Positive Living programme - £10,000
- Client interviews and survey - £7,350
- Sundry resources - £1,000
- Laptop - £550

Total: £36,853

Advice North West (ANW)

Advice North West is the local branch of Advice NI which provides a range of Welfare Services to people in relation to financial management, debt management and, accessing benefits. Within the CCCW project, ANW specifically extended their support to those living with cancer and their carers and provided an essential advice service throughout the local and rural communities in the CCCW project.

ANW's focus was to deliver support programmes for project beneficiaries by ensuring:

- Cancer patients, their carers and family have increased awareness of the sources of support and advice options available to them transcending all partner organisations.
- Higher profile for benefit uptake and maximisation supporting social, economic, and financial inclusion.
- Greater capacity and empowerment for cancer patients to maintain resourcefulness for living - via interconnection of all groups.
- Improved health and wellbeing.
- Priority target groups, i.e., women and people experiencing poor mental health to benefit from ANW'S input and specialist provision.

As part of the CCCW project ANW delivered their support at four levels:

Level 1 - General Information Talks/Focus groups
At this level ANW provided Information Talks in targeted localities to people living with cancer and their carers. These talks could be availed of by all project partners and included benefit uptake and income maximisation for cancer patients, carers and families. ANW planned to deliver 48 talks/focus groups over the life of the project.

Level 2 - Tailored Telephone Support
Clients including those living with cancer, their carers and family members availed of this tailored support from ANW through a dedicated member of staff via a telephone service regarding benefit, housing, family, and employment advice in Year 1. However, in Year 2, due to the cost-of-living crisis and its impact on the community, ANW saw an increased demand for its services. In addition, the resignation of their project staff member impacted their capacity to manage the CCCW tailored telephone service. ANW reprofiled their budget allocation to a tailored direct line support service covered by their team. They worked on allocating an inhouse code to monitor calls related to clients affected by cancer. In Year 3 of the project this area remained difficult, with ANW training up another staff member, who due to demand for services was unable to commit to the additional work. The role was filled in March 24' but the gap in between resulted in an underspend in their CCCW budget which they decided to reallocate to the other project partners to help fund the demand for their services within the CCCW project.

Level 3 - Follow-up Case management
Advice NW aimed to provide follow-up 1:1 support to people living with cancer and their carers who were either referred by the partner organisations or who had attended the Information Talk or Focus Groups. Advice NW aimed to reach 85 clients per year i.e., 255 over the life of the project.

Level 4 – Advice Clinic
During the project delivery ANW responded to the need for 1:1 advice in local and rural areas and revised their activity plan to include Advice Clinics. This service was extended across the CCCW Partnership; clients availed of a private 1:1 appointment at Advice Clinics in Derry Well Women, Care for Cancer and SWELL, Fermanagh.

Through the CCCW project ANW planned to deliver the activities outlined in table 3.

Table 3: ANW planned activities, Years 1 - 3

ANW planned activities and targets	Total – Year 1	Total – Year 2	Total – Year 3
General information talks/focus groups	4	3	4
Follow-up case management	6 hours	51 hours	60 hours
Monthly Advice Clinic – DWW	3	3	0
Quarterly Advice Clinic – Omagh	0	4	4
Quarterly Advice Clinic – SWELL	0	4	4
Quarterly Advice Clinic – DWW	0	3	4

The budget breakdown for ANW's project activities is outlined below.

Resource required:

- Direct Line support - £13,705.79
- Information Talks - £1,207.50
- Follow up Case Management - £4,938.04
- Advice Clinics - £3,666.25
- Travel - £787.42
- Administration costs - £5,103

Total: £29,408

Balance of £6,192 reallocated for distribution to CCCW Partners budgets.

Cancer Focus

Cancer Focus is a regional charity in Northern Ireland offering many services inclusive of psychosocial and therapeutic support via family services, counselling, bra fitting, art therapy and a patient driving service. They also focus heavily on cancer prevention and facilitate outreach via their stop smoking, Keeping Well and Care in the sun teams.

For the purposes of this project Cancer Focus recognised the importance of having a local delivery agent on the ground with one of their staff members (Health Promotion Officer, 14 hours per week) fulfilling this role. Within the CCCW programme, their work primarily focused on cancer prevention and health promotion as well as tapping into the specialties of its other teams throughout the lifespan of the project when needed.

During Year 2 Cancer Focus were reactive in meeting the needs of service users including adults with learning disabilities who had struggled to get support with health and cancer prevention talks and women of menopause age who required support on the topic of menopause and cancer.

As part of the CCCW project Cancer Focus delivered their support at five levels. Much of this was done through linking in with pre-existing groups within local organisations/ communities including those within the CCCW partnership – Care for Cancer Omagh and SWELL, Fermanagh.

Level 1 - Health Improvement Programme[15]:

Cancer Focus staff delivered a seven-week programme through a number of pre-existing groups. The programme promoted individuals adopting a healthy lifestyle. This was inclusive of body composition analysis, bespoke lifestyle advice, signs and symptoms of cancer as well as blood pressure checks, blood sugar monitoring and CO checks.

Level 2 - Physical Activity Programme:

In this aspect of delivery physical exercise sessions focused on the importance of physical activity and the role it plays in cancer prevention. The interactive session explored:

- The recommended levels of physical activity
- What the different levels of physical activity are
- The various benefits of partaking in physical activity
- Possible barriers to exercise
- Motivation to be more active.

Level 3 - Healthy Nutrition and Healthy Body Weight:

Healthy Nutrition sessions explored:

- The NHS Eatwell guide and the importance of a balanced diet
- Inflammation and its effects on the body

[15] The Health Improvement programme was initially known as the Older Women's programme; however, the name was changed based on client feedback and the programme being delivered to both male and female participants.

- The dangers of processed foods and salt intake
- Sugar addiction and water intake
- The link between obesity and cancer.

Level 4 - Breast Self-Examination:
In this element of their input to the CCCW project Cancer Focus used presentations, breast models and interactive workshops to communicate the signs and symptoms of breast cancer, the importance of self-examination, how to carry this out properly and what to do if you think you have symptoms or are in doubt. Information on screening services and how to access them was also shared.

Level 5 - Creative Engagement:
Using various platforms such as Zoom and MS Teams, Cancer Focus engaged with those unable to attend sessions at static sites. These sessions included a range of topics such as:

- Reducing you risk
- Nutrition and Cancer Prevention
- Physical Activity and Body Weight
- Male / Female Presentations
- Specific Cancer Presentations
- Smoking Cessation
- Cancer and Mental Health

Through the CCCW project Cancer Focus delivered the activities outlined in table 4 below. Cancer Focus planned to deliver to 431 participants over the 3-year lifetime of the project as follows:

- Health Improvement Programme – 77 participants
- Healthy Nutrition sessions – 80 participants
- Physical Exercise programme – 110 participants
- Breast self-examination – 110 participants
- Creative Engagement – 30 participants
- Focus groups – 24 participants

All targets were met for the 3-year project and extra sessions were added in Year 2 and 3 due to extra demand and particular requests from certain groups and in response to additional funding as it became available. As noted above sessions were provided for adults with learning disabilities and extra sessions were provided on Men's cancers, Menopause, and a physical activity programme for those with cancer diagnoses.

Table 4: Cancer Focus planned activities, Years 1 - 3

Cancer Focus planned activities and targets	Total – Year 1	Total – Year 2	Total – Year 3
Health Improvement programme (1 group per 7-week block of sessions)	28 sessions	35 sessions	14 sessions
Healthy Nutrition programme	3 sessions	3 sessions	2 sessions
Physical Activity programme	4 sessions	5 sessions	2 sessions
Breast self-examination	4 sessions	5 sessions	2 sessions
Creative engagement	3 sessions	3 sessions	3 sessions

The resource required and budget breakdown for Cancer Focus' involvement in the CCCW project is outlined below.

- Health Promotion Officer 14 hours per week at £15.50 per hour - £11,625 per annum including employers' NIC.
- Cost of living uplift - £600 (Allocated to guest speakers in the programme)
- ANW reallocation - £1,180 (Allocated to guest speakers for additional talks, Health Improvement programme and an 8-week Pilates programme to those with a cancer diagnosis)

Total: £36,655

Care for Cancer

Care for Cancer provide services within a 26-mile radius of its centre in Omagh - offering services which include - Transport to hospital appointments, Reflexology, Counselling, a bra fitting service (provided on a voluntary basis as part of this project) and Health and Wellbeing programmes. As part of the CCCW project Care for Cancer had planned to deliver their support at two levels:

Level 1 – One to One Support – Counselling and Complementary Therapies and transport to hospital appointments.

Due to the impact of covid restrictions on group delivery and an increased demand for transport to hospital the delivery plan and budget was reviewed in early 2022, with more focus on one-to-one support – Counselling; Complementary Therapies and drives to Hospital.

Under complementary therapies reflexology was delivered in-house at the Care for Cancer premises, in the community through home visits and to those in palliative care. Counselling was delivered in-house at Care for Cancer, via face-to-face work and telephone services. Care for Cancer also provided transport support for clients to attend for hospital treatment.

Level 2: Social Support Programmes – Creative Art Therapy and Exercise programmes e.g., flower arranging and yoga.

Within this area Care for Cancer delivered a range of creative art therapy, exercise programmes including yoga, flower arranging, paver pole and card making. Funding covered instructors and materials.

In addition, Care for Cancer clients have availed of group programmes delivered externally by project partners including Cancer Focus, Derry Well Women and Advice North West. Care for Cancer clients were therefore able to avail f additional cancer support services focusing on physical, psychological wellbeing and financial advice.

Through the CCCW project Care for Cancer planned to deliver the activities outlined in table 5.

Table 5: Care for Cancer planned activities, Years 1 - 3

Care for Cancer planned activities and targets	Total – Year 1	Total – Year 2	Total – Year 3
One to one support – counselling	162sessions	144 sessions	108sessions
One to one support – complementary therapies	160 sessions	160 sessions	120 sessions
Social support programme – Drive to hospital	2,166 miles	5,108 miles	5,108 miles

The main challenge for Care for Cancer throughout the project was the increased demand for their Drivers to Hospital service. The cost-of-living uplift and reallocation of funding from ANW was used for this purpose.

The budget breakdown for Care for Cancer's project activities is outlined below:

Resources:

- Counselling £12,670
- Complementary Therapies - £14,925
- Drive to Hospital mileage including £7,405, £600 Cost of living uplift and £1,253 ANW reallocation = £9,258

Total: £36,853

SWELL

Founded in September 2018, SWELL (Supported We Live Life) is a voluntary cancer support group located in Enniskillen to provide support to people who are affected by cancer and who are rurally and socially isolated. SWELL is a peer group addressing the emotional, psychological, and physical needs of people living with cancer in the Fermanagh locality and rural areas. SWELL aims to relieve isolation, foster friendships, and improve the wellbeing of members in a supportive environment.

As part of the CCCW project SWELL initially aimed to deliver their support at three levels. As noted below level 3 did not develop as planned, so service delivery is for two levels.

Level 1 - 1:1 Services, Counselling and Complementary Therapies.

Within this category of work, SWELL aimed to deliver 211 counselling hours to 53 clients and 64 sessions of group counselling to 96 clients. They also aimed to deliver, 330 complementary therapy sessions to 66 clients.

Level 2 - Therapeutic Group Work

Within this category of work, SWELL aimed to deliver 8 sessions of Creative Art Therapy to 210 clients. SWELL also hoped to focus on the needs of those requiring palliative care. However, due to the impact of covid and its demands on WHSCT staff, SWELL were unable to secure commitment from Trust employees to support the delivery of Palliative Care workshops. Through the CCCW team they linked with Compassionate Communities at the Foyle Hospice and with the support of Macmillan, they worked on an annual palliative workshop at no cost apart from room hire. Funding was reallocated within the budget to one-to-one and therapeutic services.

Level 3 - Social Support

Within this category of work SWELL initially hoped to form a choir, where members could come together for social connection and support in a fun, safe and supporting environment. They aimed to deliver 35 sessions with 20 participants in the choir. However following difficulties in securing a choir master, funding was reallocated within the budget to meet the increased need for one-to-one services and therapeutic group sessions.

During years 2 and 3 of the project there was a continued demand at Swell for 1:1 counselling and complementary therapies. There was also an overlap in services users attending the counsellor led support group and the weekly coffee mornings. As peer support was provided at both, SWELL decided to reprofile their group support budget and resources towards 1:1 counselling and towards complementary therapies to help meet the demand for these services.

Through consultation with service users the issue of waiting lists to be seen by a WHSCT nutritionist was raised particularly by those newly diagnosed with head and neck cancer. SWELL reacted by using the £1,253 reallocated from the Advice North West budget

underspend to provide 1:1 consultations and follow up appointments with a nutritionist for those not already being seen by the WHSCT. Through the CCCW project SWELL planned to deliver the activities outlined in table 6.

Table 6: SWELL planned activities, Years 1 - 3

SWELL planned activities and targets	Total – Year 1	Total – Year 2	Total – Year 3
Group counselling (1 group per 4-week block of sessions)	16 sessions	32 sessions	24 sessions
1-1 counselling	67 hours	96 hours	72 hours
Creative therapy/Art programme	28 sessions	32 sessions	28 sessions
Complementary therapy	111 sessions	148sessions	114sessions

The budget breakdown for SWELL's project activities is outlined below.
Group Counselling - £4,125 + £600 cost of living uplift
1:1 Counselling - £10,311
Creative Art Therapy - £5,470
Complementary Therapies - £15,684
Choir - £10
Nutritionist - £1,253 (ANW reallocation)
Total: £36,853

Section 3 Incidence of cancer diagnosis and existence, and services in the Western HSC Trust area

3.1 According to the World Health Organization (WHO) *cancer* *is a generic term for a large group of diseases that can affect any part of the body. Other terms used are malignant tumours and neoplasms. One defining feature of cancer is the rapid creation of abnormal cells that grow beyond their usual boundaries, and which can then invade adjoining parts of the body and spread to other organs; the latter process is referred to as metastasis*[16].

Other terms used in this report are provided in Appendix 2 – Glossary of Terms.

3.2 Cancer registries in the four devolved nations (England, Wales, Scotland and Northern Ireland) routinely collect cancer incidence, mortality rate and survival data. UK cancer data is considered, in a global sense, to be the most accurate.

The World Cancer Research Fund has collated the latest cancer data[17] (figures are for 2019 – 2020) from the four UK jurisdictions to give an overall UK-wide set of cancer statistics[18][19][20][21]. This data indicates that in 2019/20 387,820 people were diagnosed with cancer and 166,502 people died from cancer during these years, an increase from 366,303 and 165,267, respectively, from 2017. Breast, followed by lung, cancer remains most common in the UK. Overall, there were more cancer cases in men than in women.

3.3 The incidence or prevalence of cancer varies across Northern Ireland. Various factors impact the distribution of cancer prevalence including population density, age, gender, type of cancer etc. The following key facts are taken from the NI Cancer Registry (NICR)[22] report on all cancers across Northern Ireland.[23] Data is obtained from three main sources.[24]

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[16] Cancer (who.int)

[17] What's the story behind the new UK cancer statistics? | World Cancer Research Fund (wcrf-uk.org)

[18] Cancer registration statistics, England - Office for National Statistics

[19] Cancer | Cancer Statistics | Health Topics | ISD Scotland

[20] Cancer Incidence in Wales, 2002-2019 - Public Health Wales (nhs.wales)

[21] Cancer incidence and survival in Northern Ireland: 1993-2020 - GOV.UK (www.gov.uk)

[22] The NICR collates information on cancer diagnosis and deaths from a number or sources including:

- notification of all new cases of primary malignant neoplasms (ICD10 C00-C97), carcinoma in situ and neoplasms of uncertain behaviour from regional systems including hospital and laboratory systems
- information is also collected about benign neoplasms of the brain and other CNS.
- notifications on various premalignant conditions including Barrett's Metaplasia, Colorectal polyps, endometrial hyperplasia and Monoclonal Gammopathy of unknown significance (MGUS).
- It also receives information on all Prostate Specific Antigen (PSA) tests performed in NI.

[23] All cancers: Patients diagnosed 1993-2020 (ICD10: C00-C97),
at: www.qub.ac.uk/research-centres/nicr
Filetoupload,1649413,en.pdf (qub.ac.uk)

[24] The NICR acquires notifications of likely cancer diagnoses in the population electronically from pathology laboratories including screening data (breast, bowel and cervical), treatment (including surgery, chemotherapy, radiotherapy and hormone therapy) and hospital discharges data (Patient Administration System; PAS) and death registrations (General Registrar Office; GRO). Data sharing agreements exist with these data providers. Data is also obtained from other registers and data sets. Information taken from: Cancer Data Landscape in Northern Ireland 2018 (macmillan.org.uk)

- During 2016 – 2020 there were 7,202 male and 6,482 female cases of cancer diagnosed each year, with a ratio of 778.0 male and 678.7 female cases of cancer per 100,000 males/females in the population;
- In the period 2016 – 2020 the risk of developing cancer before the age of 75 was 1 in 2.7 for men and 1 in 3.1 for women, while before the age of 85 the risk was 1 in 1.7 for men and 1 in 2.0 for women;
- During 2016 – 2020 the median age at diagnosis was 71 for men and 69 for women;
- For the total number of cases recorded, between 2011- 2015 and 2016-2020 there was:
    - an increase of 4.2% among males aged 0 to 64, an increase of 7.3% among males aged 65 to 74 and an increase of 13.3% among males aged 75 and over;
    - an increase of 7.3% among females aged 0 to 64, an increase of 5.8% among females aged 65 to 74 and an increase of 5.5% among females aged 75 and over[25];
- For the period 2016 – 2020 the most common cancer types among men were non-melanoma skin cancer (31.0%), prostate cancer (17.5%), lung cancer (9.7%) and colorectal cancer (9.0%), while the most common cancer types among women were nonmelanoma skin cancer (24.8%), breast cancer (22.5%), lung cancer (10.1%) and colorectal cancer (7.9%);
- The annual number of cases during 2016-2020 varied in each deprivation quintile due to variations in population size and age. After accounting for these factors, incidence rates:
    - in the least socio-economically deprived areas did not Quintile 3 vary significantly from the NI average;
    - in the most socio-economically deprived areas were 6.0% higher than the NI average.
- The annual number of cases during 2016-2020 varied in each HSCT due to variations in population size and age. After accounting for these factors, incidence rates:
    - in Belfast HSCT were significantly higher than the NI average;
    - in Northern HSCT did not vary significantly from the NI average;
    - in South-Eastern HSCT did not vary significantly from the NI average;
    - in Southern HSCT did not vary significantly from the NI average;
    - in Western HSCT did not vary significantly from the NI average;
- At the end of 2020, there were 102,027 people (Males: 48,407; Females: 53,620) living with cancer[26] who had been diagnosed with the disease during 1996-2020. Of these, 47.4% were male, 38.9% were aged 75 and over, and 9.9% had been diagnosed in the previous year;
- By 2033 the number of cancer survivors in the population is projected to increase by over 40%.

3.4 Table 7 provides an overview of cancer incidence in the Western HSC Trust for the period 2015 – 2019 for all persons diagnosed, including a breakdown by type of cancer. Table 8 provides a comparison of cancer incidence across the five HSC Trust areas for Northern Ireland. The source for both tables is: Official Statistics | N. Ireland Cancer Registry (qub.ac.uk) Further data on cancer type, nation, sex and year, including projections to 2040 is published by Macmillan at macmillan-2020-cancer-prevalence-figures-and-methodology

[25] Trends in age-standardised incidence rates by age.
[26] Referred to as prevalence.

Table 7: Cancer incidence in the Western HSC Trust for the period 2015 – 2019, for all persons diagnosed[27]

Cancer type	Number of cases	Average number of cases per year	Crude incidence rate per 100,000 person years	European age-standardised incidence rate per 100,000 person years	Standardised incidence ratio compared to NI[28]	Statistical significance of standardised incidence ratio
All cancers	10,602	2,120	703.7	845.1	99.2	.
All cancers excluding NMSC[29]	7,754	1,551	514.7	611.9	101.2	.
Bladder cancer	183	37	12.1	15.3	99.7	.
Brain and central nervous system cancer	117	23	7.8	8.7	98.8	.
Colorectal cancer	915	183	60.7	73.8	101.5	.
Gallbladder and other biliary cancer	69	14	4.6	5.7	93.2	.
Head and neck cancer	268	54	17.8	20.5	95.0	.
Kidney cancer	251	50	16.7	19.3	98.3	.
Leukaemia	175	35	11.6	13.6	87.3	.
Liver cancer	101	20	6.7	8.3	92.9	.
Lung cancer	1,118	224	74.2	91.4	108.5	Higher than NI average
Lymphoma	316	63	21.0	24.6	98.9	.
Melanoma	252	50	16.7	19.4	80.7	Lower than NI average
Myeloma and plasma cell neoplasms	141	28	9.4	11.3	106.9	.
Non-melanoma skin cancer	2,848	570	189.0	233.2	94.0	Lower than NI average
Oesophageal cancer	142	28	9.4	11.1	84.2	Lower than NI average
Other malignant cancer	343	69	22.8	26.9	98.1	.
Pancreatic cancer	219	44	14.5	18.2	107.7	.
Stomach cancer	181	36	12.0	14.5	117.9	Higher than NI average
Thyroid cancer	99	20	6.6	7.1	99.8	.
Unknown primary cancer	139	28	9.2	11.7	100.1	.

[27] This table provides cancer incidence for above range of cancer types. Official statistics for the remaining cancer types will be published in 2024.
[28] This is the ratio of the number of cases/deaths observed in a population to the expected number of cases/deaths based upon the age-specific rates in the reference population.
[29] Non-melanoma skin cancer.

Table 8: Cancer incidence by HSC Trust area for the period 2015 – 2019, for all persons diagnosed

HSC Trust area – for all cancers	Number of cases	Average number of cases per year	Crude incidence rate per 100,000 person years	Standardised incidence ratio compared to NI	Statistical significance of standardised incidence ratio
Western	10,602	2,120	703.7	99.2	-
Belfast	13,227	2,645	742.4	103.9	Higher than NI average
Southern	12,819	2,564	674.3	99.4	-
South Eastern	14,268	2,854	794.8	98.7	-
Northern	18,189	3,638	766	99.1	-

3.5 From tables 7 and 8 above it appears that the incidence of cancer in the Western HSCT area falls within the normal standardised incidence ratio for Northern Ireland. The CCCW project has been developed against the backdrop of some very specific factors relating to the Western Trust area as follows:

- The Trust serves a population of approximately 300,000 across a largely rural community with unequal access to community resources and support;
- Transport is a key issue in terms of accessing services, and in relation to those reliant on public transport and limited availability of public transport routes and timing for hospital and other appointments;
- The number of cancer survivors in the population is projected to increase by over 40% by 2033; this places an increase in responsibility for families and communities caring for those who are living with cancer as a long-term condition.

In addition, it is worth noting that cancer services, like many other health-related and wider services, were challenged before the Covid-19 pandemic commenced in March 2020 because of unacceptable waiting times and significant workforce and capacity challenges. These factors – waiting lists and access to services – have worsened since the pandemic.

3.6 The geographical area covered by the Western HSC Trust includes Derry/ Londonderry, a number of county and regional towns including Enniskillen, Strabane, Omagh and Limavady, and areas covering three counties – County Londonderry, County Tyrone and County Fermanagh. The following map[30] shows the geographical coverage of the Trust area in relation to the other HSC Trusts. It is important to note that the cancer services outlined below cluster around the Derry area and the Altnagelvin hospital. Travel time to Derry from Enniskillen is approximately one hour and 30 minutes, and from Omagh, 55 minutes. For those travelling from the furthest points of County Fermanagh, cancer services are up to two hours away by car. Access to public transport is a further factor.

[30] Taken from: Health service structure | Belfast Health & Social Care Trust website (hscni.net)

Cancer services in the WHSCT include the following:

North West Cancer Centre[31]

Altnagelvin Hospital has been a well-established site for delivering systemic anti-cancer treatment (SACT) and now has a new state-of-the-art Cancer Centre on-site, providing both Chemotherapy and Radiotherapy Services. The North West Cancer Centre has been delivering radiotherapy treatments since 2016. The Radiotherapy Suite provides treatment five days a week, Monday to Friday, and is supported by a diagnostic CT and MRI Scanner in the Centre.

Chemotherapy Services are situated in a purpose-built facility within the North West Cancer Centre, made up of the Sperrin Suite Outpatient Department, Triage Service, and Ward 50 Inpatients. The Sperrin Suite delivers systemic anti-cancer treatment (SACT), and is operational Monday to Friday. The Triage service is based at North West Cancer Centre and delivers a 24-hour telephone assessment and advice to Oncology and Haematology patients. Ward 50 provides inpatient care for Oncology and Haematology patients, and is situated on Level 1 of the North West Cancer Centre with a capacity for 27 beds.

[31] North West Cancer Centre | Western Health & Social Care Trust (hscni.net)
Cancer Services | Western Health & Social Care Trust (hscni.net)

Macmillan Information and Support Service

Macmillan Information and Support service provides individuals and families with support and information throughout their cancer pathway. Based at Altnagelvin this service provides the following:

- Information
- Emotional support and a listening ear
- Can refer someone to a counsellor
- Tips on how to prepare physically, practically and emotionally for your treatment
- Benefits and financial advice
- Access local services – transport and work at home
- Complimentary therapy and workshops – individual and group
- Help to support physical/appearance element of cancer treatment

A number of other voluntary and community-based organisations (a number of which are involved as partners in the CCCW project) provide support and services throughout the Western HSCT area. These include Action Cancer[32], Cancer Connect NI[33], Cancer Focus NI[34], Derry Well Women[35], Macmillan Cancer Support[36], the Pink Ladies[37], Care for Cancer (Omagh)[38] and Friends of the Cancer Centre[39].

Mobile screening services are provided for the NHS Breast Screening programme are provided in two locations in the Trust, namely Strabane and Omagh, whilst radiology services are provided at Altnagelvin hospital, Omagh hospital and primary care complex, Roe Valley hospital and the South West Acute hospital (SWAH).

[32] Action Cancer
[33] Cancer Connect NI
[34] Cancer Focus NI
[35] Derry Well Women
[36] Macmillan Cancer Support
[37] The Pink Ladies
[38] Care for Cancer, Omagh
[39] Friends of the Cancer Centre

Section 4 Project progress and Meeting targets – Quantitative Assessment

4.1 This section reviews the quantitative data being collected as part of the CCCW project; this data is available for the first two years of project delivery (September 2021 to September 2024) and includes the following:

- Participant numbers
- Participant profile
- Marginalised groups

4.2 Evaluation of progress on numbers and targets is now outlined using a number of different areas of data and documentation:

- Community Fund – Year 1 report – submitted October 2022
- Participant numbers and activity details – for Years 1, 2 and 3, submitted by partners and collated by the lead partner.

4.3 ***Community Fund – Year 1 report***

This report, submitted in October 2022, highlighted progress in the CCCW project in the first year. This focussed on the lead-in period of setting up and launching the project (September 2021 at the Silverbirch hotel) and the recruitment of the Project Administrator (September 2021) and the Project Manager (May 2022). Initial difficulties in appointing a Project Manager were noted.

The report also detailed the development of the support infrastructure for the project including the Project Board. The Project Board was up and running at the outset and meeting regularly to develop the project. Appropriate paperwork was put in place, together with training delivered to support the project development and delivery. This included:

- Social Media training – March – April 2022
- Effective Listening for Effecting Change (ELEC) training – October 2022
- ABCD Workshop – February 2023

An evaluations report from the ELEC workshops[40] pointed to participants valuing the knowledge, learning and shared resources, with an indication that participants felt the training increased their effective listening skills, their confidence to have a conversation with someone to effect change, and their confidence to signpost. Feedback from the ABCD training indicated that participants noted learning and knowledge about the techniques and skills needed to build community relations.

During Year 1 a number of strategic relationships were explored with the Department for Health and the Western HSC Trust. At a local level these included meetings with the Western Integrated Care Partnership (ICP), the Palliative Care District Nurse team, the Hospital Social Work team, the Community Social Work team, the Physical and Learning Disability Social Work team and Older People Services. In addition, connections were made

[40] Evaluation report, ELEC.

with the All-Party Cancer Group, and a range of wider organisations at a local and operational level.

4.4 ***Participation numbers and details by partners***

The tables below set out the total number of participants associated with each of the six partners and various activities, and attendance/participation at the overall CCCW project events e.g. Gathering Sessions, Negotiating Change workshops and the final 'Commitment to Change' Conference.

A total of 2,748 participants received services across the 3-year lifespan of the project. The partnership delivery organisations provided a range of 16 interventions tailored to meet the needs of people living with cancer. The support provided included 111 therapeutic programmes, 1,020 counselling sessions, 1,300 complementary therapy sessions and three carers days. There were 89 specifically tailored welfare benefit support sessions, 30 benefit advice clinics, 133 follow-up case management appointments and seven welfare/benefits talks, 15 cancer information talks and two cancer support groups. The rural transport service provided 211 drives to hospital appointments, there were 8 Nutrition consultations and 1 research survey on the experiences of the cancer journey.

Participants were defined as individuals who presented with a cancer diagnosis, as living with cancer, who were in different stages from diagnosis to treatment to recovery or in reoccurrence or at end of life. In addition, participants in the project included carers and family members.

As a result of their involvement, participants have inputted to the development of services, pathways and improvements for the prevention of and care for cancer (linking to the overall aims outlined in Section 2.3/2.4) and have increased their own (and family) wellbeing and made suggestions about gaps in provision at a community level. Section 5 provides more details on how groups and participants have contributed to these aims, targets and outcomes.

4.5 ***Participant Profile***

Analysis of the participant information is based on client information for 2,748 participants over the three years of the project, and provides the following details:

- The project participants are largely women; in all three years the breakdown was 18% - 20% male and 80% - 82% female. The higher proportion of female participation may in part be due to the focus of some of the projects and delivery, e.g. Derry Well Women focus on females and the bra fitting service from Care for Cancer;
- The age profile of participants[41] showed the majority were in the age 50 to 69 age bracket (55% over the course of the 3-year project), with around one-fifth to one quarter in two age brackets (30 – 49 age group had 19% , and the 70 plus age bracket had 24%). 2% of participants were aged 18 – 29. The age profile is likely to be linked to a number of factors including the level of cancer incidence increasing with age, and the

[41] It should be noted that the age profile was available for 2,584 of the total 2,748 participants.

fact that many of the activities/project delivery were more accessible for those who were not working or with full-time caring responsibilities, again linked to older age groups;

- 99% of all participants for whom information on ethnicity was available were white. Those with a different ethnicity included Indian, Chinese, Polish, mixed ethnic, other ethnic, black other and Irish Traveller.
- From Year 2 the project information on 'English not first language' was also collected with six participants falling into this category in Years 2 and 3
- In addition, since Year 2 information on the type of cancer experienced by the participant (or their family member) has also been recorded. This has indicated the broad range of cancers represented amongst the total participants including anal, appendix, bladder, bowel, brain, breast, brain, cervical, kidney, liver, lung, lymphoma and Hodgkin's lymphoma, mucinous carcinoma, ovarian, prostate, rectal, skin, stomach, throat, thyroid and womb etc.

4.6 ***Marginalised groups***

Table 9 indicates that the project has been successful in reaching a wide range of individuals and groupings who are defined as in 'marginalised' groups. However, it is difficult to be categoric about these levels of take-up without reference to the incidence of these factors in the broader population e.g., the level of rural take-up could be considered low given that much of the WHSC Trust area is defined as being rural. In addition, these numbers may be dependent on what information participants were asked for and what they shared; there may be an element of self-reporting and also under-reporting across these factors.

Table 9: Marginalised groups – numbers by headings for all organisations, Years 1 - 3

Marginalised group	Total – Year 1	%age of Total participants for year (727)	Total – Year 2	%age of Total participants for year (866)	Total – Year 3	%age of Total participants for year (1,155)	Total – Years 1 & 2 & 3 (2,748)	%age of Total participants
Single parent	50	7%	47	5%	32	3%	**129**	5%
Rural Area	364	50%	346	40%	525	45%	**1,235**	45%
Learning Disability	10	1%	8	1%	36	3%	**54**	2%
Physical Disability	81	11%	111	13%	266	23%	**458**	17%
Mental Health	79	11%	75	9%	210	18%	**364**	13%
Older people – 60+	228	31%	240	28%	428	37%	**896**	33%
LGBTQ+	3	<1%	4	<1%	1	<1%	**8**	<1%
English not 1st lang	-	-	3	<1%	3	<1%	**6**	<1%

4.7 Analysis of the participant profile, including marginalised groups is useful on a number of levels. Firstly, to see the spread of representation across age, gender, ethnicity etc. Secondly, as a prompt and planning tool throughout the three years of the project. As noted above certain groups were under-represented in the project participation, i.e. males, younger people, different ethnic groups. In addition, the information recorded under the marginalised groups does not fully tally with information recorded separately. For example, the older people group in table 9 is indicating around 32% of the participants, whereas the analysis in 4.5 above would suggest that this higher.

4.8 The delivery information for Years 1, 2 and 3 is now reviewed. Overall, this provides a very positive picture in terms of the total numbers of activities and programmes delivered against what was planned, and the total clients/participants achieved, against what was projected. In Year 1 in particular it was clear that a slower than anticipated recruitment and start process for the project may have impacted the range and level of activities delivered. In addition, throughout Years 1 and 2 the impact of recovery from Covid-19 with potential participants concerned about meeting in groups and coming out again may have had an impact. Year 3 showed a return to many in-person activities and events post Covid-19, with numbers of participants increasing across all partners.

The following table also highlights:

- When a programme or activity is 'open' to participants e.g., a talk or support group, it is difficult to estimate/project how many will attend; this can lead to variation in numbers;
- The delivery of a number of the programmes and activities e.g., counselling and complementary therapies are dependent on the availability (geographically and timing wise) on practitioners;
- Levels of take-up varied across the partners, types of programme and from a geographical perspective;
- Some of the activities, as noted earlier in this report e.g. SWELL did not develop a choir due to choir master availability.

Table 10: Programme activity levels, by partner organisation Years 1, 2 and 3[42]

Derry Well Women	**Year 1 October 2021 – September 2022**			
Programmes	**Planned**	**Delivered**	**Clients**	**Achieved**
Cancer Talk (inc P Molloy talk)	7 talks	3	84	56
Cancer Support Group[43]	15 sessions	13	12	102
Counselling	30 hours	29	5	7
Complementary Therapy	30 sessions	30	10	18
Carers Support	1	1	30	15
Mental Health & Wellbeing Programme	2	2	36	16
The Well Programme	2	2	32	21
Stress Anxiety Management	2	1	45	5
Total			**254**	**240**
Year 2 October 2022 – September 2023				
Cancer Talks	7 talks	4	84	37
Cancer Support Group	15 sessions	18	12	152
Counselling	30 hrs	25	5	4
Complementary Therapy	30 sessions	30	10	13
Carers Support	1	0	30	0
Mental Health & Wellbeing Programme	2	3	36	21
The Well Programme	2	3	32	31
Total			**209**	**258**
Year 3 October 2023 – September 2024				
Cancer Talks	7 Talks	7	84	**42**
Cancer Support Group	15 sessions	14	12	122
Counselling	30 hrs	19	5	3
Complementary Therapy	47 sessions	94	15	**22**
Carers Support	1	3	30	**46**
Nutritionist 1:1 &review	4	4	4	**4**
The Well Programme	2	2	32	**17**
Total			**214**	**256**

[42] The client totals in the tables below are based on client profile forms and programme attendance sheets where provided.

[43] The CSG figures above are based on attendance records and client profile forms received. The group meet fortnightly, so it would be unfair to their experience to request a profile form every visit. The profile forms are requested as and when new clients attend and when there is an event e.g., an art therapy workshop.

Action Cancer	Year 1 October 2021 – September 2022			
Programmes	**Planned**	**Delivered**	**Clients**	**Achieved**
Complementary Therapies	103 sessions	95	17	40
Counselling	69 sessions	72	7	30
Positive Living Programme	1	1	15	8
Total	**173**	**168**	**39**	**78**
	Year 2 October 2022 – September 2023			
Complementary Therapies	138 sessions	159	23	30
Counselling	92 sessions	97	9	7
Positive Living Programme	1	1	15	11
Total	**231**	**195**	**47**	**48**
	Year 3 October 2023 – September 2024			
Complementary Therapies	52 sessions	101	9	**16**
Counselling	23 sessions	71	2	**26**
Client survey			100	**128**
Total	**75**	**172**	**111**	**170**

Cancer Focus	Year 1 October 2021 – September 2022			
Programmes	**Planned**	**Delivered**	**Clients**	**Achieved**
Health Improvement Programme	28 sessions	28	28	43
Breast Awareness	4	4	40	31
Nutrition	3	3	30	29
Physical Activity	4	4	40	37
Creative Engagement	3 sessions	3	30	30
Total	**42**	**42**	**168**	**170**
	Year 2 October 2022 – September 2023			
Health Improvement Programme	35	35	35	42
Breast Awareness	5	7	50	63
Nutrition	3	6	30	61
Physical Activity	5	6	50	52
Extra Awareness Session – Men's cancers	0	1	0	7
Creative Engagement	3 sessions	3	30	30
Total	**51**	**60**	**195**	**255**
	Year 3 October 2023 – September 2024			
Health Improvement Programme	14 sessions	35	14	42
Breast Awareness	2	4	20	63
Nutrition	2	2	20	27
Physical Activity	2	4	20	52
Extra Sessions	0	13	0	55
Creative Engagement	3 sessions	4	30	30
Total	**23**		**104**	**269**

Care for Cancer	Year 1 October 2021 – September 2022			
Programmes	**Planned**	**Delivered**	**Clients**	**Achieved**
Counselling	162 sessions	104	27	54
Complementary Therapy	160 sessions	146	40	74
Drives to hospital[44]	3443 miles	7768	40	40
Bra Fitting[45]	N/A			42
TOTAL			**107**	**210**
	Year 2 October 2022 – September 2023			
Counselling	144 sessions	135	24	71
Complementary Therapy	160 sessions	150	40	81
Drives to hospital	5108 miles	2956	40	23
Bra Fitting	N/A			55
Total			**104**	**230**
	Year 3 October 2023 – September 2024			
Counselling	108 sessions	118	18	62
Complementary Therapy	120 sessions	136	30	80
Drives to hospital	3831 miles	3221	20	39
Bra Fitting	N/A			51
Total			**68**	**241**

SWELL	Year 1 October 2021 – September 2022			
Programmes	**Target**	**Delivered**	**Clients**	**Achieved**
Group Support	16 sessions	19	24	21
1:1 Counselling	67 hrs	76	17	1
Art Therapy	28 sessions	25	70	39
Complementary Therapy	111 sessions	109	22	9
Choir[46]	3 sessions	3	20	10
TOTAL	**225**	**232**	**153**	**80**
	Year 2 October 2022 – September 2023			
Group Support	32 sessions	39	48	44
1:1 Counselling	96 hrs	112	24	25
Art Therapy	32 sessions	38	80	24
Complementary Therapy	149 sessions	142	30	19
Total	**309**	**322**	**182**	**112**
	Year 3 October 2023 – September 2024			
Group Support	24 sessions	1	36	-
1:1 Counselling	72 hrs	103	18	26
Art Therapy	28 sessions	34	70	142
Complementary Therapy	114 sessions	108	23	37
Nutrition workshop[47]	0	1	-	-
Nutrition consultations	0	4	-	-
Total	**238**	**251**	**147**	**205**

[44] Note: 211 return drives completed.
[45] This is a volunteer service.
[46] Year 1 Choir statistics based on attendance records. No profile forms submitted.
[47] No profile forms submitted for the Nutrition workshop/consultations in year 3.

ADVICE NORTH WEST	Year 1 October 2021 – September 2022			
Programmes	**Planned**	**Delivered**	**Clients**	**Achieved**
Tailored Advice Support	336 hrs	336 hrs	48	58
Information Talks[48]	4	3	36	9
Follow-up Case Management[49]	6hrs	19.5 hrs	6	11
Monthly Advice Clinics	3	3	24	9
TOTAL			**114**	**87**
	Year 2 October 2022 – September 2023			
Tailored Advice Support	56	42 hrs	8	0
Tailored Telephone Advice	TBC	-	-	-
Information Talks	3	0	24	0
Follow-up Case Management	51 hrs	21hrs	51	23
Monthly Advice Clinics	3 clinics	2	18	7
Quarterly Advice Clinics	11 clinics	8	62	31
Total			**163**	**61**
	Year 3 October 2023 – September 2024			
Tailored Advice Support/salary	434 hrs	434	62	31
Information Talks	4	7	36	-
Follow-up Case Management	74 hrs	96	95	99
Advice Clinics	12 clinics	17	68	60
Total			**247**	**190**

4.11 As noted earlier the Gathering Sessions have seen consistent levels of participation with the following numbers of participants: GS 1: 56, GS 2: 66, GS 3: 53 and GS 4: 56. Analysis of the participant profile information at the Gathering Sessions 1, 3 and 4 is outlined in Table 11.

Participant profile information was not relevant for Gathering Session 2 which was focussed on health professionals. The participant profile information and the data from the Gathering Sessions was useful as an indicator of project reach and impact, and was also used for targeting and focus in ongoing project development plans.

[48] **Information Talks** completed in open forums unsuitable to obtain client profile forms, hence no record of number or profile of participants who attended.

[49] **Follow Up Case Management** – Involves follow up work with clients who attended advice clinics or received telephone support. To avoid duplication of data, for the most part, clients were not asked to complete profile forms more than once. Although 19 profile forms were submitted from FCM, the figures above in years 1 – 3 include an additional 106 FCM based on the number of clients who received this service as recorded by ANW on evidence for their CCCW expenditure claims.

Table 11: Gathering Sessions: profile of participants

Area	GS1: Percentage	GS3: Percentage	GS4 Percentage
Gender			
Female	80%	87%	63%
Male	20%	13%	37%
Age			
18 – 29	2%	-	-
30 – 49	20%	16%	20%
50 – 69	56%	64%	56%
70 – 89	20%	20%	24%
90+	2%	-	-
Socio-economic status			
Employed (fulltime)	27%	30%	22%
Employed (part-time)	16%	13%	22%
Self-employed	5%	14%	4%
Unemployed	11%	7%	6%
Retired	33%	34%	46%
Carer	2%	2%	-
Undisclosed	6%	-	-
Ethnicity			
White	98%	98%	100%
Other	2%[50]	2%[51]	-
Marginalised groups[52]			
Single parent	7%	8%	13%
Rural area	19%	8%	37%
Living with a learning disability	-	1%	6%
Living with a physical disability	6%	16%	21%
Living with mental health issues	4%	10%	15%
Older people 60+	30%	11%	20%
LGBTQ+	6%	-	2%
English not a first language	-	3%	-
Undisclosed	33%	54%	26%

[50] Irish Traveller.
[51] Irish traveller and Indian.
[52] Total does not add to 100% because participants selected more than one option.

Area	GS1: Percentage	GS3: Percentage	GS4: Percentage
Client background			
Cancer survivor	31%	43%	24%
Bereaved	10%	2%	9%
Carer/family member	15%	18%	39%
CCCW partnership member	20%	-	-
Health professional	8%	1%	-
Living with cancer	16%	23%	28%
Undisclosed	-	13%	-
Type of cancer			
Appendix	-	-	2%
Anal	2%	-	-
Bladder	-	-	2%
Bowel	2%	7%	-
Brain	2%	-	4%
Breast (including secondary)	18%	41%	20%
Cervical	3%	3%	-
Endometrial	-	3%	-
Eye	-	3%	-
Gynaecological	-	-	7%
Hodgkins Lymphoma	4%	-	2%
Liver	-	3%	-
Lung	1%	1%	-
Mucinous carcinoma	2%	-	-
Neuroendocrine	-	1%	-
Oesophageal	-	1%	-
Prostrate	4%	-	11%
Skin	2%	-	-
Spine	-	1%	-
Thyroid	-	!%	-
Uterine	2%	-	-
Vaginal	2%	1%	-
Womb	2%	-	-
Undisclosed	53%	34%	52%

Section 5 Project outcomes and impact– Qualitative Assessment

5.1 This section provides an overview for the whole project, in terms of outcomes and impact as follows:

- Firstly, individual participant outcomes; these have been measured and recorded by the different partner organisations;
- Secondly, looking at feedback on outcomes and impact for participants/service users from the partner organisations, gathered by the evaluator during Years 2 and 3;
- Thirdly, looking at feedback on outcomes and impact from participants/service users, gathered by the evaluator during Years 2 and 3;
- Finally, outcomes in terms of the overall project aims of engagement and change management in relation to the integration and improvement of cancer care in the WHSCT area. For this element we have reviewed two areas (i) the themes suggested by participants in the feedback mechanisms and the Gathering Sessions that create barriers and need changed and (ii) the methodology developed and used by the Project Management team to engender participant involvement and co-production through the 3-tier model of engagement[53].

Individual participant outcomes

5.2 Information has been collected, collated and analysed by the six partner organisations, to indicate the change in individuals through their participation in the CCCW project; this is both quantitative and qualitative in nature. Appendix 3 provides an overview of some of the information collected in this way. No information was available from Advice North West, as individual participant outcomes are not measured in this format. From a general perspective it should be noted that there is considerable variation in the recording and evaluation systems used by the six partners; there is therefore no way of making direct comparisons across provision or across the partner organisations, in terms of individual participant outcomes. Partner organisations have used the following monitoring and evaluation tools: Measure Yourself Medical Outcome Profile (MYMOP)[54], Self-Assessment Lifestyle Inventory (SALI)[55] and Core Measurement Tools (Core-10)[56], together with their own organisational in-house evaluation forms and methods, including quantitative and qualitative approaches.

Overall, the examples included in Appendix 3 point to significant improvements in participants' health and wellbeing including their mental and physical health e.g. measured via MYMOP. These tools before a 'before' and an 'after' measurement, thus enabling insight into impact from a specific programme or activity. However, these tools do not measure aspects such as acquisition of knowledge and information, or impact of peer support etc.

[53] See Levelling Up project - https://www.derrywellwoman.org/publications/
[54] MYMOP® - Meaningful Measures - The home of MYCaW® and MYMOP®
[55] S.A.L.I developed by DWW, evaluated by University of Ulster 2000-2003. Project Team - Dr Hazel Templeton. Lecturer in Nursing UU; Mr Pat Deeny, Senior Lecturer in Nursing, UU; Ms Caroline Anketell, Assistant Psychologist Altnagelvin HSST; Dr Mary Morris Clinical Psychologist, Altnagelvin HSST; Ms Bridie Gallagher, Counselling & Trauma Programme Co-ordinator, DWW.
[56] CORE Measurement Tools (CORE-10) (corc.uk.net)

In addition, from a methodological perspective, a number of the quantitative tools used are designed to pose a series of questions to provide an overarching score for a large volume of respondents; they are not set up to examine individual cases or outcomes, rather to look at trends and patterns, usually at the end of service provision. They do not adapt well to review at different stages as the data is cumulative. Data such as the Core 10 data would need to be analysed at the end of the project in order to indicate any changes as a result of the intervention, rather than just by chance.

Feedback from partner organisations on outcomes and impact for service users

5.3 As part of the ongoing project evaluation, the evaluator met with a representative(s) of all six partner organisations during Years 1 and 2 to obtain feedback on areas including project/ programme development and delivery, as well as participant take-up and outcomes. Further feedback was provided by partners at the end of Year 3, including feedback from the WHSCT. This sub-section now reviews this feedback. Respondents were drawn from all six partner organisations plus the Macmillan Information and Support Service, and included partner organisation staff and Board members, and some respondents responsible for the provision of activities on a sessional basis, e.g. counselling, complementary therapies.

There were some common themes from partner respondents and the WHSCT about the project and the outcomes/impact for participants. These were as follows:

- Participants benefitted from having local activities and programmes in the Western HSC Trust area, rather than having to travel outside of their area. In addition, partners highlighted the positive benefits of using staff and sessional staff who knew the area and the local services. One respondent said: *She knew the area really well; she was accepted into local groups and it's not someone coming down from Belfast.*

- Participants benefitted from a project with a wide range of activities including individual and group work, support services, information, advice, counselling and complementary therapies. One partner commented on their role in the project: *I thought it was just a fabulous partnering of wonderful organisations – it seemed a natural fit.*

- As well as having practical outputs including knowledge and information, the project also provided opportunities for participants to explore what had and was happening to them. One respondent said: *it gives them space to tell their story and to explore their emotions.* This theme was repeated by other respondents. One said: *People say to us, I know the consultant has told this news 100 times but it's my first time to hear it – and I felt just like a number…feel there is a threat on my life. At times you just feel you are getting treated as a number. This service – is giving them a voice.* Often feel their time in a meeting with the consultant – *is very time limited.* Respondents emphasised that participants were more in control of their emotions, and for those at end-of-life stage, they felt control over how their last months would be spent;

- Respondents highlighted reduced client anxiety levels and improved mental health, and that there was value in the CCCW project in terms of enabling the participants to explore their feelings and find ways to cope with their past and current situation. This was

summed up by one respondent: *space is provided for them to tell the story from start to finish…often things that they haven't even shared with family, loved ones or partner – they are afraid to put this onto the family. Also, it is a place of no judgement – giving that basic space. Often, they are struggling with feelings – although they have survived they don't feel lucky and on the other hand often feel guilty. It allows them to explore their feelings and truly be themselves…. They go away feeling a bit lighter and feel they have had a light bulb moment – coping better.*

- Respondents highlighted the positive element of group work across the different activities. One respondent said: *when they are at hospital they are feeling really upset, who to turn to, don't know where to go…they are feeling isolated. Group work provides support, connection and social aspect by bringing together in a group there is peer support between people – the benefit of talking – those people are not friends and they stay in touch.*

  Respondents noted that the project enabled increased levels of social interaction for participants, and a reduction in social isolation. This came in the wake of reduced social interaction and groups as a result of the Covid pandemic, and was welcomed as a positive impact;
- Respondents noted that some participants had indicated a reduction in pain levels through treatments and therapies;

- The project and its activities are individualised, where possible, for each participant. One respondent noted: *where possible we let them pick. They feel all their choices have been taken from them and they have no voice…I tailor and adapt therapies to their needs and the type of cancer they have had.*

- Respondents highlighted that the impact of the CCCW project for some participants has been to enable or help them get back to work, return to normal tasks, start to re-engage with family, friends and socially;

- Respondents noted that the CCCW project has provided a vital role in the community in element such as signposting, the provision of transport to appointments. Some partners indicated that the project had resulted in *a spike in demand for health promotion work* in particular geographical areas. One partner responded to this by employing a full-time health promotion officer to deliver health checks, cancer awareness and prevention talks, facilitate health fairs, promote support services and signpost as appropriate;

- Partners noted the significant benefits of the project in terms of participants involvement in the Gathering Sessions, the Negotiating Change workshops and the 'Commitment to Change' conference. One partner noted: *they got to meet other participants involved in the project, interact with each other and talk about their experience…they had the opportunity to highlight issues and barriers that were pertinent to them and feed into the reconfiguration of cancer services in the WHSCT.* Partners

noted that this meant participants felt they were part of the process and that they were valued;

- At the end of Year 3 partners commented on how the project had and will continue to help shape cancer services. The WHSCT noted: *the model of engagement created time and space for the Trust to be an active participant in relation to receiving feedback.* One example of this was feedback which enabled the Trust to take action to increase staff support within the North West Cancer Centre. The Trust also noted that the project had provided them with a road map of priorities to deliver, including increasing and improving how people living with cancer are made aware of services available for support.

- The network developed in the project was noted by a number of stakeholders; noting that this network will continue to provide an opportunity to work with partners to provide support for those living with cancer.

- Overall comments on the project included:
  This was a fantastic project which will make a real difference to service users and staff.

Direct Feedback from participants on outcomes and impact for service users

5.4 As part of the ongoing project evaluation, the evaluator met with a number of service users. Respondents provided their consent to share their stories and experience of the CCCW project. Interviews took place face-to-face at partner organisations or Gathering Sessions. A total of eleven service users provided feedback – two from DWW, one from Action Cancer, three from Care for Cancer and five from SWELL. All respondents had personal experience of cancer, with some having additional experience within their wider family.

There were some common themes:

- Respondents noted generally good experiences of the health service in terms of diagnosis, treatment and wait times. However, all of those with a cancer diagnosis noted some concerns about aftercare, indicating that they felt they had been *dismissed very quickly by the consultant* with follow-up and call backs more limited that they had hoped for. One respondent talked about excellent care at the time of diagnosis and one follow-up call, but then when she later tried to get help, she noted: *it was hard to get her…I felt the service wasn't great; felt they were complacent – took their knowledge for granted but when it's yourself or your family.* Another respondent had a similar comment: *I would have liked to have someone to speak to – I just had nobody.* Respondents also said that it would have been helpful to have access to the CCCW project/programmes at an earlier stage, and that they had felt isolated during diagnosis and treatment.

- All the respondents were very positive about the programmes and activities of the partner group they were associated with, mentioning information, knowledge, awareness, peer support etc. Friendship and social interaction were also seen as equally important. Reference was also made to opportunities for physical activity,

complementary therapies including reflexology, counselling, doing a new activity and opportunities to meet with people who have had similar health experiences.

- A number of respondents had availed of a range of programme activities and services. For example, one respondent said that she had received reflexology, a one-off counselling session, bra fitting, the Move It programme and a 2-day awareness and support event; these were provided individually by four of the partners.

- In terms of the impact of the project, service users were very positive. One respondent said from a purely functional and practical point of view at the early stages of their diagnosis, that it was *a reason for getting out of bed… it's everything, it's a life-line.* Another respondent said: *Reflexology was an amazing experience. It had a positive impact on my mental health and wellbeing. She is an amazing therapist and brilliant at what she does. She has helped me switch off from everyday worries and to try and just concentrate on myself for the duration of the treatment.* A further participant said: *I have really benefitted from my counselling. It has given me a much-needed support in a very difficult period of my life. I felt the counsellor was knowledgeable and extremely helpful and supportive. The weekly sessions gave me a boost in order to be able to cope with my circumstances.*

- Peer support was important to all of the respondents – both from their own perspective and of helping others. One commented: *you might help someone in the group to open up and seek help.* Respondents said their preference was for activities that focus on the positive rather than talking about the negatives all of the time. They noted their anxiety before they went along to any of the CCCW activities and programmes; with a repeated reaction of: *do I really want to go and speak about cancer?* One respondent commented: *I was fearful going the first time – with people I don't know. I loved hearing the stories – there are women who have been there a long time and that gives you great hope. I haven't missed a week.*

- Respondents talked about the importance of the environment of the programmes and activities. One respondent talked about it being *my space, my time.*
- In talking about a specific programme one respondent said: *this had the biggest impact on me…they were subtle exercises but I was totally open to it. I knew – I need to change the way I think and I don't know how to. But there was a very positive nature and very experienced staff…it was not just a standardised programme. Before I did that programme I felt I was walking through tar; then I felt freer, lighter and more capable.*

- Another respondent talked about how they had felt when they initially went along to one of the programmes, and how they gradually changed as they interacted. *For me the benefits – it changed me, I thought about my appearance, I started to very slowly to come back to 'me' – I had felt I had left 'me' for a year….I made connections – the focus was not on the illness but on fun, positivity, looking to the future…my outlook on life has completely changed.*

- One respondent said: *this was the only place I could get help.* Another said: *I can't really explain it. But I don't know what I would have done without it. The GP didn't offer anything like this.* Another respondent summed up the impact for her: *All positive, nothing negative. All very welcoming, no judgement, don't have to talk, confidential space. It saved me – it was life changing for me, I started to accept (the cancer) and to look at a way to live with it – <u>not</u> to hide under it.*

- In terms of shaping future cancer services some participants felt that exercises like this in the past had been - *a lot of tick box exercises…feel decisions are already made.*

- Respondents had the following opinions on what needs to be done to shape cancer services in the Western HSC Trust area:
  - *We need cancer specialists in our area – we shouldn't have to travel.*
  - *People in Derry and Belfast don't really understand the distance we have to travel to get services.*
  - Referenced very early morning appointments at Altnagelvin – at 8am – have to get up very early at 5am to get there on time.
  - Travelling long distances for appointments is very hard – when you are very sick and have no energy – *I had to go every 3 weeks to be weighed and checked – for over a year – I was not fit for it. I had to get someone to drive me up and down.* Reference to fact that cancer is a very difficult illness physically and mentally – and it is traumatic having to travel long distances.
  - Accessibility and availability of services.
  - *We have a brand-new hospital – all kitted out – but no-one will come to it* (reference to lack of consultants at SWAH) – *it's been a complete breakdown.*
  - Participants also talked in detail about the lack of public transport and that there used to be a bus from Enniskillen direct to Altnagelvin, but it was never really used because it did not fit in with the timing of appointments. They noted that they now need to take a bus to Omagh and then to Derry (Cityside), and change again to take a bus to the hospital. They also referenced that there is no bus from the outlying areas of Belleek and Garrison – into Enniskillen in time to get the Omagh bus – *the outlying areas are very poorly serviced.*
  - Need for more support post-surgery from the health service, and ongoing support in the face of '*scanxiety'.*

Feedback on overall engagement in the CCCW project

5.5 This sub-section now looks at the project aims of engagement and change management in relation to the integration and improvement of cancer care in the WHSCT area.

Gathering Sessions

There were four Gathering Sessions during the course of the project. These were documented and written up by the Project Manager. The emergent themes, the barriers identified and suggestions for change are outlined below.

Gathering Session – Number and Date	Emergent themes
1 – November 2022	After care and primary Care Response to Covid Workplace support for those wanting to return to work Palliative, End of Life and Bereavement support Communication Carers, family support and childcare Financial support and 'cancer' poverty Health & Social Care services Mental health of people living with cancer and family Rurality and transport
2 – April 2023	Communication Reduced waiting times in some areas Working relationships and teamwork Patient-centred ethos Innovation Community Health North West Cancer Centre What worked well: - Community & voluntary sector support - Support from Trust staff - Primary Care and Secondary Care
3 – June 2023	What could have been better: - Some aspects of Primary and Secondary Health Care - Communication - Travel, transport and accommodation - Mental health and wellbeing - Aftercare - Financial - Support for carers - Palliative and end of life care - Women's health and menopause
4 – October 2023	Impact areas: - Emotional element of cancer journey - Impact on friends and family - Professional support - Financial worries - Aftercare - Travel and appointments

Gathering Session – Number and Date	Barriers identified
1 – November 2022	Location and rurality Public awareness Childcare Disability and cultural issues Access to primary care Financial Transport Access to clinical trials
2 – April 2023	Communication Delays and time constraints Technology and data Palliative and end of life care Fragmented pathways Difficulties for women's health Funding Geography Staffing – recruitment delays, motivation and morale Primary care and access
3 – June 2023	Access to primary care Access to secondary care Access to Cancer Nurse Specialist Communication Access to services Public awareness Accommodation Childcare Fair/equal pay for medical staff Café facilities
4 – October 2023	Access to primary and secondary health care Lack of local services including GP and pharmacy services Communication After care Travel and transport Accommodation Finance Palliative/end of life care

Gathering Session – Number and Date	Suggestions for Improvement
1 – November 2022	Suggestions from cancer patients – the positive elements of their cancer journey Home-based care and support Service development Planning Communication Managing transitions
2 – April 2023	Communication Primary Care Out of hours access for cancer patients Advanced care planning Network building & teamwork Data, outcomes and evidence Equity of services Resourcing and equipment Integration and continuity of care Collaboration and working better across the three care settings of primary, secondary and community: - Awareness and knowledge of services - Partnering with community and voluntary sector - Improved communication with primary care services -
3 – June 2023	In GS3 this was framed around what would improve individual's experience and carers' experience (some elements applied to both groups): Peer support Financial support Information on support available Communication Mental health & Wellbeing Support for male carers Support for young carers Travel and financial support
4 – October 2023	In GS4 this was framed around potential improvements for those living in rural areas: Appointments – availability and access Travel and transport Increased support services for patients, and for carers Improved collaboration between services Increased signposting to services Finance Technology and internet access in rural areas

The overall summary from the Gathering Sessions was as follows.

	Date	Focus	Attendees	Themes identified:
1	22nd November 2022	Consensus Building	56	Carers Communication Financial Family Support Mental Health Rurality Transport Covid Workplace Support Palliative, End of Life & Bereavement
2	11th April 2023	Cancer Workforce	66	Communication Time Constraints Working Relationships & Teamwork Patient Centred Ethos Community Health Innovation, Technology, Data Palliative Care Fragmented Pathways Women's Health Funding
3	29th June 2023	Families and Carers	53	Communication Information and Signposting Transport & Accommodation Mental Health & Wellbeing Aftercare Financial Women's health and Menopause
4	11th October 2023	Rurality	56	Primary Care Transport Communication Aftercare Finance Carers Palliative / End of Life Pharmacy Lack of Local Services

Feedback from the Gathering Sessions was very positive. This was gathered through feedback sheets and comments. The tables above indicate the build-up of a commonality of themes from each of the Gathering Sessions; this is important given that each Gathering Session had a different focus including cancer patients, family and carers, health professionals and covered different geographical areas, including a focus in GS4 on rurality.

Negotiating Change Workshops

There were three Negotiating Change (NC) workshops in Year 3 of the project, all held at the Silverbirch Hotel in Omagh, as follows:

NC workshop 1 – March 2024, Focus: Cancer Prevention

NC workshop 2 – April 2024, Focus: Diagnosing and treating cancer

NC workshop 3 – May 2024, Focus: Supporting people to live well and die well

The purpose of these workshops was to take the information and themes identified in the Gathering Sessions in Years 1 and 2, and to start to look at the following:

- Prioritising from the various themes, what is most important and what could make the most difference;
- Thinking about what changes would be needed, and what might be possible, to respond to the identified themes and needs;
- Starting to develop a consensus for change, which could translate into actionable recommendations and achievable improvements for the final stage of the project, i.e. the 'Commitment to Change' conference. The latter information included which organisation(s) would be responsible for taking forward any agreed change.

The themes/questions considered at the Negotiating Change workshops are outlined below.

	Date	**Focus**	**Themes addressed**	**Organisations in Attendance**
1	8th March 2024	Cancer Prevention	Education Screening Early Detection Health Awareness and Information	CCCW Partnership WHSCT Department of Health Macmillan Public Health Agency GP Federation
2	11th April 2024	Diagnosing and Treating Cancer	Communication Signposting Carers Cancer Workforce Hospital Environment	CCCW Partnership WHSCT Department of Health Macmillan GP Federation
3	2nd May 2024	Supporting People to Live Well and Die Well	Mental Health Palliative Care Pharmacy Rurality Transport	CCCW Partnership WHSCT Department of Health Macmillan Marie Curie Compassionate Communities Department for Infrastructure Easilink Community Transport Association

Commitment to Change Conference

The final element of the three-tier model of engagement was the 'Commitment to Change' conference which was held on 20th June 2024 at the Ebrington Hotel in Londonderry/Derry. The conference was chaired by Susan Gibson, Manager of Derry Well Women with speeches from Phil Mahon, Chair of Derry Well Women, Deirdre O'Neill, Project Manager of Cancer Connected Communities West, Mike Nesbitt, Health Minster, and Dr Tom Frawley, Chair of the Western Trust.

A total of 132 people attended the conference including service users from the six partner organisations, senior staff and facilitators from the six partners, and representatives from the following organisations:
Western Health & Social Care Trust
Department of Health (DoH)
Department of Infrastructure (DoI)
Public Health Agency (PHA)
Strategic Planning and Performance Group (SPPG)
Macmillan
Friends of the Cancer Centre
Foyle Hospice
Compassionate Communities
Easilink Community Transport
Fermanagh Community Transport
The National Community Lottery Fund

The full themes and questions brought to the conference are outlined in Appendix 4. The commitments outlined at the conference were the result of the themes and issues identified at the initial Gathering Sessions, and which were examined and refined at the Negotiating Change workshops with the full range of stakeholders. The commitments put forward at the conference related to a range of themes including - connecting rural communities, improving the health and wellbeing of the cancer health workforce, addressing health inequalities, supporting informal carers, modernising pathways for patients being treated at the North West Cancer Centre, improving the completion of Holistic Needs Assessments for all WHSCT cancer patients, as well as addressing and implementing changes to improve communication.

The Minister for Health, Mike Nesbitt attended the Conference and addressed the change commitments presented. He said: *the voice of those with lived experience of cancer has been central to the development of our Cancer Strategy, I want to acknowledge the contribution of everyone involved in the Cancer Connected Communities West project. This project sets a benchmark for the co-production of cancer services, and I am delighted that the lessons that have been learned over the past three years are already helping to shape how we implement the actions within the Cancer Strategy*[57].

[57] Twitter: https://x.com/healthdpt/status/1803733152801648712

Tom Frawley (Chair – Western HSC Trust) also spoke at the conference, welcoming the approach and impact of the project. He noted: *The Western Trust has been delighted to work with our Cancer Connected Communities partners on this innovative project over the past three years. It has provided us with invaluable insights and opportunities to meet and listen to those affected by cancer who live in the geography served by the Western Trust, particularly those from marginalised groups and those living in rural communities. Based on their feedback, insights and suggestions we have heard throughout this process we have reviewed our services and made changes and improvements which we presented today. The Western Trust recognises the huge potential of the model of engagement that has underpinned every aspect of this project and is committed to continuing to work with partners to support the sustainability of this model.*

The itemised commitments from the 'Commitment to Change' conference are outlined overleaf.

#	Organisation	Responsible Person	Theme	Commitment(s)
1	Western Health and Social Care Trust	Una Cardin, WHSCT - Assistant Director Operations & Service Improvement Cancer and Diagnostics	Communication	Increase the number of trained staff available to deliver the Advance Communications skills programme with a view to expansion of the programme.
2	Western Health and Social Care Trust	Celia Diver Hall (WHSCT – Lead Nurse – Macmillan Nursing Services Manager)	Communication	The WHSCT equality department to take forward a deaf sign language pilot within the NW Cancer Centre to be completed Autumn/Winter 2024
3	Western Health and Social Care Trust	Celia Diver Hall (WHSCT – Lead Nurse – Macmillan Nursing Services Manager)	Communication	A project (being driven by a consultant working with the medical team) will be launched which focuses on improving communication on the Ward, capturing location, what is said, how it's said and understanding the need for preparation and communication between team members.
4	Department for Infrastructure	Judith Andrews (Department for Infrastructure – Director of Public Transport Operations)	Rurality	Development of a new Transport Strategy which includes new Local Development Plans for North West, Fermanagh and Omagh, which will focus on improved connectivity and accessibility to the transport network. This will take account of the emerging arrangements for delivering health services across NI.
5	Department for Infrastructure	Judith Andrews (Department for Infrastructure – Director of Public Transport Operations)	Rurality	DFI are working in collaboration with the Department of Health, DAERA And Department of Education on the delivery of transport services, including services in rural areas.
6	Cancer Focus NI	Richard Spratt, Chief Executive	Rurality	Cancer Focus NI is developing a new therapeutic centre in Co. Fermanagh offering support services such as transport and nurse-led information.
7	Department of Health	Craig Donnachie (*Head of Cancer Projects, Department of Health)*	Rurality	The Department of Health is engaging with the Department for Infrastructure to look at how public, and community transport can support those patients who are travelling for appointments.
8	Western Health and Social Care Trust	Helen McCormick (WHSCT Clinical Nurse Specialist)	Ensuring a holistic and joined up service	Every patient will have an identified CNS who completes a Holistic Needs Assessment and discusses the outcomes of this with the patient to identify a personal support plan.

#	Organisation	Responsible Person	Theme	Commitment(s)
9	Western Health and Social Care Trust	Helen McCormick (WHSCT Clinical Nurse Specialist)	Ensuring a holistic and joined up service	Continued delivery of menopause workshops which were facilitated in partnership with Action Cancer, SWELL and Care for Cancer.
10	Western Health and Social Care Trust	Bridget Tourish (WHSCT Service Manager Oncology and Haematology)	Ensuring a holistic and joined up service	All patients automatically offered a referral to a benefits advisor when they are diagnosed with cancer.
11	Western Health and Social Care Trust	Bridget Tourish (WHSCT Service Manager Oncology and Haematology)	Ensuring a holistic and joined up service	Include finance as part of NWCC Health and Wellbeing Events.
12	Western Health and Social Care Trust	David Curtin (Macmillan Cancer Prehabilitation Project Manager)	Ensuring a holistic and joined up service	Continue to roll out the prehabilitation programme to more tumour sites.
13	Western Health and Social Care Trust	Shane Breen (WHSCT Assistance Director Integrated Care Systems)	Ensuring a holistic and joined up service	Introduce the new Integrated Care Systems model across NI HSC following a test in Southern Area from June 23. It is a new framework for how we plan health and care services in Northern Ireland. It is a single, joined-up system, based on the different parts of health and social care, and others who have a role in the wellbeing of the population of Northern Ireland, coming together to understand what it is that is needed, and how we can best deliver that with the resources we have.
14	Western Health and Social Care Trust	Caoimhe Lavery (WHSCT Admin Manager, Cancer Services, NWCC)	Waiting times	When booking patient appointments, the booking team will consider a number of factors including regimen and treatment duration and geographical location of the patient. Where possible, patients having to travel from further away will be given a later appointment and where a patient has requested a specific appointment time due to childcare or other personal commitments, this is recorded on file and every effort is made to accommodate this. The Western Area Integrated Partnership Board will be stood up summer 2024.

#	Organisation	Responsible Person	Theme	Commitment(s)
15	Western Health and Social Care Trust	Caoimhe Lavery (WHSCT Admin Manager, Cancer Services, NWCC)	Waiting times	Where a patient has another appointment on the same day within another service area e.g. radiology, every effort is made to align appointments as best as possible to avoid patient having to spend longer than necessary at the hospital. At present, the service will only be aware of this if patient advises that they have an issue with timing of another appointment as we cannot see every appointment on our system, this may improve with the introduction of Encompass.
16	Western Health and Social Care Trust	Caoimhe Lavery (WHSCT Admin Manager, Cancer Services, NWCC)	Waiting times	We are also working on implementation of an improved model of scheduling for treatment delivery, to assist with implementing this we have completed a test of change model to 2 tumour sites Breast and GI where a '2 step' model was tested. This means that the patient has their pre SACT (chemotherapy/treatment) bloods taken in advance and when the results are available the patient is assessed via the telephone by the doctor who assesses their fitness for treatment. Following assessment, the patient's treatment is prescribed in preparation for the patient attending the Sperrin Suite for treatment delivery.
17	Western Health and Social Care Trust	Lesley Mitchell (WHSCT Assistant Director – Nursing, Cancer & Diagnostics	Hospital Environment	NWCC and have recently placed new Art displays in NWCC which service users and our staff helped develop. We also now have more chairs in waiting areas, the coffee shop has reopened, and we have improved access to car parking. The Trust are currently undertaking the Macmillan Quality Environment Mark (MQEM) process to assess the environment and identify opportunities for improvement.
18	Western Health and Social Care Trust	Caoimhe Lavery (WHSCT Admin Manager, Cancer Services, NWCC)	Equip Patients with their own health records	A new regional IT system is being rolled out across NI. This system is currently 'live' in South Eastern Trust and Belfast Trust. Work is well underway in relation to WHSCT roll-out planned for Easter 25. This new system will mean that patients will have access to their own health related information to include clinic letters, blood results etc.

#	Organisation	Responsible Person	Theme	Commitment(s)
19	Western Health and Social Care Trust	Damien McMullan (WHSCT Consultant in Palliative Medicine)	Palliative and End of Life Care	Professor Watson palliative medicine consultant has led on the development of an integrated Fellowship programme to grow our own senior doctors and consultants who will work across palliative care, care of elderly and frailty settings. We are building our own model where our staff will increasingly work across settings.
20	Western Health and Social Care Trust	Damien McMullan (WHSCT Consultant in Palliative Medicine)	Palliative and End of Life Care	Foyle Hospice is now providing specialist palliative care across the whole Western Trust Area and the community specialist palliative care team in Omagh and Fermanagh areas is now. This improves integration and hopefully will reduce inequality
21	Western Health and Social Care Trust	Damien McMullan (WHSCT Consultant in Palliative Medicine)	Palliative and End of Life Care	Establishment of a “Co-Creating Hope” working group looking at how we can better meet the needs of our aging population.
22	Western Health and Social Care Trust	Damien McMullan (WHSCT Consultant in Palliative Medicine)	Palliative and End of Life Care	7-day access to specialist palliative medicine telephone advice up to midnight for professionals.
23	Western Health and Social Care Trust	Damien McMullan (WHSCT Consultant in Palliative Medicine)	Palliative and End of Life Care	Development of Undergraduate training – QUB final year medical students will be getting a week long hospice and palliative care placement from this August 2024 onwards in addition to the Magee students.
24	Western Health and Social Care Trust	Damien McMullan (WHSCT Consultant in Palliative Medicine)	Palliative and End of Life Care	Our first Advanced Nurse Practitioner being in post and training of additional ANPs
25	Western Health and Social Care Trust	Damien McMullan (WHSCT Consultant in Palliative Medicine)	Palliative and End of Life Care	Commitment to improve the integration of cancer services and palliative care services, we are working towards NWCC becoming a Designated Centre of Integrated Oncology and Palliative Care by ESMO – the European Society for Medical Oncology.

#	Organisation	Responsible Person	Theme	Commitment(s)
26	Western Health and Social Care Trust	Damien McMullan (WHSCT Consultant in Palliative Medicine)	Palliative and End of Life Care	Recruiting medical staff to work across both Foyle Hospice & Altnagelvin & community settings. Trying to grow our own senior doctors – recruiting more middle grade doctors who can develop and grow into future leaders
27	Western Health and Social Care Trust	Damien McMullan (WHSCT Consultant in Palliative Medicine)	Palliative and End of Life Care	Extension of 7-day community specialist palliative care across the trust – currently in the northern part of the trust only
28	Western Health and Social Care Trust	Marie Donnelly (WHSCT Palliative Care Nurse)	Palliative and End of Life Care	The "Just in Case" box pilot. This service was piloted through a Quality Improvement initiative and has now been rolled out across all primary care in the WHSCT since December 2023. It is early days, but we have used 2,000 Just in Case Box Prescribing Booklets and Patient Information Leaflets during this time. We do not have reoccurring funding for further resources, but this is something that we are exploring. We have been asked to present this service to colleagues in other Trusts and the Department of Health in the hope that it may be rolled out regionally.
29	Western Health and Social Care Trust	Anne Friel (WHSCT Head of Pharmacy and Medicines Management)	Palliative and End of Life Care	<u>Increased access to medicines used in palliative care in the West:</u> The Western Trust set up a meeting with pharmacy representatives from Department of Health, SPPG, a range of Trust professionals working in palliative care and the regional Consultant Palliative Care Pharmacist to look at a range of solutions to help access medicines needed in palliative care especially out-of-hours and outside hospital. To support this work going forward, the Trust has just recruited two part-time palliative care pharmacists based in Omagh and Altnagelvin Hospitals to join the palliative care team who as part of their role will continue to review access to medicines.

#	Organisation	Responsible Person	Theme	Commitment(s)
30	Western Health and Social Care Trust	Anne Friel (WHSCT Head of Pharmacy and Medicines Management)	Palliative and End of Life Care	Widening the number of people who can prescribe palliative care medicines in the community: A Foyle Hospice Pathfinder Task & Finish group aims to improve access to prescription only medicines for individuals with palliative care needs in the community. It will provide HS21 prescriptions to Hospice medical and non-medical prescribers. These professionals can then prescribe medicines for patients when they visit them at home as opposed to asking the GP to prescribe, resulting in patients getting medicines faster. The Pathfinder is due to go live by July 2024 and will run for 4-6 months to give sufficient data to support regional roll out. This work is in collaboration with the regional new models of prescribing programme and the Medicines Optimisation and Innovation Centre. We wrote Guidance to support the prescribing of palliative medication by district nurse non-medical prescribers. A number of District Nurses are now actively prescribing with ore in training.
31	Western Health and Social Care Trust	Anne Friel (WHSCT Head of Pharmacy and Medicines Management)	Palliative and End of Life Care	Improving Communication and Access: A direct line to the out of hours GP for District Nurses/ Marie Curie nurse plus an on ongoing pilot in some nursing homes to assess appropriate use of the service. It also includes advising on how to contact Specialist Palliative Care advice in and out of hours. The Trust has access to a Palliative Care Consultant Advice line from 17:00-24:00 Monday to Friday and from 09:00-24:00 weekends and Bank Holidays

#	Organisation	Responsible Person	Theme	Commitment(s)
32	Department of Health	Heather Monteverde, Professional Advisor, Department of Health	Cancer Workforce	Going forward we need to develop new roles such as advanced practice nurses and allied health professionals to undertake some roles currently done by doctors. This is current practice in most other places across the world. Not only will it enable new ways of providing health care it will provide opportunities for nurses and allied health professionals to develop their careers and remain working clinically
33	Department of Health	Deborah Hunter (Macmillan Personalised Care Facilitator)	Cancer Workforce	Ensure continuous support for the cancer workforce via Health and Wellbeing Steering Group as well as addressing training needs.
34	Western Health and Social Care Trust	Una Cardin, WHSCT - Assistant Director Operations & Service Improvement Cancer and Diagnostics	Clinical Care closer to home, in the home or in a more localised community setting	WHCST have commenced work over the last 12 months moving the delivery of some supportive therapies to community services and we are planning to expand further (this will be dependant of the drug treatment and available resources). Due to its complex nature and associated on-site equipment, Radiotherapy cannot move
35	Western Health and Social Care Trust	Una Cardin, WHSCT - Assistant Director Operations & Service Improvement Cancer and Diagnostics	Clinical Care closer to home, in the home or in a more localised community setting	A medication dispensing machine has been purchased for the collection of take-home medications (oral) this will provide an opportunity for patients to collect their medications at a time that suits them and in turn will reduce patient waiting time. This work will be taken forward as a project plan.
36	Department of Health	Craig Donnachie (Head of Cancer Projects, Department of Health)	Mental Health and Tailored information/Signposting	The Department of Health has developed a directory of cancer support services hosted on the Family Support NI website. It contains a range of support services which are applicable to cancer patients and their families, including financial support, and carers. The directory which has been developed in conjunction with cancer charities is live, but will officially be launched this, Autumn. This directory is recurrently funded, and there is a permanent team responsible for maintaining the information and promoting services.

#	Organisation	Responsible Person	Theme	Commitment(s)
37	Western Health and Social Care Trust	Lesley Mitchell (WHSCT Assistant Director – Nursing, Cancer & Diagnostics)	Mental Health and Tailored information/Signposting	Each patient will have an identified CNS who completes a HNA and discusses the outcome with the patients to identify a personal support plan. The CNS then with the consent of the patients refers them to other support services, the Trust has appointed a Macmillan Personalised Care Facilitator to improve HNA completions.
38	Western Health and Social Care Trust	Lesley Mitchell (WHSCT Assistant Director – Nursing, Cancer & Diagnostics)	Mental Health and Tailored information/Signposting	Earlier signposting to Macmillan Information & Support so the CNS will refer at time of diagnosis allowing for earlier intervention and support
39	Department of Health	Craig Donnachie (Head of Cancer Projects, Department of Health)	Cancer Screening	The Department of Health has invested in Rapid Diagnosis Centres (RDCs) available regionally across NI. The clinics allow GPs to refer people with vague but worrying symptoms, who would not otherwise present as a red flag cancer pathway referral, to receive an earlier diagnosis of cancer or in some cases a diagnosis of a serious condition which is not cancer. Work is underway to look at new symptomatic cancer diagnostic pathways that would benefit from the RDC model.
40	Department of Health	Craig Donnachie (Head of Cancer Projects, Department of Health)	Cancer Screening	Work to meet the commitments outlined in the NI Cancer Strategy (2022-32) to lower the age range and/or further reduce the sensitivity level in bowel screening (Action 7) and to introduce screening for lung cancer (under Action 10) are ongoing but must be viewed within the context of wider financial and capacity challenges within the supporting services.

#	Organisation	Responsible Person	Theme	Commitment(s)
41	Department of Health	Gary Maxwell (Health Development Policy, Department of Health)	Cancer Prevention and Early Detection	Evidence shows that only 20% of health outcomes are a result of the clinical services we receive, with the social determinants of health – the economic, social, and physical environment in which we live – being a much larger driver of health outcomes and inequalities. To help address this the Department of Health leads on the executive's public health framework, Making Life Better, which seeks to align and join up actions across the executive and the wider public, community and voluntary, and private sectors. We also work with the Department of Agriculture, Environment and Rural Affairs on some of the wider environmental risk factors that can impact on cancer.
42	Department of Health	Gary Maxwell (Health Development Policy, Department of Health)	Cancer Prevention and Early Detection	DOH is working to develop place-based approaches to improve health and address inequalities. These will seek to address the needs of individuals and communities in their local areas and take an asset-based approach to meet people where they live and support them by through interventions and signposting.
43	Department of Health	Gary Maxwell (Health Development Policy, Department of Health)	Cancer Prevention and Early Detection	The PHA continue to run the "Be Cancer Aware" programme, and where possible we will seek to develop and build on this as we move forward.
44	Department of Health	Gary Maxwell (Health Development Policy, Department of Health)	Cancer Prevention and Early Detection	It is vitally important that we build prevention and early intervention into the pathway, and we keep a focus on this issue to make a real difference in the long term.
45	Western Health and Social Care Trust	Jacque Warwick (Macmillan Consultant Nurse)	Supporting People to Live Well Beyond Cancer	Implementation of e-HNA across all sites will help to identify those patients needing support earlier, and signpost to appropriate services

#	Organisation	Responsible Person	Theme	Commitment(s)
46	Derry Well Women	Phil Mahon (Chairperson)	Supporting People to Live Well Beyond Cancer	Derry Well Women will enhance and expand on its existing cancer services by • Training facilitators of the Well Programme to expand delivery across a broader geography to cancer group partners and emerging groups • Recruiting and training a team of cancer counsellors for a dedicated cancer counselling service • Developing cancer support groups to other cancer sites Retaining and expanding ancillary services e.g. nutrition and benefits clinics. • Retaining and expanding complementary therapy service to include a wider variety of treatments • Developing services to support specific target groups e.g. carers, young women living with cancer, menopausal women, women at end of life. • Developing resilience mental health programmes • Continuing to lead the Cancer Connected Communities engagement process. • Feeding into the current work DWW is doing to develop a NI Women's Health Strategy. DWW will increase capacity to achieve the above by having: 1. A dedicated Cancer Services Coordinator and sessional support team to coordinate direct service delivery. 2. Continue to develop partnerships to ensure care is more integrated.

#	Organisation	Responsible Person	Theme	Commitment(s)
47	Action Cancer	Ruth Fleming (Service Development Manager)	Supporting People to Live Well Beyond Cancer	We have recently developed a new Integrative 3 tier Cancer Care Model with a focus on mental health, pain and symptom control, nutrition and physical activity. Tier one - 1:1 service. Tier two - Group, face to face & and online events held via zoom. Tier three – services will involve developing a new range of resources to address issues raised by cancer survivors and family members during a large NI survey carried out in 2023 in partnership with QUB, part funded by CCCW project. One of the key findings of the survey was limited access to cancer specific and tailored information and advice relating to nutrition. We will work with QUB and UU in developing evidence-based resources accessible to all across NI on a range of topics.
48	Action Cancer	Ruth Fleming (Service Development Manager)	Supporting People to Live Well Beyond Cancer	We stay committed to continuing our provision of 1:1 and group services in the WHSCT area to support people impacted by cancer and will continue to work closely with statutory and charity partners in delivery of these services.

#	Organisation	Responsible Person	Theme	Commitment(s)
49	Western Health and Social Care Trust	Anne Friel (WHSCT Head of Pharmacy and Medicines Management)	Longer term goals	• Trying to make things simpler including explaining how to access palliative care medicines. • Plan to develop pathway with GPs and Community Pharmacists to streamline access and avoid families visiting multiple pharmacies to have medication dispensed. • Scoping of potential application of an electronic direction to administer for syringe-driver charts (regional work). • Having electronic prescribing in place in primary care in Northern Ireland would greatly streamline access to medicines, with prescriptions being sent from GPs to community pharmacists electronically. It is hoped that this will be rolled out in the next few years.
50	Western Health and Social Care Trust	Una Cardin, WHSCT - Assistant Director Operations & Service Improvement Cancer and Diagnostics	Longer term goals	• Explore within the next 5 years – Oncology & Haematology unscheduled care unit (like a minor injuries unit). This will mean that there will be a dedicated assessment unit for Oncology and Haematology to avoid patients having to go to A&E for assessment (where their clinical condition relates to their cancer diagnosis, there will always be occasions where a patient may need to attend A&E for assessment where their condition is of a general medical nature e.g.: respiratory infection. • Continue to work with Department of Health and SPPG colleagues with regards to implementation of cancer strategy and continued increase and development of our cancer workforce. • Wok to develop a dedicated website for patients/families/carers attending NWCC • Development of a NWCC App • Continued link with Community and Voluntary sector to expand access to services and transport options

Three-tier model of engagement

The comments in this sub-section come from the interviews with the lead partner and other partner organisations, together with the evaluator's assessment. The development of the CCCW project was based on the methodology of the three-tier model of engagement. DWW have used this model over a long time period, winning awards from the King's Fund for its usage in other services. Previous projects noted: *It aims to enable women to negotiate for improved services and has developed a model of engagement to involve women in discussions about their needs and gain feedback on the quality of their healthcare services*.[58]

Feedback from the lead partner emphasised the need, in tier 1 to involve and listen to the service user, helping them to develop their voice. Comments included: *It's not just listening to what was said – but what's not said. We are working through practitioners who are delivering complementary therapy, group work and they have a programme to deliver on – and these are people who are hugely skilled at interpretive listening. And actually interpreting and analysing what they hear…and translating that into something.* Reference was made to the importance of the ELEC training in underpinning this part of the model.

Within this stage the lead partner noted the need to involve all parties, including health professionals. They said: *In order to move to negotiating change – not only should it become an incremental sharing of things that are emerging, but we need to listen to the health staff…so GS2 was very much designed to hear the issues of the staff – as they are part of the system… We know there are issues – but we need to understand what the challenges for them. And that is hugely important. So that when we come to the negotiating change bit, everyone that's in the system has felt listened to.*

At tier 2 gathering of information has been undertaken in a number of different ways, through group work and individual feedback, and to a large extent through the Gathering Sessions. It was acknowledged that this element of the model had enabled all cancer services and groups throughout the Western HSC Trust area to become involved, and to develop through the provision of training, policy and funding. The lead partner noted: *the 3-tier model was the best way to do that – and the Trust really supported that. The premise for us is that all boats must rise together.*

At tier 3 engagement will include a level of enablement to move towards the next stage – that is negotiating change and agreeing the project outputs. The lead partner noted: *That will happen at a roundtable so that there will be the prioritised issues that are presented, and there will be a solution-based approach used. There will be no surprises – so that the HSC Team will have a sense of what's emerging, because we're not here to confront or to surprise – we're here to negotiate… Those who are effecting change are brought into the room with those who are seeking change…these issues are hammered out around the table, in a way that is respectful and each listen to the other.*

The overall process was summarised as follows:

[58] 2009 GSK IMPACT Awards brochure (kingsfund.org.uk)

Everyone is recognising the value of individual journeys and the power of individual stories – you have the power of the individual stories to effect change, you have skilled, trained people to deliver the services – not just to listen but to listen effectively – so that they can interpret and translate what they hear into something – that can be delivered to those who can make a change in it – and have the capacity to do so. That's where the big impact (and its measurements) *lies – because that was the whole purpose of the project…. it's how does it actually deliver on the notion of effecting change…And that change can be right through the system – and how can you effect a system. It's so unwieldy, so reluctant to change, so diverse – the whole system is complex, and all of those people experiencing cancer are somewhere lost or caught up in that system.*

Section 6 Feedback on delivery of the project to date

6.1 This section provides a review of the feedback from the lead partner and partner organisations on the development and delivery of the CCCW project under the following themes:

- Development difficulties and challenges
- Operational difficulties
- Positives about the CCCW project
- The model of engagement

6.2 ***Development difficulties and challenges***

Comments in this sub-section relate to the early development of the project, and initial challenges in getting the project up and running in Year 1. Recruitment challenges were noted. Whilst an initial appointment for the Project Manager post had been made in September 2021, this postholder left at a very early stage, leaving the project with no lead staff member from October 2021 to May 2022. However, this challenge was mitigated by leadership and support from within the lead partner DWW and with the appointment of the Resource member of staff (see names of staff).

Other challenges arose through the gelling together of a wide partnership, with different approaches and standards across the membership. One respondent noted: *the partnership reflects different levels of development, different levels of being capable of community focus or extension of services – geographical extension of services – to be more penetrative. Some had a history of working in partnership, some didn't have a history of working in partnership.*

Two of the partners (Care for Cancer and SWELL) acknowledged that they had not previously participated in a funded project of this nature. One said: *we never did a funded project before and we have found it is very time consuming and the forms needed changed and tweaked.* However, these partners also noted the positive nature of this for them – for example, now on the back of this able to kick start other funding, has increased their knowledge and skills etc. From DWW's perspective this did create some difficulties – *having to support the groups – there was a lot of learning in that – having to do their plans, difficulties in getting paperwork back. Helping them to think about how to spend funds and how to manage underspends.*

Other factors, from a strategic and planning point of view were noted. Some respondents felt that there should have been more input to the evaluation and monitoring process, including the engagement of an external evaluator from the beginning of the project, standardisation of measurement tools and agreement on monitoring and feedback options. It was suggested that having one tool or suite of tools for monitoring and evaluation would have been more helpful for the project.

Partners highlighted other items which they felt had been initial shortcomings at the start of the project, but which were later resolved. For example, where there was initially no

payment for sessional staff where clients did not show up or cancelled at the last minute, although this was then resolved.

6.3 ***Operational difficulties***

Respondents from the partner organisations noted a small number of difficulties they had encountered with the CCCW project; there was an element of overlap between these comments:

- The actual amount of paperwork, with respondents saying they would have preferred to see the time spent on more direct delivery. However, although this was described as *arduous amount of paperwork*, partners also noted that this was understandable given the funding and accountability required for the project;
- Difficult to do the paperwork and forms until you have built a relationship with the person – as some of it is quite personal – and in some cases you are just seeing them as one-off. They have already had to do a lot of health service paperwork and this reinforces all of that.
- It's often not the right time - *if someone bursts out crying you can't just produce forms – or they may be very quiet – and it's hard to bring out all the forms – when they say they just felt like a number.*
- It's not the right focus – *if we are doing a complementary therapy session it takes away from the purpose…*
- The financial system whereby the lead partner requires 100% verification for every transaction – respondents noted that this is very time consuming. Reference made to other Lottery funding which has used a risk-based audit approach so random invoices have been requested and proof – which is much less time consuming for financial departments[59].

Some respondents suggested that it might have been better to have had an additional session funded with the client just to concentrate on the project paperwork, and enable the production of a fuller case study rather than trying to integrate it into existing sessions. Overall the partner organisations said that the above items were fairly minor, and that there were minimal difficulties in relation to service delivery or the operation of the project.

6.4 **Positives about delivery of the project**

Overall, there were positive comments about the delivery of the CCCW project. One partner organisation noted: *Overall DWW have done a good job in leading this project and building the relationships with the WHSC Trust which will help with negotiating change. When partner issues have been raised they have been willing to listen and help come to compromises.* Another said: *we would like to state how good the CCCW project team have been throughout the project… The staff members have been very approachable and transparent in their communication. There was never any issue regarding responses to queries or requests and they have made a huge contribution to the success of the project.*

[59] This comment should be set in the context that DWW is the lead partner and hold overall accountability and responsibility for the project. The partners therefore need to adhere to DWW's financial processes as well as the Lottery requirements.

A range of positive attributes were noted in relation to the project as follows:

- Buy-in from all the partner organisations and the statutory sector at senior management level. One respondent said there had been a sense of having a common goal, noting: *How to establish a coherent voice or vehicle – aimed at supporting those experiencing cancer.*
- Good partnership working – *everyone has been open to listening and working together. There is a sense of having a common goal…there is no competition.* Respondents also noted learning and support from each other, and the sharing of good practice with a view to strengthening the sector*;*
- A collaborative force with no sense of competition between partners over funding or opportunities. This was also highlighted in terms of the benefits of having different groups with different areas of expertise providing different services, with a viewpoint on avoiding duplication;
- The spread of the delivery model and programme. One respondent noted: *The breadth of the partnership and the range of services, and the various locations – across the whole of the Western HSC Trust area. That's a great success in itself – people working together.*
- The flexibility of the project was noted, and how plans and activities had been changed in response to different client needs and circumstances. One partner said: *DWW allowed us to be very flexible – to bring in external people and counselling as needed. Principles of good practice were in place. They have said 'no' to nothing. DWW focus on the needs of the groups and the service users.*
- There was positive feedback about the lead partner and the project staff members. This was summed up by one partner: *DWW have been excellent to work with – always contactable, brilliant to work with. Transparent and good for claims. No major issues have come out of the Steering group. All has been running very smoothly*
- The funding split was seen as a positive attribute; with respondents noting that each partner got *a slice of the cake and got the same amount;*
- Another area of work which partners were very positive about was around 'working together'. Examples were given in terms of the methodology of working between the six partners including referrals from the partner organisations to Advice North West, for their clients who need financial, benefits or other types of advice; and partners delivering programmes with a different partner's clients. Examples of this include Cancer Focus working with SWELL and Care for Cancer to delivery programmes such as Healthy Nutrition, Physical Activity and Breast self-examination to their clients.

Overall partner organisations acknowledged the importance of the project: *this is recognising how the lived experience of being a cancer patient in the health system can powerfully influence decision makers and service providers.*

Another respondent highlighted the need for the CCCW project stating: *reviewing and improving cancer services is always important, particularly after Covid and the devastating impact on cancer experiences of clients. This project helps gather the experiences of clients*

at all stages in the cancer journey – what has gone well and what needs improved, and feed this directly back to the HSC Trust to assess what actions can be taken to improve services.

Partner organisations also referenced the three-tier model of engagement that the project is based on; noting that in many cases a participant had come to the project for a particular service e.g. counselling, had then moved into group sessions and support groups and from there had attended a Gathering Session. This was summed up by one respondent: *initially they come for counselling, then move to group activities and then to participation.*

6.5 ***The model of engagement***

Whilst largely supportive of the model some partners made the following comments for consideration in Years 1 and 2. These were taken into account in Year 3 in preparation for the Negotiating Change Workshops and the 'Commitment to Change' conference

- Some respondents felt there should have been more opportunities for the partners to get to know each other;
- The linkage between people availing of services and then attending a Gathering Session, was weak in some cases and it was difficult to encourage people to make that step because of fear of the unknown, fear of big events etc. *The Gathering Sessions are very hard to explain to the clients;*
- Concern that the lists produced at the Gathering Sessions were incomplete and that there had been a rush to prioritise these;
- Annoyance that Gathering Sessions had different focus – patients at G1 and health professionals at GS2 – one partner organisation said that everyone should have been together at all of the sessions;
- Concern that as a partner they were not part of the overall movement towards consultation and negotiation. One respondent said: *As a partner I don't feel part of the plan…the partners should be more developing the plan and the agenda…*

The lead partner and partners were positive about the potential for change that the CCCW project could produce. One respondent noted: *there is real potential for the project to influence change – senior managers within the Trust are actively engaged in the project and are keen to listen to clients and make changes where they can. The full extent of the change will not be evident until after the negotiation event and in in the next year or two.*
Respondents also acknowledged the need to think through the next stages carefully including:

- How to effect change – how to make changes at the different levels?
- How to ensure that the service user voice is heard – and can influence service development and service delivery?
- How to involve all the sectors and Departments that need to be involved – if change is to occur, including outside of the circle of health service delivery?
- How to ensure cross-sectoral issues get dealt with?

In addition, the partner organisations noted the need to look beyond the project; one said: *It would be good if a channel for feeding back issues raised by clients continued after the CCCW project ended.*

6.6 Overall impact

Partner organisations were asked to comment at the end of Year 3 on whether the project had been able to influence strategic changes in the field of cancer services in the WHSCT area. Some partners felt it was too early to be conclusive. One noted: *I think it might be a bit early to say the project has made any strategic changes to date…However, there have been people of influence involved in the project and its lifespan, i.e. the WHSCT as a project partner, DoH, PHA, regional charitable organisations and senior managers from various governmental departments. The issues raised at grassroot level and raised during the gathering sessions, negotiating change workshops and final conference are hopefully now on the agenda of these decision makers and we hope to see tangible changes as a result.*

The WHSCT noted that they had benefitted by the project, by receiving feedback on various aspects of current service provision, and that this would be used to improve services.

Feedback from partner organisations highlighted the overall benefit of the project, noting the following:

- Platform of the project for patients and carers to have a voice, that had not been available previously;
- Use of lived experience and co-production methods to ensure robust consultation and that participants' voices were heard through a wide variety of methods and were now at the centre of development for cancer care;
- Identification, through sharing of information and stories, of systemic flaws in the system;
- Identification of difficulties in 'navigating the system' with suggestions for improvements;
- Indication of what needs to be done in terms of a better joined up approach between the primary/secondary healthcare systems, and in relation to the community and voluntary sectors;
- Identification of what needs to be done in terms of post cancer care.

Partner organisations also indicated what they felt were the top priority items that now need to be addressed in terms of a cancer strategy in the WHSCT area. Respondents noted the following:

- Early detection and screening provision, including increased availability and accessibility and relevant public awareness campaigns, together with improvements in diagnosis and waiting times;
- Better use of existing resources and greater access to services like the SWAH in order to expand the use of chemotherapy and radiotherapy services in the area, thus reducing the need for people in some parts of the area to make long journeys to the NW Cancer Centre or Belfast. Respondents referred to this as *developing closer to home services*

and highlighted the need for better localised availability and access of community, primary and secondary services;

- Ensuring seamless integration across the different stages of the cancer care continuum, providing integrated care pathways – including coordination between primary care, specialised oncology services and support services to provide holistic and continuous care for patients;
- Increased transport support for patients in order to remove barriers for accessing timely healthcare, particularly in the most rural and isolated areas;
- Funding for local support services across the WHSCT in relation to health promotion, cancer awareness, therapeutic support and transport support;
- Supporting patients, families and carers throughout their cancer journey and beyond.

Section 7 Co-production as a model of engagement

7.1 This Interim report now reviews the relevant literature relating to co-production and how this influences the development of integrated health (cancer) care and partnership working in cancer services. Whilst these two areas are important themes in their own right, the focus of this section is to look at them from the viewpoint of co-production. Co-production was defined earlier in Section 2.9.

This section aims to respond to the evaluation aim: *To identify and benchmark good practice in relation to integrated care and co-production, and to reflect on the implementation of the project against those benchmarks*

This section firstly reviews the literature on co-production in more detail, highlighting what the principles of co-production and the building blocks for good practice in co-production. It also uses the literature to reflect on co-production to date in the CCCW project – what has been incorporated? What has worked well? What could be further developed?

The second half of this section then looks at examples of co-production across health, and specifically, cancer services including the development of strategies using co-production through to co-production as tool/process for developing places and spaces, services in hospitals and the community, and information leaflets and social media. This are included as examples of how the final stages of the CCCW project could utilise co-production as a methodology for working towards the project's overall aims and objectives.

7.2 ***Literature on co-production***

The 2018 Care Quality Commission Report *Quality improvement in hospital trusts*[60] noted: *putting the patient at the centre of the quality improvement (QI) journey sharpens the focus on delivering high-quality patient care and aligning improvement activity to outcomes and experience. To deliver this, patients must be involved and enabled as true and equal partners for QI.*

Co-production is a term and methodology which is increasingly being used in service development and delivery across the UK. The term is not exclusively linked to health services; with wider usage in housing and homeless services, and care and after care services. Co-production is not just about service delivery. It is also used in primary research as a mechanism to collaborate with all the stakeholders involved in a service. In the context of health research, Redman et al note: *co-production is a collaborative model of research that includes stakeholders such as patients, the public, donors, clinicians, service providers and policy makers*[61]. They also note: *Co-production has been embraced because of its potential to improve the quality and relevance of research and its effect on policy and practice.*[62][63][64]

[60] Integrated Care System Northern Ireland - HSCB (hscni.net)
[61] *Co-production of knowledge: the future,* the BMJ, S Redman, T Greenhalgh, L Adedokun, S Staniszewska, S Denegri, 2021.
[62] World Health Organization. *World report on knowledge for better health: strengthening health systems*. 2004.

Commentators[65] note the need to co-produce or co-create their research and findings, but also point to the need to use the knowledge gleaned in 'knowledge translation' and learning. They also point to the difficulties in using and optimising the use of participant's feedback. These are important points for the CCCW project in terms of how it is integrating the feedback from participants and at Gathering Sessions.

Commentators[66] also note that tensions can arise in the process of co-production. Again, this is something worth noting for the CCCW project as it enters the negotiating change stage. In particular Boivin highlights the tensions that can arise when professionals and lay people work together, for example in priority setting or understanding each other's conflicting concerns e.g. budgets, lines of management etc. The difficulty of achieving the 'co' part of co-production is not under-estimated in terms of real shared decision-making. Holmes et al[67] note: *Committing to co-creation – and all it implies with regard to shared decision-making – means acknowledging that co-production is challenging: it requires role clarity, attention to power imbalances, difficult discussions about research rigour versus research relevance, and constant monitoring. It also means putting in place the mechanisms to support it.*

The power balance in any consultation and negotiation process arising from co-production is of critical importance. Boivin et al[68] note three areas for attention as follows:

- *Credibility* – participants need to learn each other's language and be seen as valued and relevant sources of knowledge for each other.
- *Legitimacy* – participants need to be clear on whose behalf they speak (e.g. people in the same profession, users of a particular service, patients with the same condition, employees in a specific organisation) and be supported to do so.
- *Power* – all participants must be able to influence decisions.

Evaluation of the CCCW project to date suggests that these the first two areas – credibility and legitimacy have clearly been addressed. Work has been done from the outset of the project to understand the systems, language, governance arrangements of each of the six partners together with the relevant cancer services. The legitimacy of the project is based on the three-tier model of engagement and delineation of feedback from different groups, for example in the Gathering Sessions. As the project moves towards the negotiating change and commitment to change stages, attention should be paid to the power balance, acknowledging that this will depend on the different groups' status and legal position, but

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[63] Greenhalgh T, Hinton L, Finlay T et al. *Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot. Health Expect*2019;22:785-801. doi:10.1111/hex.12888. pmid:31012259

[64] Oliver K, Kothari A, Mays N. *The dark side of coproduction: do the costs outweigh the benefits for health research? Health Res Policy Syst*2019;17:33. doi:10.1186/s12961-019-0432-3. pmid:30922339.

[65] Bev J. Holmes, I*nterim President and Chief Executive Officer of the Michael Smith Foundation for Health Research* in: On the co-production of research: why we should say what we mean, mean what we say, and learn as we go | Impact of Social Sciences (lse.ac.uk)

[66] What Are the Key Ingredients for Effective Public Involvement in Health Care Improvement and Policy Decisions? A Randomized Trial Process Evaluation - BOIVIN - 2014 - The Milbank Quarterly - Wiley Online Library

[67] Mobilising knowledge in complex health systems: a call to action in: Evidence & Policy Volume 13 Issue 3 (2017) (bristoluniversitypressdigital.com)

[68] Op cit.

equally could be a stumbling block if the participants/findings from the CCCW project find it difficult to ultimately influence decision making around cancer services.

Boivin et al point to practical steps which can be taken in all three areas. Firstly, in terms of credibility they note participants' experience and expertise, which can also be built through access to additional information or skill-building. There is clear evidence of skill-building in the CCCW project. In terms of legitimacy, they point out the difference between statistical representativeness of a group (correspondence between the descriptive characteristics of a sample and those of the population from which they are drawn) and representation. The former is difficult and expensive; the latter, where individuals speak for a wider constituency, is feasible through appropriate connections, for example access to community groups or related data. Again, analysis of the CCCW project suggests that legitimacy has been built through appropriate connections, networks and the six partner organisations.

The authors point to some structural factors in order to help achieve a balance of power, these being – facilitation, simple strategies like seating plans and titles, as well as ground rules and agenda-setting. Whilst the CCCW project are already cognisant of this, as noted at the Gathering Sessions, these are important factors for the next stages in the project. Other commentators[69] highlight that co-produced research, such as the CCCW project, will only be as successful as the broader system enables it to be, including funders and academic organisations. This is perhaps a further tier for consideration by the CCCW project.

Difficulties in co-production are outlined by various commentators[7071], pointing to how various factors can lead to bias and misrepresentation of participant's input, culminating in the wrong direction of travel for service development and delivery. Appropriate checks need to be in place to confirm and re-confirm findings from co-production. Evaluation of the CCCW project at this point suggests that they have adopted good practice in checking and confirming findings, e.g. by asking the same question to different groups of respondents at the Gathering Sessions, by using a snow-ball technique of testing findings to date.

7.3 *Examples of co-production in the health service and cancer services*

Northern Ireland

At the outset of this Interim Report reference was made to the *Cancer Strategy for Northern Ireland 2022 – 23*[72]. It is worth emphasising that this Strategy highlights how co-production is already being used in a NI context in relation to cancer services. The following box illustrates.

[69] Allan Best & Bev J. Holmes Six actions to mobilise knowledge in complex systems – Integration and Implementation Insights (i2insights.org)
[70] The dark side of coproduction: do the costs outweigh the benefits for health research? - PubMed (nih.gov)
[71] Lost in the shadows: reflections on the dark side of co-production - PubMed (nih.gov)
[72] Op cit.

Page 2 - *This Strategy has been co-produced with people living with cancer and staff providing treatment and care under the leadership of Professor Charlotte McArdle and Ivan McMinn MBE. As we move towards implementation, we will ensure that this collaborative working continues.*

Page 6 - Strategy Development *The development of the Strategy has been based on co-production which has brought together people with lived experience of cancer and healthcare professionals from across all the Health and Social Care Trusts (HSC), the Public Health Agency (PHA), Health and Social Care Board (HSCB), Primary Care, policy makers and cancer charities. The Strategy aims to place Northern Ireland at the forefront of world-class cancer prevention, treatment and patient experience.*

Page 27 - *There is evidence that people from lower socio-economic groups often have lower recognition of signs and symptoms of cancer. This is likely to be the case for other seldom-heard and harder to reach groups, particularly those from ethnically diverse backgrounds and those with learning disabilities. Awareness raising campaigns must be co-produced and specifically tailored to be more easily understood.*

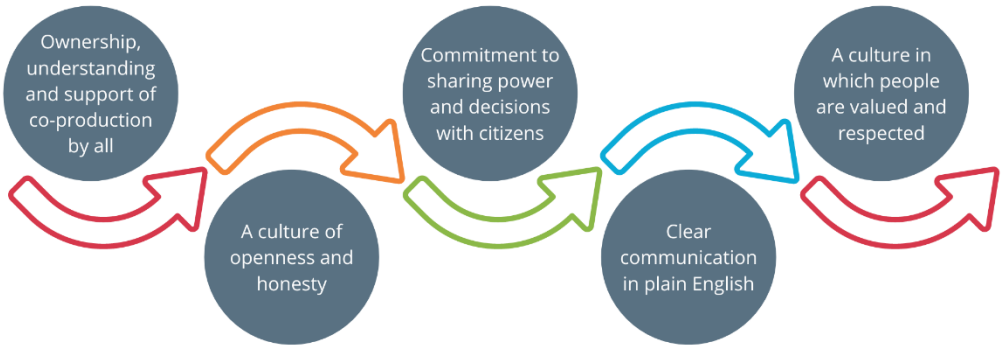
Page 114 - *In order for the delivery of the Strategy to be released over the next decade, collaboration and co-production will be crucial. This will involve maintaining and building on the many successful developments implemented over the past years in response to the pandemic, and learning from what could have been done better. Collaboration between HSC organisations, across sectors and with people affected by cancer including families and carers will be a key enabler to effecting meaningful change.*

NHS England

NHS England outlines its usage and affiliation to co-production in the development of health and care services[73]. They confirm the process/system and the importance of using co-production and the need for equal partnership in the arrangement: *Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation.*

Co-production acknowledges that people with 'lived experience' of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives. Done well, co-production helps to ground discussions in reality, and to maintain a person-centred perspective. Co-production is part of a range of approaches that includes citizen involvement, participation, engagement and consultation.

[73] NHS England » Co-production



The image above is from A Co-production Model produced by NHS England and the Coalition for Personalised Care. The image is described as follows. The image displays the following values and behaviours needed to ensure co-production becomes part of the way we work:

1. Ownership, understanding and support of co-production by all
2. A culture of openness and honesty
3. Commitment to sharing power and decisions with citizens
4. Clear communication in plain English
5. A culture in which people are valued and respected.

The evaluation assessment is that the CCCW project embodies all of these values in its delivery mechanism. It may be useful for the CCCW project to develop its own value base, for the final year of the project and for whatever ongoing co-production work comes out of the project's recommendations.

Another important factor for consideration by the CCCW project is that co-production is not a stand-alone process or approach. NHS England produces statutory guidance[74] on working in partnership with people and communities. Their focus is to identify the legal duties organisations are required to make to ensure that people are appropriately 'involved' in planning, proposals and decisions regarding NHS services. They suggest a blended approach to working partnership with people and communities, involving a number of approaches including co-production. These are outlined in the image below[75].

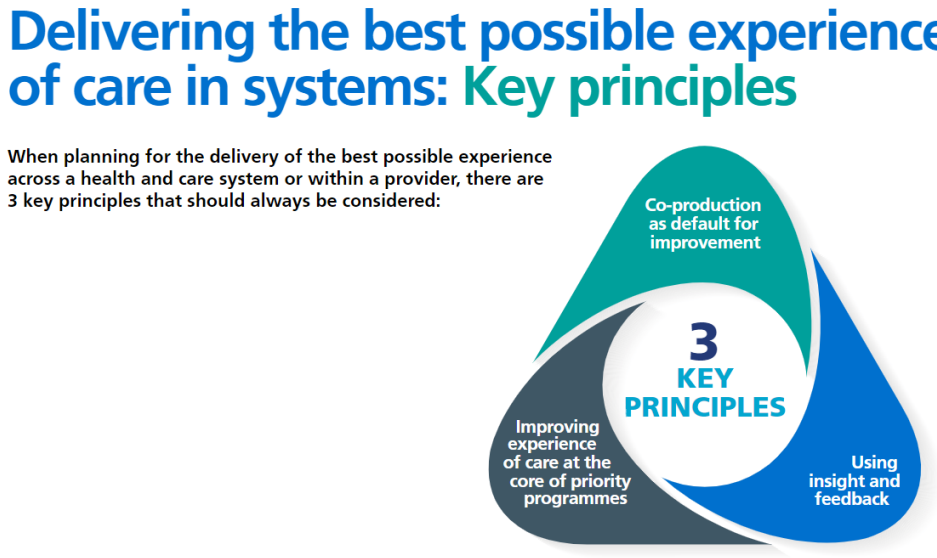
[74] NHS England » Working in partnership with people and communities: statutory guidance
[75] NHS England » Working in partnership with people and communities: Statutory guidance Annex A: Implementation.

This image illustrates the different ways of working with people and communities, one of which is co-production.

- **Inform**: Sharing information about proposed changes so people understand what they mean.
- **Consult**: Asking for people's opinions on one or more ideas or options.
- **Engage**: Listening to people to understand issues and discuss ideas for change.
- **Co-design**: Designing with people and incorporating their ideas into the final approach.
- **Co-production**: An equal partnership where people with lived and learnt experience work together from start to finish.

Another framework incorporating a co-production approach is from the National Quality Board. In their October 2022 report[76], they identify three key principles that they suggest should always be considered when planning for the delivery of the best possible experience across a health and care system or provider. This is illustrated in the image below.

[76] NHS England » Improving experience of care: A shared commitment for those working in health and care systems.



This image displays the key principles of:

1. co-production as default for improvement
2. using insight and feedback
3. improving experience of care at the core of propriety programmes.

This report suggests that co-production as the default for improvement is an essential part of improvement methodology. This is a useful comparison for the CCCW project, which has closely knit co-production into their 'improvement methodology' for health and care services.

Cambridge Cancer Research Hospital

Cambridge Cancer Research Hospital has a co-production policy and practice[77], aimed at working closely with current or former cancer patients and their families, as well as staff and other stakeholders. They emphasise the focus of this: *to build the best hospital to meet everyone's need* and note that this is across all workstreams and reported to their Joint Delivery Board. The co-production approach is led by the Cancer Patient Partnership Group, which has had input to a range of projects over the last 10 years.

East of England Cancer Strategy

The East of England Cancer Alliance incorporates co-production, through those with lived experience of cancer, into the design of all cancer services[78]. This has included working with Eastern European communities in Wisbech and the Luton Outcomes work within Bedfordshire, Luton, and Milton Keynes Integrated Care System. The Luton outcomes work is outlined in more detail in the Strategy document at page 12.

Co-production has also been used by the East of England Cancer Alliance to engage with teenagers and young people, in order to use and expand social media platforms. This project has enabled young people to recognise what is normal for their bodies, what symptoms

[77] What is co-production? | Cambridge Cancer

[78] East_of_England_Cancer_Strategy_19.pdf (canceralliance.co.uk)

should not be ignored, and the impact of risky behaviours to their wider and future health, helping to make information more accessible and applicable to them. The end result of better information on social media is focussed on improving outcomes for young people with cancer across the East of England.

Macmillan Cancer Co-production Group – Every-One

Macmillan Cancer have developed a Living with Cancer programme[79] which aims to develop person-centred, local support for people living with and beyond cancer, their carers and significant others in Lincolnshire. The approach uses co-production. One example of what they have worked on is an improved Cancer Care Review to be used by all Lincolnshire GP practices[80]. The co-production group also works on co-creating information and guidance materials for their area.

Northern Cancer Alliance

The Northern Cancer Alliance has developed a cancer awareness project focused on co-production. The group produced a 'Be cancer aware' peer education project[81], with a specific focus on improving cancer services and experiences for people with a learning disability.

Alliance Macmillan Scotland

In this example, the Lived Experience programme under the *Transforming Cancer Care Lived Experience programme*[82] in Scotland worked closely with 14 people affected by cancer to gather and report on their insights from their own experiences, and to use these to inform the national design and development of cancer prehabilitation services.

[79] Macmillan Cancer Co-production Group - Every-One
[80] Lived Experience of Cancer and Co-production - Every-One
[81] Be-cancer-aware-Process-evaluation.pdf (northerncanceralliance.nhs.uk)
[82] The ALLIANCE Macmillan Transforming Cancer Care Lived Experience programme 2021 review - Health and Social Care Alliance Scotland (alliance-scotland.org.uk)

Section 8 Conclusions and recommendations

8.1 This section now summarises a number of conclusions and recommendations arising from the final evaluation. The conclusions identify and examine the extent to which the stated objectives, aims and themes of the CCCW project have been delivered over the course of the 3-year project. Over 2,748 participants have taken part or received services as part of the CCCW project in this timeframe, with the spread and variety of activities outlined earlier in table 10. **Learning points** (recommendations) have been included in the table below.

Objectives	Details	Evidence
Objective: to closely connect people affected by cancer to each other	This overarching objective links to one of the key aims of the project: to create an integrated movement of organisations in this area committed to working together to secure improvement for prevention of and care for cancer	There is considerable evidence from the individual partners of activities and programmes that the project brought people affected by cancer together. This has included for those who are cancer patients, those who are living with ongoing or post cancer, their carers and families. Activities which have brought people together have included Support Groups, group counselling, Wellbeing groups and programmes etc. Sections 4 and 5 highlighted the range of groups and activities and the numbers participating. Quotes from participants indicate that they have met new people and made new connections, and overall that they have benefitted significantly from the peer support element of the project.
Objective: to connect people affected by cancer to support in the community	This overarching objective links to the key aim: to simplify the complexity of post cancer care ensuring people find the right pathway for them to the right service at the right time	Again, there is considerable evidence from the project evaluation that people affected by cancer have received support throughout the project. This has included support around physical health/activity, mental health, financial and benefits information/advice, emotional support and counselling. Other important factors that are evidenced included: the location and proximity of the support (in their community), the signposting and information provision by all partners etc. Quotes from participants again highlight the importance to them of receiving support through the CCC project, with some respondents noting that it was a lifeline to them.

Objectives/ Project Aims	Details	Evidence
Objective: to link people affected by cancer to people who deliver cancer services so they can use their experiences to make improvements	This overarching objective links to the key aim: to ensure that people living with cancer in this geography, especially those who have difficulty accessing services, are front and centre in the development of their cancer care provision and that their specific needs are heard and met.	This element of the project is well-documented in the reports from the Gathering Sessions, Negotiating Change Workshops and the questions put forward at the final 'Commitment to Change' Conference. . The GS and NC workshops highlight the level of participation including the numbers and backgrounds of participants. They also point to the issues raised by participants which are personal to them, the breadth of knowledge from personal experience, the barriers and obstacles identified, and the suggestions put forward for change.
Project Aim: To engage marginalised groups for whom cancer services may be limited and for whom barriers to access exist	This project aim was to ensure that marginalised groups and those most marginalised were included in the CCCW project, and ultimately that their needs were represented in the project.	Analysis of the participant information in Section 4 indicates that the majority of participants are female (80% plus), over half are in the age 50 – 69 age bracket and the vast majority (99%) are white. Measures were put in place throughout the project to expand the reach of the project to under-represented groups across gender, age and ethnicity. Analysis of participation by marginalised groups shows evidence of the CCCW project's engagement in this area. However, it is difficult to be categoric about these levels of take-up without reference to the incidence of these factors in the broader population e.g. the level of rural take-up could be considered low given that much of the WHSC Trust area is defined as being rural. In addition, these numbers may be dependent on what information participants were asked for and what they shared; there may be an element of self-reporting and also under-reporting across these factors.

Project Aims	Details	Evidence
Project Aim: To deliver support programmes	This project aim was the backbone of the project in terms of a wide range of support services targeted at those affected by cancer.	Evidence from Years 1 – 3 of the project highlights an extensive and varied range of support programmes across all the delivery partners. Assessment of the take-up and participation in programmes, together with the qualitative data gathered for this evaluation suggest that as a result of their involvement, participants have inputted to the development of services, pathways and improvements for the prevention of and care for cancer and have increased their own (and family) wellbeing and made suggestions about gaps in provision at a community level.
Project Aim: To listen to cancer programme participants	This aim has been well covered in the above project objectives.	The evaluation has noted clear evidence of listening to cancer programme participants at group/partner level and at the Gathering Sessions and Negotiating Change Workshops. Paragraph 2.8 and Table 11 above indicates the number of attendees at the Gathering Sessions, where the focus was on listening to participants. The numbers attending the Negotiating Change Workshops is also recorded. The CCCW project has been enhanced by the ELEC training - Effective Listening for effecting change.
Project Aim: To set priorities for improved cancer services and to directly articulate priorities to service planners to influence strategic change	Two project aims have been combined here.	The evaluation clearly shows, through the model of engagement and co-production, how individuals and partners have been able to articulate their personal issues, and then how these have been brought together into listing and reviewing priorities, and ultimately into questions and answers at the 'Commitment to Change' conference. The model of engagement established for the project, based on both co-production approaches and the 3-tier model of engagement, has been crucial to this project aim. It has enabled participants to have a voice at local level, and then to come together at the Gathering Sessions and Negotiating Change workshops. In addition, engagement with the service planners and statutory services, and their involvement throughout the project has been critical. Other important factors in the process have included: training (for facilitators, therapists and partner organisations), support and funding for direct provision of activities, and the structured approach to consensus building adopted at the Gathering Sessions and Negotiating Change workshops.

Themes	Details	Evidence
Theme: To identify the factors contributing to the success or otherwise of delivery against the stated project aims (including project plans, role of partners, users, staff and external forces)	This theme looks at what has contributed to the success to date of the CCCW project.	This element has been examined by the evaluator and is outlined in Section 6.4 of this Report based on independent assessment of the project, together with feedback from the lead partner, partners and participants. A number of success factors are noted in Section 6, together with reference to areas which were considered to be difficult/challenging during the development period, i.e. recruitment, different partners track record in funded projects, delay in engaging an external evaluator etc. and some operational difficulties around paperwork and forms. These factors were all resolved within Years 1 – 2 of the project. Success factors were identified as including buy-in from all the partner organisations and the statutory sector at senior management level, good partnership working, no sense of competition between partners over funding or opportunities, no duplication and the spread of the delivery model and programme, the flexibility of the project, the expertise and professionalism of the DWW staff members etc.
Theme: To identify and benchmark good practice in relation to integrated care and co-production, and to reflect on the implementation of the project against those benchmarks	This theme looks at other examples of good practice.	At this point the evaluator has produced a review of the literature around co-production in health services, with a particular focus on cancer services. This is covered in Section 7.

Themes	Details	Evidence
Theme: To provide a source of learning and development during and after the life of the project to both CCCW partners and other interested parties.	This theme looks at learning from Years 1 and 2 of the project.	This theme is evidenced by ongoing communication between the evaluator and the project team, and the production of an Interim report, and then a final report. A key focus was on ensuring that the data collected and collated by the lead partner (DWW) is in a format that is useable for evaluation purposes. DWW have already adapted how the information is recorded and stored e.g. project year. It should be noted that there is considerable variation in the recording and evaluation systems used by the six partners; there is therefore no way of making direct comparisons across provision or across the partner organisations, in terms of individual participant outcomes. Partner organisations have used the following monitoring and evaluation tools: Measure Yourself Medical Outcome Profile (MYMOP), Self-Assessment Lifestyle Inventory (SALI) and Core Measurement Tools (Core-10), together with their own organisational in-house evaluation forms and methods, including quantitative and qualitative approaches.

The project aims and conclusions link closely with the hoped for targets and anticipated outcomes from the CCCW project, which are as follows:

- Reducing the incidence and impact of cancer in our communities;
- Promoting increased attendance/engagement at health screening within local communities;
- Overcoming the challenges in maintaining holistic wellbeing through the cancer journey by addressing all dimensions of wellbeing as relevant to programme participants, i.e. physical, social, emotional, spiritual, financial, mental health;
- Addressing the gaps in the current community provision of support services for people living with and beyond cancer.

Whilst the evaluation evidence and conclusions can confirm that some of these targets have been contributed towards, it is difficult to make categoric 'cause and effect' statements. For example, it would be impossible to say that the CCCW project had reduced the incidence of cancer; albeit that undoubtedly the project has eased the impact of cancer on many participants through the programmes and activities.

Furthermore, it is impossible to know categorically if the CCCW project has resulted in a direct increase in attendance and engagement at health screening in the locality; again, the causal linkage would be difficult if not impossible to confirm. From the evidence above, it is clear that the CCCW project has helped individuals, and their families and carers, to overcome challenges in maintaining their holistic wellbeing.

Appendix 1 – Evaluation Methodology

The CCCW team requested a formative evaluation of the project from an independent consultant. A **formative evaluation** is primarily viewed as an evaluation that commences at the outset of project delivery, and then feeds into the project development on an ongoing basis throughout the project's delivery timescale. *A formative evaluation is an evaluation that occurs during the development of the program. Formative evaluations can help improve and enhance the program as it is developing or occurring. Data from formative evaluations can be used to make changes in program delivery or methods*[83]. According to Robson *formative evaluation is intended to help in the development of the programme, innovation or whatever is the focus of the evaluation*[84].

That being the case a formative evaluation should have commenced in September 2021; however, that was not possible. The agreed evaluation methodology Is using a **hybrid evaluative approach**; in part formative (which can feed into the ongoing project development) and part **summative**[85] which concentrates on assessing the impact.

Table 12 below outlines the agreed evaluation approach. This includes reference to how data (quantitative and qualitative) is gathered, analysed and reported on. In addition, this table provides an indication of outputs at different stages in the formative evaluation.

[83] What is a formative evaluation? – Evaluation (extension.org)

[84] *Real World Research,* 4th Edition, Colin Robson & Kieran McCartan, 2015, ISBN: 978-1-118-74523-6

[85] A summative evaluation can be defined as: *concentrates on assessing the effects and effectiveness of the programme.* From *Real World Research,* 4th Edition, Colin Robson & Kieran McCartan, 2015, ISBN: 978-1-118-74523-6

Table 12: Evaluation approach, aims and outputs

Area/Method	Aim	Outputs
Establishment of Project Advisory Group (PAG), initial and ongoing meeting(s) and contact	To ensure that project proposal is in line with CCCW project requirements – and that evaluation gets off to strong start. The Terms of reference note the CCCW Project Board – this may be the PAG for this evaluation, or a separate group may be needed.	Project Initiation document (PID)
Interaction with all 8 partners	To ensure access to data from all partners via the CCCW project. And to set up reporting systems within the evaluation process.	Understanding of project for consultant
Review of all relevant project paperwork and academic/grey literature	Scoping the background/context – on cancer care in the Western HSC Trust area, the documented obstacles/issues, outlining rates of cancer diagnosis, reviewing service provision, reviewing literature on co-production and integrated care including benchmarks	**Working Paper 1 – Setting the scene** Formative input to the CCCW project in terms of potential changes
Review of all quantitative data on the CCCW project	Review of all data available will include number of referrals, take-up of project training, gathering sessions, breakdown of attendees etc. This will demonstrate in the evaluation the level of interest and need	**Working Paper 2 – Evidenced need for the CCCW project** Formative input to the CCCW project in terms of potential changes. Summative impact information.

Area/Method	Aim	Outputs
Evaluation fieldwork	The aim of **primary fieldwork** will be to get feedback on the **impact of the project** on key stakeholders as follows, using co-production approaches, and obtaining qualitative and quantitative outcomes: - The 8 partner organisations, including the relevant voluntary and statutory services. This will examine what themes have emerged through the project activities. **(suggested 1-1 interviews and focus groups in partner organisations as appropriate)** - The participants. This will examine what they believe are (a) the key obstacles to obtaining integrated cancer care in the WHSCT area and (b) their suggestions on what could be done to effect change. In addition, this element will include an impact assessment of participation in the project. It is proposed to use a wellbeing scale[86] to measure this, potentially at the earliest possible point in the project and then towards the end of the project. **(suggested as a minimum 1-1 interviews with 16 service users – 2 from each of the 8 partner organisations)** More may be possible through the consultant attending gathering/key events. This stage will also include the production of some **anonymised participant case studies**, which highlight service user journeys; - Wider stakeholders including housing, councils, education, transport – to seek their views on the emerging 'change requests' **(suggested to be done as phone or email feedback – from min of six organisations)**	**Working Paper 3 – Evidencing the outputs and outcomes from the project – a Qualitative view** **Production of Interim report** (timing to be agreed with CCCW project board) Formative input to the CCCW project in terms of potential changes. Summative impact information.

[86] Potential scales that could be drawn on include the WEMWBS questionnaire for measuring mental well-being, developed by researchers at Warwick and Edinburgh Universities (see Tennant R, Hiller L, Fishwick R, Platt P, Joseph S, Weich S, Parkinson J, Secker J, Stewart-Brown S (2007) The Warwick-Edinburgh Mental Well-being Scale (WEMWBS): development and UK validation, Health and Quality of Life) or the Leuven scale which is traditionally used with children/school settings, but can be adapted for use with all ages - What Is the Leuven Scale and How to Use it (learningjournals.co.uk)

Area/Method	Aim	Outputs
Evaluating the co-production approach and development of the Commitment to change	The aim of this element will be to evaluate the development and production of the CCCW project model, and the methodology of co-production through the different elements – training, provision, consensus building, negotiating change, agenda for change etc. Feedback will be obtained via the methods outlined above, i.e. the fieldwork stage will cover this element as well as the impact assessment. During this phase the consultant will build on the benchmarking work which will have commenced earlier in the identification of benchmarks around co-production, integrated care and partnership working in the field of cancer services. This stage will include a desk-based review of these benchmarks and good practice models. For example, this may cover integrated care standards in other UK or Republic of Ireland jurisdictions or other models of cancer care e.g. Scotland.	**Working Paper 4 – Evaluating the co-production approach of the CCCW project model, and highlighting benchmarks and best practice** Formative input to the CCCW project in terms of potential changes. Summative impact information.
Production of final evaluation report and any presentations	The aim of this element will be to pull together the final evaluation report, using all data gathered/analysed and the four Working Papers. Conclusions and recommendations in relation to how the project can continue or be incorporated into wider existing practice.	**Final report/ presentations**

Appendix 2 – Glossary of Terms

Age-Standardised
The rates are calculated by applying the age-specific rates for the location being studied to a theoretical world-wide standard population, usually expressed per 100,000 persons per year.

Cancer Incidence Rate
The number of new cancers of a specific site/type occurring in a specified population during a year.

Cancer Prevalence
The number of people now living who have ever been diagnosed with cancer. It includes people diagnosed with cancer in the past as well those who were recently diagnosed.

Clinical Nurse Specialist or CNS
A clinical nurse specialist (CNS) is a nurse specially trained to provide expert advice on treatment and care for a particular type of cancer.

Health and Social Care Board (HSCB) and Health & Social Care Trusts (HSCT)
A statutory organisation that arranges or 'commissions' health and social care services for the population of Northern Ireland (Board) and delivers services at a regional/local level (Trust).

Mortality rate The number of deaths occurring in a specified population during a year, usually expressed as the number of deaths per 100,000 population.

Multidisciplinary teams A group of healthcare workers who are members of different disciplines or professions each providing specific services to the patient.

Northern Ireland Cancer Network (NICaN) This brings together Health and Social Care organisations, charities, cancer specialists and service users to improve cancer outcomes and experiences for patients.

Palliative Care
Palliative care is treatment that attempts to help the patient feel better and may be combined with an attempt to treat the cancer. Palliative care includes action to reduce physical, emotional, spiritual and psycho-social distress. Unlike treatment that is aimed at directly killing cancer cells, the primary goal of palliative care is to improve quality of life. People at all stages of cancer treatment typically receive some kind of palliative care; however, it is often referenced in relation to when people approach end of life.

Prehabilitation The process of supporting patients to enhance their functional capacity or fitness ahead of treatment to enable them to cope with the treatment and to improve their outcomes after treatment.

Public Health Agency (PHA) The major regional organisation for health protection and health and social wellbeing improvement.

Rapid diagnostic centres/hubs These are designed to provide earlier and faster cancer diagnosis by providing a single point of access to diagnostic tests for all patients with symptoms that might suggest cancer.

Stage of presentation The stage at presentation describes the severity of a person's cancer based on the size and/or extent of the primary tumour and whether or not cancer has spread in the body.

Survival rate The percentage of people in a study or treatment group who are alive for a given period of time after diagnosis.

Systemic Anti-Cancer Treatment (SACT) The two main types of systemic therapy are chemotherapy (which uses drugs) and hormone therapy (which uses hormones). They can be given to increase long-term survival, control tumour growth and sometimes manage symptoms arising from the cancer.

Appendix 3 Monitoring and Measurement information – by partner organisations

Derry Well Women

DWW provided a range of reports, including a number of evaluation tools i.e. My Mop and the Self-Assessment Lifestyle Inventory (SALI). In Year 1, DWW evaluated their Complementary Therapies programme for the period December 2021 – May 2022. Using My Mop, this reported that all participants showed improvement in their mental, physical, and general wellbeing. 75% showed significant improvement in reducing mental or physical symptoms e.g., anxiety and fatigue; in accessing a physical, social, or mental activity and in their general wellbeing. Participant feedback included the following quote: *I feel much brighter over the last few weeks. The treatments have helped me to be calmer. This was a fantastic experience. Derry Well Women is a fantastic place for cancer care.*

DWW evaluated the Stress Anxiety Management programme for the period January – March 2022. This evaluation indicated an increase in all levels of wellbeing (physical, emotional, spiritual, mental and reliance on health) with a slight decline in behaviour lifestyle. Participants provided feedback highlighting that they felt much better after the course and able to deal with the stress of everyday life. One participant said: *Feeling much more positive having attended this programme. Very well facilitated and very informative. Don't feel as isolated having met others going through similar experiences being able to open up hare my experiences for first time have been therapeutic.*

DWW used the Core 10 evaluation tool to evaluate the counselling provided to participants in the period February – September 2022. This indicated that all clients showed improvements with 60% showing significant improvement in their health, wellbeing and functioning.

DWW evaluated their Mental Health & Wellbeing Programme for the period May – July 2022. Using the SALI evaluation tool, an assessment was made for the five women who completed the programme. They all reported a significant improvement in their health and wellbeing. One participant said: *Every topic covered taught me something new and encouraged me to challenge my thinking and look at alternative perspectives.*

DWW also ran their Complementary Therapies from January – June 2023. Evaluation using My Mop showed improvement in mental, physical and general wellbeing, with one third (37.%) of participants showing significant improvement in reducing mental or physical symptoms e.g. insomnia, anxiety and physical pain, and in accessing a physical, social or mental activity. A range of participant feedback was obtained ranging from one individual saying it was *life-changing* to others talking about their feelings and reporting feeling more relaxed and able to sleep better.

DWW evaluated their Mental Health & Wellbeing programme which ran from February – March 2023. Using the SALI evaluation tool, all indicators pointed towards women noting that their life had physically improved including increased energy, diet, exercise, pain levels and sleep.

DWW ran counselling sessions from November 2022 – April 2023. Using the Core 10 evaluation tool, all clients showed improvement, with around half showing significant improvement in their health, wellbeing and functioning. One participant concluded: *DWW is invaluable; my counsellor*

was superb and stayed with me emotionally at every stage of my changing emotions. Counselling allowed me to unpack and reassess my priorities.

Quotes from participants:
The Well programme: *this venue is a much-needed refuge for people with cancer. It is not set up for a focus on health, more of a tribe of people in the same boat.*

Mental health wellbeing programme: *every topic covered taught me something new and encouraged me to challenge my thinking and look at alternative perspectives.*

In Year 3 DWW monitored and evaluated their complementary therapies programmes using My Mop, and their Well Programmes (run at Care for Cancer and DWW) using SALI. All of these evaluations showed improvements for participants in their mental, physical, symptoms and social and general wellbeing. Quotes from participants included: *I have so much more positive daily attitude. And a better skill set and better equipped to deal with days when I don't feel so positive.*

Action Cancer
At the end of Year 3 Action Cancer noted that evaluation of their services had shown:
Counselling service – 83% of clients showed improvements in quality of life;
Complementary therapy service – 64% of clients showed improvements in quality of life.

Quotes from participants:
Counselling: *You have helped me begin to process my grief, although I now realise that this is a journey and not a destination.*

I have really benefitted from my counselling. It has given me a much-needed support in a very difficult period of my life. I felt the counsellor was knowledgeable and extremely helpful and supportive. The weekly sessions gave me a real boost in order to be able to cope with my circumstances.

I availed of the counselling service via telephone. The counsellor provided really bespoke care – listening and understanding. I felt that she understood. Probably for the first time when I spoke to the counsellor I was able to address the practical aspects of cancer.

Positive Living programme: *I have found the whole programme very beneficial. It helped me explore my thoughts, behaviours and beliefs. I learnt that I have the resources inside me to support me move forward.*

Complementary therapy: *My time with the therapist was absolutely amazing and has made the biggest difference to my life. It has highlighted how essential it is to make time for yourself, how stressed and worried I felt for it to melt away during the sessions and after, and I feel it is something I will most definitely integrate into my life.*

I have just completed 5 sessions of reflexology. The experience and benefits have been brilliant. It came just at the right time in the few weeks in the lead up to my 3 monthly review. I didn't realise how tense and anxious I was. The sessions have helped reduce stress

and tension and increase my feeling of well-being. I am feeling better able to cope, more relaxed, in good form and I find I am sleeping much better.

Advice North West

Quotes from advice staff:

The client felt relief knowing their entitlement and that there is help out there.

The client left feeling reassured that there are more options and services to advocate on her behalf and support her through this journey.

Cancer Focus

All of the targets were met for the 3-year programme and extra sessions were added in Years 2 and 3 due to extra demand and particular requests relating to the needs of certain groups.

A system of pre- and post- programme questionnaires were used in the 7-week Health Improvement programmes; 488 participant evaluation forms were completed following the programme. These questionnaires provided a series of 12 statements including – *I am making changes to improve my health,* and *I feel confident talking to other people about my health*. Analysis of these responses found that participants noted improvements in 11 of the statements/areas from before to at the end of the programme. Overall, these indicated the growth in their own health and wellbeing as well as an increase in their knowledge based on things like signs and symptoms of different types of cancer, cancer screening programmes and about accessing help from other services.

Quotes from participants:

Group programme: *I have better knowledge of healthy living and got tips on living healthy…I have information on what's in my area that could help to improve my health.*

Creative engagement programme: *Even before I went, I thought what am I doing because I don't do things like that – going to places where I don't know anyone, I wouldn't find it easy to do but it was nearly as if we had always known each other and it was lovely!*

Care for Cancer, Omagh

During Year 1 Care for the Well Programme was delivered by DWW in Omagh for Care for Cancer from February to April 2022. Using the SALI, participants indicated an improvement in all areas, with only a slight dip in behaviour lifestyle. Participants were very positive about how the course had given them better understanding of their body, coping mechanisms and opportunities to talk with other people in a similar situation. One participant said: *I have learnt the importance of the balance of spiritual, emotional, mental and physical wellbeing.*

The Mental Health and Wellbeing Programme was delivered by DWW in Omagh for Care for Cancer for the period October – December 2022. Using the SALI evaluation tool, an assessment was made for the five women who completed the programme, with all reporting a significant improvement in their health and wellbeing. One participant said: *Every topic taught me something new and encouraged me to challenge my thinking and look at alternative perspectives.*

Quotes from participants:
Counselling: *The service from Care for Cancer is excellent and I look forward to my counselling sessions…*

Transport to hospital: *Many clients in Co. Tyrone and Fermanagh have told us that they could not attend their hospital appointments or receive cancer treatment if they did not have the use of our transport service.*

SWELL

During Year 1 the Mental Health and Wellbeing programme was delivered for SWELL from February to April 2022. Eight women participated and all reported a significant improvement in their health and wellbeing. One of the most important changes the women reported was feeling safe, supported and less isolated. They said they benefitted from the experience of others and the non-judgemental space to speak freely, and how to focus on the positive elements of life. One participant noted: *You gave me so much information and knowledge and tips on mindfulness and how to deal with emotions…*

The Mental Health and Wellbeing programme delivered by DWW for SWELL which ran from May – June 2023, was evaluated. The SALI evaluation tool recorded improvements across the board in physical, mental and emotional health. One participant said: *I really learnt a lot about the importance of taking care of ME and having compassion for myself.*

Quotes from participants:
Support group: *I would be lost without SWELL. A great support group…Much needed peer support during difficult times.*

Arts and Crafts: *Really takes my mind off things. It was the first time in a long time I forgot about my worries.*

Counselling: *I feel more in control of my life after this counselling. I would never have looked at my problems in this way before.*

Appendix 4 Themes and questions from the 'Commitment to Change' Conference

Conference Questions

Q	Theme	Question	Name of Questioner	Name of Responder
1	CCCW Model	How can this model and process be sustained, where those with lived experience are not just listened to but influence change and shape services?	**Pauline McKenna** (*Service User, Care for Cancer*)	1. **Heather Monteverde** (Department of Health – Professional Advisor) 2. **Una Cardin** (*WHSCT - Assistant Director Operations & Service Improvement Cancer and Diagnostics*)
2	Communication with Patients and Carers	The timing and mode of communication has been raised as an area of improvement, particularly around communicating a diagnosis. When communicating with patients, how can you ensure patient confidentiality, their understanding of their diagnosis and their treatment regime as well as including their family and carers at important appointments?	**Sean Kelly** (*Service User, Care for Cancer*)	1. **Una Cardin** (*WHSCT - Assistant Director Operations & Service Improvement Cancer and Diagnostics*) 2. **Celia Diver Hall** (WHSCT – Lead Nurse – Macmillan Nursing Services Manager) 3. **Lesley Finlay** (Manager of Macmillan Wellbeing Campus)
3	Rural Patients	Rural cancer patients continue to feel isolated and struggle to access services. How can patients from rural communities be better connected and supported throughout their cancer journey? Specifically in relation to public transport and community transport.	**Mark Robinson** (*Service User, SWELL*)	1. **Judith Andrews (**Department for Infrastructure – Director of Public Transport Operations**)** 2. **Bridget Tourish (**WHSCT - Service Manager Oncology and Haematology**)**

				3. **Richard Spratt** (Chief Executive – Cancer Focus) 4. **Craig Donnachie** (Head of Cancer Projects, Department of Health)
4	Complex Patients	Patients with additional conditions to their cancer diagnosis feel like they can fall through cracks in the care pathway and have no one owning their overall care. How can you ensure a more holistic and joined up service?	**Claire Quinn** *(Service User, DWW)*	1. **Helen McCormick** (WHSCT Clinical Nurse Specialist) 2. **Bridget Tourish (**WHSCT - Service Manager Oncology and Haematology**)** 3. **David Curtin** (Macmillan Cancer Prehabilitation Project Manager) 4. **Shane Breen** (WHSCT Assistance Director Integrated Care Systems) 5. **Craig Donnachie** (Head of Cancer Projects, Department of Health)
5	Hospital Environment	Patients and carers spend a long time in hospital due to waiting times. How can you reduce waiting times? Or how can you improve this experience for patients and utilise the waiting time, so they have opportunities to access information and support?	**Caroline Murphy** *(Service User, DWW)*	1. **Caoimhe Lavery** (WHSCT Admin Manager, Cancer Services, NWCC) 2. **Lesley Mitchell** (WHSCT Assistant Director – Nursing, Cancer & Diagnostics)
6	Integration of Communication	How can you equip patients with access to their own health records and information?	**Aileen Laird** (*Service User, Care for Cancer*)	1. **Caoimhe Lavery** (WHSCT Admin Manager, Cancer Services, NWCC)
7	Palliative Care	Through the workshops we attended, we have heard of many issues relating to palliative care. For example, different mindsets between oncologists, palliative staff, patients, and families on what palliative is. As well as	**Patricia Moore** (*Carer, SWELL*)	1. **Damien McMullan** (WHSCT Consultant in Palliative Medicine)

		other issues such as accessing specialist drugs in Fermanagh during out of hours. Will palliative care services be improved? And what work is underway or planned to effectively support those who are at palliative and end of life stages, including their family members?		2. **Marie Donnelly** (WHSCT Palliative Care Nurse) 3. **Anne Friel** (WHSCT Head of Pharmacy and Medicines Management)
8	Supporting the Cancer Workforce	At our Gathering Session for health professionals working in cancer care last year, we heard of the pressures the cancer workforce face daily. How can you look after and retain the current cancer workforce? And how can you make it an attractive job / career students when applying to health courses?	**Marietta Connor** (WHSCT *Breast Imaging Service Manager*)	1. **Deborah Hunter** (Macmillan Personalised Care Facilitator) 2. **Lesley Mitchell** (WHSCT Assistant Director – Nursing, Cancer & Diagnostics) 3. **Heather Monteverde** (Department of Health – Professional Advisor)
9	Localised Cancer Care	Cancer care does not exist exclusively in hospitals. Cancer patients don't live in hospitals. How can you ensure more clinical cancer care will be provided closer to home, within the home or in a more localised community setting?	**Martina Morris** (*Care for Cancer*)	1. **Una Cardin** (*WHSCT - Assistant Director Operations & Service Improvement Cancer and Diagnostics*) 2. **Jean Frizzell** (Cancer Programme Director, SPPG)
10	Information Sharing / Mental Health	We have heard that cancer patients do not know what services and support is available in their area and have come across information by chance. This has negatively impacted their mental health by not accessing the right support at the right time, for example financial information. How can you improve signposting patients and can a directory for all cancer services be developed?	**Roley McIntyre** (*Counsellor, SWELL*)	1. **Craig Donnachie** (Head of Cancer Projects, Department of Health) 2. **Lesley Mitchell** (WHSCT Assistant Director – Nursing, Cancer & Diagnostics)

11	Carers	Carers continue to feel invisible, neglected and out of their depth with the pressure to look after their loved ones from home. How can you better support carers in their complex caring needs?	**Gearldine Duddy** (*Service User, DWW*)	1. **Bridget Tourish (**WHSCT - Service Manager Oncology and Haematology**)**
12	Screening / Early Detection	Research has shown that someone who is diagnosed via screening appointments has a better outcome. Northern Ireland is behind the rest of the UK in cancer screening - how can you ensure capacity to extend our screening range as per the cancer strategy, particularly in relation to Bowel and Lung?	**Aoife Mullan** *(Service User, DWW)*	1. **Craig Donnachie** (Head of Cancer Projects, Department of Health) 2. **Ruth Flemming** (Service Development Manager, Action Cancer)
13	Cancer Prevention Campaigns	How will you support an ongoing programme of public awareness for Cancer Prevention and Early Detection?	**Claire Quinn** *(Service User, DWW)*	1. **Gary Maxwell** (Health Development Policy, Department of Health)
14	Aftercare	How can you support people to live well beyond cancer?	**Leanne Devlin** *(Service User, DWW)*	1. **Jacque Warwick** (Macmillan Consultant Nurse) 2. **Phil Mahon** (Chair, Derry Well Women) 3. **Ruth Flemming** (Service Development Manager, Action Cancer)
15	Long term goals	Are there any longer-term goals that haven't been mentioned today that you would like to highlight?	**Susan Gibson (*Chair*)**	1. **Donna Breslin** – (Macmillan Partnership Quality Lead) 2. **Una Cardin** (*WHSCT - Assistant Director Operations & Service Improvement Cancer and Diagnostics*) 3. **Craig Donnachie** (Head of Cancer Projects, Department of Health)

Conference Responses

Each person who asked a question at the conference had been affected by cancer either personally or through caring for someone affected by cancer. They were involved in the project through attending programmes and workshops. Each questioner shared their own personal reflections and insights on the specific question topic before asking the question directly to the relevant service planners and providers in the room.

See below the submitted responses to each question. This was delivered on the day in a dynamic, personal manner.

1. **How can this model and process be sustained, where those with lived experience are not just listened to but influence change and shape services?** (Pauline McKenna Service User, Care for Cancer) (Pauline McKenna, Service User, Care for Cancer)

Heather Monteverde, Professional Advisor, Department of Health:

This model, developed and led by Derry Well Women, has worked exceptionally well in the very successful delivery of this project. I am really impressed that 2000 people have been engaged in this process to date. I believe this methodology could and should be used to engage with service users not only in health and social care but across other sectors.

Una Cardin, WHSCT - Assistant Director Operations & Service Improvement Cancer and Diagnostics:

The WHSCT has really valued the model of engagement utilised throughout the cancer connected community project and are committed to continue to work with partners to support sustainability of this model. The Trust would be keen to re-establish the cancer locality group as it is believed that this project has now provided a clear roadmap for the improvement required for cancer care for patients within the WHSCT and has been a significant lever for highlighting these at both a local and strategic level.

2. **The timing and mode of communication has been raised as an area of improvement, particularly around communicating a diagnosis. When communicating with patients, how can you ensure patient confidentiality, their understanding of their diagnosis and their treatment regime as well as including their family and carers at important appointments?** *(Sean Kelly, Service User, Care for Cancer)*

Una Cardin, WHSCT - Assistant Director Operations & Service Improvement Cancer and Diagnostics:

Advanced communication skills training is currently a requirement within the peer review process for professionals who are core members of cancer and specialist palliative care multidisciplinary teams. Cancer Strategy Action 53 (DoH, 2022b). This dedicated course is currently delivered to all relevant staff working within cancer in the Western Trust. The Trust is currently working on increasing the number of trained staff available to deliver this programme with a view to expansion of the programme. In addition the Nursing Cancer Career Framework includes communication skills for nurses as a core component.

Communication is the core skill within health and social care. Communication is not merely the transition of information. Communication-by verbal, (words, volume, tone, pace, inflection) and non-verbal means influences how we relate and engage with others. It conveys core values, whether

positive such as respect and compassion, or negative such as indifference. The need to communicate well is magnified in caring situations: when people are anxious, vulnerable or grieving, when they need to trust others to take care of them or their loved ones, and when they are trying to process information, and make decisions on this information.

This has particular relevance in the context of cancer care where the person's future becomes uncertain, treatments are complex, harsh and require assessment of risk and benefit and where the consequences of a cancer diagnosis ripple out to all aspects of the person's and their family life. When undertaken well, health professional-patient communication reduces distress and anxiety and facilitates the delivery of person-centred, compassionate care. When undertaken badly, it mars the quality of care, it can fracture relationships between the person and the practitioner and can have a lasting impact on their total experience.

Communication skills training aims to:"…enhance what learners already do well, expand each learner's repertoire of skills, work with applying comfortable skills in more complex circumstances and break habits that serve neither clinician nor patient well."(Kurtz & Cooke, 2017

Summary of Key Points

- Communicating well is a relational process underpinned by values of respect, honesty, compassion and trust.
- Therapeutic communication in health and social care is a skill which can be taught and which results in positive outcomes for patients and for professionals.
- Experiential, learner centred teaching methods are necessary to grow professional competence and confidence and to achieve behaviour and attitude change.
- Every member of staff who engages with a person with cancer throughout their treatment and care requires communication skills training, but not the same training.
- Communication skills training will be most effectively and viably delivered through a tiered training approach built around the nature of communication within roles.
- A tiered approach should entail foundation level training for all. Intermediate and advanced communication skills training will be required by those who engage in more and most complex discussions respectively.
- Advanced communication skills training remains an important element within a tiered framework.

Celia Diver Hall (WHSCT – Lead Nurse – Macmillan Nursing Services Manager):

Other improvement education that has been put in place:

- The Trust has undertaken a number of key areas of work focused on improving communications with our patients, cares and families. An overview of this is provided below.
- Work on the ward delivered by Practice Educators
- Sage and thyme training
- Training provided by CNS on family centred cancer care; to provide support for parents. Approx. 40 staff in NWCC attended training. Also eLearning link was shared.
- Work underway with the Trust equality department to take forward a deaf sign language pilot within the NWCC and it is hoped that this work will be completed in the Autumn/Winter 2024.

- Macmillan offer information in different formats and these can be readily accessed by staff for their patients for e.g. easy read, braille, audio and translations.
- Macmillan offer free learning resources, online courses, and professional development tools through learn zone which are utilised by staff and are easily accessible.
- A Consultant is working with the medical team to drive forward a project focusing on improving communication on the Ward, this captures location, what is said, how it's said and understanding the need for preparation and communication between team members.

Lesley Finlay (Manager of Macmillan Wellbeing Campus):

- Cancer Focus have a dedicated family support service and links are currently being made in relation to this.
- Cancer Fund for Children offer range of supports to those up to the age of 24 years.
- Healing Hearts (Foyle Hospice) offer pre and post bereavement support to children & young people
- C.L.I.M.B programme was offered pre COVID and is currently being explored (subject to available staff capacity to be trained and deliver).
- Local libraries provide a selection of books for children- List available through MSC/MISS & plans to purchase copies through E&G to provide to families
- Cancer Hair Care programme currently being piloted within the HWB Campus and it is hoped this may include provision of dolls and story to support children understand hair loss due to treatment. (This is available through CHC regardless of continuation of programme & we have a small no of volunteers knitting them at MSC)
- We have access to a youth support worker, employed by cancer fund for children – Youth Support Worker for Adolescent and Young Adults – post holder commenced late May 2024
- Roisin Herron TYA CNS p/time for children & yp diagnosed with cancer living in WHSCT area – new monthly support group staring this month at Macmillan Centre
- Complementary therapy provided by Action Cancer for children & yp aged 5+ - Macmillan Centre & Belfast
- Counselling for children & yp aged 5+ - Macmillan Centre & Belfast
- SWELL offers play therapy and equine therapy for children in Fermanagh area
- Action Cancer recently offered 2 x 1 hr sessions on talking to your children about cancer
- UU have developed an eLearning resource for health & social care professionals supporting end of life conversations with adults who have caregiving responsibilities for children under 18. Approx 40 cancer services staff & community & voluntary sector colleagues attended ½ day classroom-based training May 23 & info on the eLearning resource has been circulated to colleagues

3. **Rural cancer patients continue to feel isolated and struggle to access services. How can patients from rural communities be better connected and supported throughout their cancer journey? Specifically in relation to public transport and community transport.** *(Mark Robinson, Service User, SWELL)*

Judith Andrews (Department for Infrastructure – Director of Public Transport Operations):

The Department for Infrastructure (DFI) subsidises Translink for the provision of the public transport network. Ulster bus provides the majority of the rural network, as well as inter-urban services and rural and smaller town services and it is clear that improved public transport helps connectivity across all of the North.

DfI also provides grant funding to 11 Community transport organisations to support the delivery of rural Dial-a-Lift (DAL) Scheme transport services across Northern Ireland. Dial-a-Lift (DAL) is a door-to-door service for those who live in rural areas and who are rurally or socially isolated due to lack of transport. Easilink Community Transport and Fermanagh Community Transport deliver the DAL scheme in the western region. The Scheme improves access to goods and services, keeping people connected to their local communities and often is the only travel option for those who are rurally isolated.

Work is underway on a new Transport Strategy, which includes the development of new Local Development Plans – for the North West and Fermanagh and Omagh, which is focusing on improved connectivity and accessibility to the transport network. This will take account of the emerging arrangements for delivering health services across Northern Ireland.

DfI are working in collaboration with the Department of Health, DAERA and Department for Education on the delivery of transport services, including services in rural areas.

Bridget Tourish (WHSCT - Service Manager Oncology and Haematology):

Transport that is currently available includes:

- Northern Irish Cancer Care
- Care for Cancer
- Palliative Transport Service
- Cancer Focus (covers only the Mid-Ulster)
- Macmillan benefits service/Macmillan Information and Support service can assist with support to access benefits and grants to go towards transport/accommodation and advise about reclaiming travel expenses

Richard Spratt (Chief Executive – Cancer Focus):

Cancer Focus NI having undertaken an extensive scoping exercise has identified gaps in cancer support provision in the peripheral, rural communities around Northern Ireland. This has influenced its organisational strategy to develop new therapeutic centres around the country, the first of which will be located in Co. Fermanagh where patients have particular challenges in accessing both support services and cancer treatments. Specifically, regarding transport Cancer Focus NI has partnered with a small local charity, Palliative Transport Service, to build its capacity and scope and will be expanding a patient driving service for patients to access treatments at either Belfast City Hospital, Altnagelvin or other locations. This is an extension of Cancer Focus NI patient driving service now operating in all trust areas in NI. The centre will also provide a cluster of nurse-led information and support services for the people of the greater Fermanagh and Tyrone areas based in Enniskillen. The

facility will act as a model and a pilot for other centres in the years ahead. It is vital that the critical mass of cancer support services, both from a statutory perspective and including the community and voluntary sector provision is decentralised so as not to disadvantage rural patients in the future. It is vital there is collective will and advocacy to improve the status quo.

Craig Donnachie (Head of Cancer Projects, Department of Health)

We recognise the challenges that many patients can face when accessing health and social care services. The way in which cancer services is delivered continues to evolve. New procedures and techniques, often requiring specialist equipment and expert supervision necessitate that some elements of care can only be delivered from regional centres. However, where care can be delivered close to home, it should be. Ambulatory care services which provide care close to the patient's home are key and this is recognised in the Cancer Strategy.

Support is available for those who may face difficulties in travelling for appointments. Patients should be made aware of this support when they are given their appointment. Consideration of the distance travelled, and ability of patients to travel should also be taken into consideration in terms of the appointment times allocated to these patients – where possible, a later appointment time should be offered to patients who are travelling longer distances. Community transport, and volunteer driver services may also be available to patients.

The Department of Health is also engaging with the Department for Infrastructure to look at how public, and community transport can support those patients who are travelling for appointments.

4. **Patients with additional conditions to their cancer diagnosis feel like they can fall through cracks in the care pathway and have no one owning their overall care. How can you ensure a more holistic and joined up service?** *(Claire Quinn, Service User, DWW)*

Helen McCormick (WHSCT Clinical Nurse Specialist):

Each patient will have an identified CNS who completes a HNA and discusses the outcome with the patients to identify a personal support plan. The CNS then with the consent of the patients refers them to other support services, the Trust has appointed a Macmillan Personalised Care Facilitator to improve HNA completions.

An example of how we respond to HNA would include the:

Menopause and fertility support:

Funding was utilised from cancer Endowment & Gift funds for menopause workshops in Derry/Londonderry, Omagh and Enniskillen Autumn/Winter 23/24 in partnership with Action Cancer, SWELL & Care for Cancer with over 100 attendees.

Anticipated further funding could be requested for these as required e.g. 1 -2 per year.

Bridget Tourish (WHSCT - Service Manager Oncology and Haematology):

All patients are now automatically offered a referral to a benefits advisor when they are diagnosed with cancer. The benefits advice team has expanded, new Macmillan benefits advisor in post since summer, more opportunity for face-to-face appointments. Staff training will be rolled out re signposting or earlier identification for need to refer to finance services scheduled for Friday 28th June. - Liz Kennedy, Macmillan Welfare Benefits Co-ordinator will provide a brief overview of the

Macmillan Welfare Benefits Service including information on how to refer, eligibility for referral, how the Welfare Benefits Service can support people with cancer and their carers and updated information on recent changes to Macmillan grants.

The team is exploring potential for including finance as part of the health and wellbeing events. Open access to the MISS and MSC at any stage of the cancer trajectory allows for patients to get supported with financial concerns/worries and onward signposting where appropriate.

David Curtin (Macmillan Cancer Prehabilitation Project Manager):

We are testing a new model of holistic service delivery before treatment, called prehabilitation, or prehab. Prehab is seen as an essential opportunity to empower patients to partake in physical activity, improve their nutrition and to prioritise their psychological and emotional well-being in the lead up to treatment. So, before treatment even starts patients are screened and signposted to the right support and services close to home. Prehab is linked to Action 17 of the NI Cancer strategy and early results have demonstrated that prehabed patients are both physically fitter and more mentally ready starting their treatment. This positively impacts quality of life, alongside a cost-benefit in there being less reliance on secondary care services leading up to and during treatment. We hope to continue to roll out the prehab programme to more tumour sites in the months ahead.

Shane Breen (WHSCT Assistance Director Integrated Care Systems):

The DoH are working to introduce the new Integrated Care Systems model across NI HSC following a test in Southern Area from June 23. It is a new framework for how we plan health and care services in Northern Ireland. It is a single, joined-up system, based on the different parts of health and social care, and others who have a role in the wellbeing of the population of Northern Ireland, coming together to understand what it is that is needed, and how we can best deliver that with the resources we have.

The local body established will be called an Area Integrated Partnership Board and we expect the Western AIPB to be stood up this summer.

The principles of prevention, early intervention, signposting and prehabilitation mentioned by Helen and Bridget are in line with the principles of the new model.

5. **Patients and carers spend a long time in hospital due to waiting times. How can you reduce waiting times? Or how can you improve this experience for patients and utilise the waiting time, so they have opportunities to access information and support?** *(Caroline Murphy, Service User, DWW)*

Caoimhe Lavery (WHSCT Admin Manager, Cancer Services, NWCC):

The service works to run clinics as efficiently and effectively as possible. Dedicated clinic templates are in place for each Dr to allow appropriate clinic slots to provide patient and clinician with appropriate time needed to see, assess and review patient needs effectively. These templates are reviewed on a regular basis to ensure that they continue to meet patient need.

The booking team work closely with the medial team delivering the clinics to ensure regular monitoring of clinics in terms of capacity and ensuring that patients are seen as timely as possible.

Unfortunately, we do have to acknowledge things can happen that will interfere with clinic times e.g. patient coming unwell at clinic resulting in clinic running over, however we do our best to manage these situations.

Timing of appointments:

When booking patient appointments, the booking team will consider a number of factors including regimen and treatment duration and geographical location of the patient. Where possible, patients having to travel from further away will be given a later appointment and also where a patient has requested a specific appointment time due to childcare or other personal commitments, this is recorded on file and every effort is made to accommodate this.

In addition, where a patient has another appointment on the same day within another service area e.g. radiology, every effort is made to align appointments as best as possible to avoid patient having to spend longer than necessary at the hospital. At present, the service will only be aware of this if patient advises that they have an issue with timing of another appointment as we cannot see every appointment on our system, this may improve with the introduction of Encompass.

Some of our patients receive combined radiotherapy and chemotherapy and the two teams work closely together to ensure a joined-up booking process for these patients and this is achieved via a weekly huddle.

Unfortunately, the timing of appointments can be restricted due to regimen and chair/pharmacy time and also restricted for patients coming by ambulance (as we have to work with the availability from NIAS) and those patients requiring interpreters.

2 step model:

We are also working on implementation of an improved model of scheduling for treatment delivery, to assist with implementing this we have completed a test of change model to 2 tumour sites Breast and GI where a '2 step' model was tested. This means that the patient has their pre SACT (chemotherapy/treatment) bloods taken in advance and when the results are available the patient is assessed via the telephone by the doctor who assesses their fitness for treatment. Following assessment, the patient's treatment is prescribed in preparation for the patient attending the Sperrin Suite for treatment delivery.

This reduces the amount of time spent in the hospital waiting for treatment delivery, by having a specific time to attend rather than attending for full day. The success of this test of change now allows to consider further roll out to other tumour sites in the future, as this will require significant change management processes, we need to consider the order we will take forward etc.

This model of virtual assessment will not suit all patients due to clinical conditions this needs considered as part of the implementation.

Lesley Mitchell (WHSCT Assistant Director – Nursing, Cancer & Diagnostics):

We have been working on improving our hospital environment within NWCC and have recently placed new Art displays in NWCC which service users and our staff helped develop. We also now have more chairs in waiting areas, the coffee shop has reopened, and we have improved access to car parking. In addition, the Trust are currently undertaking the Macmillan Quality Environment Mark (MQEM) process to assess the environment and identify opportunities for improvement.

Other areas of work include the following:

- Macmillan Health and Wellbeing manager are working with Trust partners to improve signage including the sign outside NWCC directing to the Macmillan Health and Well-being campus
- Increased visibility of Macmillan Information and Support staff/volunteers at NWCC for people to access information and support
- Colleagues are currently working on gathering information on local supports services etc. for rotational display on the TV screens within NWCC

6. **How can you equip patients with access to their own health records and information?** *(Aileen Laird, Service User, Care for Cancer)*

Caoimhe Lavery (WHSCT Admin Manager, Cancer Services, NWCC):

<u>Encompass</u>

A new regional IT system is being rolled out across NI. This system is currently 'live' in South Eastern Trust and Belfast Trust. Work is well underway in relation to WHSCT roll-out planned for Easter 25. This new system will mean that patients will have access to their own health related information to include clinic letters, blood results etc.

7. **Through the workshops we attended, we have heard of many issues relating to palliative care. For example, different mindsets between oncologists, palliative staff, patients, and families on what palliative is. As well as other issues such as accessing specialist drugs in Fermanagh during out of hours.**

   Will palliative care services be improved? And what work is underway or planned to effectively support those who are at palliative and end of life stages, including their family members? *(Genevieve Irwin, SWELL)*

Damien McMullan (WHSCT Consultant in Palliative Medicine)

The first thing I would say is that 'what palliative care is' will be different for each patient and family– it's up to us to get to know each person and find out what 'good palliative care' would look like for them and support them accordingly.

The second thing I would say is that it's ok to have Different Mindsets. Each member of the multidisciplinary team brings their own perspective and expertise. No one person has all the answers – especially when there is uncertainty. But together these different perspectives and mindsets are powerful and bring a richness to assessment and support of the patient and family. We learn and grow as a team by embracing this.

Thirdly – I would just like to emphasise that we have very good working relationships with our oncology and haematology colleagues – we're on the same corridor – I can knock on Una's door or Bridget's door and often do or pick their brains in the lift . The North West Cancer Centre grew out of a strong ethos of collaboration and that remains the case on the ground. We share a desire to do the best we can for patients and families. Good communication and respect are key – especially when it seems that cancer treatments are potentially becoming futile and more burdensome. Having honest conversations at the pace of the patient and family, is key to helping them plan ahead and get the right care at the right time.

I'll outline challenges we face; strengths we have; work underway; the work planned; and some things we need.

To improve, we have to be aware of the challenges we all face together and the reality in which we live:

- Workforce challenges and gaps throughout the healthcare system
- including significant gaps in the palliative medicine consultant workforce
- difficulty recruiting consultants
- This puts pressures on workforce, puts our services at risk, but also makes it difficult to take the step back needed to think strategically.
- Demographic changes:
- The need for palliative care is increasingly rapidly and patient's needs are becoming more complex.

Our population is growing, ageing, becoming more frail, more people are living with multiple serious health conditions

- Early identification of patients with palliative care needs
- Need for better integration and coordination within the health system
- Funding challenges – the non-recurring funding of posts/ services where we don't know if posts will continue to be funded into the next year – places services in jeopardy e.g. our 7-day community specialist palliative care nursing service (in the Northern Part of the WHSCT), carer support, counselling services and medical support for community hospice team. This makes it harder to recruit and retain staff and develop services.
- Lack of care packages and carers meaning patients are not able to get home for end-of-life care when that is their wish
- Gaps in carer support and Out of hours services
- Legislative gaps – no electronic prescribing; palliative care is now a right in England (not the case here in Northern Ireland)
- Lack of awareness of the wonderful community organisations and support available.
- We have no current palliative care strategy

What strengths to we have:

- Committed and caring workforce – we want to do our best for patients and families and ethos of going the extra mile
- Strong MDT working
- Ethos of Collaboration – WHSCT/ Foyle Hospice/ NWCC/ community organisations
- A variety of specialist palliative care services across different settings – hospice/ palliative care ward, hospital palliative care teams in AAH, & SWAH, Community teams, outpatient clinic and Day Hospice services
- Excellent district nursing, GPs and primary care colleagues
- Fantastic community groups and organisations as exemplified by today's meeting and the work of your collective in recent years
- Fantastic volunteers.
- The lived experiences you bring which are so powerful in making the case to improve and change for the better.

- PCiP – palliative care in partnership programme for Northern Ireland which helps set priorities which we'll mention shortly
- Public health approach to raising awareness of palliative care and the need to have conversations about the future earlier – our colleagues in the Compassionate communities' team have been leading the way with this.
- The 10-year cancer strategy for NI – this needs to be implemented which will require resources.

What is underway?

- Recognition that we have to think in a different way to meet the growing challenges and workforce realities such as not being able to recruit consultants.
- Recognising the workforce gaps and lack of consultants – Professor Watson palliative medicine consultant has led on the development of an integrated Fellowship programme to grow our own senior doctors and consultants who will work across palliative care, care of elderly and frailty settings. 3 excellent fellows have been in post now for over 6 months. Similarly, we are building our own model where our staff will increasingly work across settings.
- The Co-creating hope conference 2 weeks ago – again led by Professor Watson – looked at how we can better meet the needs of our ageing and increasingly frail population by working in a different way. Consultants from the Integrated Care Team in Hull presented their excellent work around a more community facing model of service delivery. Professor Watson has set up a Co-creating Hope Working Group to tap the great energy that there was around this and see how we can take this forward.
- Foyle Hospice is now providing specialist palliative care across the whole Western Trust Area and the community specialist palliative care team in Omagh and Fermanagh areas is now. This improves integration and hopefully will reduce inequality.
- The regional PCiP work priorities which include early identification and timely intervention for palliative care patients; improved coordination of palliative care services; development of a regional PEOLC education and training framework and a public health approach via the compassionate communities' model mentioned
- 7-day access to specialist palliative medicine telephone advice up to midnight for professionals.
- Training of our first specialist palliative care Advanced Nurse Practitioner
- Undergraduate training – Magee Medical students have been getting a week-long hospice/ palliative care placement.

What is planned? This hinges on having adequate resources and workforce.

- Improving integration of cancer services and palliative care services, we are working towards NWCC becoming a Designated Centre of Integrated Oncology and Palliative Care by ESMO – the European Society for Medical Oncology.
- Supporting the training of the integrated fellows and hopefully recruitment of additional fellows in time and with resourcing
- Recruiting medical staff to work across both Foyle Hospice & Altnagelvin & community settings. Trying to grow our own senior doctors – recruiting more middle grade doctors who can develop and grow into future leaders.

- Our first Advanced Nurse Practitioner being in post and hopefully training of additional ANPs.
- Provided the resources and staff are in place – extension of 7-day community specialist palliative care across the trust – currently in the northern part of the trust only.
- Provided resources are in place – a day hospice service for the southern part of the trust – like that based at Foyle Hospice. This will require significant planning and resources.
- Development of UG training – QUB final year medical students will be getting a week-long hospice and palliative care placement from this August onwards in addition to the Magee students.

What we need?

- We will need some additional resource to stabilise the workforce and ensure that it can meet and adapt to the exploding needs of our people in the coming years. We can achieve a lot if we integrate our services across, hospital, hospice and community – so that people get the care they need in the right setting and can stay and be supported at home when that is their wish. The Co-creating hope conference and working group presents a way forward.
- The Co-creating hope conference also highlighted the need for a directory of services of all the fantastic community groups and organisations that are out there to support patients, families and carers – to improve awareness, sign posting and access.
- Improved access to carers in the community.
- Non-recurring funding for current services highlighted above needs to be made recurrent.
- Bereavement services – address gaps and meet needs for adults and children.
- We need a Palliative care strategy – we are currently the only nation in the UK without such a strategy. Our most recent strategy elapsed nearly 10 years ago.
- We await implementation of the Advance Care Planning Policy to be implemented.
- Legislative change e.g. We need a health and care social care bill like in England which recognises palliative care as a statutory right for commissioners to provide.
- Legislation to support electronic prescribing
- Most importantly we need high level Leadership and courage to think differently and develop a more integrated and coordinated health system that is built around patient and family needs, that is less reactionary; more proactive and more community facing. This will require closer collaboration between the community, the health service and local leaders.
- Hopefully we can take forward the great energy and collaborative ethos and hope from today. Thank you.

Marie Donnelly (WHSCT Palliative Care Nurse):

The Just In Case Box Service

This has been an example of a variety of Health Care Professionals working together with patient representatives to provide a small improvement that can make a difference for patients and their families towards the end of life.

The Just In Case Box service is the coordination and standardisation of providing anticipatory medicines into a person's house in advance of their need "Just in Case" they might develop pain, nausea and shortness of breath amongst other symptoms.

Where the use of anticipatory medicines is not new in the provision of end-of-life care, in the past they may have been introduced at a time of a crisis, resulting in a rush to try and get these medicines prescribed, often out of hours, causing distress for the person and families, often having to travel long distances to get these medicines or even sometimes resulting in an unwanted admission to hospital. By having these medicines introduced in "In-Hours" to help prepare for "Out-Of-Hours" and earlier rather than later, it is hoped these difficult circumstances can be minimised by having the right medicines for the right patient at the right time in advance of their need "Just in Case".

One of the first elements in this process is staff recognising when it might be appropriate to introduce the Just in Case Box. This is followed by honest but sensitive conversations with the person and their families in what the Just In Case Box is, what it aims to do, why it might be helpful at this time and how the person and their families can seek help should troublesome symptoms occur, especially out of hours. This is supported with a Patient Information Leaflet to clearly explain these steps and can facilitate further conversations in what really matters to the person at this time. We have also created a Prescribing Booklet to help support the prescriber to access regional guidance to select the right medicines at the right time for that individual person.

This service was piloted through a Quality Improvement initiative and has now been rolled out across all primary care in the WHSCT since December 2023. It is early days, but we have used 2,000 Just in Case Box Prescribing Booklets and Patient Information Leaflets during this time. We do not have reoccurring funding for further resources, but this is something that we are exploring. We have been asked to present this service to colleagues in other Trusts and the Department of Health in the hope that it may be rolled out regionally.

Patients and families tell us that they find it reassuring to know that the Just In Case Box is in place.

Anne Friel (WHSCT Head of Pharmacy and Medicines Management)

Increased access to medicines used in palliative care in the West

The Western Trust set up a meeting with pharmacy representatives from Department of Health, SPPG, a range of Trust professionals working in palliative care Trust and the regional Consultant Palliative Care Pharmacist to look at a range of solutions to help access medicines needed in palliative care especially out-of-hours and outside hospital.

To support this work going forward, the Trust has just recruited two part-time palliative care pharmacists based in Omagh and Altnagelvin Hospitals - to join palliative care team who as part of their role will continue to review access to medicines.

We realise there is no one thing that will increase access to these medicines and we continue to work on a number of projects in prescribing, improving communication and dispensing medicines for palliative use.

Widening the number of people who can prescribe palliative care medicines in the community

- A Foyle Hospice Pathfinder Task & Finish group aims to improve access to prescription only medicines for individuals with palliative care needs in the community. It will provide HS21 prescriptions to Hospice medical and non-medical prescribers. These professionals can then prescribe medicines for patients when they visit them at home as opposed to asking the GP to prescribe, resulting in patients getting medicines faster. The Pathfinder is due to go live by July 2024 and will run for 4-6 months to give sufficient data to support regional roll out.

This work is in collaboration with the regional new models of prescribing programme and the Medicines Optimisation and Innovation Centre.

- We wrote Guidance to support the prescribing of palliative medication by district nurse non-medical prescribers. A number of District Nurses are now actively prescribing with ore in training.

Improving Communication and access

- Just In Case Boxes – Marie Donnelly is responding re this
- Out-of- hours and in- hours pathways have been developed to increase accessibility to both advice for healthcare professionals on palliative medicines, and prescriptions if required. This includes a direct line to the out of hours GP for District Nurses/ Marie Curie nurse plus an on ongoing pilot in some nursing homes to assess appropriate use of the service. It also includes advising on how to contact Specialist Palliative Care advice in and out of hours. The Trust has access to a Palliative Care Consultant Advice line from 17:00-24:00 Monday to Friday and from 09:00-24:00 weekends and Bank Holidays.

- There is on-call rota cover to support patients with palliative care needs if there is a gap in the Western Urgent Care rota out-of-hours.

Dispensing medicines

- The Trust aims to supply palliative medicines when patients are discharged in anticipation of the need to use them in the future.
- A community pharmacy palliative care on-call service is in place at weekends and on bank holidays. This is accessible through Western Urgent Care. The question focused on access to medicines in Fermanagh out –of-hours. A 2023 review of the Community Pharmacy On-call service highlighted that although patients in Fermanagh were the highest users of this service (given lack of extended community pharmacy opening), only 9 out of the 79 call outs were out of hours Monday to Friday over a 38-month period. The Medicines for End-of-Life Care for Patients in Primary Care working group felt this was a positive reflection on all the other efforts to improve access to Palliative Medicines including the improvements in anticipatory prescribing.

Work just starting

- Trying to make things simpler including explaining how to access palliative care medicines.
- Plan to develop pathway with GPs and Community Pharmacists to streamline access and avoid families visiting multiple pharmacies to have medication dispensed.
- Scoping of potential application of an electronic direction to administer for syringe-driver charts (regional work).

Electronic Prescribing in primary care

Having electronic prescribing in place in primary care in Northern Ireland would greatly streamline access to medicines, with prescriptions being sent from GPs to community pharmacists electronically. It is hoped that this will be rolled out in the next few years.

8. **At our Gathering Session for health professionals working in cancer care last year, we heard of the pressures the cancer workforce face daily. How can you look after and retain the current**

cancer workforce? And how can you make it an attractive job / career students when applying to health courses? *(Marietta Connor, WHSCT Breast Imaging Service Manager)*

Heather Monteverde, Professional Advisor, Department of Health:

Whilst more people are being diagnosed with cancer more people are surviving cancer. This means that the numbers of people needing care is rising year on year. The cancer strategy recognises the fact that in order to care for and support increasing numbers of people living with cancer we will need to do things differently. Going forward we need to develop new roles such as advanced practice nurses and allied health professionals to undertake some roles currently done by doctors. This is current practice in most other places across the world. Not only will it enable new ways of providing health care it will provide opportunities for nurses and allied health professionals to develop their careers and remain working clinically.

Deborah Hunter (Macmillan Personalised Care Facilitator)

I am going to describe how in NWCC we have been specific in our response to staff wellbeing so to look after and retain our workforce and also to attract staff from all around the world who want to work in NWCC because of its reputation as a centre of excellence.

- Recently developed a Mission statement "Working together to provide our patients with excellent and compassionate cancer care" also with logo development in the pipeline where we will utilise a SU involvement approach in the design.
- NWCC "staff health and wellbeing steering group" is now operational - We formalised our group to ensure representation from across all areas within NWCC.
- Facilitated a – you said we did – staff HWB survey & using the findings from engaging with staff we developed a comprehensive action plan and road map developed focusing on staff wellbeing.
- Last year we organised 55 events on wide range of health promoting and team bonding activities with 332 staff attending various programmes and workshops including Yoga, Pilates, Aromatherapy, Bach remedies, Christmas wreath making workshops, staff health checks. We are currently working on our overview of activities for 24-25.
- We have utilised internal and external comms to raise the profile of NWCC through good news stories such as CE visits, research and innovation, public donations and arts project coverage
- We have improved internal communications to share NWCC HWB wellbeing activities via team updates, emails, Staff WB notice boards and tea rooms. We also promote the wider TW work and the link with the We are With you Staff WB Programme e.g. corporate rates, swim scheme.
- We produce 3 editions per year of NWCC Buzz Newsletter to share learning and celebrate successes around the NWCC – compliments, awards, celebrations, staff out and about. It creates a feel-good buzz and staff get to know each other and celebrate successes together
- PD - We encourage staff to develop their skills & expertise through courses, or attendance at conferences.
- We recognise and celebrate our staff through nominations various Staff Awards
- We have developed a clear process for staff accessing 1:1 personalised coaching sessions
- If needed, staff can receive support from specific - Critical Incident Stress Management sessions following a traumatic event

- Spiritual support for staff is available through our Non-denominational Chaplain Peter Fleming
- Psychological support is available to staff delivered by our Health Psychology Team 028 7161 1407. If a staff member needs to be seen urgently OH department aim to book in ASAP via Management or a self-referral. Emergencies should go via their GP.
- We support those colleagues who are carers via the WHSCT Carers Framework.
- I'm sure you agree we have a beautiful environment in NWCC – we have used the Arts to further enhance wellbeing and atmosphere in our centre by installing 3 different art pieces involving staff in developing art to support our environment
- We have engaged in the international recruitment drive and welcome colleagues from Egypt, Africa, India, Singapore, and Philippines - our practice educators have developed a specific programme to welcome and settle these colleagues into their new role. Our Equality and diversity group, chaired by Aisling Haughey ensures our ongoing work and developments are considering the equality and diversity implications and are fair to all.
- Overall, our approach to create a positive working environment, with a culture of care and support for our staff ensure staff where they feel valued and feel NWCC is a great place to work.

Lesley Mitchell (WHSCT Assistant Director – Nursing, Cancer & Diagnostics)

Regional cancer nursing framework:

Cancer services nursing staff attend local careers event and the annual sessions to provide information on cancer nursing as a career.

Work experience and volunteering opportunities are encouraged at the NWCC.

9. **Cancer care does not exist exclusively in hospitals. Cancer patients don't live in hospitals. How can you ensure more clinical cancer care will be provided closer to home, within the home or in a more localised community setting?** *(Martina Morris, Care for Cancer)*

Una Cardin (*WHSCT - Assistant Director Operations & Service Improvement Cancer and Diagnostics*):

We will always have aspects of care that require hospital delivery, currently chemotherapy and radiotherapy are delivered at the NWCC. As part of the Cancer Strategy implementation, there is a recommendation to review the model of delivery of Systemic Anti-Cancer Treatments including the delivery of near/close to home SACT. WHCST have commenced work over the last 12 months moving the delivery of some supportive therapies to community services and we are planning to expand further (this will be dependant of the drug treatment and available resources). Due to its complex nature and associated on-site equipment, Radiotherapy cannot move.

Additionally, a medication dispensing machine has been purchased for the collection of take home medications (oral) this will provide an opportunity for patients to collect their medications at a time that suits them and in turn will reduce patient waiting time. This work will be taken forward as a project plan.

Jean Frizzell (Cancer Programme Director, SPPG):

The strategic direction and drivers for cancer care closer to home are clear within the 10 Year Cancer Strategy and its actions including:

Action 17: Develop and implement prehabilitation and rehabilitation services on a regional basis for all those who will benefit

Action 19: Implement Enhanced Recovery After Surgery Programmes on regional basis following major cancer surgery

Action 23: Develop near to home phlebotomy services

Action 24: Review model of delivery for systemic anti-cancer treatment services including delivery closer to home

Action 28: Develop ambulatory care haematology units in each of the Trusts and establish near to home treatment services for suitable patients.

Action 30: Develop appropriate pathways and accessible services for older people with cancer, adults with learning disabilities, communication needs and chronic mental health problems, rare cancers and metastatic cancers.

There is a number of other actions in the strategy that include development of pathways around person centred care, holistic needs assessment and the palliative care Actions (47-51) that aim to support cancer patients more effectively closer to home. However, it is estimated that the Cancer Strategy will require an additional investment of £145m over a 10-year period to take forward and fully implement the Strategy Actions. In the first three years since the Cancer Strategy launch in 2022, approximately £10.6m has been made available to take forward actions and the initial focus in the first 2-3 years has been to stabilise cancer provision and protect vulnerable cancer services, including funding of regional oncology and haematology stabilisation plans. A dispersed model closer to home whilst the right direction and model of care is dependent upon stable staff structures within Trusts, better skill mix teams and will require significant further investment. The scale and pace of available funding will influence the speed at which these actions and service proposals for care closer to home can be taken forward.

10. **We have heard that cancer patients do not know what services and support is available in their area and have come across information by chance. This has negatively impacted their mental health by not accessing the right support at the right time, for example financial information. How can you improve signposting patients and can a directory for all cancer services be developed?** *(Roley McIntyre, Counsellor, SWELL)*

Craig Donnachie (Head of Cancer Projects, Department of Health):

At the launch of the Cancer Strategy, we committed to ensuring that all people living with cancer have access to a full range of information and support services.

Action 41 "All people with a cancer diagnosis will be referred to a Cancer Information and Support Service at diagnosis."

The Department of Health has developed a directory of cancer support services. This is hosted on the Family Support NI website, which also contains a range of other support services which are applicable to cancer patients and their families, including financial support, and carers. The directory, which has been developed in conjunction with cancer charities is live, but will officially be launched this, Autumn.

This directory is recurrently funded, and there is a permanent team responsible for maintaining the information and promoting services.

There are also Macmillan Information and Support Managers / Workers in each Trust with a breadth of knowledge and expertise and signpost people living with cancer appropriately.

Lesley Mitchell (WHSCT Assistant Director – Nursing, Cancer & Diagnostics):

- Each patient will have an identified CNS who completes a HNA and discusses the outcome with the patients to identify a personal support plan. The CNS then with the consent of the patients refers them to other support services, the Trust has appointed a Macmillan Personalised Care Facilitator to improve HNA completions.
- Earlier signposting to Macmillan Information & Support so the CNS will refer at time of diagnosis allowing for earlier intervention and support
- We've used our social media platform to raise awareness of our Macmillan Wellbeing and Support Campus with signposting information for better aftercare

- The Health and Wellbeing campus manager has been working with Community and Voluntary sector to expand services and the awareness of what is available to people both at the centre and closer to home.
- Health and Wellbeing events are being provided post treatment for the continued delivery of information and support, these are available for all tumour sites and held on an annual basis.
- Within the core information, patients will receive the booklet which highlights all the supportive services that they can access, and it is divided into the local areas.
- There is currently a review of the core information pack being undertaken regionally to determine what information is required and at what point in the pathway.
- We have a carer's service in trust / support team. They collect names on a database once registered and email all upcoming events etc. for carers to those who ae registered.
- Carers have access to complimentary therapies and counselling as part of our charitable groups. We have a TYA CNS funded by Teenage Cancer Trust to support younger population of patients diagnosed with cancer
- Macmillan information and support staff, during an interaction will identify anyone with a caring responsibility and will offer verbal and written information to support their individual needs.

- Macmillan Information and Support Service appointments available for carers to provide a listening ear and signposting to carer's service along with website.

11. **Carers continue to feel invisible, neglected and out of their depth with the pressure to look after their loved ones from home. How can you better support carers in their complex caring needs?** *(Geraldine Duddy, Service User, DWW)*

Bridget Tourish (WHSCT - Service Manager Oncology and Haematology**)**
We have a carer's service in trust. They collect names on a database once registered you will be emailed all upcoming events etc. for carers. Those who ae registered Carers have access to complimentary therapies and counselling as part of our charitable groups. We have a TYA CNS funded by Teenage Cancer Trust to support younger population of patients diagnosed with cancer Macmillan information and support staff, during an interaction will identify anyone with a caring responsibility and will offer verbal and written information to support their individual needs. Macmillan Information and Support Service appointments available for carers to provide a listening ear and signposting to carer's service along with website.

12. **Research has shown that someone who is diagnosed via screening appointments has a better outcome. Northern Ireland is behind the rest of the UK in cancer screening - how can you ensure capacity to extend our screening range as per the cancer strategy, particularly in relation to Bowel and Lung?** *(Aoife Mullan, Service User, DWW)*

Craig Donnachie (Head of Cancer Projects, Department of Health):

Cancer is a particularly cruel and indiscriminate disease, and despite the progress that has been made in recent years it tragically remains the leading cause of death in Northern Ireland. That is why there is, and must remain, an absolute focus and determination to deliver improved cancer outcomes for patients.

Evidence shows that earlier diagnosis is key to improving outcomes for patients. Unfortunately, those who are presenting with symptoms of cancer are often waiting too long for a diagnosis. This is symptomatic of the wider pressures that we are facing in terms of our diagnostic capacity.

The Department of Health has invested in Rapid Diagnosis Centres (RDCs). These are clinics that allow GPs to refer people with vague but worrying symptoms, who would not otherwise present as a red flag cancer pathway referral, to receive an earlier diagnosis of cancer or in some cases a diagnosis of a serious condition which is not cancer.

RDCs are now available regionally and GPs across Northern Ireland can refer their patients into these clinics. Work is also underway to look at new symptomatic cancer diagnostic pathways that would benefit from the RDC model.

Work to meet the commitments outlined in the NI Cancer Strategy (2022-32) to lower the age range and/or further reduce the sensitivity level in bowel screening (Action 7) and to introduce screening for lung cancer (under Action 10) are ongoing but must be viewed within the context of wider financial and capacity challenges within the supporting services. It is important to note that screening programmes are a pathway and not just a 'test'. As such, where a Screening Programme makes changes to its eligibility, it is important that the associated infrastructure, to include diagnostic capacity and any treatments that may be required, are aligned.

Ruth Flemming (Service Development Manager, Action Cancer):

Action Cancer is the only cancer charity in the UK and Ireland to provide free breast screening service for women who by virtue of age fall outside the NI Breast Screening Programme. Currently screening circa 8,000 women per annum aged 40 t0 49 and 70 plus Action Cancer detected in 2023/2024 circa 9 early-stage breast cancers for every 1,000 women screened. In addition, since January 2023 Action Cancer has also provided a free skin cancer detection service, detecting in 2023/2024 some 80 cancers. Both services along with health checks are available at the Action Cancer clinic in Belfast and also onboard the charity's iconic mobile screening clinic the "Big Bus" which specifically targets populations of highest deprivation across N. Ireland including a significant proportion within the WHSCT area. Both unique services are unique and not available elsewhere in Ireland and the UK.

As a charity we are fully committed to continuing with the provision of early breast cancer and skin cancer detection services and have already engaged with the Department of Health over the delivery of a Lung Cancer Screening service targeting highest risk people. In 2003 we initiated and facilitated the introduction of the Bowel Cancer screening test and have remained committed ever since to its development, expansion and accessibility.

13. **How will you support an ongoing programme of public awareness for Cancer Prevention and Early Detection?** *(Claire Quinn, Service User, DWW)*

Gary Maxwell (Health Development Policy, Department of Health):

Thank you for recognising this important issue. Awareness raising, prevention and early diagnosis/intervention is key to reducing the impact of cancer across Northern Ireland. We also need to recognise within this, the inequality that exists in this area, with incidence rates being around 21% higher in the most deprived areas versus the least deprived.

This inequality is a complex issue that requires a systematic response. In fact, evidence shows that only 20% of health outcomes are a result of the clinical services we receive, with the social determinants of health – the economic, social, and physical environment in which we live – being a much larger driver of health outcomes and inequalities. To help address this the Department of Health leads on the executive's public health framework, Making Life Better, which seeks to align and join up actions across the executive and the wider public, community and voluntary, and private sectors. We also work with the Department of Agriculture, Environment and Rural Affairs on some of the wider environmental risk factors that can impact on cancer.

The Department of Health also leads on a number of health improvement strategies that can help to address some key cancer risk factors, such as tobacco, UV radiation, alcohol, food and nutrition, physical activity, , etc. As appropriate these strategies seek to raise awareness of these issues, and their potential link to cancer.

We are also working to develop place-based approaches to improve health and address inequalities. These will seek to address the needs of individuals and communities in their local areas and take an asset-based approach to meet people where they live and support them by through interventions and signposting. Peers can play a key role in this, by sharing their lived experience and helping inform policy and practice, as well as sharing their stories with others,

The PHA continue to run the "Be Cancer Aware" programme, and where possible we will seek to develop and build on this as we move forward.

Finally, it is vitally important that we build prevention and early intervention into the pathway, and we keep a focus on this issue to make a real difference in the long term.

14. **How can you support people to live well beyond cancer?** *(Leanne Devlin, Service User, DWW)*

Jacque Warwick (Macmillan Consultant Nurse):

- Implementation of e-HNA across all sites will help to identify those patients needing support earlier, and signpost to appropriate services
- Macmillan off Volunteering services for community patients (buddy, household chores, company etc.)

- MISS can meet with patients on request to discuss range of opportunities that are available e.g.:
    - -Macmillan Buddying
    - - HIVE-befriending service
    - - Action Cancer- peer mentoring
    - - Range of other services and support provided by cancer charities and local C&V organisations.

- MISS can also support with onwards referrals where appropriate. However practical support and transport to social opportunities can be limited.
- Spiritual needs of the patient/carer can be supported through the NWCC chaplain and wider chaplaincy service.
- Offering H&WB events to all tumour sites would also be an important tool to provide information and onward support.

Consultant Nurse role (specific work)

- Prostate early signs of late effects
  Actions from this include patient information on hormone effects and how health care is a partnership and by small changes you can help.
- Adding a pre-education event pre-treatment to discuss common side effects from hormones and to alert staff for onward referral.
- Macmillan project on Relationships due to treatment complications just scoping exercise phase, aid to improve education awareness and timing of the information.

Phil Mahon (Chair, Derry Well Women):

Derry Well Women will work towards enhancing its existing services by:

A) Training facilitators of the Well Programme to expand delivery across a broader geography to cancer group partners and emerging groups

B) Recruiting and training a team of cancer counsellors for a dedicated cancer counselling service

C) Developing cancer support groups to other cancer sites

C) Retaining and expanding ancillary services e.g. nutrition and benefits clinics.

D) Retaining and expanding complementary therapy service to include a wider variety of treatments

E) Developing services to support specific target groups eg carers, young women living with cancer, menopausal women, women at end of life.

F) Developing resilience mental health programmes

G) Continuing to lead the Cancer Connected Communities engagement process.

H) Feeding into the current work DWW is doing to develop a NI Women's Health Strategy

DWW will need further support to achieve all the above and to increase capacity by:

1. Having a dedicated Cancer Services Coordinator and sessional support team to coordinate direct service delivery.
2. Continue to develop partnerships to ensure care is more integrated.

Ruth Flemming (Service Development Manager, Action Cancer):

Action Cancer has been providing support services for people with cancer for over 50 years and specifically in the current WHSCT area for the last 12 years. Our services are accessible by people diagnosed with cancer as well as family members, carers and children and young people, as we recognised the importance of supporting the whole family during the cancer journey. Our services include: Counselling bereavement Counselling; Complementary therapies; Pain and symptom control therapies such as Emmett therapy and Auricular Acupuncture; Life Coaching; and group support programmes such as Positive Living Programme.

We have recently developed a new Integrative Cancer Care Model with a focus on mental health; pain and symptom control and nutrition and physical activity. The model includes 3 tiers – tier one includes our 1:1 service as mentioned above. Tier 2 involves a wide range of group face to face and online events held via zoom which allows greater access to support from across NI in a timely manner. We have begun this tier 2 extension of our services and now provide online sessions on topics such as: Acupressure techniques; Strategies for managing surgical scars; Bach Flower Remedies; Strategies to aid sleep; Relaxation techniques; and Talking to children about a cancer diagnosis. Group face to face sessions include: self-care talks, menopause and bereavement talks.

Our Tier 3 services will involve developing a new range of web resources to address issues that were raised by cancer survivors and family members during a large NI wide survey carried out in 2023 in partnership with QUB and part funded by the Cancer Connected Communities project. One of the key findings in this survey was the limited access to cancer specific and tailored information and advice relating to nutrition. We will work with QUB and University of Ulster in developing evidence-based resources that will be accessible to all across NI on a wide range of topics.

We stay committed to continuing our provision of 1:1 and group services in the WHSCT area to support people impacted by cancer at all stages in the cancer journey and will continue to work closely with both statutory and charity partners in the delivery of these services.

15. **Are there any longer-term goals that haven't been mentioned today that you would like to highlight?**

Una Cardin, WHSCT - Assistant Director Operations & Service Improvement Cancer and Diagnostics:

- Explore within the next 5 years – Oncology & Haematology unscheduled care unit (like a minor injuries unit). This will mean that there will be a dedicated assessment unit for Oncology and Haematology to avoid patients having to go to A&E for assessment (where their clinical condition relates to their cancer diagnosis, there will always be occasions where a patient may need to attend A&E for assessment where their condition is of a general medical nature e.g.: respiratory infection.
- Continue to work with Department of Health and SPPG colleagues with regards to implementation of cancer strategy and continued increase and development of our cancer workforce.
- Wok to develop a dedicated website for patients/families/carers attending NWCC
- Development of a NWCC App
- Continued link with Community and Voluntary sector to expand access to services and transport options