



Transforming Care After Treatment Final Wrap Up Report

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The views expressed in this report are those of Edinburgh Napier University TCAT Evaluation Team and do not necessarily represent those of Macmillan Cancer Support and their partners.

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EXECUTIVE SUMMARY

This is the wrap up evaluation report of the National Evaluation of the five-year Transforming Care After treatment (TCAT) Programme. It builds on the findings presented in the Baseline and Interim reports and directs readers to the related, previously disseminated Evidence and Learning Bulletins.

TCAT was operationalised via the commissioning and funding of 25 local projects, tasked with the development, testing and evaluation of new models of 'care after treatment' service delivery and practice. The bottom up programme design and bidding process resulted in diversity in approach across Scotland and has supported responses to address locally identified needs and service gaps.

TCAT was not however one model of 'care after treatment' set up in different locations, but 25 different projects linked by the programme's overarching objective to transform care after cancer treatment across Scotland.

The purpose of this final report is to set out the lessons learnt from the implementation and impact of TCAT and present the key principles of successful reform, system development and practice enhancement.

The findings and recommendations relate both operationally and strategically to the shared aspirations of the Scottish Government's 2016 Cancer Strategy Beating Cancer: Ambition and Action. TCAT provides insight how evidence based practice can be delivered to enable *"health, social care and third sector services to deliver sustainable and innovative approaches to cancer care which meet the changing requirements of people with cancer to support them to live healthy lives at home."*¹

The findings will also assist providers to achieve the National Health and Wellbeing Outcomes², and the 2020 Vision³ to *"have a healthcare system where we have integrated health and social care, a focus on prevention, anticipation and supported self-management."*

The principles of reform elicited from the experiences and impact of TCAT are aligned with the overarching aims of health and social care, which include improved patient experiences and outcomes and more efficient resource use such as reducing unnecessary clinical follow-up. As such the principles and recommendations from TCAT should be applied to all living with and beyond cancer initiatives including Cancer Prehabilitation, Rehabilitation, Improving your Cancer Journey, Macmillan@Glasgow Libraries, Macmillan One to One and Move More.

What has been learned from TCAT is not cancer-specific. The findings resonate with the Principles of the Modern Outpatient⁴ which like TCAT aims to strengthen knowledge exchange and self-management in the community with the patient at the centre and ensure patients can access decision support, care planning and care services in the community wherever safe and appropriate.

KEY LEARNING

TCAT initiatives have confirmed the need for services and individual practice to consistently view diagnosis and treatment for diagnosis of cancer, not as distinct event in a person's life, or a separate component of care delivered at a set time in that pathway – but as a linked part in their whole life's journey. To be effective, the planning and provisions of 'care after treatment' cannot be an afterthought or introduced to patients and their families at the end of treatment.

For example, the value of a care plan to PABC was reported in the Scottish Cancer Experience Survey⁵. However, only 22% of patients said they had received one and the question was framed within aspects of their 'overall NHS Care'. This not only suggests that many people do not receive a plan, but that its purpose is predominantly linked to diagnosis and treatment by the NHS and not, as it should be to living well with and beyond cancer using all the sectors, assets and resources available in each individuals local community.

TCAT has been a catalyst for the development of Treatment Summaries and the drive towards eHealth approaches and shareable formats, linked to after treatment care plans must be continued.

There is also large potential benefit for PABC if cancer care is integrated within generic or long-term condition community based assessments, support and health and well-being events that are organised locally.

If the cancer pathway is to be truly stretched and strengthened to include living with and beyond cancer, HNAs, care plans and the other components of the Recovery Package cannot continue to be delivered as one off interventions. To do so will merely perpetuate a segmented silo'd sequence of standalone interventions. The future delivery of HNAs and Care Plans must be implemented in the context of the whole cancer journey, the whole recovery package and the whole person.

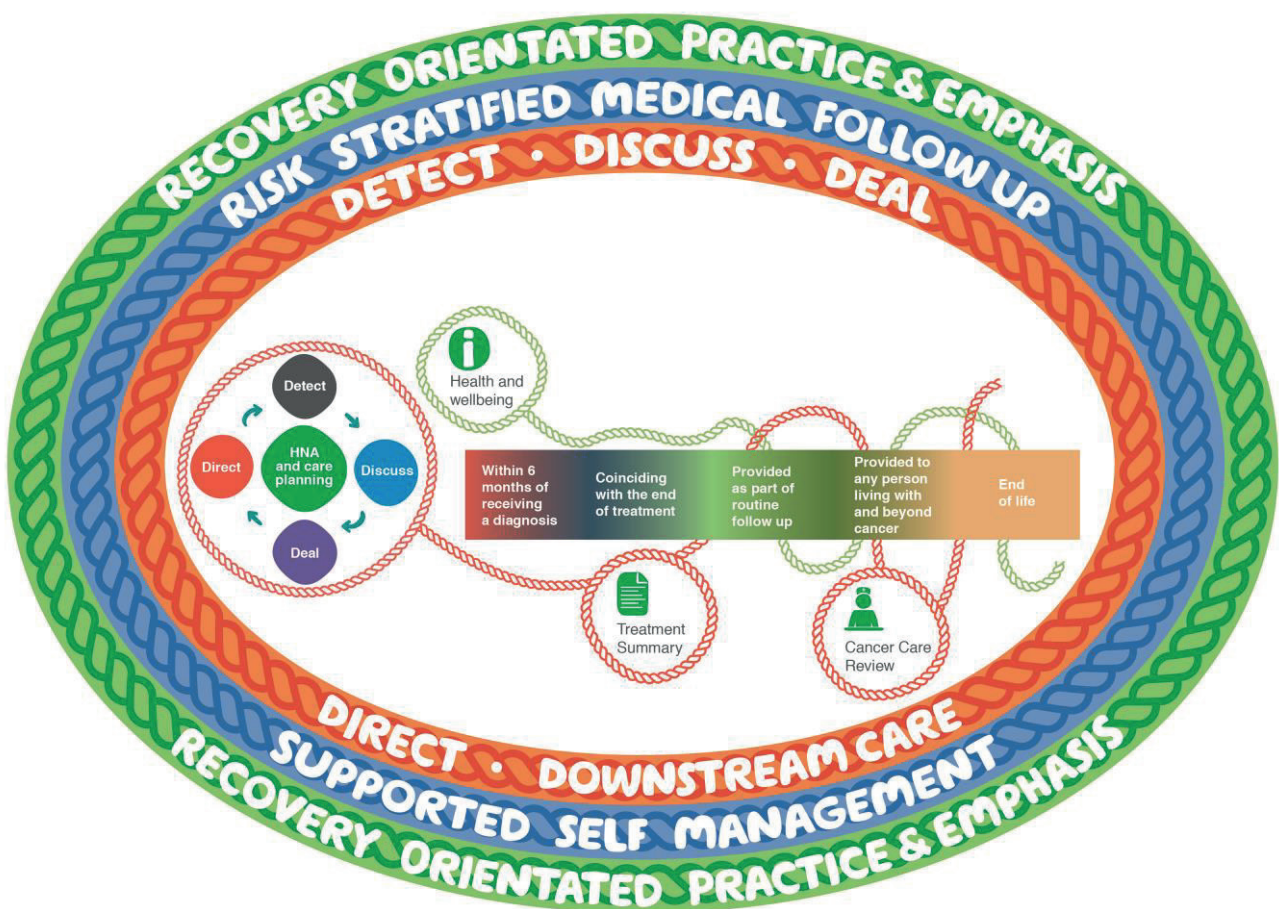
TCAT has demonstrated the need for Recovery Orientated Practice and Emphasis (ROPE) to be embedded at the start of the cancer journey and sustained throughout. Key to shining a light on the need for Recovery Orientated Practice and Emphasis (ROPE) was the diversity of the programme. Had it lacked variety or ambition it would have failed to demonstrate and reinforce as starkly that in order to have a significant impact on the experiences and outcomes of care after treatment there is a need for all those involved in the care of PABC to reframe our understanding and approach to 'care after treatment'.

Seven Principles of Recovery Orientated Practice and Emphasis

1. ROPE requires that all new services must acknowledge and understand from a patient perspective the connectivity and interdependence of strategic and operational service implementation decisions being made to improve cancer care. Moving forward recovery services should by default be jointly provided by capitalising on the extensive groundwork and preliminary embedding of relationships, necessary for the required future joint practice. Without an overall partnership approach to ROPE, care after treatment will merely continue to be a set of single, silo'd interventions.
2. The strategic sustainability of the transformation of care after treatment is contingent upon a commitment to ensuring and enhancing the evidence of its success. There is a need for the commissioning of longer term projects with robust evaluation systems that can follow patients through their cancer pathways for many years. Future research effort should also be concentrated on understanding the extent to which services people are signposted to after an assessment, have been taken up and investigate further the characteristics of and reasons why people do not use a 'recommended' or 'referred' to service.
3. Identification and assessment of concerns/need at key transition points must be understood as only a means to an end. In the future ROPE services must guard against the danger of the assessment tool 'wagging the dog'. Recovery Orientated Practice and Emphasis is not about what you do but the way that you do it. In relation to HNAs for example – the question 'how many HNAs and Care Plans have been done' becomes 'how should this assessment and care plan be delivered and assured?' Such a shift will need increased understanding of required competencies and skills at each patient/service interaction. This will assist service commissioners to ensure that PABC interact with the right person, with the right skills at the right time.
4. For ROPE to be truly effective it needs strong networks of accessible, available support, appropriate to the individual circumstances to actually meet the need. The focus of service developments must move towards the actual provision of ROPE services and support in the community. This shift in emphasis will enforce a reduced reliance on 'signposting' as an adequate or effective action to meet an individual's needs. These services should maximise connecting PABC to community resources and assets and initially focus specifically upon the most commonly reported enduring concerns of fatigue, worry/fear/anxiety and also address cancer specific functionality.
5. Orientating all cancer care towards recovery requires 'listening' to be embedded as a key principle of reform. TCAT has demonstrated that patients benefit from having the time and space to voice their concerns and how that

can support self-management. The powerful testimonials and case studies collated during the TCAT Programme offer a valuable dossier of information for initial discussions with stakeholders as to how best to ensure practitioners operate in a system that values ‘listening’.

6. The new cancer story rightly places the patient at the centre and emphasises their role and responsibilities in their own individual ‘recovery’. Essential for the future embedding of ROPE is the inclusion and influence of the voice of people affected by cancer – and essentially enhancing the ability of PABC to ‘own their own story’.
7. TCAT identified and endorsed four key components of successful user influence. ROPE must ensure that the patient voice is supported, embedded, positive and meaningful. These components combine to offer a final principle for the successful transformation of TCAT into ROPE.



RECOMMENDATIONS

- HNA and Care Planning must be offered to all PABC from diagnosis as part of a co-ordinated intervention throughout their cancer journey. All HNA and care planning consultations must be recovery focussed and contribute to understanding of complexity and clinical need to inform individualised risk stratification of a patient's clinical follow up.
- The concerns checklist is an important tool for detecting and legitimising concerns and its continued use as a tool to aid recovery is recommended for PABC. Consideration going forward should be given to how best to use the Concerns Checklist with carers and people in the palliative stages of cancer.
- Provision of adequate time and space to the patient is vital within the delivery of patient led holistic assessment and care planning to support self-management. HNA and care planning appointments must be implemented as recovery focussed consultations, where the assessment and care planning processes are the sole objective of the meeting.
- Any future patient reported outcome/experience measure of HNA and care planning must include that PABC feel that they have had the opportunity to talk about their concerns and report consistently that these were actively listened to.
- Optimally assessors will act as a conduit between treatment centres, primary care and community assets to provide the required consistent point of contact for reassurance, reinforcement and maximisation of receptivity to using community resources to enhance their own self-management. The extension of Cancer Care Reviews and the role of Practice Nurses and the wider primary care team (and Primary Care embedded workers such as Scottish Government Link Workers or Community Connectors) offer significant potential. They are uniquely placed to act as a conduit between the NHS and community assets, from diagnosis, can offer a consistent approach to review and coordination of care and develop referral/signposting activity to improve uptake.
- Going forward action must focus on ways to increase the uptake of self-management support in the community. There is a need for longitudinal research into the drivers and barriers to service uptake post assessment ⁶.
- Care plans must be reviewed periodically to reinforce self-management activity, through support and reiteration of the message of recovery. The reinforcement through review takes the chance out of a one off appointment coinciding with the PABC being receptive to support and self-management.

Care planning and care plans for people affected by cancer have been shown to contribute to an improved overall experience but their utility must be further evaluated as a matter of priority.

- The aggregated data gathered from TCAT provides a valuable opportunity to understand the needs of people after treatment for cancer and further interrogation of the data should be commissioned.
- Service commissioners and practitioners must prioritise the design and delivery of locally accessible services and support to help PABC manage the predominate concerns of fatigue and worry.
- Every person affected by cancer must have a Treatment summary at the end of each episode of treatment detailing the diagnosis, their treatment, its intent and side effects.
- All health boards should review their rapid access to palliative care policies and services for those individuals where treatment is not an option, against the Proactive Best Supportive Care exemplar.
- Service piloting and broader research are recommended to further enhance the efficacy of HNA and Care Planning:
 - A longitudinal evaluation of the utility and effectiveness of Care planning and Care plans for cancer survivors and their role in increasing uptake of support in the community through reassurance and reinforcement.
 - A needs assessment of required training and mentoring to support optimal implementation of HNA and Care planning.

In taking forward the work required to implement the recommendations made in this report the strategic partners of TCAT must now:

- Ensure and enhance primary care teams as key partners in the development of services to support PABC
- Re-address the dominance of NHS representatives within the partnerships established via TCAT

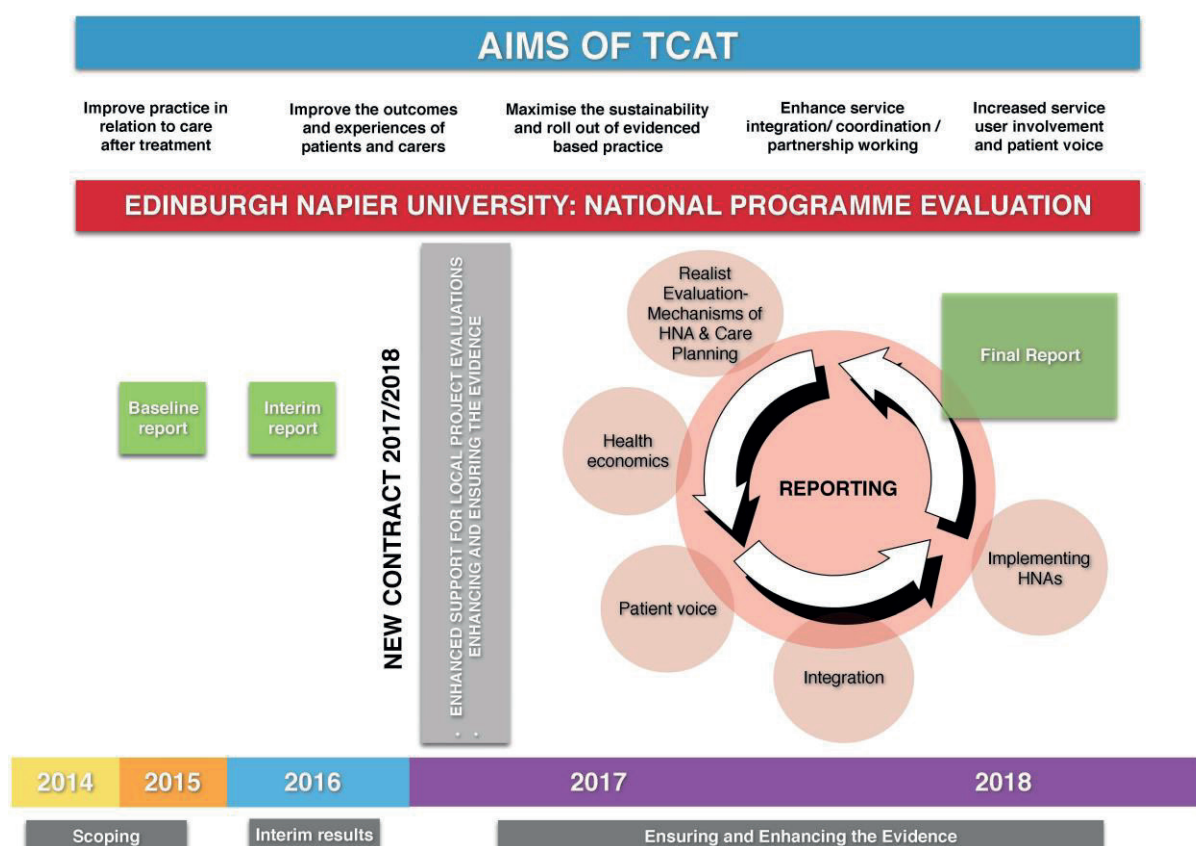
- Determine and disseminate the future TCAT role of the Cancer Networks in furthering the integration agenda to support people affected by cancer
- Consider how local integration and service coordination can be enhanced and maintained, without the impetus of funding and focus provided by the national programme.
- Ensure that TCAT is instrumental in driving forward the new narrative of Recovery Orientated Practice and Emphasis. The programme has resonance in Scotland and further developments should link themselves to this 'brand'.

1. PURPOSE AND CONTENT

This is the final wrap up report of the National Evaluation of the five-year Transforming Care After treatment (TCAT) Programme. It builds on the findings presented in the Baseline and Interim reports and directs readers to the related, previously disseminated Evidence and Learning Bulletins.

- Measurable Outcomes from TCAT
- TCAT and the Patient Voice: From Involvement to Influence
- Impact of TCAT on partnership, integration and co-ordination
- Holistic Needs Assessment: Implications for Practice
- Mechanisms of HNA and Care Planning – A Realist Evaluation

The diagram below illustrates the relationship over time of the aims of TCAT, to the evaluation activity and fieldwork and the national evaluation Reports and Bulletins.



The purpose of this final report is to set out the lessons learnt from the implementation and impact of TCAT and present the key principles of successful reform of care after treatment.

Firstly, the report outlines the aims of the five-year TCAT programme and the scope and coverage of the National Evaluation. It then discusses the impact the five-year TCAT programme has had on:

- Developing practice and innovative care after treatment services
- Improving the outcomes and experiences of after care for people affected by cancer
- Influencing attitudes, behaviours and priorities related to after care locally, regionally and nationally

2. TCAT and the National Evaluation

2.1 TCAT as a 5-year Programme

Transforming Care After Treatment (TCAT) was a five-year programme (2013-2018) funded by Macmillan Cancer Support. Focused on the care and support of people after treatment for cancer it was a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland, local authorities and third sector organisations that aimed to:

- enable people affected by cancer to play a more active role in managing their own care;
- provide services which are more tailored to the needs and preferences of people affected by cancer;
- give people affected by cancer more support in dealing with the physical, emotional and financial consequences of cancer treatment;
- improve integration between different service providers and provide more care locally.

TCAT aimed to test new models of health and social care directly relevant to the National Health and Wellbeing Outcomes², and the 2020 Vision³ to *“have a healthcare system where we have integrated health and social care, a focus on prevention, anticipation and supported self-management.”*

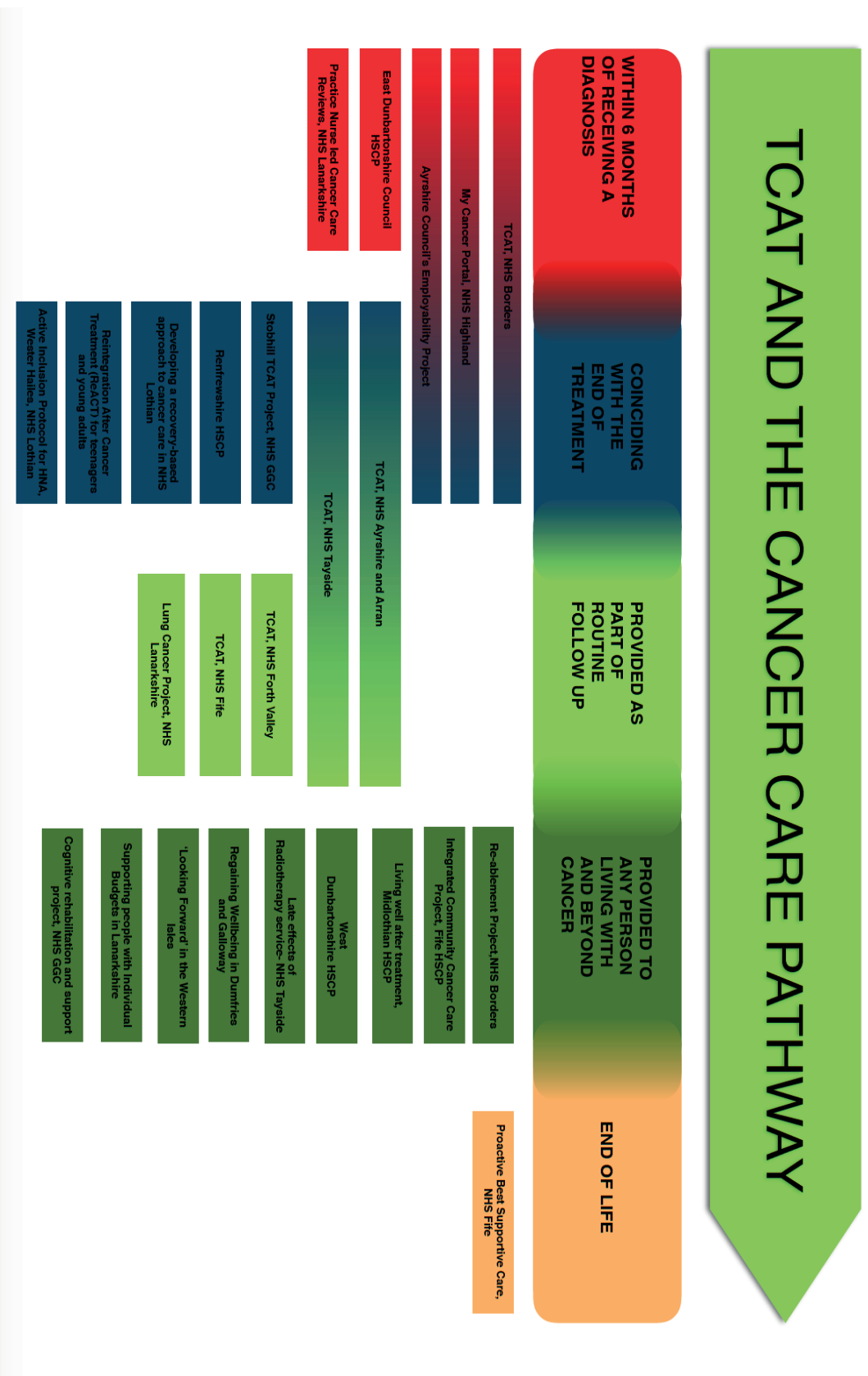
With a focus on care after treatment, operationally and strategically, TCAT shared the aspiration of the Scottish Government’s 2016 Cancer Strategy Beating Cancer: Ambition and Action *“for health, social care and third sector services to deliver sustainable and innovative approaches to cancer care which meet the changing requirements of people with cancer to support them to live healthy lives at home”*¹

2.2 TCAT as 25 individual local projects

TCAT was operationalised via the commissioning and funding of 25 local projects, tasked with the development, testing and evaluation of new models of 'care after treatment' service delivery and practice. The bottom up programme design and bidding process resulted in diversity in approach across Scotland and has supported responses to address locally identified needs and service gaps.

TCAT was not however one model of 'care after treatment' set up in different locations, but 25 different projects linked by the programme's overarching objective to transform care after treatment across Scotland. The figure below illustrates where on the patient pathway each local project focussed their work (see Figure 1).

Figure 1: Focus of local TCAT Project activities across the cancer pathway



2.3 The National Evaluation of TCAT

Edinburgh Napier University was commissioned by Macmillan Cancer Support in May 2014 to conduct a national evaluation of the TCAT programme.

An Appreciative Inquiry approach⁷ was used by the Edinburgh Napier University Evaluation Team. Appreciative inquiry focuses on identifying what works well and taking time to understand why this is so, then adapting practices to capture success. Appreciative Inquiry approaches were embedded into fieldwork tools such as interview and group discussion topic lists and online survey questions. This approach has proved invaluable as the national evaluation covered numerous local multi-component interventions within a complex local, regional and national programme.

Further details of the evaluation work strands and fieldwork undertaken over four and a half years are presented in detail in the Baseline and Interim reports and accompanying Technical Appendix.

As the national evaluation was commissioned as an overall programme evaluation there was no expectation from the commissioners for the national evaluators to report at project level but the commissioners stated that they wanted to *“align the project self-evaluations with the programme evaluation”*⁸

Macmillan Cancer Support acknowledge that “large-scale transformative programmes of work take longer to deliver and even longer to see the full results”⁹. TCAT is a dynamic transformative programme of change and as such no time-limited evaluation can claim to capture comprehensively all its moving parts or spin offs.

At the end of 2016, it was acknowledged that the commissioned capacity of the evaluation team was insufficient to address the extensive number of components within the programme. As a result, the dedicated work streams within the national evaluation work do not cover:

- End of Treatment Summaries
- Health and Wellbeing Events
- Information provision (service mapping and service directories)
- Impact of work commissioned as Phase 3 of the programme

The second contract for the national evaluation work for 2017 and 2018 established additional work strands to enhance and ensure the evidence for the predominant intervention in the Recovery Package – holistic needs assessment (HNA) and care planning. The results of the realistic evaluation of HNA and care planning are reported separately.

3. THE IMPACT OF TCAT

This section discusses the impact the five-year TCAT programme has had on:

- Developing practice and innovative care after treatment services
- Improving the outcomes and experiences of after care for people affected by cancer
- Influencing attitudes, behaviours and priorities related to after care locally, regionally and nationally

3.1 TCAT and the Recovery Package

As a result of the TCAT programme, the Recovery Package (RP) has been implemented across Scotland, testing different 'combinations' of the components that form the RP: Holistic Needs Assessment, Treatment Summaries, Cancer Care Reviews, and Health and Wellbeing Events. These components of the RP when combined would support self-management and be complemented by assistance with, physical activity as part of a healthy lifestyle, managing consequences of treatment, and information, financial and work support.¹⁰ No local TCAT project however attempted to include all RP components within their work, with most focussing on one or two only. The majority focused on the Holistic Needs Assessment and Care Planning.

3.1.1 HNA and Care Planning

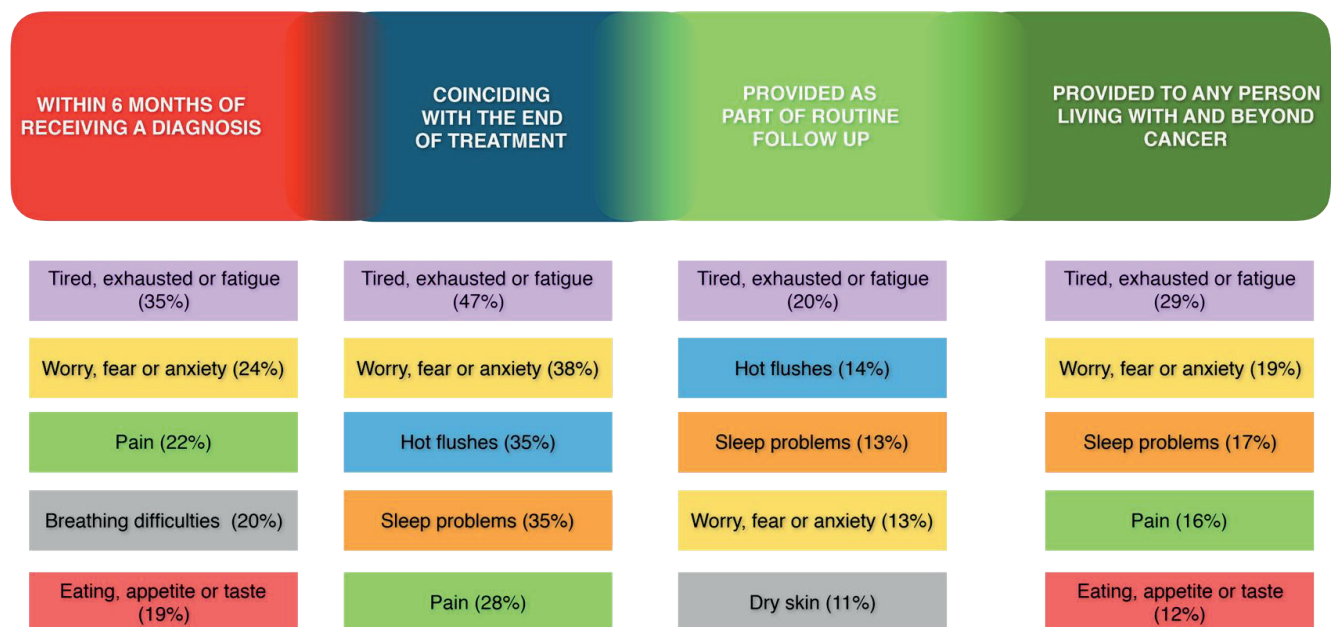
Nineteen projects tested the use of an assessment and care-planning tool. More than 2,800 holistic needs assessments have been completed during the programme. Of these, 14 used of the Concerns Checklist. The five other projects used a different tool: the Sheffield Profile for Assessment and Referral for Care, the Canadian Occupational Performance Measure, or developed already in use assessment protocols (such as prostate specific assessments, multi-disciplinary protocols for lung and Self-Directed Support assessments) or developed a local questionnaire to assess the needs of patients.

The concerns checklist is an important tool for detecting and legitimising concerns and its continued use as a tool to aid recovery is recommended for

PABC. Consideration going forward should be given to its use with carers and people in the palliative stages of cancer.

The concerns of patients living with a cancer diagnosis are also clearer thanks to the work of the TCAT programme. In addition to helping practitioners to tailor care and support to address identified needs, it “also gives a valuable source of information for research purposes and local service planning and commissioning”¹¹. The aggregated data gathered from TCAT provides a valuable opportunity to understand the needs of people after treatment for cancer. Figure 2 illustrates the enduring nature of some of these concerns by presenting the top five concerns reported by PABC at different stages of their cancer journey.

Figure 2: Top five reported concerns of patients^a



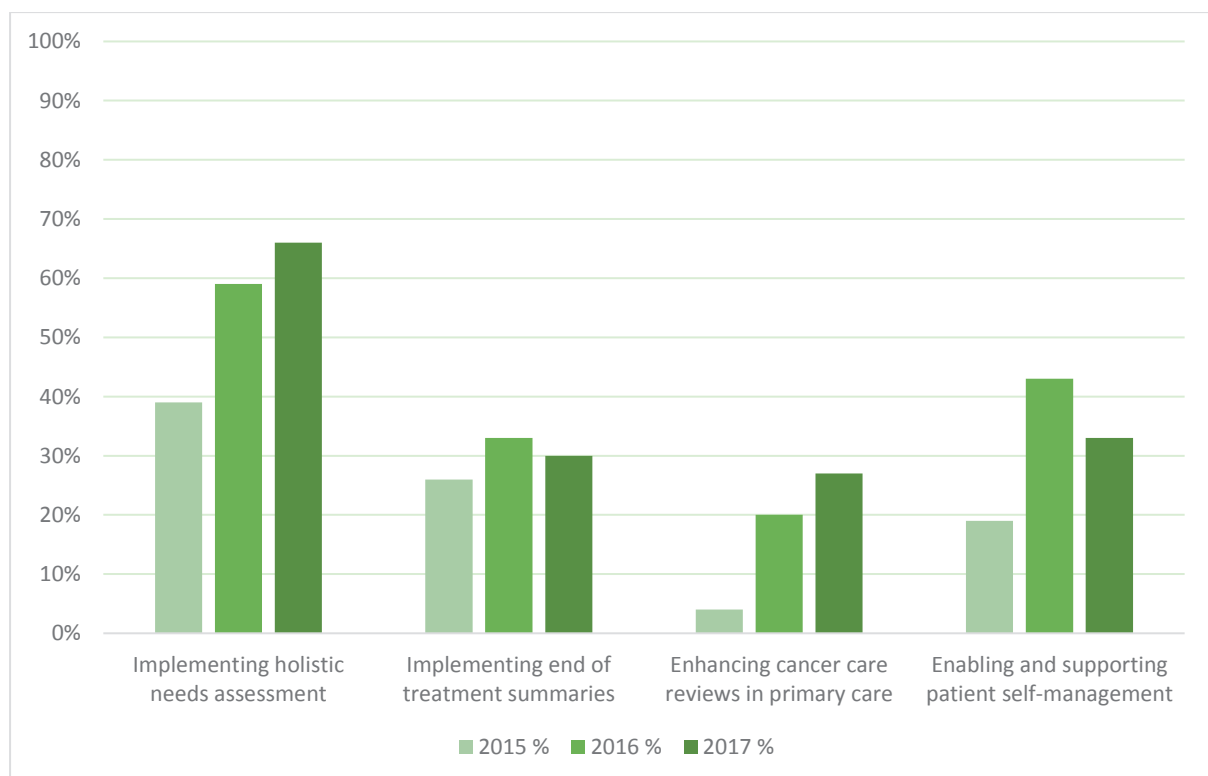
^a Based on analysis of concerns data from 1,488 HNAs. The ‘timing of the assessment’ relates to the location of the PROJECT on the care pathway and not the elapsed time from diagnosis to assessment.

As can be seen from the figure above – at all stages of the cancer journey – the concern of ‘tired, exhausted or fatigued’ tops the list of reported concerns. It should be noted that this data is from a mixed sample of cancer diagnosis – further illustrating the prevalence of this concern. In addition, PABC report in large numbers being affected by ‘worry, fear and anxiety throughout their cancer journey.

In order to meet the needs of people living with and beyond cancer, service commissioners and practitioners must prioritise the design and delivery of locally accessible services and support to help PABC manage fatigue and worry.

The three-year longitudinal online survey^b Of TCAT's wider stakeholders asked annually about the perceived impact of the programme on the key elements of the Recovery Package and its ultimate aim – that of supporting self-management. Figure 3 presents this data.

Figure 3: Percentage of stakeholders reporting TCAT has had, to a great extent a direct impact on key components of the Recovery Package (2015, 2016, and 2017)



^b An online survey of wider stakeholders (defined as local project’s Steering Group members, regional and national stakeholders) conducted in 2015 (n = 195/responses = 73) and repeated in 2016 (n = 371/responses = 134) and 2017 (n = 371/responses = 106).

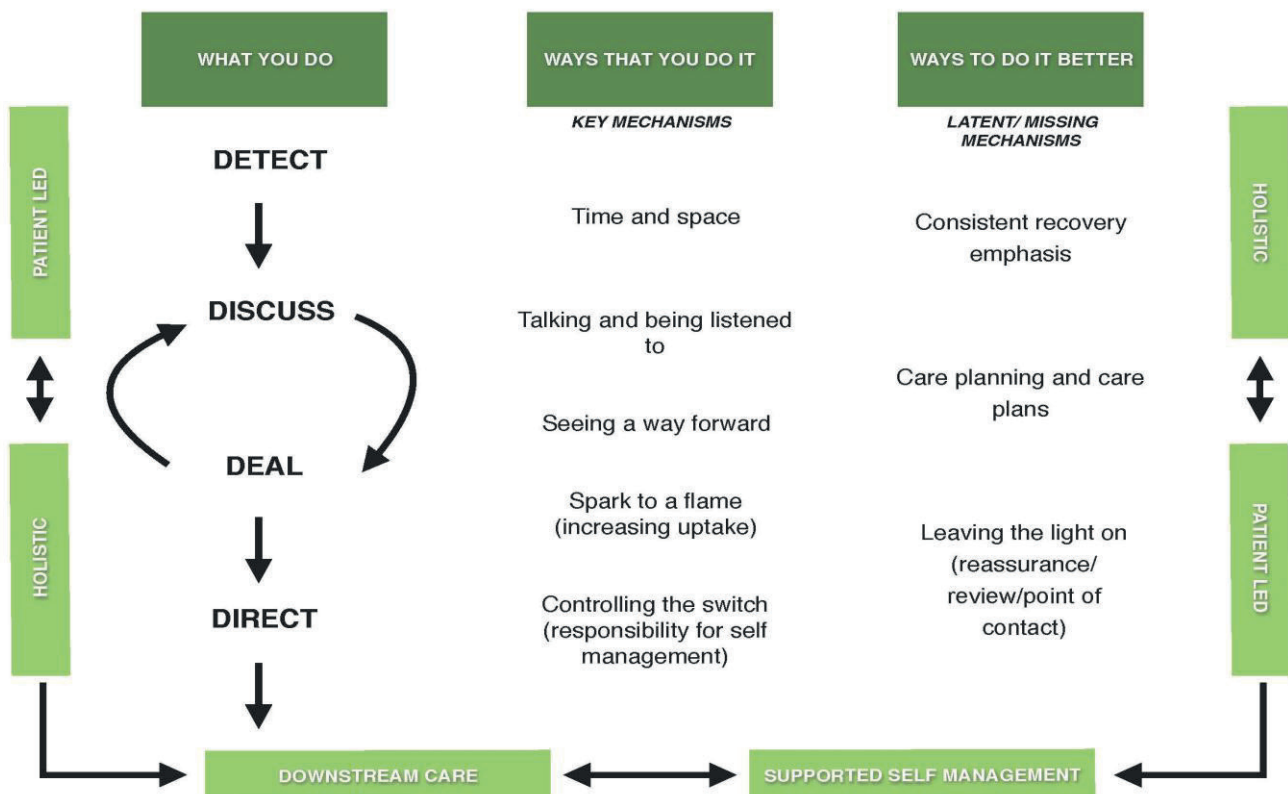
A key area of greatest activity and impact for TCAT has been in the implementation of HNA and care planning. In 2017, 66% of TCAT wider stakeholders in comparison to 39% in 2015, considered TCAT to have impacted on the implementation of HNA 'to a great extent'. This illustrates the impact of the programme on this key intervention over the duration of TCAT. TCAT has demonstrated different approaches to the cornerstone of any intervention to improve outcomes – that of 'identifying or detecting' the concerns and unmet needs of PABC.

Enabling and supporting self-management was found within the planned outcomes of all 25 TCAT projects. However, the reported perception of impact is low, with only a third (33%) in 2017 considering TCAT has 'to a great' extent had a direct impact enabling and supporting self-management.

It is not possible to explain in-depth this lower level of reported 'impact' in relation to supported self-management. To some extent it is a complex and intangible concept and as a result less likely to attract wholesale endorsement in a simple Likert scale.

However some answers were provided by the Realist Evaluation of HNA and Care Planning, undertaken as part of the national evaluation of TCAT. A summary of the realist evaluation findings is presented in Figure 4 and the recommendations in Box 1.

Figure 4: Key causal mechanisms of HNA and Care Planning



Box 1: Six recommendations to improve the implementation of HNA and Care Planning

1. To ensure adequate time and space which is vital to patient led holistic assessment and support, HNA and care planning appointments must be implemented as recovery focussed consultations, where the assessment and care planning processes are the sole objective of the meeting
2. Any future patient reported outcome/experience measure of HNA and care planning must include that people affected by cancer (PABC) feel that they have had the opportunity to talk about their concerns and report consistently that these were actively listened to.
3. HNA and Care Planning must be offered to all PABC from diagnosis as part of a co-ordinated intervention throughout their cancer journey. All HNA and care planning consultations must be recovery focussed and contribute to understanding of complexity and clinical need to inform individualised risk stratification of a patients clinical follow up.
4. Optimally assessors will act as a conduit between treatment centres, primary care and community assets to provide the required consistent point of contact for reassurance, reinforcement and maximisation of receptivity to using community resources to enhance their own self-management. Practice Nurses and the wider primary care team offer most potential.
5. Care plans must be reviewed periodically (mechanism) to reinforce self-management (outcome) in the person with PABC, through support and reiteration of the message of recovery. The reinforcement through review takes the chance out of a one off appointment coinciding with the PABC being receptive to support and self-management (outcome/mechanism).
6. The utility of care planning and plans must be further evaluated and enhanced.

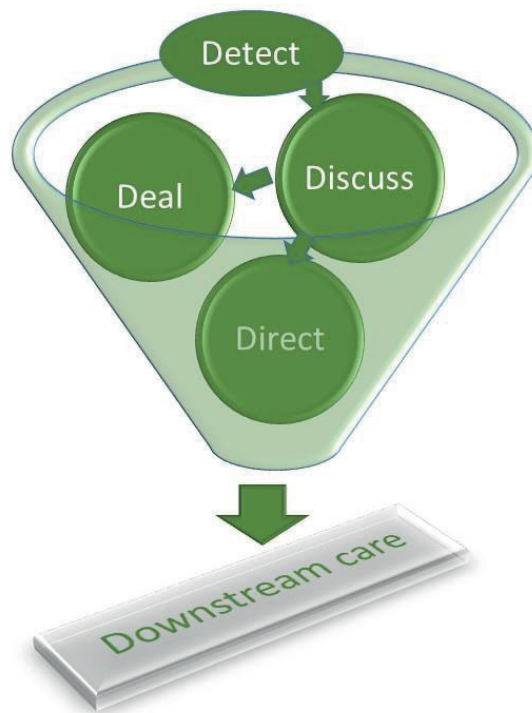
Edinburgh Napier University undertook an independent/non-funded systematic review to complement this realist investigation of the assessment and care planning process. It found that many of the relevant 'triggers' to enhanced self-management are found in the interaction between the assessed and the assessor.

Both the realist evaluation and the literature review suggest that *the way* in which an HNA is implemented is much more important to our understanding of outcomes than *what* is implemented. The key ways an assessment's construct will impact on experiences and outcomes are related to the extent to which assessors can effectively *detect* concerns, *discuss* these with the patient and/or in some cases *deal* with concerns and *direct* them to appropriate support (*downstream care*).

These five components of an HNA are critical to patient outcomes and it is proposed that they provide a valid premise for a much-needed conceptual framework for HNA processes and actions. This conceptual framework offers researchers and practitioners “a network, or a plane, of interlinked concepts that together provide a comprehensive understanding of phenomenon or phenomena”¹².

Accordingly, the utilisation of these four delineated and identifiable components of HNA for people affected by cancer within a conceptual framework will provide an empirical basis for further research of this intervention specifically and wider survivorship research. An outline of the proposed framework is given in Figure 5.

Figure 5: Premise for conceptual framework of HNA and care planning¹³



TCAT projects illustrate how uptake can be improved by developing new referral routes into services. One example is a project establishing links with Breast Cancer Care to create a direct referral route for women to attend this charity’s ‘Moving Forward’ course. Other projects formalised links to local Macmillan Move More projects. Signposting too has been enhanced by TCAT Projects. For example, as a result of the NHS Lothian Phase 1 TCAT project, Clinical Nurse Specialists reported changes in their signposting practices. Previously dominated by Maggie’s Centre’s ‘Where Now course’ and the Macmillan Information Centre, PABC now benefit from a variety of other local resources and non-cancer specific services such as

befriending schemes. Other projects also report similar widening access to services and support.

“at a local level we have already seen an uptake in services that were not well known” (Wider Stakeholder)

“I think there’s huge untapped help we can be getting from community sources...and I think it’s the trust that they’re building up like X never referred to Y, but they have now because they’ve met each other at events.” (Local Project)

Five local TCAT projects developed or enhanced the coordination of available aftercare services. These were the projects in Dumfries and Galloway, NHS Lothian’s Phase 2 project based at Wester Hailes, NHS Borders (Phase 2) and Fife Council’s phase 2 project – Integrated Community Cancer Care project and Ayrshire and Arran (Phase 1). Each project illustrated it was important for the routes to ‘downstream care’ to be visible and understandable to both professionals and recipient patients and their carers.

Such strong referral routes can improve the uptake of services designed to address the concerns of PABC. There is growing evidence service use, and uptake post assessment contributes more to concern alleviation than the assessment process itself.

As a result of implementing HNAs within TCAT, practitioners have increased awareness of available services and support in their local areas. This has improved their ability to *direct* PABC to appropriate, local sources of support. **Going forward action must focus on ways to increase the uptake of self-management support in the community. In this the role of an effective care plan is critical.**

The value of a care plan to PABC was reported in the Scottish Cancer Experience Survey. However, only 22% of patients said they had received one and the question was framed within aspects their ‘overall NHS Care’. This not only suggests that many people do not receive a plan, but that its purpose is predominantly linked to diagnosis and treatment by the NHS and not, as it should be to living well with and beyond cancer using all the sectors, assets and resources available in each individual’s local community.

All sectors must work to strengthen direct links between HNA and care planning and local sources of support (referred to in this report as ‘downstream care’). There is also a need for longitudinal research into the drivers and barriers to service uptake post assessment.

Service piloting and broader research are recommended to further enhance the efficacy of HNA and Care Planning:

- **A longitudinal evaluation of the utility and effectiveness of Care planning and Care plans for cancer survivors and their role in increasing uptake of support in the community.**
- **A needs assessment of required training and mentoring to support the optimal implementation of HNA and Care planning.**

3.1.2 Treatment Summaries

TCAT has been a catalyst for developments in this important area, but more work is needed. The reported impact of TCAT on the implementation of end of treatment summaries stayed constant over the three years of the wider stakeholder survey (26% in 2015; 33% in 2016; 30% in 2017). This is despite the fact that across the TCAT Programme, nine local projects and the national project (TYA) included a commitment to develop and/or introduce an end of treatment summary in their plans. However, with the exception of NHS Forth Valley (who received additional funding), progress has been limited to the testing of paper based summaries by a small number of projects (National Teenagers and Young Adults project, Ayrshire and Arran Phase 1, Borders Phase 1 and Greater Glasgow and Clyde).

Every person affected by cancer must have a Treatment summary at the end of each episode of treatment detailing the diagnosis, their treatment, its intent and side effects.

3.1.3 Cancer Care Reviews

Twenty-seven per cent of all wider stakeholders in 2017 reported that TCAT has had 'to a great extent', a direct impact on enhancing Cancer Care Reviews (CCR) as an approach to care after treatment. This is a dramatic increase from the 4% (1 person) in 2015. Understanding better and exploring potential roles of primary care in the support of PABC after treatment is of interest to many, including Macmillan Cancer Support. Within TCAT however, only one local project fully tested the feasibility of Practice Nurses carrying out CCRs using the Concerns Checklist. A second project conducted a small test of change of this intervention in East Dunbartonshire.

The findings suggest that the extension of Cancer Care Reviews and the role of Practice Nurses and the wider primary care team (and primary care embedded workers such as Scottish Government Link Workers or Community Connectors) offer significant potential. They are uniquely placed to act as a

conduit between the NHS and community assets, from diagnosis, can offer a consistent approach to review and coordination of care and develop referral/signposting activity to improve uptake.

3.1.4 Health and Well Being events

Physical activity, nutrition and UV exposure, are key action areas within the Scottish Cancer Strategy of 2016. Local TCAT projects are excellent examples of how these national 'actions' are being implemented on the ground through health and wellbeing initiatives.

Five local TCAT projects implemented some form of programme, series or one off health and wellbeing event. They were in Tayside (2), Western Isles, Borders, and Fife. These events were diverse in scale, scope and timing of provision. Overall, they had an emphasis on physical activity, managing the consequences of treatment, financial and work support and general information.

Going forward, some projects are collaborating with local community-based organisations to provide cancer related information and advice as part of wider health and wellbeing events in their local area.

Health and Wellbeing events are a way to help people access the support they need by bringing health, social care and third sector agencies together in one place. There is considerable potential benefit for PABC if cancer care is integrated within generic or long-term condition health and well-being events that are organised locally.

3.2 Innovative approaches to care after treatment

Beating Cancer: Ambition and Action¹ reinforced the need to develop new and innovative ways of working to support people affected by cancer. As a result of the testing and piloting work funded by the TCAT programme, there are now evidenced exemplars of approaches to care after treatment, including creative, collaborative service provision, the utilisation of technology and a new model of care at the end of life.

3.2.1 New Services established

Ayrshire Councils – Employability Project

This project was set up to improve the support available for people affected by cancer who want to return to work. It worked with people with cancer, and carers, to help

them overcome the barriers to work. The project also worked with local businesses to help them understand how best to support employees affected by cancer.

NHS Greater Glasgow and Clyde Cognitive Rehabilitation Project

The project is raising awareness among patients and health professionals of some of the side effects cancer patients can experience because of their treatment, including issues with memory and attention. The aim is to make sure people who are experiencing these kinds of problems get the support they need. The project is also running cognitive rehabilitation courses for patients and carers to assist with concentration and memory problems.

3.2.2 New Approaches Piloted

Supporting People with Individual Budgets in Lanarkshire

This project offers people who have finished cancer treatment control of a small budget that they can use to fund an activity or make a purchase. This approach recognises people as the expert in their own life, and the £250 budget was used as a platform from which self-management was promoted and supported. The budget was offered alongside three sessions of support where they talk through how post-treatment PABC can move forward.

A new model of Proactive Best Supportive Care (NHS Fife)

The project offered people with lung cancer who were unable to undergo cancer treatment, a comprehensive assessment of all their needs, followed by a care plan and coordinated support. This led to better care for patients and those close to them and also reduced the number of unnecessary days they spent in hospital.

3.2.3 Technology based care

Two local TCAT projects approached the transformation of care after treatment using eHealth approaches and IT systems (NHS Highland and NHS Lanarkshire Phase 1).

NHS Highlands – My Cancer Portal

This project created an online platform and app called 'My Cancer Portal' that people with cancer used to communicate with their cancer care teams including the completion of an HNA and having access to their treatment summary. This project received additional TCAT funding to build additional features into the cancer portal and spread its use to other health boards.

NHS Lanarkshire - Lung Cancer Project

This project tested how technology could be used to support the delivery of person-centred care. It offered patients with lung cancer, online assessments of their support needs, followed by a care plan and support from a lung cancer nurse specialist face to face or via the telephone.

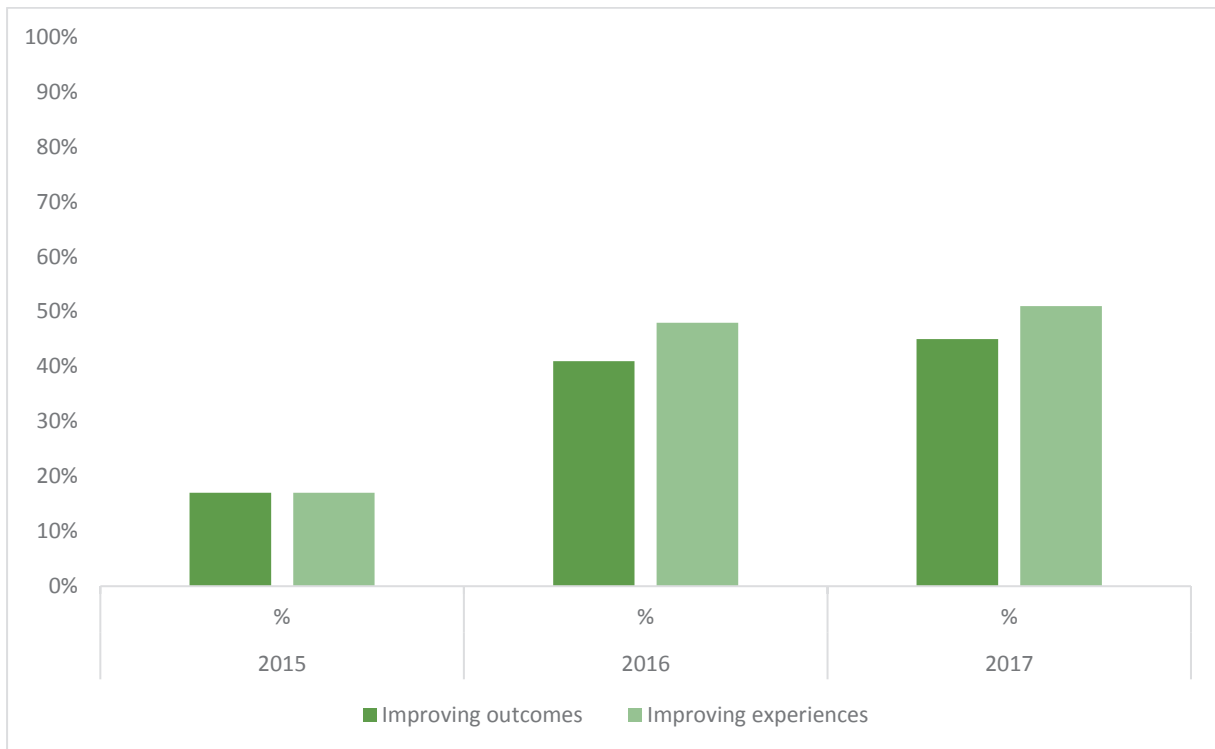
4. IMPROVING THE OUTCOMES AND EXPERIENCES OF AFTER CARE FOR PEOPLE AFFECTED BY CANCER ^c

Macmillan Cancer Support acknowledge that “large-scale transformative programmes of work take longer to deliver and even longer to see the full results”¹⁰. A limiting factor in the development of a strong evidence base from TCAT in relation to patient outcomes was the short -term nature of the local projects.

It is, however, encouraging to report that over three years a growing number of wider stakeholders consider that TCAT has to a ‘great extent’ had a direct impact on outcomes and experiences. One year into the Programme (in 2015) only 17% of wider stakeholders considered as ‘to a great extent’ TCATs impact on outcomes and experiences. In 2017, however, this had risen to 45% (in relation to outcomes) and 51% who felt that TCAT was having ‘to a great extent’ an impact on improving patient experiences.

^c A separate briefing paper reports on the measurable outcomes from TCAT. This provides an overview of the outcome measures employed locally across the TCAT programme in relation to both patients and services. It presents the learning from the health economic work strand of the national programme evaluation. It places these messages in the wider context of the overall measures of impact and outcomes for TCAT.

Figure 6: Percentage of stakeholders reporting TCAT has had ‘to a great extent’, a direct impact on improving outcomes and experiences (2015, 2016, 2017)



It has been previously reported that there was less quantifiable evidence of patient outcomes, such as the possible impact on health and wellbeing. This is in part due to the small numbers of patients in some projects, the pragmatic necessity for local projects to conduct a ‘snapshot’ evaluation of patient views and experiences rather than over long periods of time, resulting in a reliance on self-reported patient feedback and limited local collection of baseline information for comparative purposes.

Many of the anticipated TCAT outcomes and longer-term impact will not be observable for many years. Evaluation effort during the lifetime of one or two-year local projects and indeed a five-year programme therefore naturally focuses on the measurement of progress or *distance travelled* towards these longer term goals^{14,15}By identifying and evaluating ‘intermediate ‘outcomes’¹⁶ and short term impact.

From a thematic analysis of the qualitative patient feedback provided within the local evaluation reports (n = 16), it was possible to identify three key aspects of care after treatment that were reported consistently, as being of particular value to patients.

- The HNA process resulted in patients understanding (sometimes for the first time) that it was legitimate and ‘normal’ to have concerns after treatment and being invited to such a consultation reinforced this legitimisation. (see for

example Practice Nurse led Cancer Care Reviews in Lanarkshire and TCAT in Renfrewshire).

- Being invited to attend an appointment with dedicated time and space to talk about their concerns. Related to this was the value patients placed on being 'listened to'. (see for example Recovery Clinics in NHS Lothian, Integrated Community Cancer Care in Fife).
- Being put in contact with or *directed* to local, community resources and services, via a referral or signposting. But of more value was actually attending the *downstream* service; enjoying it and gaining benefit from doing so (see for example Re-ablement Project in NHS Borders, Regaining Well being in Dumfries and Galloway and Wester Hailes, NHS Lothian Active Inclusion Project).

The thematic analysis of the twenty-six interviews of patients within four projects also elicited these areas of value and benefit. In addition, they provided further insight into the ways in which the HNA process can be beneficial and contribute over time to enhanced capacity to self-manage. These intermediate outcomes, of course, all cumulatively contribute to longer term patient outcomes and experiences, but for clarity, each part (of the whole) is presented as individually as possible.

A number of quotes from the patient interviews are presented in Box 2 to illustrate the cumulative effect and inter-relatedness of the benefits of an HNA and Care Plan. In summary they were found to be:

- Feeling reassured that (a) concerns were 'normal' and (b) that they were coping ok or well
- Feeling supported in that they had established a 'point of contact' should they need help or advice going forward, had raised their 'legitimate issues'
- Positive experience – from which they drew 'strength' (and reassurance and a feeling of support) and for some this experiences could then act as a catalyst for increased 'self-management' and been listened too
- The value of actual 'downstream care' in actually taking up referrals and signposted services, 'downstream' of the assessment.

Box 2: Patient voices explaining how an HNA benefitted them

“No, I think they really got to know how I was feeling and that helped a lot, and then them able to give me information that I wasn’t alone in feeling like that, and other patients, other cancer sufferers have had these same feelings, you’re not on your own here.”(Patient 3)

I got to the point I suppose; I was clutching at straws and glad that anything was going to happen. And having the opportunity to talk about some of the issues that I was going through, that in itself would be helpful because apart from my wife, I have nobody to talk about it. So I haven’t really had anyone, that I could sit down and say, these are the issues for me. So I guess, having the opportunity to talk to somebody for longer than five minutes was a good thing. And then actually having someone come up with a few ideas... [assessor] listened, for a start, which was the first time I’d really had anyone sit down and listen to what I had to say., I suppose, since I’ve had the treatment, that I’d had the opportunity to sit down and actually list and quantify the various effects that the treatment had on me and how it was affecting me. (Patient 20)

But I think with me; it’s been more about reassurance than practical. I mean, maybe more practical advice from the dietician, and the speech and language, well, with the dietician, more. The speech and language therapist was more about reassurance, and this is par for the course, you know, because you’re wondering if you’re doing all right, you know, with these symptoms, is this gonna get better, when is this gonna get better, you know. And although I probably would have managed all right, you know, it was just... that these health professionals were focused on me, and gave me the time to talk about the issues that I had, and the reassurance. (Patient 7)

Well, it couldn’t have come at a better time, because I was going through a bad spell this year, because it’s only this year that I got in touch with [assessor], just couldn’t come to terms with why I was feeling the way I was, and I thought by that time I should be over the effects of treatment... and then I started unloading everything to [assessor] about the way that I’ve never felt the same since my chemo and radiotherapy, and I don’t understand it. And what I learned from [assessor] is that sometimes with patients, [assessor] says what we’ve found is that it’s on-going, the after effect, and this is probably why you’re feeling the way you are. I mean, a lot of times I’m...I’ve got bad days, I think just [assessor] explaining to me about these things just helped me to see and cope with it better... I just felt that took me on a better road...Well, it took a lot...it made me feel better in myself, the fact that somebody knew where I was coming from, that it wasn’t in my head. I just think [assessor] seemed to have the ability to understand, and somebody understanding means an awful lot, because you can talk to your friends, you can talk to your family, but if they’ve not maybe dealt with people that’s had the treatment that I’ve had...I mean, when, my consultant at the very beginning said to me, this is very harsh treatment, I never thought for a minute what it was going to do to my body, I just thought, I’m going to be ill, but because [assessor] was able to help me there, and going to the Maggie’s

centre, I must say, they helped me to see that there's the on-going things, that that's what I was needing to come to terms with, and I think that's where I've benefitted. (Patient 3)

And I think because of, [assessor] that I meet more people, go to my classes and things. Yeah, I need it because I want to find out about other people. And I found that very helpful. So, happier, and I thought I was going to be left alone, after when, you know, oncology said, oh no, that's it now. And you don't need me anymore because it's okay. All the persons are going to look after me is the surgeon, and that's once a year. So what's in between? Nothing. So the [Assessor], you know, put me in the right place... I'd probably just sit in the house, or if I have a problem, phone my nurse, you the nurse that is actually looking after me. Which I did a few times and then she said that I think you are okay now.... Because a nurse is busy, it's not just me, you know, its other people as well. (Patient 13)

Yeah, I feel good, I feel like I've, you know, I've given [assessor] my news, and [assessor] offered assistance in other ways, if I need it, or I've told [assessor] things that I'm proud that I've achieved, and things like that. Probably things that, you know, you'd tell your partner or your friends, and stuff, as well. But having somebody else outside the family and friends, as well, I think it's nice too. But to have, not a pal, you know, or something, but just actually somebody who's got your back...It feels like you've got, you know, somebody is listening, and that person at the other end of the table is listening. And they have the ability, and the resources, to help you, do you know what I mean. (Patient 4)

So, I was very thankful about that advice [assessor] gave me. So it gave me that insight, that turnaround, so yeah. And now, which is good because we have this group, and they arrange meetings, and we kind of update, now and again. So, it's a good window of opportunities to speak to other cancer patients. So I wasn't on my own after all, you know, yeah... So it's a good way of support, after, obviously, medical wise, it does end there, I don't have any other medication to take. But at least I have somebody to give me support, you know, to get back to, have self confidence, and get my focus, and have a priority, you know, to realise what, the main things to prioritise in my life, after what I've been through. (Patient 5)

Without that whole outreach and all the support network that's there, and the HNA is part of that, I would have suffered. I would have suffered silently because you don't...those people make you aware what's out there to help you and you're able to go and get that help, whereas I wouldn't have known that help was out there...They can help you go and get it if you're not able, I was very lucky, my husband and one of my best friends were there supporting me and they ran me lots of places and took me to get the help that I needed. I had that support network behind me that once we knew about it we were able to go and find out about it and get it, rather than if we hadn't known about it, we wouldn't have been able to do anything about it. (Patient 15)

I just thought it would be helpful to talk to somebody because I'm very aware when you go to the doctor that time is limited. And I have lots of issues that worry me and I, kind of, felt, well maybe through this I would be able to get just some support or feedback on what I was feeling ...I was feeling pretty low...I just felt that the most valuable aspect of the meeting was that I felt I wasn't, sort of, left, kind of, wallowing around. I had some pointers to areas that might help me to get more back to where I felt was normal (Patient 2)

But on my last consultation with the consultant, you were just left to get on with it really. I felt that I didn't want to ask questions because you are vulnerable at that time, and I felt it was not conclusive enough for me; I didn't really get a prognosis. I know where I am and what I am but I don't know what else to expect. And I think you get there and I'm maybe using the words wrong, but you're kind of written off as all right, and it's not as easy as that. Cancer is a very lonely illness; it's very difficult to get back when you're at that stage that you're well. You've got to build that... Well, I think it kind of shows you the way forward. I think at the time when [assessor] saw me, I wasn't sure what direction I was going in, and I think it was a very positive meeting, and I felt reassured by it in a way, and another thing it was, it was a commitment. So if you've been unwell and your confidence is maybe down a bit, and it takes you back out into the world if you like, you know, so it had a lot of advantages (Patient 19)

Readers are recommended to also view the powerful testimonials and case studies provided by a number of local projects. (See for example, Re-ablement Project NHS Borders and Wester Hailes Active Inclusion Project, NHS Lothian).

5. IMPACT ON INFLUENCING ATTITUDES, BEHAVIOURS AND PRIORITIES RELATED TO AFTER CARE

While there are few 'quick wins' in cultural change, the evaluation findings demonstrate the positive impact TCAT has had over the last five years on the attitudes and priorities to after care. Those involved with TCAT understood that "redesigning follow up care is as much about cultural change and winning the hearts and minds of the clinicians on the ground as it is about logistics"¹⁷.

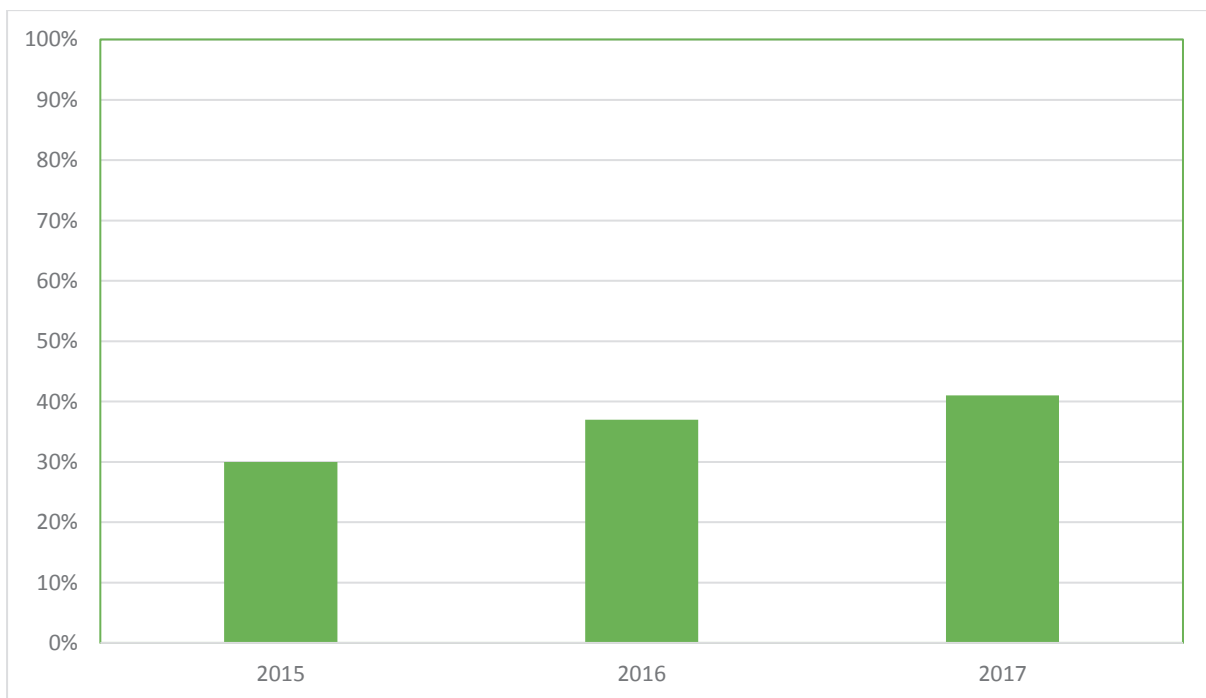
In 2017, over half (56%) of wider stakeholders thought that the TCAT programme was having a direct impact on increasing awareness and acceptance of the importance of care after treatment 'to a great extent'. This reflects a growing acknowledgement of impact in this area over three years, up from 38% in 2015.

Evaluation work has not been directed at 'quantifying' changing levels of awareness or attitude, but qualitative analysis of interviews, surveys and group discussions found a positive narrative of TCAT's impact

TCAT has proved to be a positive vehicle for influencing attitudes, behaviours and priorities in relation to care after treatment. The Interim Report found that much of the early evidence of ‘shift’ could be attributed to the local commitment and enthusiasm of the project staff themselves. Overall, however, the programme infrastructure, provided by TCAT in many areas of Scotland, provided tangible opportunities for cross-sector working to develop partnership solutions that will contribute positively to the strategic and operational demands faced by health and social care services in Scotland^d

Among all wider stakeholders, the percentage reporting that the TCAT programme had a direct impact on influencing attitudes, behaviours and priorities related to aftercare grew from 30% in 2015 to 41% in 2017 overall.

Figure 7: Percentage of stakeholders reporting TCAT has had a direct impact to a great extent on influencing attitudes, behaviours and priorities related to aftercare (2015, 2016, 2017)



Two main areas of attitudinal ‘changes’ or reinforced thinking as a result of TCAT were found. Firstly, that **to be effective care after treatment cannot be an afterthought or introduced to patients and their families at the end of treatment.**

^d A separate briefing paper reports on the impact of TCAT on partnership, integration and co-ordination.

“if we want people to feel supported and enabled afterwards, that has to start earlier” (Project)“ the programme, aftercare is what happens after acute treatment is finished. I really struggle with that, because, I “think if you’re going to transform care after treatment is finished....., then you have to start at diagnosis and work through the diagnosis and treatment” (Stakeholder)

“it would probably be open to a few different interpretations because obviously through treatment you need care for that, care through treatment. I suppose what I'm saying is you need it at every stage of the pathway”. (Project)

Secondly, **TCAT initiatives have raised awareness around the need for services and individual practice to consistently view diagnosis and treatment for diagnosis of cancer, not as distinct event in a person’s life, or a separate component of care delivered at a set time in that pathway – but as a linked part in their whole life’s journey.** Attitudinally too, TCAT stakeholders and practitioners reinforced the benefit of seeing the whole person in their interactions and responding to this. The prime importance of holism has been highlighted by TCAT and illustrated in quotes below.

“I think the question for me is, especially looking at the patient population, people don’t come with cancer as their sole illness, they’ve got loads of other conditions and sometimes cancer’s not the most appropriate thing and especially with the local authority project I think there are the opportunities for people to be more engaged just in their whole health and wellbeing out and about in the community” (Local Project).

“But I think what this has given people an opportunity to do is to sort of step out of that hamster wheel that you’re constantly going round and come and see people in a wellbeing setting, you know; come and see people who are more relaxed, they’re not coming to an appointment, they’re coming along of their own free will and they want to find out and they want to engage with you. So yeah; the cultural change is massive, you know” (Local Project)

“..... what is it about TCAT that’s enabled them or facilitated them to get it? I think because it articulates a concept which they were perhaps working towards part of their day to day work....but I think they are more aware and understand better about the wider needs of patients and the experiences of patients. It’s not just about survival outcome. And I can see that, you can hear that dialogue happening” (Core Stakeholder)

From its inception a key aim of TCAT was to ensure the sustainability and roll out of evidence based practice to transform care after treatment for people affected by cancer. The Interim Report found that the local ownership commitment and leadership of projects created a positive platform for operational, local sustainability of many components of the TCAT Projects. It did however flag up the inherent risk of loss of momentum in areas where funding and focus is not also sustained.

"At the moment everyone has got the dedicated time, you've got the enthusiasm, you've got the momentum, and I've been involved in other projects, not in cancer services, but other projects maybe like across health improvement and things like that, where you finish, and you do have all these really good ideas and the things that could be really positive and could really improve things for patients. But, once the dedicated resource has gone, then they do begin to slip because everybody has got other priorities. I just think it would be a right shame for TCAT and the investment in TCAT if our learning from our project doesn't...we're not able to use that to influence things going forward because of limited resources, limited time, limited whatever. " (Local Project)

Locally and nationally, TCAT has not only raised awareness of the importance of care after treatment but also contributed to the necessary wider cultural and policy shift within health and social care provision in Scotland. This is required to reduce episodes of secondary care, move care closer to home and to promote and support of self-management.

The extensive groundwork and preliminary embedding of relationships, necessary for future joint practice has been carried out as a result of the programme. As a result, the programme has significant potential in the future to continue to support solutions and contribute positively to the strategic and operational demands faced by health and social care services in Scotland.

If the cancer pathway is to be truly stretched and strengthened to include living with and beyond cancer, HNAs and the other components of the Recovery Package cannot continue to be delivered as one-off interventions. To do so will merely perpetuate a segmented silo'd sequence of standalone interventions. The future delivery of HNAs must be implemented in the context of the whole cancer journey, the whole recovery package and the whole person. The strategic partners of TCAT must now turn their attention to how to:

- **Ensure and enhance primary care teams as key partners in the development of services to support PABC**
- **Re-address the dominance of NHS representatives within the partnerships established via TCAT**

- **Determine and disseminate the future TCAT role of the Cancer Networks in furthering the integration agenda to support people affected by cancer**
- **Consider how local integration and service coordination can be enhanced and maintained, without the impetus of funding and focus provided by the national programme.**

TCAT has also demonstrated that it could be insufficient and ineffective to continue to categorise, implement or evaluate care after treatment solely within the delivering sector or service, the cancer type of the recipient, or the profession of the assessor. Wider stakeholders were asked what was required to enhance the sustainability and across three years of responses, there was an acknowledgement that sustainability would only come from cross-sector collaboration. Disconnected systems have been described as a ‘plague’ to transitions and a wider perspective is required. TCAT tells us that where systems aren’t joined up, only a segmented silo’d sequence of standalone, one off interventions for people affected by cancer will be possible. Moreover, standalone interventions may not be sustainable if only the responsibility of one provider.

“the most helpful way to think about it is, what is the purpose of integration? And the purpose of integration is for the person at the centre to get access to the services that they need, at the time that they need them. So the challenge for people who organise services, is, how do we help that to happen?” (Local Project)

“I think, given how the funding is looking at the moment and everybody’s belt’s getting a bit tighter, I think it needs to link in about what your strategic direction is and how it becomes a whole system rather than a single piece of work for a specific group of individuals”. (Local Project)

“I think it’s just really important to kind of chip away at it and kind of show people what the mutual gain is in the future and how everybody links in and how important each is, no matter how small their contribution” (Local Project)

The changing cancer story demands a changing care after treatment story and TCAT must continue to be instrumental in driving forward this new narrative. TCAT has resonance in Scotland and further developments should link themselves to this ‘brand’.

6. TCAT AND THE TRANSFORMATION OF CARE AFTER TREATMENT

This five-year programme set out to transform care after treatment, not to tweak it. It has done this by illuminating further the need for consolidation and extended and fundamental cultural¹⁸ and attitudinal shifts that effect both *'hearts and minds'*.

The Programme's experiences and successes indicate that unless further attitudinal and practice shifts occur, the outcomes and experiences of people living with and beyond cancer will remain framed around traditional service pathways. TCAT tells us that all developments and systems targeted at improving the lives of people living with and beyond cancer must be anchored to a stretched and strengthened pathway that wholly encompasses 'after treatment'.

"I think what helps going forward is creating an expectation, creating a culture, because that's what it is, it's a big cultural shift, that this is part of your care pathway, this is still part of your care, rather than a luxury add on, oh, this is just for the people that really need...for the needy people, for it to be presented as something that's, this is part of your follow up or part of your recovery, it's standard". (Local Project)

TCAT has demonstrated the need for Recovery Orientated Practice and Emphasis (ROPE) to be embedded at the start of the cancer journey and sustained throughout.

6.1 TCAT informed Recovery Orientated Practice and Emphasis (ROPE)

Key to shining a light on the need for **Recovery Orientated Practice and Emphasis (ROPE)** was the diversity of the programme. Had it lacked variety or ambition it would have failed to demonstrate and reinforce as starkly that in order to have a significant impact on the experiences and outcomes of care after treatment there is a need for all those involved in the care of PABC to reframe our understanding and approach to 'care after treatment'.

In rethinking the approach to care after treatment as ROPE the current emphasis on 'after' recedes allowing a more seamless, person centred holistic cancer pathway to be constructed. What each individual person requires to live well with cancer is assessed and delivered in the context of the whole cancer journey and the whole person. By illustrating that care after treatment is best provided via ROPE, TCAT has reinforced that care after treatment is everyone's responsibility and not an add on. By distinguishing between direct practice and emphasis this new approach also

illustrates that responsibility for care after treatment / recovery is different at different stages. In understanding the ebb and flow of effective practice and essential emphasis, both practitioners and patients can better clarify their own roles and responsibility for recovery and 'the right person, with the right skills at the right time' can become more of a reality.

The changing cancer story demands a changing recovery story. Prioritising the need for all services to be recovery orientated in their practice and emphasis, will prepare patients better for transition points, introduce aspects of self-management at an earlier stage in the journey and make the norm the utilisation of community resources and assets throughout the journey. The ambition for TCAT in the future must be for Recovery Orientated Practice and Emphasis to be a way of life for people affected by cancer and the professionals who support them, not a way of developing approaches to 'care after treatment'. A way of life in which recovery and rehabilitation and goal setting is the direction of travel from the start. From the point of diagnosis, TCAT has demonstrated that "there needs to be a fundamental shift in the nature of the conversations that happen between clinicians and their patients so that they reflect the importance of not just living longer but living as well as possible"¹⁷.

Achieving this will require attention similar to that suggested for the safeguarding of person centred care in other conditions or diseases¹⁹. Therefore focus must be targeted at how ROPE is initiated by service commissioners and practitioners on the ground, integrated into practice and safeguarded within a system driven service with limited capacity.

The continued aim of TCAT must be to capitalise on the fertile ground that the programme has created over the last five years to ensure that each individual's cancer story is prefaced by the provision of recovery orientated practice and emphasis from the beginning.

6.2 Seven Principles of Recovery Orientated Practice and Emphasis (ROPE)

1. ROPE requires that all new services must acknowledge and understand from a patient perspective the connectivity and interdependence of strategic and operational service implementation decisions being made to improve cancer care. Moving forward recovery services should by default be jointly provided by capitalising on the extensive groundwork and preliminary embedding of relationships, necessary for the required future joint practice. Without an overall partnership approach to ROPE, care after treatment will merely continue to be a set of single, silo'd interventions.
2. The strategic sustainability of the transformation of care after treatment is contingent upon a commitment to ensuring and enhancing the evidence of its

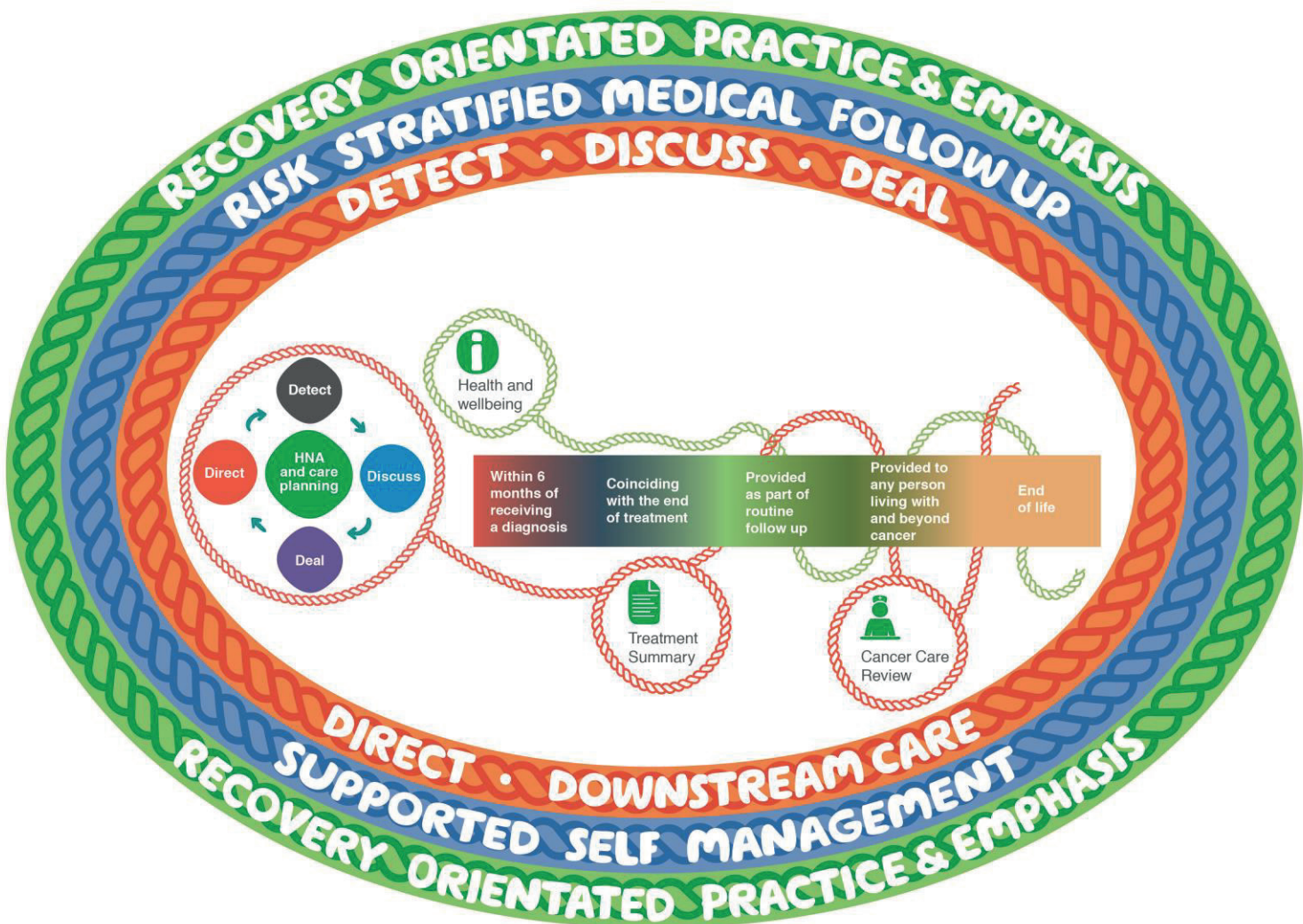
success. There is a need for the commissioning of longer term projects with robust evaluation systems that can follow patients through their cancer pathways for many years. Future research effort should also be concentrated on understanding the extent to which services people are signposted to after an assessment, have been taken up and investigate further the characteristics of and reasons why people do not use a 'recommended' or 'referred' to service.

3. Identification and assessment of concerns/need at key transition points must be understood as only a means to an end. In the future ROPE services must guard against the danger of the assessment tool 'wagging the dog'. Recovery Orientated Practice and Emphasis is not about what you do but the way that you do it. In relation to HNAs for example – the question 'how many HNAs and Care Plans have been done' becomes 'how should this assessment and care plan be delivered and assured?' Such a shift will need an increased understanding of required competencies and skills at each patient/service interaction. This will assist service commissioners to ensure that PABC interact with the right person, with the right skills at the right time.
4. For ROPE to be truly effective it needs strong networks of accessible, available support, appropriate to the individual circumstances to actually meet the need. The focus of service developments must move towards the actual provision of ROPE services and support in the community. This shift in emphasis will enforce a reduced reliance on 'signposting' as an adequate or effective action to meet an individual's needs. These services should maximise connecting PABC to community resources and assets and initially focus specifically upon the most commonly reported enduring concerns of fatigue, worry/fear/anxiety and also address cancer specific functionality.
5. Orientating all cancer care towards recovery will benefit from embedding listening as a key principle of reform. Listening is a fundamental principle of reforming care after treatment – it is crucial at a patient: practitioner level. Furthermore of critical importance are for patients to have the ear of service makers and policy makers. The powerful testimonials and case studies collated during the TCAT Programme offer a valuable dossier of information for initial discussions with stakeholders as to how best to take ROPE initiatives forward.
6. The new cancer story rightly places the patient at the centre and emphasises their role and responsibilities in their own individual 'recovery'. Essential for the future embedding of ROPE is the inclusion and influence of the voice of people affected by cancer – and essentially enhancing the ability of PABC to

'own their own story'. (see for example TCAT in North and South Lanarkshire for an alternative approach to what ROPE principles look like in practice).

7. TCAT identified and endorsed four key components of successful user influence. ROPE must ensure that the patient voice is supported, embedded, positive and meaningful. These components combine to offer a final principle for the successful transformation of TCAT into ROPE.

The diagram below illustrates the seven principles of ROPE in relation to the Recovery Package and the whole PABC journey: Holistic Needs Assessment, Risk Stratified Medical Follow Up, and Supported Self Management.



This final report has set out the lessons learned from the implementation and impact of TCAT. The insight and learning must now be used to embed the key principles of successful reform, enhance integrated system development and ensure evidence-based practice.

The findings and recommendations relate both operationally and strategically to the shared aspirations of the Scottish Government's 2016 Cancer Strategy Beating Cancer: Ambition and Action. TCAT provides insight how evidence based practice can be delivered to enable *“health, social care and third sector services to deliver sustainable and innovative approaches to cancer care which meet the changing requirements of people with cancer to support them to live healthy lives at home.”*¹

The findings will also assist providers to achieve the National Health and Wellbeing Outcomes², and the 2020 Vision³ to *“have a healthcare system where we have integrated health and social care, a focus on prevention, anticipation and supported self-management.”*

The principles of reform elicited from the experiences and impact of TCAT are aligned with the overarching aims of health and social care, which include improved patient experiences and outcomes and more efficient resource use such as reducing unnecessary clinical follow-up. As such the principles and recommendations from TCAT should be applied to all living with and beyond cancer initiatives including Prehabilitation Cancer Rehabilitation, Improving your Cancer Journey, Macmillan@Glasgow Libraries, Macmillan One to One and Move More.

Finally the learning from TCAT is not cancer specific. The findings, for example, resonate with the Principles of the Modern Outpatient⁴ which like TCAT aims to strengthen knowledge exchange and self-management in the community with the patient at the centre and ensure patients can access decision support, care planning and care services in the community wherever safe and appropriate.

7. RECOMMENDATIONS

- HNA and Care Planning must be offered to all PABC from diagnosis as part of a co-ordinated intervention throughout their cancer journey. All HNA and care planning consultations must be recovery focussed and contribute to understanding of complexity and clinical need to inform individualised risk stratification of a patient's clinical follow up.
- The concerns checklist is an important tool for detecting and legitimising concerns and its continued use as a tool to aid recovery is recommended for

PABC. Consideration going forward should be given to how best to use the Concerns Checklist with carers and people in the palliative stages of cancer.

- Provision of adequate time and space to the patient is vital within the delivery of patient led holistic assessment and care planning to support self-management. HNA and care planning appointments must be implemented as recovery focussed consultations, where the assessment and care planning processes are the sole objective of the meeting.
- Any future patient reported outcome/experience measure of HNA and care planning must include that PABC feel that they have had the opportunity to talk about their concerns and report consistently that these were actively listened to.
- Optimally assessors will act as a conduit between treatment centres, primary care and community assets to provide the required consistent point of contact for reassurance, reinforcement and maximisation of receptivity to using community resources to enhance their own self-management. The extension of Cancer Care Reviews and the role of Practice Nurses and the wider primary care team (and Primary Care embedded workers such as Scottish Government Link Workers or Community Connectors) offer significant potential. They are uniquely placed to act as a conduit between the NHS and community assets, from diagnosis, can offer a consistent approach to review and coordination of care and develop referral/signposting activity to improve uptake.
- Going forward action must focus on ways to increase the uptake of self-management support in the community. There is a need for longitudinal research into the drivers and barriers to service uptake post assessment ²⁰.
- Care plans must be reviewed periodically to reinforce self-management activity, through support and reiteration of the message of recovery. The reinforcement through review takes the chance out of a one off appointment coinciding with the PABC being receptive to support and self-management. Care planning and care plans for people affected by cancer have been shown to contribute to an improved overall experience but their utility must be further evaluated as a matter of priority.
- The aggregated data gathered from TCAT provides a valuable opportunity to understand the needs of people after treatment for cancer and further interrogation of the data should be commissioned.
- Service commissioners and practitioners must prioritise the design and delivery of locally accessible services and support to help PABC manage the predominate concerns of fatigue and worry.

- Every person affected by cancer must have a Treatment summary at the end of each episode of treatment detailing the diagnosis, their treatment, its intent and side effects.
- All health boards should review their rapid access to palliative care policies and services for those individuals where treatment is not an option, against the Proactive Best Supportive Care exemplar.
- Service piloting and broader research are recommended to further enhance the efficacy of HNA and Care Planning:
 - A longitudinal evaluation of the utility and effectiveness of Care planning and Care plans for cancer survivors and their role in increasing uptake of support in the community through reassurance and reinforcement.
 - A needs assessment of required training and mentoring to support optimal implementation of HNA and Care planning.

In taking forward the work required to implement the recommendations made in this report the strategic partners of TCAT must now:

- Ensure and enhance primary care teams as key partners in the development of services to support PABC
- Re-address the dominance of NHS representatives within the partnerships established via TCAT
- Determine and disseminate the future TCAT role of the Cancer Networks in furthering the integration agenda to support people affected by cancer
- Consider how local integration and service coordination can be enhanced and maintained, without the impetus of funding and focus provided by the national programme.
- Ensure that TCAT is instrumental in driving forward the new narrative of Recovery Orientated Practice and Emphasis. The programme has resonance in Scotland and further developments should link themselves to this 'brand'.

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