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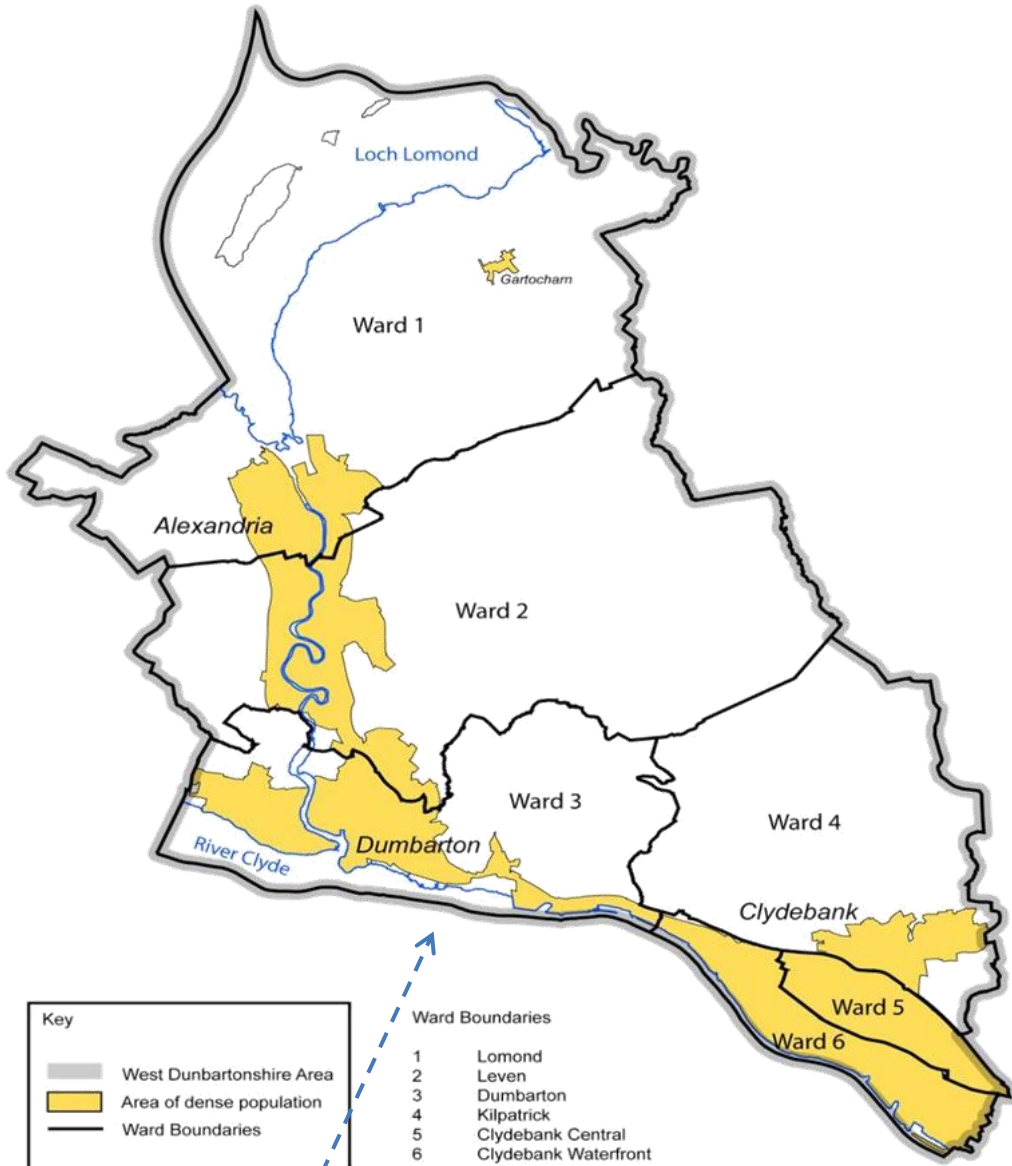
 **TRANSFORMING
YOUR
CANCER CARE**

West Dunbartonshire - Macmillan Transforming
Care after Treatment Project Evaluation

May 2018



West Dunbartonshire Multi Member Ward Map



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Executive Summary

There are many people in West Dunbartonshire dealing with the after effects of cancer and while we know through consultation some are confident about many aspects in managing their condition. They do, however have some misgivings about their knowledge of and access to additional support services.

The TCAT project was established in West Dunbartonshire to address these misgivings by providing access to community-based support to complement the medical support received and improve the quality of life for people that have undergone treatment for cancer.

The West Dunbartonshire project is one of 25 projects supported by Macmillan Cancer being delivered throughout the country. With a modest investment of £84,000 the project was established as a two-year action-based approach to the project that sought to:

1. review and improve the assessment of need processes;
2. review and improve the supply and availability of information;
3. establish a co-ordinated gateway approach to service provision and
4. maximise opportunities for work, learning and money and other specialist support.

Information gathered through the evaluation reinforces, to some extent, the issues and expectations gained from earlier consultation. Our desk-based review suggests that **good** progress has been made in bringing together key partners, developing the resources required to establish and embed a support service to meet the needs.

The evaluation found:

1. *Establish a co-ordinated gateway approach to service provision;*

There are important strengths and with appropriate partners involved, progress to establish a gateway to service provision has been made. However, there are areas for improvement including the need to ensure the correct blend of strategic partners is in place with a common agreed vision and with clear roles and responsibilities. As such, the strengths outweigh the weaknesses and **good** progress has been made towards the development of a co-ordinated approach to service provision.

2. *Review and improve assessment of need processes*

Progress towards the improvement of assessment and process was characterised by a number of strengths including the development and distribution of the HNA, the creation of an information toolkit and associated process documentation. While the strengths have had a positive impact there are some weaknesses. While these weaknesses have not had a substantial, negative impact, some work will be required to address them. As such **satisfactory progress** has been made towards the project aim of reviewing and improving assessment of needs process.

3. *Review and improve the supply and availability of information*

Stakeholders and analysis of project documentation identifies important strengths and progress has been made. However, the stakeholders identified the need for the development of web-based information. Although beyond the scope of the project, the lack of a regularly updated and maintained information base is cited as a weakness. Nonetheless the strengths outweigh the weaknesses and as such **good progress** has been made towards reviewing and supplying information.

4. *Maximise opportunities for work, learning and money service support and other specialist support*

Important strengths in progress toward this aim are identifiable and taken together these strengths outweigh areas for improvement. The role of Working4U was viewed as a central component of the successes achieved by the project.

However, there is also recognition and an expectation that ways to improve partnership working and input will be explored. Nevertheless, **good progress** has been achieved and this has established a strong foundation for further development of services to improve the cancer journey.

The evaluation concludes with a recommendation in support of further exploration of the remaining challenges that were identified. This exploration should in the first instance be led by Working4U in recognition of its role in the TCAT project and involve all appropriate partners.

It is also recommended that exploration of a number of themes, based on the findings of the TCAT project evaluation, with associated challenge questions would assist the development of aims, objectives and approaches for the future *'improving the cancer journey'*.

Key to this will be the strategic involvement of key senior personnel/heads of service from Health (primary and secondary care) and Social Care services and West Dunbartonshire Council. Important service areas would include those that can deliver services associated with the HNA: *physical, practical, family relationship, emotional wellbeing, spiritual, lifestyle and information needs'*

In addition it is suggested that exploration of themes and associated challenge questions should include, but not be limited to:

Theme	Challenge Questions
<i>Strategic Leadership</i>	How do we ensure: <ul style="list-style-type: none"> • We have established a coherent vision, set of values and aims? • We have shared the vision? • We can sustain the vision?
<i>Delivery Processes</i>	How do we ensure the service is <ul style="list-style-type: none"> • Well planned and ensures it engages with service users? • Flexible enough to adapt services to meet changing need? • Delivered to a consistently high standard?
<i>Impact on service users</i>	How do we ensure: <ul style="list-style-type: none"> • The service is accessible and targeting those who need it most? • The service draws on appropriate specialist support? • The service has a positive and sustained impact on people's lives? • Capture evidence to demonstrate that change?
<i>Performance Outcomes</i>	How do we ensure <ul style="list-style-type: none"> • That we set challenging targets that lead to improvement? • We have appropriate systems in place to demonstrate our progress against outcomes and targets?

Introduction

West Dunbartonshire – The Area

West Dunbartonshire has a population of approximately 90,000 people and occupies an area of 98 square miles, in the west of Scotland. West Dunbartonshire shares borders with Argyll and Bute, East Dunbartonshire and Stirlingshire, Renfrewshire and Glasgow.



The area has a lot of strengths including, for example, significant sites of natural beauty and heritage, good transport links and close proximity to Glasgow and its airport. The area has a rich past, shaped by its world-famous shipyards along the Clyde, and boasts many attractions ranging from its historic whisky warehouses, the iconic Titan Crane and Dumbarton Rock and castle, to the beauty of the Loch Lomond and the Trossachs National Park.

Despite its strengths West Dunbartonshire is one of the areas in Scotland most affected by post-industrial decline. Its three town centres, Alexandria, Clydebank and Dumbarton have experienced steady decline in their comparative economic performance with some areas affected by wide ranging deep rooted poverty and deprivation.

While there are considerable variations across the country, West Dunbartonshire residents have life expectancy rates that are statistically worse than the Scottish average. For example, the mortality rate for men in West Dunbartonshire is 11.6 per 1,000 population compared to the figure of 10.4 for Scotland. For women the mortality rate is 11.8 per 1,000 population, this also compares unfavourably with rate of 10.5 per 1,000 for Scotland.

The main cause of death in West Dunbartonshire in 2016 was cancer. As a cause of 29% of deaths, this is 3% higher than the Scottish average. The combined incidence of relative deprivation and higher than average incidence of cancer strongly suggesting the need for Transforming Care After Treatment with a starting point in managing debt and maximising income as a springboard for addressing other 'social' challenges.

Transforming Care after Treatment

TCAT was set up in response to research showing that many people weren't getting the right support to deal with the emotional, financial, practical and physical problems caused by cancer.

The national TCAT programme is made up of 25 projects that are testing and spreading new models of person-centred care throughout the NHS and local authorities. While each project responded to the needs and circumstances in their respective areas, they also delivered at least one aspect of Macmillan's Recovery Package. A package designed to ensure that people living with cancer secure the care and support they want.

The TCAT project in West Dunbartonshire was established to make it easier for people affected by cancer to identify and access the support services they need to improve their quality of life. The aim was to establish support in the community to complement health interventions with additional support; including welfare, debt and income maximisation that was identified through Macmillan's '*Holistic Needs Assessment*'. Better co-ordination between the local support services across the welfare, health and social care arena was seen as key to this aim. The

project also sought to test the conditions and establish the resources that would allow this support to be delivered by volunteers.

Pre TCAT Participation Questionnaire

A questionnaire was prepared and distributed to potential service users with the aim of identifying key issues and emerging challenges faced by post treatment cancer patients in West Dunbartonshire. The questionnaire was distributed to 30 respondents and analysis of the questionnaire was carried out by Edinburgh Napier University.

The questionnaire was intended to provide baseline information about the likely range and intensity of issues being faced by people emerging from treatment for cancer. The questionnaire focussed on people's reflections on their confidence about self management and support available. The questionnaire also explored perceptions on issues and concerns around a number of topics that would be explored within the context of the holistic needs assessment. These included, for example physical, practical, emotional, spiritual, lifestyle and family relationships.

Of the 30 people who responded:

- 17 were men, 13 were women;
- A significant minority (46%) live in the two most deprived quintiles of deprivation (Scottish Index of Multiple Deprivation);
- A significant minority (33%) live alone;
- The majority (53%) were retired; and
- the largest cancer groups were lung (32%,9) and Breast (29%,8).

Confidence and Support

Respondents were asked about their confidence about self management and the quality of support they received after treatment. **Table 1** summarises the responses.

Table 1: Confidence and Support after Treatment						
	Score 1 - 4		Score 5 - 7		Score 7+	
	N	%	n	%	n	%
Confidence after treatment						
When your treatment finished how confident were you that you could manage your condition by yourself? Here "managing" means understanding ways to cope and knowing where to seek help if needed. With 1 being "not at all confident" and 10 being "very confident"	7	23.33%	8	26.67%	15	50.00%
Support after treatment						
Overall, how would you rate the support you have received since your treatment finished? Here 'support' includes any appointments, advice you have been given, information, being referred to or signposted to people or organisations that could help you. With 1 being "very poor support" and 10 being "very good support".	5	16.67%	6	20.00%	19	63.33%

Table 1 suggests the key points to emerge were:

- 50% of those asked were either not confident or just about confident that they could manage their own condition; and
- approximately 37% had some misgivings about the support they had received.

When asked about who they received support from, patients often listed more than one person for support. The most frequent response was "family" (12). This was followed by specialist nurse (4), benefit officer (4), friends (4), GP (4), Vale of Leven staff, (3) and consultant (2).

Meeting needs

Patients were asked how they would rate the support they received since their treatment finished. Support was defined as appointments, advice received, information provided and referrals/signposting to people or organisations that could provide support.

Table 2 summarises the responses.

Table 2: To What Extent Were Your Needs Met										
In relation to...	Completely Met		To some extent		Not at all		Didn't need it		Not relevant	
	N	%	N	%	N	%	N	%	N	%
Managing side effects/consequences of treatment?	14	47%	9	30%	4	13%	2	7%	1	3%
Knowing where to seek help if you need it?	17	57%	12	40%	1	3%	0	0%	0	0%
Understanding who to ask for help if you need it?	15	50%	14	47%	1	3%	0	0%	0	0%
Awareness of support available to your family/carers?	12	40%	4	13%	8	27%	5	17%	1	3%
Knowing about other support services or groups you could use?	10	33%	9	30%	7	23%	4	13%	0	0%

Table 2 suggests the key points to emerge were:

- A substantial minority felt that their needs were met to some extent or not at all in managing side effects, knowing where to seek help and having awareness of support for family and carers;
- A majority felt that their needs were met to some extent or not at all in understanding who to ask for help and knowing about other services or groups they could use.
- The most significant area of concern among patients centred on knowing about other support services or groups they could use.

Experience After Treatment

Respondents were asked to consider their experiences after treatment finished.

Table 3: Experience After Treatment							
To what extent do you agree with the following statements? (1- Strongly Disagree, 10- Strongly Agree)...	returns	Score 1 - 4		Score 5 - 7		Score 7+	
		N	%	n	%	n	%
I was passed around from person to person without getting the support I needed.	30	24	80%	3	10%	4	13%
I was assisted to get other services and help, and to put everything together.	27	8	30%	5	19%	14	52%
I have been involved in decisions about regaining my wellbeing.	30	5	17%	2	7%	23	77%

Table 3 suggests the key points to emerge were:

- Respondents didn't feel as if they had been passed around organisations without obtaining support;
- The majority felt they had been assisted;
- A significant majority felt they had been involved in decisions about regaining their well being;
- The greatest area of concern was expressed around assistance to obtain access to other services.

Confidence about emerging concerns

The questionnaire explored the degree of confidence patients had in managing potential concerns after treatment has finished. Managing in this context meant understanding ways to cope and knowing where to seek help if needed.

Table 4: Confident About Emerging Concerns							
I am confident in my ability. (1- Strongly Disagree, 10- Strongly Agree)...	returns	Score 1 - 4		Score 5 - 7		Score 7+	
		N	%	n	%	n	%
To manage my physical condition	30	4	13%	8	27%	18	60%
To manage practical concerns such as shopping, housework and travel	28	7	25%	4	14%	17	61%
To manage any financial concerns	29	2	7%	8	28%	19	66%
Getting back to work	12	4	33%	2	17%	6	50%
To manage family/ relationship issues	28	4	14%	8	29%	16	57%
To manage my lifestyle for example diet and level of physical activity	30	5	17%	8	27%	17	57%
To manage any emotional concerns	30	8	27%	15	50%	7	23%
To manage any spiritual or religious concerns	19	5	26%	3	16%	11	58%

Table 4 suggests the key points to emerge were:

- The majority of respondents were confident about managing concerns in all areas apart from emotional concerns, where only 23% of respondents were confident;
- Among those who responded; getting back to work, albeit among a lower number of respondents, was the area of greatest concern;
- Emotional (27%) spiritual/religious (26%) and practical (25%) concerns were the areas to emerge as most prominent.

Baseline Questionnaire Summary

The issues emerging from the baseline questionnaire suggest that the majority of service users would likely be retired and come from areas experiencing comparatively higher levels of deprivation. Approximately half had some misgivings about coping with the challenges they faced after treatment. However, when asked about specific issues on an individual basis the majority believed they would be able to cope.

In West Dunbartonshire specific areas of concern to emerge from the baseline questionnaire centred getting back to work, emotional, spiritual, and practical issues. The combined impact of these among some people is likely to have significant negative impacts on the lives of individuals dealing with life after treatment.

Section 1: West Dunbartonshire TCAT Evaluation Method

The TCAT partners in West Dunbartonshire have conducted an evaluation of the approach and its achievements. The evaluation was carried out by the Working4U compliance team with support from Edinburgh Napier University.

During the evaluation we reviewed project documentation and talked to paid staff, service users and strategic partners. We wanted to find out about the strategic leadership of the TCAT project, the developing partner relationships; and resources developed to support service provision.

We also looked at how the Working4U staff developed their own practices alongside health practitioners and service users, built capacity and attempted to create local solutions to the challenges of integrated service provision.

The aim of the evaluation is to identify strengths and weaknesses; identify lessons learned from the TCAT project in West Dunbartonshire and use these as a springboard for the further development of effective services for people living with cancer.

The evaluation was conducted as a staged process which included:

- a desk-based review;
- stakeholder consultation;
- evaluation draft report;
- consultation event; and
- final reporting.

The evaluation report will provide details emerging from each stage in order to draw conclusions and offer recommendations for going forward and will focus on the extent to which each of the key objectives were achieved. The key objectives were identified as:

1. establishing a co-ordinated gateway approach to service provision;
2. reviewing and improving the assessment of need processes;
3. reviewing and improving the supply and availability of information; and
4. maximising opportunities for work, learning and money and other specialist support.

In the conclusion and as a commitment to continuous improvement we will provide an assessment about the extent to which these aims were achieved based on a scale from excellent to unsatisfactory.

- Excellent – fully achieved with clear examples of good and best practice.
- Very good – suggests significant strength with few weaknesses; and
- Good – the project is thought to be good because there are clear strengths in progress that clearly outweigh any weaknesses identified in the evaluation process
- Satisfactory – the project aims have been partially met, some strengths, but work required to consolidate the gains;
- Unsatisfactory – the project aims have not been achieved in any way;

Section 2: TCAT Desk Based Review

The desk based review focussed on reviewing the various documents associated with the development and delivery of the TCAT project. Our aim was to establish the project context and method of delivery in order to fully understand and explain how the TCAT project was delivered in West Dunbartonshire.

The project management and governance documentation was reviewed to provide an indication of:

- The stages and components of project delivery;
- The challenges associated with governance;
- How project decisions were implemented;
- How risks were managed; and
- The process for developing the West Dunbartonshire TCAT toolkit.

We also used the information gathered at the desk-based review stage to inform the questions used in the stakeholder consultation.

TCAT in West Dunbartonshire

The service agreement between West Dunbartonshire Council and Macmillan TCAT Development Service established in May 2015 provides details of the scope of the project.

The '*Transforming Care after Treatment*' (TCAT) was established as a partnership approach in April 2016, with the specific aim of contributing to the transformation of care for people affected by cancer and improving their quality of life as a result. The demonstration project was set against a backdrop in which services in West Dunbartonshire appeared to be fragmented and difficult to access. As such, the focus of the project centred on improving the co-ordination of, and access to, services and availability of information for people affected by cancer, their carers and families.

Modest investment of £80,925 from Macmillan Cancer was provided for the two year delivery period.

The financial investment allowed the delivery lead partner, '*Working4U*', to employ a project manager (0.1 full time equivalent) and one fulltime equivalent member of staff to develop the project and work towards the stated aims.

Information Box: Working4U

Working4U is an integrated (work, learning, money) service that supports West Dunbartonshire's residents to improve their skills, learning and financial situations; assisting all to improve their quality of life, secure their rights and assisting them to make progress towards their personal ambitions.

Working4U's main goal of improving the quality of life and resilience of West Dunbartonshire residents are achieved through services that focus on case managed and customised support, delivered on a one to one or group basis for the provision of:

- (1) credible benefit/debt and income maximisation information, careers guidance, education and support to help residents to make informed choices and enjoy improved life chances;
- (2) good quality advice and learning assisting all to make positive and sustained contributions to their family and community;
- (3) support to improve residents' employability and resilience, making a positive contribution towards increasing employment rates within our community and closing the gap with Scotland.

The Project focus was intended to complement and find ways to build on the Macmillan Cancer support service being provided by Working4U.

Information Box: Working4U- Macmillan Cancer support Service (Beatson)

The Macmillan team operate from the Beatson West of Scotland Cancer Centre, Gartnavel General Hospital Respiratory Unit and the Vale of Leven Hospital Haematology Clinic (which includes Haematology, Breast and Lung.)

The Macmillan Team supported 1,078 people during 2016/17 to maximise their income supporting them to claim £3,497,908.79 in benefits. Team members hold the City and Guilds in Energy Awareness and provide free independent energy advice to Macmillan clients.

During 2017/18, working in partnership with Energy Action Scotland's Warm at Home Scheme, 300 Macmillan clients have been supported to obtain new white goods such as washing machines, tumble driers, cookers etc; central heating systems; boilers; and £250 cash crisis grants.

The team also supported their clients to access debt and money advice from their colleagues in the wider Working4U Money team.

However, the TCAT project would be an action-based demonstration project and as such, it was intended that engagement with any potential service user would be mainly be on this basis. That is, designed to establish and test: appropriate methods for providing access to the project support as a gateway to community-based services; the methods to facilitate access to the additional services needs emerging as a result of the Macmillan Cancer '*Holistic Needs Assessment*'.

However, as the project delivery was being led by Working4U where benefit maximisation/money advice was required this this would be delivered by the Macmillan Benefit Team and their colleagues.

Service Access

It was anticipated that referrals to the project would be supported by staff and volunteers and referral sources would be wide ranging. This would include, for example, West Dunbartonshire Council services, Health and Social Care Partnership, NHS services and key third sector partners including Carers of West Dunbartonshire, Community Voluntary Service and local Macmillan groups.

The referral method would include phone, online and email. Personal referral through, for example, One Stop Shops, Health Centres, and local Hospital would be encouraged.

Service Support Volunteers

Volunteers to the project, who would act as a gateway in the community to provision and support service delivery, would be drawn from existing organisations currently offering volunteering opportunities for people in West Dunbartonshire. Connection with the third sector would be critical to achieving this aim.

Target Group

The demonstration project was aimed at people affected by cancer, their carers and families. Equal consideration was given to improving awareness and resources for staff and volunteers who would act as the point of contact in the community and deliver the service provision.

Project Progress

Progress towards the project aims would be demonstrated when:

- a wide range of key public and third sector staff and volunteers to contribute to service development;
- an audit of 30 cancer survivors and carers was carried out to establish experience following cessation of treatment;
- a Toolkit was designed to provide information about establishing a TCAT project approach, the services available for the service users and other relevant information;
- 20-30 service users, staff and volunteers participated in the development of the project and implementation of its aims;
- enhancements to Working4U service were implemented to maximise access to work, learning and money opportunities; and
- 11 HNAs were carried out.

Project Governance and Management

Three groups were to be established to provide governance, management and direction for the project. These groups were to be comprised of representation from key partners and stakeholders and were responsible in some part for developing key aspects of project delivery.

These groups were:

The TCAT Strategic Steering Group, - While WDC Corporate Services and the Health and Social Care Partnership were to lead the Project, it was anticipated that their representatives would be joined by representatives from other West Dunbartonshire Council service departments. This would also include representatives from Housing/Economic Development and Education Services.

The TCAT Operational Group – it was anticipated that this would include lead officer representation from Corporate Services Advice Service and Data Protection; Health and Social Care Partnership Strategy, Health Improvement Team, Care at Home, Older People and Adult Services.

The TCAT User Involvement Group. The user involvement group would draw representation from the Cancer Support Group (Clydebank) – and local Macmillan Fundraising Groups and the Carers' Service (West Dunbartonshire wide).

In addition, it was anticipated the project would draw on the expertise and resources, including support from volunteers, from the Advice Service/Care at Home & Volunteer Service (Macmillan).

The Implementation Steering Group Key personnel represented the project at the West of Scotland Cancer Network (WoSCAN). This enabled the project to be part of the wider TCAT governance structure, facilitating learning, minimising programme risk and supporting successful outcomes.

Project Delivery

The project was agreed and established in August 2015. The project initial stages centred on establishing the Strategic Steering Group, employing staff and appointing a project manager.

Following considerable restructure and associated changes in personnel within West Dunbartonshire Council, the project manager role was fulfilled by a Working4U team leader (financial inclusion) and delivery staff of one full-time equivalent. This was a shared post.

A project plan was established by the Project Steering Group in November 2015 and this identified key overarching milestones that would contribute the project aims. The initial milestones from the plan are reproduced in **Table 5**.

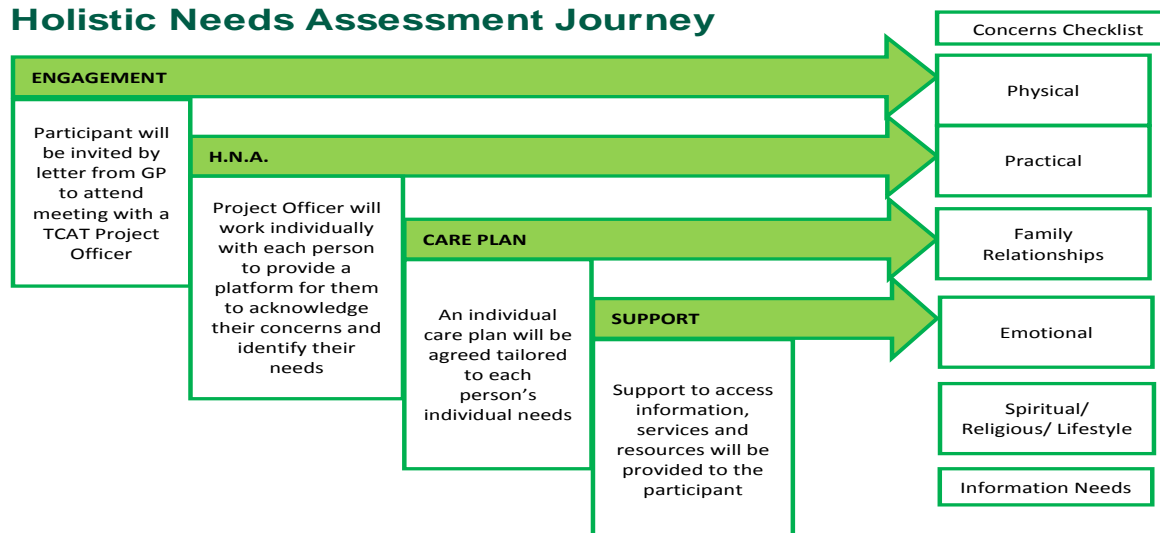
Table 5: Stages and Milestones		
Stage	Actions and Milestones	Anticipated Date
1	Complete 30 Pre TCAT Questionnaires	Nov 16
2	Form Directory of Services/Support	Oct 17
3	Raise Awareness/Promotion/Referral Pathway	May 17
4	Offer HNA to 20 people	May 17
5	Complete 20 Post TCAT Questionnaires	Dec 17
6	Form Patient Advisory Group (service user group)	Nov 16

The Service User Journey

The project team established an ideal type service user journey to provide an indication of the method of access to services and to identify the type of support that would be available.

The original service user journey, reproduced from the West Dunbartonshire TCAT Toolkit is illustrated in **Diagram 1**:

West Dunbartonshire TCAT Holistic Needs Assessment Journey



Following engagement a *'Holistic Needs Assessment'* would be conducted. This would focus on the six areas of concern within the 'Concerns Checklist'. Through discussion on these issues the service user will establish a customised 'Care plan'. The care plan would identify priority areas of required support and the service user would be assisted to address these issues.

Review of Holistic Needs Assessment Delivery

At the time of writing 11 people of the target of 20 had undertaken a holistic needs assessment. A number of issues are identified as sub sets of each category in the HNA and service users are asked to consider the extent to which each of these issues is affecting the quality of their lives. This provides a baseline assessment of key issues and assists in the joint development of a care plan that is used to focus on addressing the priority issues.

Appendix 1 reproduces a copy of the HNA.

Table 6 provides summarises information about the service demands and intensity of needs.

Table 6 Summary of Participant Issues (actual)						
	physical	practical	family	emotional	spiritual	lifestyle
11 cases - total number of issues	47	9	5	15	0	10
11 cases - average number of issues presented	4	2	2	3	0	2
11 cases - total score of issues assessed	70	34	18	45	0	39
11 cases - Highest Score	10	8	9	8	0	10
11 Cases - Lowest Score	3	4	4	5	0	6
11 cases - average intensity of issue	6	6	6	7	0	7

Table 6 illustrates that the most significant number of issues to emerge, with 47 incidents, centred on physical issues. Lifestyle, Emotional, Practical and Family issues were also prevalent.

The average number of these issues provides an indication of the scale of challenge each respondent feels. Physical and emotional issues appearing to be most prevalent. Each participant is asked to provide a score on a scale from 1 - 10 of an initial indication of the intensity of the issue. Each of the issues that emerged scored, on average, around 6/7 out of 10; in effect, important facets that require support to address.

Each participant, can score a maximum of 60 (up to 10 for each category) when assessing their circumstances against each of the areas.

Further analysis of the caseload illustrates that of the 11 participants:

- The highest self assessment established a score of 35 out of 60 – a substantial number of issues with intense support requirement;
- The lowest score for one of the respondents was five, one issue of the six requiring support.
- The average score of 18 out of 60 suggests that we could anticipate that we will be faced by caseloads where the vast majority of people will have at least one area of substantial concern.

While the scoring provides an overview of the types, prevalence and intensity of issues, further analysis of caseloads provides an indication of the reality of concerns. We have summarised some of the emerging issues within each category.

Outcomes of Concerns raised on completion of Holistic Needs Assessments

Physical Concerns

Of the six headings listed on a HNA the most concerning factor for the eleven participants are physical concerns. Every client interviewed had some physical issues, some had extensive concerns. One person had as many as ten different types of physical issues.

Tiredness/exhaustion/sleep issues and getting around was cited by all participants. Breathing and swollen limbs emerged as issues and general levels of fitness were cited.

Practical Concerns

More than half of those interviewed cited practical concerns. Three participants had financial concerns and issues with transport. Issues with employers were cited; others had concerns over managing their daily tasks such as washing/dressing, meal preparation and doing housework.

Family Relationship Concerns

Just less than a third of those interviewed raised relationship issues. This included the view that their families did not fully appreciate what they had experienced and expected more from them. Other issues emerged around perceptions of self following treatment and concerns about how their diagnosis had affected dependents.

Emotional Concerns

Emotional concerns had high prominence with concerns around sadness/depression and worry, fear or anxiety, including the fear of recurrence of their cancer. Difficulty in expressing feelings emerged as an issue as did difficulty in making plans.

Spiritual Concerns

None of the participants listed any Spiritual Concerns. Some of those interviewed reported having reconciled their spiritual needs at point of diagnosis.

Lifestyle or information needs

Over half of those interviewed raised concerns over Lifestyle or information needs. The desire for smoking cessation was highly prevalent. Others were interested in support groups and looking for complimentary therapies to help with relaxation and to overcome anxiety.

Summary of HNAs in West Dunbartonshire

While not achieving the anticipated number of HNAs, some early conclusions can be drawn. The main points include:

- It can be anticipated that the most likely people to seek support will be retired and live in disadvantaged communities.
- Those in work will have concerns about returning to work.
- Despite service user optimism about dealing with physical issues expressed in the baseline pre TCAT questionnaire, this emerged as a significant issue with most concern expressed by service users.
- Emotional (27%) spiritual/religious (26%) and practical (25%) concerns were the areas to emerge as most prominent in the pre TCAT questionnaire – all except spiritual concerns were prominent;

These areas could be taken into consideration when developing the training for staff to support service users and developing partner relationships with external and specialist organisations supporting service user needs.

Project Policy, Process and Progress Documentation

A review of the project documentation provides an indication of the progress, associated challenges, risk as and issues that emerged as the project unfolded.

The documentation where the information was drawn from for this review includes:

- The project plan (project milestones, risks, issues);
- Strategic Group meeting minutes;
- Operational Group Minutes;
- Project manager and staff progress reports.

The milestone progress associated issues and associated plan changes are detailed in **Table 7**.

Table 7: Summary of key milestone progress, associated issues

Milestone/aim	Challenge	Impact	Action	Result
Complete pre TCAT Questionnaires	The challenge centred on identifying and connecting with appropriate people to complete the questionnaires. Initial discussions with medical centre staff and GPs were not as encouraging as anticipated.	The delays in identifying appropriate service users to complete the initial questionnaire delayed their completion.	Continued development of working relationships with external organisations allowed the full completion of the pre service questionnaires	30 pre TCAT questionnaires were completed.
Establish directory of services. (to provide service users with information on available services and a resource for those conducting HNAs)	A number of organisations and resources were identified. Including on-line resources. The challenge centred on how best to provide this information and what format this would take.	Reliance on personal knowledge of service provision among those supporting the HNA could limit the information (and services) available for service users.	The team compiled the TCAT Toolkit. This was designed to provide information about establishing a TCAT project approach, the services available for service users and other relevant information	This resource provides the basis for understanding what services and support is available. The experience also identified the need for technical skills to develop on-line services. It was suggested this on-line resource could be best achieved centrally (national on-line service, with locally based landing pages achieving consistency and economies of scale)
Raise awareness and establish referral pathway	There are a number of organisations delivering support for the target group. The challenge lay in identifying and connecting with potential service users at the earliest point of contact. GP/medical practices were seen as key to this.	Without buy in from medical staff at an early stage, connecting with potential service users becomes more difficult.	Action required includes continuing to work with appropriate professionals within the health sector to embed an effective referral service.	Good working relationships have been established at some, not all, medical centres. The buy-in continues to be a challenge and more work is required to reinforce the relationships.

Table 7: Summary of key milestone progress, associated issues

Milestone/aim	Challenge	Impact	Action	Result
<p>Establish access to service through volunteers</p>	<p>Using volunteers to act as a gateway to services in the community and the first point of contact for conducting the HNA was seen as a key element of the project. Having a pool of volunteers would be an important element and existing volunteer led services were seen as a source. However, these groups were established around specific priorities and aims and were unwilling or unable to provide access to volunteers.</p> <p>The aim to recruit volunteers included: using the Link Up project as a source of volunteers to deliver the HNA. This was considered inappropriate by Community Voluntary Services and the LinkUp volunteers.</p> <p>Using existing volunteers operating from libraries. – This too was considered inappropriate by existing volunteers</p>	<p>Without access to, or input from, volunteers would prevent the project from assessing the potential for adopting this as an approach.</p> <p>By December 2016 it became clear there were significant challenges around developing the service on the basis of volunteers conducting the HNA.</p>	<p>Challenges around using existing resources and volunteer networks as a source of volunteers became intractable. The requirement to recruit volunteers direct to the TCAT project became an apparent solution and recruitment and volunteer management policy was developed.</p> <p>The TCAT team worked closely with Community Learning colleagues who have extensive experience in using volunteers in community learning to address literacy and numeracy deficits.</p> <p>Requirement to ensure the development of the project and assess referral routes, the decision was taken for Working4U staff to become the point of contact for the initial HNA.</p>	<p>Exploration of potential use of existing volunteer networks and associated delays led to the requirement for a change in approach in order to achieve the project aims.</p> <p>Lessons around the use of volunteers, how to recruit and manage them were learned as a result of the project challenges.</p>
<p>Complete post TCAT Questionnaires</p>	<p>Connecting with participants and maintaining connection was difficult because relationship with health sector required further development.</p>	<p>Number of people completing HNA was limited and therefore fewer people available to complete the post service questionnaire.</p>	<p>Working4U staff took on role of conducting HNA to increase the numbers available for post service evaluation.</p>	<p>The aim of securing 20-30 completed post service questionnaires was partially complete.</p>

Key Risks

Further review of the project documentation, 'TCAT Project Progress Reports', identifies a number of risks that featured at the early stages and throughout the project delivery. These include among others:

- Organisational changes in key staff due to restructure within West Dunbartonshire Council affecting the continuity of project development ;
- Recruitment of staff for delivery affecting the potential start date for activities (March 2016 staff recruited);
- Inability to make progress in recruiting volunteers to act as gateway to services in the community;
- Establishing and maintaining contacts within health care and health partners;
- Commitment to the strategic and operational steering group requires review in the light of limited participation by key agencies and third sector.

Summary of Desk-based Review

The project aimed to achieve a number of objectives. We can begin to establish some initial views of progress on the basis of the desk-based information.

1. Establish a co-ordinated gateway approach to service provision;

There is evidence to suggest that progress has been made towards establishing a co-ordinated gateway to service provision. Working relationships have been established between the delivery team and some of the health service facilities in the community. However, further work is required to reinforce and build on these relationships.

A wide range of organisations and individuals have contributed to the project aims. This is apparent in the commitment to working with the various project development groups. However, the risks and issues identified during the project development and delivery would suggest more can be done, particularly in the development of strong working relationships with health services and the third sector.

The service user group played a key role in developing resources for engaging with future service users. This included finalising elements of the holistic needs assessment and associated care plan, developing the letter inviting potential service users to take up the service and reviewing the contents of the toolkit.

A referral process for service users to gain direct access to the service from their medical support has been partially established. More work required to fully establish this process.

2. Review and improve assessment of need processes

The Holistic Needs Assessment was developed and formally adopted by the project team. The early focus was placed on using volunteers as the gateway to service provision. This approach focussed on existing volunteer service provision to secure these services. This was found to be difficult for a number of reasons. It was thought that the volunteers working with CVS LinkUp project could be trained for the use of the HNA. LinkUp was established for a particular purpose including specific aims around support for the 60+ age group. The decision not to use LinkUp became clear in November 2016.

By December 2016 the view was that it would be inappropriate to ask volunteers within libraries to conduct the HNAs and as a result Working4U (TCAT) staff took on the role of assessing needs using the Holistic Needs Assessment. The view that Working4U staff could/should conduct the HNA began to emerge as a result. The TCAT project team explored the potential for recruiting volunteers directly to the project and the team established a set of policy documents for managing and supporting volunteers. These resources drew on good practice in the provision of community based learning for the delivery of literacy/numeracy and support for English for speakers of other languages (ESOL) This will be a valuable resource should this approach be pursued in the future.

The challenges associated with the aim of using volunteers were clearly identified within the project documentation. The frontline delivery staff was given the task of conducting the HNAs and 11 of the anticipated 20 were carried out at the time of the review. This experience and associated learning and resources will provide information to inform future decisions about options for delivery.

3. Review and improve the supply and availability of information

A review of available information for supporting service users was undertaken. In addition, analysis of the methods for updating the information was undertaken and evidence of good practice was drawn from service provision in other areas. This includes, for example, access to web-based information.

The team established a local TCAT Toolkit that was designed to provide information about establishing a TCAT project approach, the services available for service users and other relevant information. This provides information that will assist staff and volunteers who want to signpost service users to support in their community. The '*West Dunbartonshire Transforming Care After Treatment Toolkit*' brings together important information about the project and contains:

Part 1: information about West Dunbartonshire's TCAT project – Background, aims and governance chart to identify the partners.

Part 2: HNA Referral Pathway describing the HNA, training requirements to deliver the HNA, the service user access route to the service and a series of templates for letters to service users, script and care plan letter and outcome letter.

4. Maximise opportunities for access work, learning and money service support and other specialist support

The holistic needs assessment clearly identifies the opportunity to discuss and provide support that will improve the quality of lives for those seeking care after treatment. It also suggests the need for access to a broad range of specialist support. The referral process between Working4U Money, Learning and Work are more firmly established and provides access to these services. Access to specialist support that may emerge as a result of the holistic needs assessment has progressed. The full development of the integrated service will assist this to be developed further.

The desk-based review of the project documentation suggests there is evidence to clearly demonstrate progress towards the project aims has been achieved. However, it also suggests more work is required. The stakeholder consultation was designed to explore this further and assist us to draw more comprehensive conclusions.

Section 3: Stakeholder Consultation

We carried out a programme of consultation with the key stakeholders, including

- Strategic stakeholder (members of the governance group and delivery partners);
- Operational stakeholders (delivery staff and associated health professionals);
- Service User Group;
- Service users (Questionnaire pre and post support analysed by staff from Edinburgh Napier University).

This included a series of face to face interviews, focus groups and a questionnaire.

The Strategic Stakeholders

The strategic stakeholders we spoke to on a one to one basis included the project sponsors and members of the West Dunbartonshire TCAT project steering group. We developed an open-ended, semi-structured approach in order to explore perceptions and experiences. Our focus was placed on:

- The extent to which the project aims were achieved with reflections on:
 - challenges and achievements;
 - partnership working;
 - project governance and management;
- Lessons learned;
- Good practice;
- Other issues of concern/note.

We expected to conduct face to face interviews with nine strategic stakeholders.

Appendix 2 has a copy of the semi-structured questionnaires we used in these interviews.

We have summarised the key points emerging from discussions around each of the questions put to the strategic stakeholders.

1. What is your understanding of the TCAT Project?

There was a general consensus that the TCAT project was set up in West Dunbartonshire to overcome the limited or fragmented access to services that would improve the quality of lives for people after their treatment for cancer. It was recognised that it was one of a number of projects being delivered throughout the country with West Dunbartonshire focussing on using community assets and peer group support to deliver the holistic needs assessment.

The strategic partners emphasised the important role that the third sector could or should play. There was a general view that links to medical services would be critically important. There was a clear recognition that this had been difficult and the project had changed from the original aim of developing a social prescribing model based on delivery by volunteers and the suggestion for the need for clarity of purpose in how the service would use volunteers.

Comments from strategic partners included the views that:

- *TCAT is an integrated model that has to take in the overarching primary and secondary health care sectors including social care and social work;*
- *The original model changed from the volunteer model to the GP attachment model;*
- *The project was set up to provide access to support from the third sector and health and social care, the way it is being delivered has changed.*

2. Were the appropriate partners involved in the development and delivery of the project

A general consensus centred on the view that the project was developed with the correct partners in place. However, the level of participation and commitment changed as the project progressed. Included among the reasons were substantial changes as a result of restructuring

within West Dunbartonshire Council and the Health and Social care Partnership and lack of clarity about the range of participants from various Macmillan Cancer services.

It was suggested that although the project was driven to some extent by the NHS and Health and Social Care Partnership, their support was not fully developed. The result, suggested by some of the partners, was Working4U was left to drive the project forward. However Working4U could only provide some of the services and without the support of the NHS/HSCP the aims of the project would be compromised.

Other stakeholders expressed the opinion that the third sector/voluntary sector were only marginally involved or only included as an afterthought. This is a view that was reinforced by a voluntary sector representative who was invited along to the strategic steering group, but was unclear about the role expected of them.

The view was expressed that the project did not necessarily require representation from health and social care to achieve its aims. However, this was laced with the caveat that greater engagement of these services would have been of benefit. And, while some work with primary health care and GPs was carried out, more could have been done.

It was suggested more work could have been done to understand the health and social care infrastructure and the role of the localities as the best method to involve GPs, as such this was seen as a lost opportunity. Furthermore, the view that additional work with secondary health care, for example, referrals from hospitals, would have been of benefit.

However, there were a number of partners that contributed regularly and made a positive contribution towards the project objectives, for example, the view that, operationally the appropriate partners have always been involved from the start and made a good contribution to the development and delivery of the project.

3. How well have the partners worked together to manage the programme, and what could have been done differently?

On the one hand some of the partners believed the partners worked very well together. This process was aided when the strategic and operational groups were divided. This was described as positive as the single group had become too unwieldy. The work carried out between Working4U and the libraries was seen to be positive.

On the other hand, significant changes in personnel, particularly at the early stages, meant some of the partnership momentum was lost, resulting in some erosion of leadership. This may have had a knock on consequence on directing the work of the frontline staff, leaving them for a period to develop some of the project priorities.

On balance, it was felt the partners involved worked well together, but when asked what could be done better it was felt that a bit of trust and commitment to the common vision would have helped and there was a lack of health involvement, which led in some way to a change in the project emphasis. This, it was suggested, could have been overcome if potential operational partners had more information about the bid from the start.

There was some consideration of the decision making process; with the view that it could have been quicker. It was suggested perhaps staff could have been empowered to develop the project and associated activities rather than, what appeared at times, waiting for endorsement.

4. Did the partnership establish a simple and effective pathway to a range of services?

While a simple and efficient pathway has not been fully established, efforts to date have achieved a lot. There was a consensus around the view that some good work had been carried out, favourable relationships developed and progress made, but it was still a work in progress and more time would be required to achieve this aim. The work on developing the pathway, it was suggested, would act as a good foundation for 'improving the cancer journey'. However without a sustainability plan, particularly with GPs, it will be difficult, it was suggested to fully achieve this aim in West Dunbartonshire.

This sustainability plan and clear recognition of the need to reassure GPs that compliance with standards around gathering and using patient information was being addressed. In effect, before referral it was suggested that GPs would have to be sure that any information gathered would be used properly and lead to clear action for the benefit of the patient.

5. Were methods to cross refer to reduce the need for patients to navigate complex health and social care services when people are at their most vulnerable established?

There was clear recognition of progress including the development of a health improvement directory, screening process and the 'toolkit'. The consideration of feedback on referrals is a good departure, but work remains to be done to fully embed the approach.

In addition the referrals between groups and within Working4U services may be clearer, because it was suggested that staff within Working4U who operate on the frontline were very good at cross referring. However developments with GPs have proven to be more difficult.

It was suggested that cross referral could be improved, if perhaps, staff within groups delivering health, well-being, fitness, mobility and social skills, when dealing with people with cancer, could conduct the HNA and ensure access their respective services.

On balance, some good progress was made, but as with the effective pathway to services, more work has to be done.

6. Were appropriate resources developed to support for people to maximise their recovery and restore their confidence and independence?

The 'toolkit' was cited as an important resource. It was recognised, however, that this has to be a 'living document' that is regularly updated. The toolkit captures details and information that should not be lost and it has the potential to assist the exploration of a range of delivery options.

It was also felt that the toolkit could be developed in a range of formats and could be accessed in a number of ways. For example, it was suggested that an on-line resource would be beneficial and a further suggestion to explore the use of NHS Inform. Not only was NHS Inform seen as a potential source of information it would have the added benefit of a dedicated resource to keep it up to date.

7. What were the challenges the approach was likely to face?

The strategic stakeholders provided a number of examples of the challenges that the project team would face when delivering the project. These included:

- Establishing a multi-agency approach;
- The time required to build networks;
- Developing a third sector approach based on the use of volunteers;
- Engagement with GPs;
- Encouraging patients to participate; and
- The need to address data sharing protocols.

The 'social prescribing' type of approach in West Dunbartonshire was seen as a positive development. However, this was always going to be challenging and would pose difficulties among health professionals who were more familiar with a clinical approach to support.

It was generally recognised that the project while having a modest financial investment was trying to achieve major changes in scale and scope of support. At a local level, it was suggested the project was adapted to pursue aims around the coordination of care and integrating resources to meet that aim. This flexibility was required to meet the challenges that the project team faced and progress was made as a result.

8. Were these challenges addressed?

There was a consensus around the view that the project addressed some of the challenges and some real joined up work was identified as evidence of this success. The scale and scope of the objectives, it was suggested, were always going to make the challenge difficult and the challenges became increasingly complex as the project developed.

The changes in the project delivery, which were designed to address some of the key challenges around, for example, using volunteers, meant some of the challenges were addressed.

The stakeholders identified potential lessons that could be applied and support the delivery of improving the cancer journey. This include, for example, exploring:

- The need to strengthen the steering group and operational group membership;
- The need for more time to develop the relevance and potential for using volunteers;
- The future role of (directly employed) link workers in the future delivery of an HNA model;
- The need for more links with organisations such as CR:UK;
- The potential to generate referrals from diagnosis through GPs and Information Services Division (ISD¹).

9. What in your view worked well in the project?

There was a consensus that the project established good networks, mapped resources and raised the profile of cancer as an issue. This expanded an understanding of what was, and was not, available.

Some stakeholders cited the importance of the steering group and operational group and others noted that the frontline staff worked well together and their experience was extremely beneficial in managing some of the uncertainties.

The commitment of the frontline staff was seen as key to developing and supporting the service user group. This group made a strong contribution to the project aims.

The additional training that was identified as a requirement for people delivering the HNA was a positive development.

The general view is that as a result of the project there is a greater understanding of the challenges and potential solutions for developing a co-ordinated gateway approach to service provision.

10. What do you think TCAT has delivered to date?

The stakeholders cited a number of achievements to date. These included, for example:

- The creation of a user involvement group, providing a patient 'critical eye' on developments;
- Identified and engaged with GP practices;
- Greater awareness and potential for key partners to participate in the development of the model;
- Established the learning for further developments such as Improving the Cancer Journey;
- A sound basis for service development (the toolkit);
- Recognition that the frontline staff at Working4U have the capability to drive this forward; and
- Shone a light on emerging issues for the health and social care partnership that wouldn't have been the case otherwise.

The number, range and experience of the stakeholders clearly demonstrates a commitment to recognising that 'cancer is everyone's business' in West Dunbartonshire and there is a

¹ The Information Services Division (ISD) is a division of National Services Scotland, part of NHS Scotland. ISD provides health information, health intelligence, statistical services and advice.

willingness to meet the associated challenges. Cancer has been established as an issue in its own right. The TCAT project has provided the opportunity to consider how best to establish appropriate pathways to support and delivery of that support.

11. On reflection what could we have done differently and what lesson learned can we take forward?

For some stakeholders there was a clear view that the project should have been led by the Health and Social Care Partnership. This was not posed as a criticism of the Working4U leadership, but rather a view that more partnership links could have been established and maintained more effectively if the networks and expertise of the HSCP was more readily available.

It was suggested that the project could have learned more from what other people were doing and how they had established their steering groups. This would have perhaps assisted in clarification of roles between local authority and third sector.

It was noted that the original bid deadlines were very tight. That posed challenges in ensuring all partners were fully involved in the development of the bid and subsequent aims and objectives. In hindsight, it was suggested that a more concentrated series of strategic steering groups at the early stage may have cemented the buy in of key partners.

The need for a national electronic, web based service directory was identified. This would complement the local toolkit and could provide access to a broader range of information and service provision. This could be complemented by local information; however central development and maintenance was seen as important in overcoming developmental and maintenance issues.

12. Were there any unexpected benefits to emerge as a result of the project?

The unexpected benefits identified include:

- The development and sharing of professional networking;
- Frontline staff have had the opportunity to network with a huge variety of organisations;
- Intensified understanding of the HNA and how it should be used;
- Greater understanding of the need for staff development (what areas of development would be most beneficial);
- Improved working relationships that establishes West Dunbartonshire in a better place to take forward projects such as 'Improving the cancer Journey'.
- Closer working with housing staff, leading to one service user avoiding eviction;
- More integration with HSCP does not necessarily guarantee secondary health involvement in the project (continued effort to maintain these relationships are required);
- Development of an understanding of improving the cancer journey.

13. How do you think learning gained within the programme could be implemented within future patient cancer/self-management support programmes?

The stakeholders suggested that the understanding of the important role played by the service user group will be key to future developments, as is the importance of early buy in from GPs. In addition, it was suggested that the method for providing patients to promote self-help through supported HNA was seen as extremely important.

The project has also supported the project management skills among the team and a digital platform for sharing good practice may help to develop this further.

It was also suggested that it may be beneficial for the community if in future developments, people suffering from other long term conditions have access to the services.

The Delivery Stakeholders

Working4U Staff and Operational Group

This consultation with the staff and operational group included face to face discussions with the project manager and frontline staff and a focus group with the operational group. The discussions were based around progress towards project objectives, challenges and achievements and lessons learned.

Working4U Staff

The frontline and management staff was asked a number of questions about the delivery of the project. The staff members felt that the project has been a success and while the numbers of participants was not as anticipated the information generated was good quality and will contribute to the learning for the project.

The staff felt that the development of the toolkit, scoping of local service provision and training required for service delivery all served to improve partnership working and linking of services. There was specific mention of how well Working4U, WDC Carers, the Health Improvement Team and library staff worked together.

The additional benefits that were identified include a reinforced awareness of existing partners and services. This was supported by the pre-existing knowledge and expertise the team already possessed. However, this was countered by drawbacks such as lack of experience in project work, changes to internal and external partners due to restructure and delays and change in project direction that emerged as a result.

The staff felt that a clearer definition of stakeholder responsibilities at an early stage would have benefitted the project and directional changes in the project affected the project timeline. Some of the changes were identified as necessary were driven by circumstances, such as:

- Referral pathway changed and this required the development of working relationships with new partners;
- HNA baseline reduced due to lack of participants nominated by GPs; and
- The anticipated role of volunteers within the project did not materialise.

The key lessons identified by members of staff include:

- Partner commitment to the project is essential;
- HSCP and health input is crucial ingredient for success; and
- User involvement group is pivotal for providing feedback and direction for project.

The latter point was reinforced with the opinion that the service user group members should be able to attend the other governance, management and operational groups.

TCAT Operational Group – Focus Group

The operational focus group centred on discussion of three statements:

- Simple and effective pathway to access a range of services has been established as a result of TCAT in West Dunbartonshire;
- Methods to assist patients to navigate complex health and social care services have been developed as a result of the TCAT project; and
- A strong foundation for supporting people to improve their cancer journey has been established in West Dunbartonshire.

Participants were asked to consider the extent to which they agreed with the statement and what they would do to improve their perceptions.

Simple and effective pathway to access a range of services has been established as a result of TCAT in West Dunbartonshire.

The operational group stated there was excellent user involvement and the team overcame significant challenges with support from other organisations. They also emphasised the positive input from staff, the extensive review of resources that was carried out by them and the buy-in to the project from the operational group.

The operational group members suggested, on the negative side, that the project was 'sold to GPs' as a pilot and that lost some potential for achieving sustainability and insufficient time to truly establish the effectiveness of the pathway.

Changes that would bring about a positive improvement in their perceptions include stronger senior management team buy in and quicker decision making from steering group to change direction. It was also suggested that a stronger original proposal could have helped to clarify the purpose at times of uncertainty.

Methods to assist patients to navigate complex health and social care services have been developed as a result of the TCAT project,

On the positive side it was suggested that using partnership from other TCAT/Macmillan projects was important as was the skill set of the staff delivering the project. Utilising contact from the operational group assisted in the development of methods for support and the project team staff completing HNAs highlighted the emerging challenges very quickly.

Again the lack of time to implement the methods was seen as a negative and future improvement centred on the potential development of on-line resources. However, it was noted that the pace of development of on-line resources may be quickened through the further development of NHS Inform.

A strong foundation for supporting people to improve their cancer journey has been established in West Dunbartonshire

The operational group participants noted that strong foundations have been established between partner organisations and good networks have been established. However this has highlighted gaps in provision and a lot of lessons to address these have been identified. The group noted that this work is transferrable across other long term conditions and will lay a solid foundation for the developing approaches to improving the cancer journey.

On the negative side organisational restructure leading to personnel changes in West Dunbartonshire Council, the HSCP and third sector has led to disruption affecting the development of the project. They also noted the negative impact emerging from the lack of information sharing across the third sector.

The operational group expressed concern around the need to continue the service and apply the approach to other long term medical conditions. In addition, further information about the services that the third sector could provide the Health and Social Care Partnership, they feel would reinforce the foundation for improving the cancer journey in West Dunbartonshire.

Health Centre Staff

We conducted face to face interviews separately with two members of staff within the health centres. We asked about their understanding of the project, the extent to which it enabled access to additional services, and what could be done to increase referrals. In addition, we asked what lessons could be taken from the project and for any other comments.

The initial expectation was that HNAs would be conducted by primary care staff. However it was found to be interesting and welcome that West Dunbartonshire would adopt a different approach. The benefits of the approach were cited as improved communications with staff delivering the TCAT project and making the process of engagement simpler.

It was felt that engagement with patients may have been a bit more difficult because of the changes to the QoF, the formation of GP clusters and the new GP contract. The health centre staff suggested that recruiting more GP practices a tear off slip on the invitation letter would perhaps increase uptake. Introducing the service to patients at first patient chat at consultation

would also help as would inclusion of project details on the West Dunbartonshire Council, Citizens Advice Bureau and WDC Carers centre web sites.

It was felt that the TCAT project has not had time to fully assess the impact and value it can bring to the area. In terms of lessons learned, it was suggested the project team should approach the health board for discussions around a service agreement and a number of additional stakeholders could add value to the project. These stakeholders include, for example:

- Practice Nurse Support and Development Team – This team can provide the opportunity to deliver education sessions to Practice Nurses to increase awareness of TCAT project.
- Primary Care Development Officer – The PCDO can provide intelligence to tailor GP practice engagement, they can also distribute communications to cluster leads and practice quality leads to influence topics for quality improvement.
- NHSGGC GP Cancer Lead – The GP lead can play an influencing role throughout GP practice education, GP forums and overall endorsement of the project.
- NHSGGC Macmillan GP – On the back of the Macmillan Primary Care Toolkit, the TCAT project has an opportunity to follow up with GP practices that are already familiar with the HNA (dependent on Macmillan releasing information on which practices have completed the toolkit).
- West Dunbartonshire Health Improvement – The HI team are currently conducting a test of change regarding screening inequalities, which is still in the early days however one of the audiences they would like to engage with is GP practices. It would make sense to dove-tail into this work to avoid multiple organisations trying to work with GP practices.

The project was considered to be a valuable asset and both consultees would like to see it continued.

Service User Group Focus Groups

We staged a focus group with the service user group to:

- understand the impact of involvement on group members;
- understand what members believe the outputs and impact of the project to be vs planned outputs/impact;
- to understand what the involvement group would like to see happen locally as a result of the project and their input to date

We adopted a participatory method to explore two key statements about the project. The statements were:

- Simple and effective pathway to access a range of services have been established as a result of TCAT in West Dunbartonshire; and
- I found participation in the user group to have been a positive experience.

Participants provide a notional score (out of 10- 0 totally disagree and 10 totally agree) on the extent to which they agree with the statements and asked: why they didn't score lower, why they didn't score higher and what would have to change for them to score higher in the future.

Simple and effective pathway to access a range of services has been established as a result of TCAT in West Dunbartonshire;

The service users pointed to the establishment of the HNA and associated processes as evidence to suggest that a pathway is partially developed. However, they agreed that as the process has only started and is set within three GP practices, there remains work to be done.

On the negative side they recognised that the project started late and there was some difficulty in identifying who ought to deliver the HNA. There was some frustration around the willingness of GPs to engage with the process.

Going forward the service user group suggested that improvements in their perception would stem from access to an on-line toolkit similar to the version available in East Renfrewshire; and further roll-out of services to additional health centres throughout the whole of West Dunbartonshire.

It was suggested that future project delivery and management would be well served with the inclusion of a service user group. However, it was felt that the numbers on the group should be limited in order to maintain its effectiveness as a working group.

I found participation in the user group to have been a positive experience.

The group felt that participation had been a positive experience and this to some extent was because of good project leaders. The group also felt that it had been useful, their opinion mattered. As a result they had improved their own awareness of services and they enjoyed the company and positive support from fellow group members.

The group were frustrated with what they saw as some of the project setbacks and the lack of clarity about the role of the various groups associated with the project.

Moving forward they suggested that they would limit service user groups to about eight members and they would welcome user group membership/participation on the operational group.

The general experience was felt to be positive and examples of where their input to the process was evident. This included the development of the HNA and the invitation letter that is to be sent out to potential service users.

POST-TCAT: Service Users - Patient Views and Experiences

With support from Napier University, we distributed our final questionnaire to service users with which Napier University conducted analysis and provided feedback for our local evaluation.

Analysis Edinburgh Napier University - March 2018

This paper presents a review and analysis of 10 questionnaires completed by patients who had completed an HNA as part of the West Dunbartonshire TCAT Project.

The data analysis was approached in two ways. The responses to individual questions posed were analysed and secondly a broader thematic analysis² of the qualitative responses was undertaken.

All those interviewed about their experience of the TCAT project were positive in their feedback and all stated that they would recommend it to others if it was made available to all cancer patients in West Dunbartonshire. Of note is the enthusiasm with which the participants endorsed this service. For example one stated they would recommend it: “150 percent” and another said: “Everybody finishing cancer should have this service to see what particular things are needed at that time”.

Eight of the 10 participants interviewed met the TCAT Project Officer in a library. Of these, 7 reported that this location was convenient to them as it was near where they lived. The participants, when questioned, were satisfied with various aspects of the facilities within the library. In addition to being a familiar, convenient place, the availability of disabled access facilities (such as a lift and/or a ground floor room) was welcomed.

The fact that the library was a public building was not an issue for participants. Seven specifically commented that within this ‘public’ building, their appointment was conducted in a ‘private room’. Going forward the importance of ensuring HNA appointments are not conducted in ‘open plan’ areas will have to be considered.

The TCAT Project also offers the HNA appointment in people’s own homes. Two people stated that this would not have been suitable for them. However the respondents, who had received a home visit, welcomed this as their ability to attend the library was limited by their personal mobility issues or personal preference.

Half the participants reported that they hoped to get general advice and information by attending the appointment. For others, attending their attendance at the meeting was viewed as an opportunity to discuss their concerns. One hoped to reassure themselves that “they were not alone” in facing issues post treatment and two highlighted this opportunity as of potential value, as it was with someone who was not a family member.

The figure below illustrates the key aspects of the service that led participants to recommend the Project. Of note from this broader analysis is the emphasis placed on the TCAT Project providing opportunities to people affected by cancer to be listened to, heard and to talk about post treatment concerns.



A word cloud illustrating key aspects of the service. The words are arranged in a grid-like fashion. The largest words are 'helpful', 'services', and 'listened'. Other prominent words include 'talk', 'friendly', 'speaking', and 'reassurance'. The words are in various shades of green and brown.

² Guest, G., MacQueen, K., Namey, E. (2012) Applied Thematic Analysis. London. Sage Publications Ltd

The analysis of the responses also identified that the TCAT Officer played a role in connecting people affected with cancer with services that could assist them. Those interviewed provided a number of examples of how, as a result of meeting the TCAT Officer they now know, and in most cases use, local services in their area to help meet their needs.

Two reported using the Macmillan Library Services as a result of attending their appointment in the same location. Another spoke of how the TCAT Project Officer had put them in touch with the Benefits Service and another felt that they now knew where to go and what questions to ask to address their concerns.

The role of the TCAT Officer sign posting participants so services and support is valued and important.

“The Officer listened, told me about services I knew nothing about. I now attend these services regularly. It has taken the weight of the world off my shoulders”

“I would not have known who to contact. I was pointed in the right direction”

Opinion among those who were interviewed as to the timing of the TCAT Project, for them, was split. Six considered the timing of the invitation to have arrived ‘too late’ to be of maximum benefit. These participants suggested that attending the TCAT project closer to the end of their treatment would have been better for them. Four reported that the timing of the appointment in relation to the end of their treatment was ‘fine’.

Participants were asked what they would have done about their concerns if they had not met with one of the TCAT Project Officers. Three stated they would have approached their own GP. The predominant response was however ‘nothing’. The responses convey that without the intervention of TCAT, those with concerns after finishing treatment for cancer would just have ‘soldiered on’.

Review of Stakeholder Consultation

We have reviewed the stakeholder consultation information against the four aims of the project.

1. Establish a co-ordinated gateway approach to service provision;

The stakeholder consultation has provided evidence to suggest that progress has been made in establishing a co-ordinated gateway to service provision. There are important strengths, which outweigh the weaknesses that have been identified by individuals within each of the stakeholder groups.

The review carried out by Edinburgh Napier University demonstrates that those people who have used the service have found it to be a positive experience and would recommend the service to others in their circumstances. As such there is evidence to suggest that a gateway to service provision has been established.

In addition progress is further evidenced because:

- The various management and service user groups have been developed and each has a clearer understanding of their role in developing the gateway to services;
- Connections have been made with medical practices to improve access and first point of contact for patients;
- Additional support services within the community have been identified, beyond Working4U income maximisation, debt management support and learning services which includes access to housing services and family opportunity hub support (delivered from within schools);
- Service users have a meaningful input to important aspects of developing and maintaining the service.

The weaknesses identified by stakeholders include:

- The need to broaden the partnership to include input from the third sector;
- The requirement to ensure NHS and Health and Social Care Partnership representation and input to the development, management and delivery of the service;
- The need to engage with more GP Practices;
- The need to establish an on-line presence and resource.

From a stakeholder perspective the strengths have an important impact, but work has to be done to reinforce the strengths, address the weaknesses and take action on the weaknesses. As such the project, from this perspective has achieved good progress.

2. Review and improve assessment of need processes

The stakeholders are clear that an assessment of need process has been established. This centres on:

- The development and distribution of the HNA. This was supported by the service user group, a key stakeholder in the process;
- A pathway service provision is documented within 'toolkit' and a range of resources to support patient progression towards the range of services they require has been developed;
- It has been recognised that in the absence of a well-managed, dedicated and trained team of volunteers the most appropriate people to support the HNA would be agency staff with a strong knowledge of service provision and networks and local contacts to assist patients to obtain quick access to the available support; and
- The additional training required to support staff working with HNAs has been identified.

The weaknesses identified by stakeholders were:

- The requirement to clearly identify the appropriate way to introduce a volunteer-based approach;

- The need for clarity around who would conduct the HNA in the absence of managed volunteers – i.e. staff from which agency?
- The need to increase the rate of decision making and the pace in which decisions are implemented.

From the stakeholders perspective satisfactory progress has been made because a number of strengths have been identified. The weaknesses though apparent are not important enough to have an adverse effect on the future development of a service designed to improve the cancer journey.

3. Review and improve the supply and availability of information

The stakeholders have identified important strengths in the project. For example:

- The 'toolkit' represents a good source of information for organisations who want to establish a TCAT model of support and a good source of information for staff/volunteers who are supporting service users with the HNA;
- The toolkit is based on an extensive review of resources and has drawn of examples of good practice from other areas ; and
- a number of unintended benefits that are related to the supply of information have been secured, they include:
 - Intensified understanding of the HNA and how it should be used;
 - Greater understanding of the need for staff development (what areas of development would be most beneficial to assist in supplying advice, guidance and referral);
 - Improved working relationships that increases the access to a broader range of information about services and establishes West Dunbartonshire in a better place to take forward projects such as 'Improving the cancer Journey'.

However the stakeholders identified the need for the development of web-based information and the lack of a regularly updated and maintained information base is cited as a weakness.

The strengths around the toolkit outweigh the weaknesses and as such good progress has been made towards reviewing and supplying information albeit within technical constraints. The toolkit will require regular update, to become a 'living document', however this area of weakness could be addressed through the development of a regional web based resource or the use of NHS Inform (with local updates).

4. Maximise opportunities for access work, learning and money service support and other specialist support

The role of Working4U was viewed as a central component of the successes achieved by the project. The combined work, learning and money services provide ready access to benefits and debt advice and learning opportunities. When considered alongside Working4U's strategic delivery partners in the Information and Advice Partnership, Adult Learning Partnership and Youth Alliance, Working4U is well situated to act as a gateway to service users seeking non health related support to improve their quality of life after treatment.

The strategic stakeholder have identified important strengths emerging as a result of participation to suggest the benefit of promoting Working4U as a key lead partner in developing responses to improving the cancer journey in West Dunbartonshire.

Learning from the TCAT project includes:

- A greater understanding of the roles and responsibilities of key stakeholders and how to include them in the development of services;
- Greater understanding of the challenges associated with the development of a case managed support service based on the HNA and subsequent development and delivery of a non-medical 'care plan';
- An understanding of the potential for specialist input.

As a result, the stakeholders have identified major strengths in the approach. However there is also recognition and an expectation that ways to improve partnership working and input will be explored.

Section 4: Evaluation Key Findings:

The project established ambitious aims with modest investment and, given the role of Working4U in delivering a broad range of services the project was delivered by an appropriate lead partner.

There is clear evidence to suggest the project was supported by appropriate partners. However, some work has to be done to reinforce these partnerships and ensure the project aims are met.

The progress towards the project aims, taking into account the support provided to service users, the project desk based review and the stakeholder perspectives can be summarised as:

1. Establish a co-ordinated gateway approach to service provision

There are important strengths and with appropriate partners involved, progress to establish a gateway to service provision has been made. For example, there is evidence to demonstrate a governance infrastructure was established with a reporting structure that has the capacity to plan for change and consider how to manage project risks.

However, there are areas for improvement including the need to ensure the correct blend of strategic partners is in place with a common agreed vision and with clear roles and responsibilities. There was also some concern about the rate of decision making and the pace of implementation of decisions.

Despite this cancer has been established as an issue for consideration in its own right in West Dunbartonshire. The TCAT project has provided the opportunity for key health and social care partners, delivery stakeholder and service users to consider how best to establish appropriate pathways to support and delivery of that support. Commitment to achieving this aim is strong.

As such, the strengths outweigh the weaknesses and as such *good* progress has been made towards the development to a co-ordinated approach to service provision.

2. Review and improve assessment of need processes

Progress towards the improvement of assessment and process was characterised by a number of strengths including the development and distribution of the HNA, the creation of an information toolkit and associated process documentation. As this was supported by the service user group, a key stakeholder in the process, this was considered to be a key strength. A pathway service provision is documented within 'toolkit' and a range of resources to support patient progression towards the range of services they require has been developed.

However, the questions and challenges around the use, or otherwise, of volunteers to deliver the HNA was not completely resolved. Trained staff stepping in to fulfil the role appeared, to many of the stakeholders, as a positive departure and provides a clear option for the future delivery of services designed to improve the cancer journey.

While the strengths have had a positive impact there are important weaknesses; including, for example the fact that fewer than anticipated HNAs were carried out. While these weaknesses have not had a substantial impact, some work will be required to address them. This generated discussion and divided opinion between those stakeholders who felt good progress had been made and those that perceived it to be satisfactory. On balance, consensus was reached on the view that *satisfactory* progress has been made towards the project aim of reviewing and improving assessment of needs process.

3. Review and improve the supply and availability of information

Again there are important strengths and progress has been made. Examples of the strengths include the 'toolkit'. This represents a good source of information for organisations who want to establish a TCAT model of support and a good source of information for staff/volunteers that are supporting service users with the HNA.

However, the stakeholders identified the need for the development of web-based information and the lack of a regularly updated and maintained information base is cited as a weakness. The development of a web based resource was beyond the scope of the project and, if pursued,

would have compromised progress in other aspects of the project. For example, the development of the toolkit and the policy and procedures required to manage a TCAT service.

Nonetheless the strengths around outweigh the weaknesses and as such *good* progress has been made towards reviewing and supplying information.

4. Maximise opportunities for work, learning and money service support and other specialist support

Important strengths in progress toward this aim are identifiable and taken together these strengths outweigh areas for improvement. The role of Working4U was viewed as a central component of the successes achieved by the project.

Learning from the TCAT project includes:

- A greater understanding of the roles and responsibilities of key stakeholders and how to include them in the development of services;
- Greater understanding of the challenges associated with the development of a case managed support service based on the HNA and subsequent development and delivery of a non-medical 'care plan';
- An understanding of the potential for specialist input;
- And the development of a clear focus on cancer as an issue in its own right has been established.

However, there is also recognition and an expectation that ways to improve partnership working and input will be explored. Nevertheless, *good* progress has been achieved and this has established a strong foundation for further development of services to improve the cancer journey.

Section 5: Recommendations

The evaluation has found important areas of strength and good progress has been made towards demanding and complex objectives with modest resources. The evaluation, through desk-based review and stakeholder consultation and assessment of issues emerging through the delivery of HNAs has identified a number of lessons and areas where work is required to consolidate progress to date.

During the latter stages of the TCAT project, West Dunbartonshire was identified for the further development of the regional Improving the Cancer Journey programme and resources have been secured to carry out this work. The progress to date in the TCAT project has important lessons for future development of *'Improving the Cancer Journey'* and delivery of appropriate responses to patient needs.

Key to this will be the strategic involvement of key senior personnel/heads of service from Health (primary and secondary care) and Social Care services and West Dunbartonshire Council. Important service areas would include those that can deliver services associated with the HNA: *physical, practical, family relationship, emotional wellbeing, spiritual, lifestyle and information needs*.

It is recommended therefore that there is further exploration of these issues and lessons from TCAT with a view to establishing a plan for the continued development of services to improve the cancer journey for people in West Dunbartonshire.

This exploration should in the first instance be led by Working4U in recognition of its role in the TCAT project and involve all appropriate partners, drawing on the expertise of those who contributed to the development of the TCAT project.

It is recommended that this exploration can begin with a development session, facilitated by an external organisation or partner such as Edinburgh Napier University, in order to gather the thoughts of key stakeholders as part of the process.

It is recommended that the following themes, based on the findings of the TCAT project evaluation, with associated challenge questions would assist the development of aims, objectives and approaches for the future *'improving the cancer journey'*.

Theme	Challenge Questions
Strategic Leadership	How do we ensure: <ul style="list-style-type: none"> • We have established a coherent vision, set of values and aims? • We have shared the vision? • We can sustain the vision?
Delivery Processes	How do we ensure the service is <ul style="list-style-type: none"> • Well planned and ensures it engages with service users? • Flexible enough to adapt services to meet changing need? • Delivered to a consistently high standard?
Impact on service users	How do we ensure: <ul style="list-style-type: none"> • The service is accessible and targeting those who need it most? • The service draws on appropriate specialist support? • The service has a positive and sustained impact on people's lives? • Capture evidence to demonstrate that change?
Performance Outcomes	How do we ensure <ul style="list-style-type: none"> • That we set challenging targets that lead to improvement? • We have appropriate systems in place to demonstrate our progress against outcomes and targets?

Appendices

Appendix 1: Holistic Need Assessment and Care Plan.

Appendix 2: Consultation Resources

Appendix 3: Partner Logos

Appendix 1: Holistic Needs Assessment and Plan

National Cancer Survivorship Initiative – Concerns checklist

Holistic needs assessment

Identifying your concerns

Discussed by: _____
 Date: _____
 Designation: _____
 Contact details: _____

Patient's name or label

This self assessment is optional, however it will help us understand the concerns and feelings you have. It will also help us identify any information and support you may need in the future.

If any of the problems below have caused you concern in the past week and if you wish to discuss them with a health care professional, please tick the box. Leave the box blank if it doesn't apply to you or you don't want to discuss it now.

I have questions about my diagnosis/treatment that I would like to discuss.

Physical concerns

- Breathing difficulties
- Passing urine
- Constipation
- Diarrhoea
- Eating or appetite
- Indigestion
- Sore or dry mouth
- Nausea or vomiting
- Sleep problems/nightmares
- Tired/exhausted or fatigued
- Swollen tummy or limb
- High temperature or fever
- Getting around (walking)
- Tingling in hands/feet
- Pain
- Hot flushes/sweating
- Dry, itchy or sore skin
- Wound care after surgery
- Memory or concentration
- Taste/sight/hearing
- Speech problems
- My appearance
- Sexuality

Practical concerns

- Caring responsibilities
- Work and education
- Money or housing
- Insurance and travel
- Transport or parking
- Contact/communication with NHS staff
- Housework or shopping
- Washing and dressing
- Preparing meals/drinks

Family/relationship concerns

- Partner
- Children
- Other relatives/friends

Emotional concerns

- Difficulty making plans
- Loss of interest/activities
- Unable to express feelings
- Anger or frustration
- Guilt
- Hopelessness
- Loneliness or isolation
- Sadness or depression
- Worry, fear or anxiety

Spiritual or religious concerns

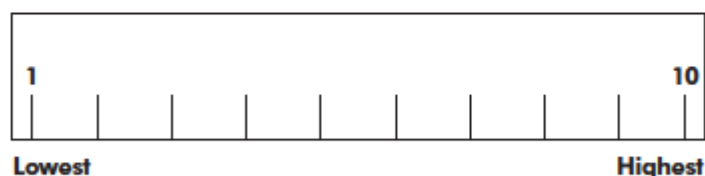
- Loss of faith or other spiritual concern
- Loss of meaning or purpose of life
- Not being at peace with or feeling regret about the past

Lifestyle or information needs

- Support groups
- Complementary therapies
- Diet and nutrition
- Exercise and activity
- Smoking
- Alcohol or drugs
- Sun protection
- Hobbies
- Other

Please mark the scale to show the overall level of concern you've felt over the past week.

You may also wish to score the concerns you have ticked from 1 to 10.



National Cancer Survivorship Initiative – Concerns checklist

Care plan

Completed by: _____
 Date: _____
 Designation: _____
 Contact details: _____

Patient's name or label

Level 1: Score 0–3 Mild concerns

Discuss sources of concern with the patient, include information, contact details and monitor.

Level 2: Score 4–6 Moderate concerns

As above for level 1 and provide information and discuss with a colleague if necessary and signpost to support. Use second level assessment tool if appropriate e.g. HADs.

Level 3: Score 7–10 Significant concerns

As above in Level 1 and 2 and use second level assessment tool if appropriate e.g. HADs and refer to specialist services if required.

Overall score on the scale: _____

Main concerns	Score	Description of concern	Plan of action

Copies sent to:

Next review due:

Appendix 2: Consultation Resources

Strategic Group Stakeholder Consultation (semi structured interview)

Interview Background Information

The '*Transforming Care After Treatment*' (TCAT) was established as a partnership approach in April 2016, with the specific aims to contributing to the transformation of care for people affected by cancer and improve their quality of life as a result.

The demonstration project would operate in West Dunbartonshire for two years and through the development of appropriate processes and input from volunteers the partnership would establish:

- simple and effective pathways to access a range of services;
- methods to cross refer to reduce the need for patients to navigate complex health and social care services when people are at their most vulnerable; and
- Support for people to maximise their recovery and restore their confidence and independence.

Questions

1. What is your understanding of the TCAT Project?
2. Were the appropriate partners involved in the development and delivery of the project
3. How well have the partners worked together to manage the programme, and what could have been done differently?
4. Did the partnership establish a simple and effective pathway to a range of services?
5. Were methods to cross refer to reduce the need for patients to navigate complex health and social care services when people are at their most vulnerable established?
6. Were appropriate resources developed to support for people to maximise their recovery and restore their confidence and independence?
7. What were the challenges the approach was likely to face?
8. Were these challenges addressed?
9. What in your view worked well in the project?
10. What do you think TCAT has delivered to date?
11. On reflection what could we have done differently and what lesson learned can we take forward?
12. Were there any unexpected benefits to emerge as a result of the project?
13. How do you think learning gained within the programme could be implemented within future patient cancer/self-management support programmes?

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