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Transforming Care After Treatment

Implementing Holistic Needs Assessment: Learning and Evidence Bulletin

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Purpose

This Bulletin presents the evidence and learning on the implementation of holistic needs assessment (HNA) within 11 completed local projects from the national evaluative perspective. The data sources used are given in Appendix One.

It focusses on different approaches to implementing holistic needs assessment using the Concerns Checklist (Appendix Two).

It is not a 'How To' guide or 'Toolkit' for the implementation of HNA. Neither has it been written to compare the projects directly. The key purposes are to disseminate what is known as a result of the programme and to share important lessons with health and social care practitioners and assessors, service managers in all sectors and service commissioners to optimise local implementation.

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.

Structure of the Bulletin

The emerging evidence and learning on the implementation of HNA from TCAT has been structured around what has been discovered about key components of the design and delivery of HNAs. They are:

- Why implement an HNA

- Where the HNA takes place

- When: timing of HNA within the cancer journey

- How often: planned frequency of HNA

- Who: characteristics of the assessed and the assessor

- How: it's the way that you do it

The Bulletin concludes by presenting what has been learned in relation to interpreting and using what the assessed tell us. This is key to optimising the implementation of HNA across the care pathway and the continued development of a firm evidence base to inform its effectiveness and sustainability.

Summary of Key Learning

As a result of the testing and piloting work funded by the TCAT programme there are now evidenced demonstration case studies and local exemplars of how HNAs can be implemented. The overarching lesson from the national evaluation is that when implementing HNA, it is critical to understand and consider the connectivity and inter dependence of implementation decisions on processes that people affected by cancer (PABC) experience and the subsequent short and longer term outcomes of carrying out an HNA.

- **If the cancer pathway is to be truly stretched and strengthened to include living with and beyond cancer, HNAs cannot continue to be one off 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 approach taken to implementing HNA will determine, to a large extent, who receives a HNA and at what stage. It is important for service commissioners and practitioners to interrogate available data on who has an HNA. Doing this will ensure that HNA is well targeted. In addition, gaps in provision can be identified and unintended consequences of implementation decisions discovered.**

- **Who is <u>not</u> assessed is as important as who is. Future services cannot be delivered or commissioned effectively if they only draw on the data of those who have received it. A consistent method for recording and differentiating the reporting of 'no concerns' from someone who turns down the offer of a HNA is required**.

- **It is important to understand the extent to which people are not taking up a service and to understand the reasons why.**

- **Practitioners and service providers must interrogate both the locally and nationally, derived data on reported concerns and use it as a basis for the planning and provision of effective <u>post assessment responses</u>.**

- **Practitioners and service commissioners must construct an internal and external implementation HNA infrastructure to support the processes and actions of the assessor.**

- **The content and utility of care plans resulting from HNAs must be evaluated and their contribution to improving outcomes identified and assessed.**

- **There is a need for better insight into the impact the different approaches to implementing HNA actually has on short and longer term patient outcomes. The realist evaluation of HNA and Care Planning being conducted by Edinburgh Napier University will assist with this.**

Background

Across the United Kingdom, the numbers who are living with a cancer will increase from 2 million to 4 million by 2030. For Scotland, this is an increase from 190,000 in 2010 to around 340,000 by 2030 if current trends continue[i].

Data on healthcare utilisation indicates that there is a significant level of health care usage in the period 1-5 years after diagnosis[ii]. Amongst those aged 65 and over living with cancer, many have co-existing diseases (co-morbidity)[iii].

Transforming Care After Treatment (TCAT) was designed to address many of these challenges by providing strategic direction and drive for new, integrated follow up /after care models relevant to the wider reform of public services including:

- developing new models of care to address unmet needs and wider service challenges
- maximising the sustainability and roll out of evidenced based practice
- enhancing service integration and coordination and health and social care partnership working in relation to services for people affected by cancer
- providing cost effective solutions and a more appropriate use of resources than current practice

Operationally and strategically, TCAT mirrors the aspiration of the Scottish Government's 2016 Cancer Strategy "Beating Cancer: Ambition and Action". The work undertaken by the programme and each separate TCAT project is of direct value and relevance to the 2020 Vision and new National Health and Wellbeing Outcomes [iv].

> *"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"* [v]

TCAT has been 'operationalised' via the commissioning and funding of 25 local projects, tasked with the development, implementation and evaluation of new models of service delivery and practice.

The bottom up programme design resulted in diversity of approach to changing models of follow up across Scotland to address locally identified needs and service gaps. TCAT is therefore a diverse programme that encompasses numerous complex interventions within local, regional and national programme structures.

Each individual TCAT project has tested different 'combinations' of the recovery package[vi], a key delivery mechanism for TCAT. The interventions are: Holistic Needs Assessment, Treatment Summaries, Cancer Care Reviews, and Health and Wellbeing Events. These elements combine to support different aspects of self-management

through, for example, managing consequences of treatment, encouraging physical activity as part of a healthy lifestyle, providing information, financial and work support.[vii]

A key component of the TCAT programme is holistic needs assessment, with nineteen of the 25 projects prioritising the use of an assessment and care planning tool. A number of local projects selected to implement the Patient Concerns Checklist[viii] within their local TCAT model of HNA and care planning (see Appendix 2).

HNA is a structured method of consultation. By using the Patient Concerns Checklist, it aims to cover a wide range of different concerns a patient may have: physical, emotional, family, lifestyle, practical and spiritual concerns. The HNA is designed to be a patient self-administered tool, to be completed prior to consultation with the assessor who then uses it to guide the consultation and agree a care plan.[ix]

Edinburgh Napier University was commissioned by Macmillan Cancer Support in May 2014 to conduct a national evaluation of the TCAT programme. Each of the 25 local TCAT is producing a self-evaluation report. The results of the national programme evaluation have to date been presented in a Baseline Report (2015) and Interim Report (2016). In 2017 it was agreed that findings from the national evaluation would be disseminated through a rolling programme of Evidence and Learning Bulletins on specific topics:

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

Why implement an HNA

The purpose of HNA is multi-faceted. The work undertaken within TCAT reveals that the priority purpose, that is the significant why, has implications for design and implementation.

We identified two significant priority reasons for implementing HNA, across the individual projects. We define them separately as:

- Routine: This related to enhancing existing follow up through the implementation of HNA, by increasing the appropriateness and effectiveness of review appointments and within that the managing of risk

- Recovery: this relates to an emphasis on living well after cancer and supporting self-management

Although most projects were seen to have elements of both operating concurrently, within each project one reason was given priority. It should be remembered that this Bulletin is focussed solely on the HNA aspect of TCAT projects. Therefore, the HNA process only is categorised as either routine or recovery.

Table 1: Priority Reason for HNA [1],[2]

Routine	Recovery
NHS Lanarkshire	NHS Lothian/ Westerhaven
NHS Tayside	Fife HSCP
NHS Fife (melanoma)	Midlothian HSCP
NHS Forth Valley	NHS Ayrshire & Arran (HWBC)
NHS Ayrshire & Arran (EofT)	Renfrewshire HSCP
NHS Borders	NHS Lothian

For those projects that prioritised 'routine' the HNA was embedded within already established routine follow up clinics, either in a hospital, primary care or community hospital setting. Recovery focussed assessments were always provided through an additional service.

The priority reason for implementing HNA impacted upon several key aspects of delivery including the location and timing of the assessment, the length of appointment, who was assessed and the profession of the assessor.

Where the HNA takes place

The six hospital based projects predominantly undertook assessments face to face, within an out-patient/follow up clinic in a hospital or community hospital. The Primary Care Project held assessments in the Medical/GP practice centres. Practice Nurses undertook these as Cancer Care Reviews. A very small number (for example in NHS Borders, NHS Lothian and NHS Lanarkshire) were conducted over the telephone.

Community based projects held assessments within local, accessible buildings such as outreach centres, libraries and NHS community or primary care centres. The project in NHS Lothian/Westerhaven was co-located within a medical practice. PABC within the community projects were also offered the opportunity to undertake the assessment over the phone or to have the assessment within their own home. For the Fife HSCP project all HNAs were undertaken in people's homes.

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[1] Data from the project in NHS Ayrshire and Arran occurs twice. Data was available for patients who attended the TCAT Health and Well Being Clinic. In addition, concerns data only was available for patients gathered by CNS at the end of treatment clinic. Where relevant this is presented
[2] Glossary: EofT - End of Treatment; HSCP - Health and Social Care Partnership; HWBC - Health and Well being Clinic

Timing of HNA

When?

During a patient's cancer journey the time point at which the assessment is offered is of key importance. TCAT is contributing intelligence as to the practice implications of <u>when</u> and <u>how often</u> HNA is carried out.

The emphasis of TCAT was 'care after treatment'. The evaluation illustrates that for the projects this could mean one of four things for the delivery of an HNA.

- Within 6 months of receiving a diagnosis
- Coinciding with the end of treatment
- Provided as part of routine follow up
- Provided to any person living with and beyond cancer

The Primary Care hosted project in Lanarkshire, conducted HNA at the point of diagnosis as part of a Cancer Care Review. Three hospitals and one community hosted projects implemented HNA specifically at the end of active cancer treatment. For NHS Ayrshire and Arran this was implemented on discharge from the treating hospital and then again at a Health and Wellbeing Clinic scheduled 6 to 8 weeks post treatment. Table 2 details when HNAs typically took place if implemented at diagnosis or the end of active treatment.

Table 2: Months from diagnosis if HNA at end of active treatment or at diagnosis

Project	Mean (months)	Median (months)	Range (months)
NHS Lothian	10	9.6	3-50
NHS Borders	1	2.3	0-26
NHS Ayrshire and Arran (EofT)	2.6	1	1-12
NHS Ayrshire and Arran (HWBC)	7	7	0-13
Renfrewshire	16	10	1-145
NHS Lanarkshire	9	3	0-376

If the HNA is made available to people at any stage on their cancer journey (which could include at the end of active treatment) the HNA takes place around 2 years after a diagnosis (Table 3).

Table 3: Months from diagnosis if HNA is offered to people living with and beyond cancer

Project	Mean (months)	Median (months)	Range (months)
NHS Lothian/Westerhaven	20	8	0-123
Fife Phase 2	26	12	
Midlothian	29	18	0-66

Embedding HNAs into routine follow up clinics, either in a hospital or community hospital setting resulted in the average time from diagnosis to assessment being much greater. (Table 4)

Table 4: Months from diagnosis if hospital based HNA is implemented as part of routine follow up

| Project	Mean (months)	Median (months)	Range (months)
NHS Forth Valley	65	83.7	3-282
NHS Fife (Melanoma)	10	18.8	0-192
NHS Tayside	25	27.8	0-86

For example, people with melanoma are followed up for 5 years, depending on the specifics of their diagnosis. The range in follow-up times for these three projects (supporting people with melanoma, prostate, head and neck cancers and colorectal cancer) was between 0 and 282 months. The length of time from diagnosis to assessment reflects current clinical 'follow-up' guidelines.

Length of assessment

The priority reason (routine or recovery) for implementing HNA was found to affect the length of the assessment appointment/consultation with recovery appointments tending to be longer than routine appointments. The majority (55%) of 'routine' HNA consultations undertaken in hospitals by Clinical Nurse Specialists (CNS) took 20 minutes or less (Figure 1).

Also defined as 'routine' was the HNAs undertaken by Practice Nurses and a third (32%) of HNAs took 20 minutes or less.

**Figure 1: Length of HNA consultations: Routine and Recovery HNA**
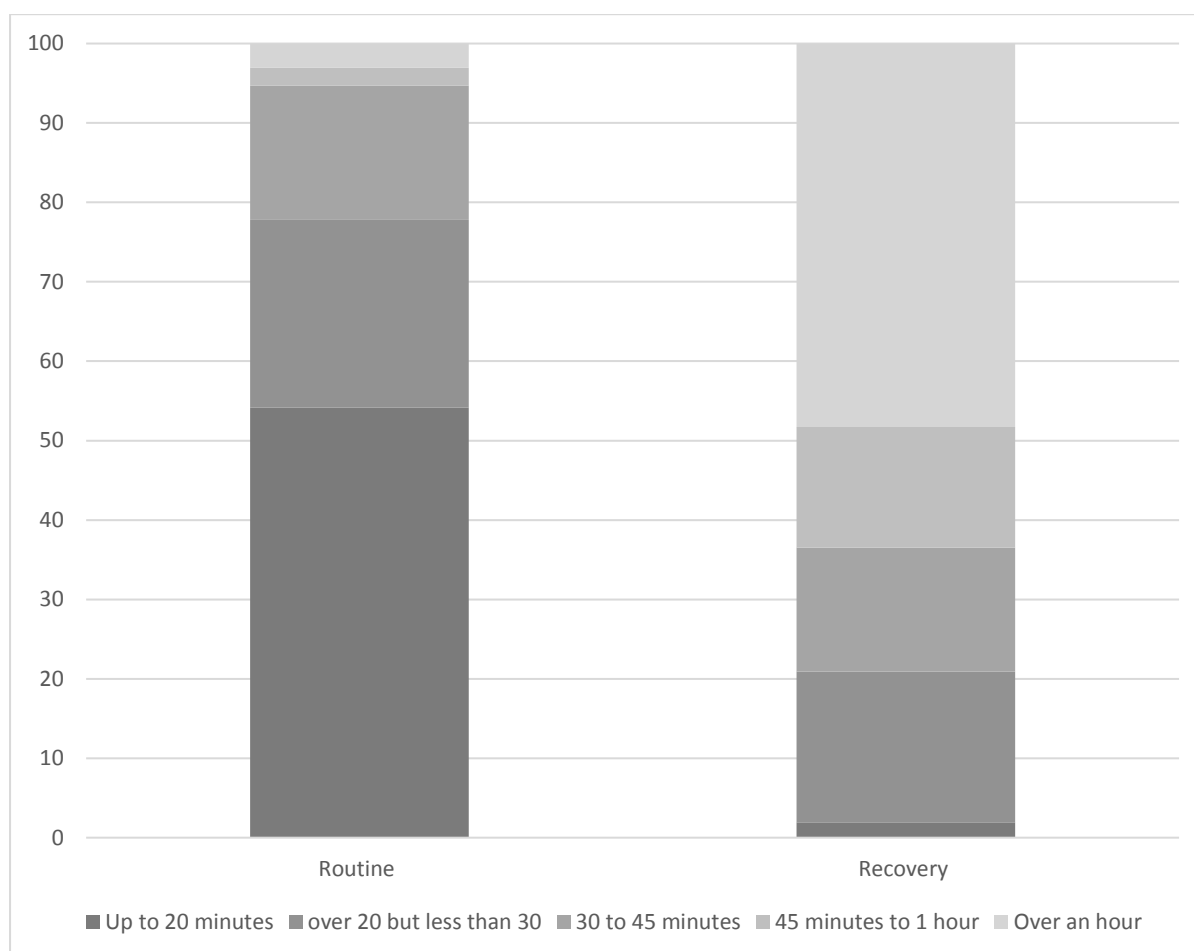
In contrast, data available for 3 recovery focussed, community based projects shows that a negligible number (less than 2%) of HNAs take up to 20 minutes or less. Overall, a high percentage (80%) were recorded as having taken over an hour. In these projects, no pre-determined length of appointment was set. However, in NHS Ayrshire and Arran recovery focused Health and Wellbeing Clinic appointments were scheduled for 30 minutes and as a result 73% took between 20 and 30 minutes. Both across and within the projects there was little consensus as to the most appropriate length of time an HNA should take or did take in practice.

Planned frequency

In seven of the 11 projects, the HNA was a 'one off' intervention. All those assessed by the projects were informed they could contact the assessor (i.e. self-refer back into the project) if they felt the need. Informal feedback from projects revealed that few did. Informally, individual assessors used their discretion to offer further appointments to some patients.

Three hospital based projects implemented (or planned to implement) HNA at more than one set time point. For NHS Borders and NHS Ayrshire and Arran the first assessment was planned to coincide with receiving a diagnosis of cancer/ or initial treatment plan post diagnosis. All three implemented 'end of active' treatment HNAs and for NHS Lothian and NHS Ayrshire and Arran a further 'assessment' appointment was offered. In NHS Lothian this was described as a review/follow up appointment after the first HNA which had been carried out at the TCAT Recovery Clinic (6 to 12 weeks later). A Health and Wellbeing Clinic appointment was established in Ayrshire and Arran, which formed the third HNA opportunity in this health board.

Figure 2: Planned frequency and timing of HNAs in 6 Hospital Projects
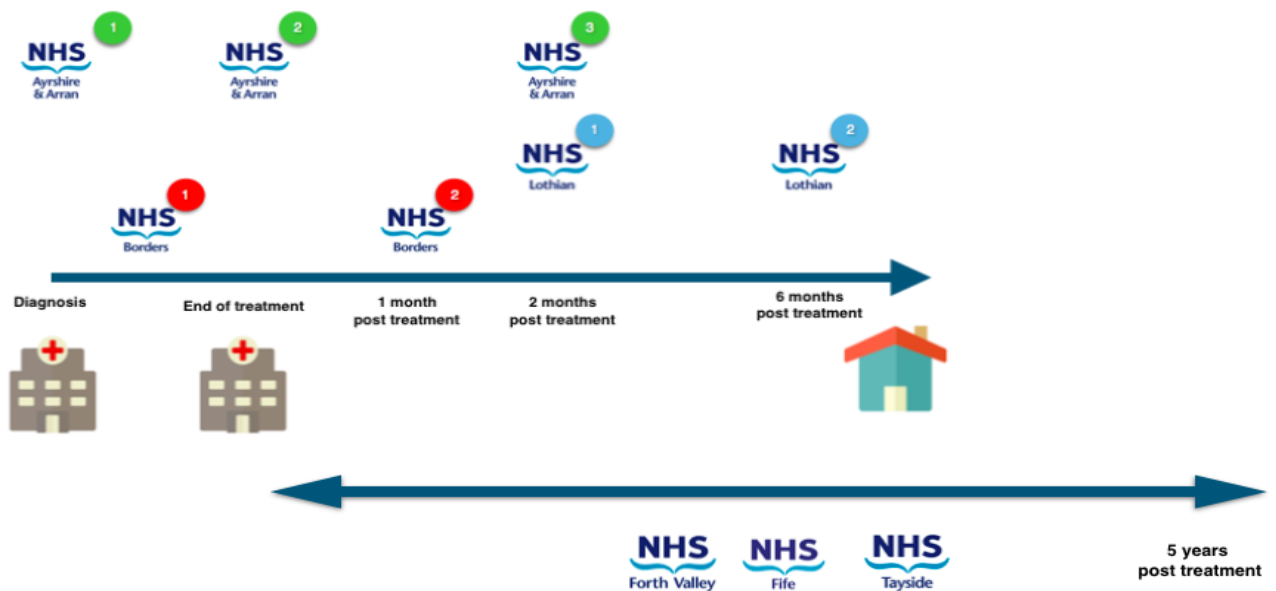
The Phase 2 project in Fife report that an assessor on average saw PABC who had an HNA, three or four times.

On completion of their 'test' period, most projects had not yet fully determined when the best time to first carry out an HNA was and how often the process should be repeated to maximise patient benefit.

Published guidance emphasises that an HNA should be carried out at key points in a cancer journey.[x] However, as has been highlighted by the TCAT projects described, that there is little consensus about when these key points are, or which are most acceptable or useful to PABC. Moreover, the UK Guidelines for the implementation of HNA and care planning for PABC emphasise that ideally HNA should not be a 'one off' intervention. Few projects within the TCAT programme however <u>formally</u> implemented more than one HNA into their local care pathway. For this reason more work needs to be done to assess the adequacy of a single HNA within a cancer

journey. **If the cancer pathway is to be truly stretched and strengthened to include living with and beyond cancer, HNAs cannot continue to be one off interventions.**

Who is assessed?

Who is assessed is a key implementation decision for HNA and care planning. Within TCAT, the small pilots, made focussed, local and pragmatic decisions to engage with relevant tumour types and professions.

Within TCAT, five of the hospital based projected restricted their project to a specified tumour group or group(s), and one (NHS Borders) offered the assessment to all patients with cancer, in a defined geographical area, regardless of cancer type.

The Renfrewshire Community based project also determined specific cancer types. However, the implementation was slower than anticipated which meant that most of those assessed had breast cancer. The other three community based projects implemented HNA for PABC with any cancer type and at any stage of their cancer journey.

Table 5: Cancer types assessed by project

Project	Cancer Types
NHS Lothian	Breast, Gynaecological, Anal/Rectal & Lung
NHS Borders	All
NHS Forth Valley	Prostate
NHS Fife (Dermatology)	Melanoma
NHS Tayside	Colorectal, Head & Neck and Prostate
NHS Ayrshire & Arran (E of T)	Breast
NHS Ayrshire & Arran (HWBC)	Breast
NHS Lothian/ Westerhaven	All
Fife HSCP	All
Midlothian HSCP	All
NHS Lanarkshire	All
Renfrewshire HSCP	Breast (predominantly)

The national evaluation team assisted local projects to gather consistent demographic data on the PABC they assessed. Within local evaluation reports, each project has described the main characteristics of those who were assessed and some projects, mentioned above describe those who were not assessed.

For example, within the implementation of 'routine' HNAs, it is most likely that patients have to 'opt out', whereas 'recovery' based implementation are more dependent on PABC 'opting in' to the offered assessment

For example, in Forth Valley, over 60% of those offered an HNA opted out. A high level of 'opting out' or declining the assessment was also reported by NHS Lanarkshire's project on Cancer Care Reviews, with 36% of invited patients declining to have an HNA.

Although not statistically robust, some projects (for example NHS Fife, NHS Lothian/Westerhaven and NHS Lanarkshire) who reviewed available data, reported that PABC who lived in more deprived communities were most likely to opt out or not attend for the offered HNA. Analysis by Forth Valley found that those declining the assessment had a similar demographic profile to those attending HNA.

However not all projects recorded the number or characteristics of people who 'declined' or opted out of the HNA process as part of their test work. There was also not a consistent method for documenting when a patient reported 'having no concerns'. For example, in some projects PABC with 'no concerns' were recorded as zero concerns, and in others, the HNA could appear not to have been undertaken.

The approach taken to implementing HNA for PABC will determine to a large extent who is assessed. It is important for service commissioners and practitioners to understand fully whose concerns the data relates to. Doing this will ensure that HNA and support services are well targeted. Gaps in provision identified and unintended consequences of implementation decisions discovered.

Also of note from the national synthesis of this local data is the work some projects undertook with <u>carers</u> of people diagnosed with cancer and the scale, within some projects, of people in the <u>palliative stages</u> of their disease.

Two community projects (Fife and Westerhaven) reported a high proportion of people engaged in their TCAT project were in the palliative stages of their cancer. For Westerhaven, over half those assessed were at or near end of life (54%) and in Fife the figure was 29%.

Hospital and primary care HNAs were implemented only for people with a diagnosis of cancer. In the community, the projects engaged with carers of the diagnosed. This was particularly true of the projects within Fife and Westerhaven.

Who is <u>not</u> assessed is as important as who is. Future services cannot be delivered or commissioned effectively if only informed by those already 'receiving it'. A consistent method for recording and differentiating the reporting of 'no concerns' and a non-completed Concerns Checklists is required. It is also important to understand the extent to which people are not taking up a service and to understand the reasons why.

Who are the assessors?

Within TCAT, nurse-led assessment is the predominant model within hospital based HNAs. Practice Nurses conducted NHS Lanarkshire's HNA. Within the community projects, assessors did not need to be clinically trained – however in two projects this was the case (Ayr HWBC and one of two assessors in Midlothian).

TCAT has demonstrated that a range of professions can undertake HNAs. However, a resulting key finding of the national evaluation is that to a large extent, the success of HNA and care planning for PABC is not who does it, but how it is done.

It's the way that you do it

The importance of how an HNA is conducted holds true at two levels. Firstly at an individual assessor level. The 'actions' as a result of an HNA will be dependent upon the skills and competencies of each individual assessor both in recognising the unmet need but also in knowing what options might be available Secondly, the way in which assessors can utilise HNA and maximise the value of the intervention for PABC is affected by the implementation infrastructure.

Core skills and competencies

The process of assessment is not a new process or practice for experienced professionals in health and social care. However, for some, the structured use of the Concerns Checklist or other assessment tool is. The analysis of focus group discussions and a synthesis of the local evaluations did not provide quantifiable or definitive evidence to determine who or which profession is best suited to undertake HNA with people affected by cancer. More evident was the necessary skills to undertake HNA.

Across the 11 projects, different emphasis was found in relation to HNA specific training for assessors and desired core skills and competencies for the role. A number of TCAT assessors (mostly CNS or Nurse Specialists) had previous experience of using assessment tools as part of patient consultations. The hospital-based project in NHS Tayside recommended that staff attend Sage and Thyme communication training for helping people in distress and implemented an HNA specific training programme (See Box 1). Some community based projects made use of available training from Macmillan Cancer Support, including:

- Communication Skills
- Dealing with Loss, Grief and Bereavement
- Emotional Wellbeing
- Managing Volunteers
- Motivational Interviewing
- Understanding Cancer and its Treatment

Box 1: Training Outline: Assessment of Concerns (HNA)

Aims of Training programme

As part of the Transforming Cancer Care project in Tayside, this training aims to explore the rationale for transforming cancer care and offers an opportunity to develop clinical staff' skills, knowledge and confidence relating to holistic needs assessment and effective care planning. Initial training will focus on caring for patients with head and neck, or prostate or colorectal cancer. Contemporary cancer care requires staff to have evidence based knowledge not only about cancer and treatment but care strategies along the cancer pathway to achieve high standards of holistic patient and family care and support. Fundamental to this is effective, timely assessment and shared care planning, incorporating aspects of self-management, rehabilitation and signposting to community sources of support

Pre-requisites

Tayside Staff attending training will have current experience of working with people affected by cancer and their families. 8 hrs (4 x 2hr) sessions. Staff will attend at least one 2 hr session (depending on their prior experience) as part of learning and reflection during the programme before implementing holistic needs assessment. Monthly drop in reflective sessions will be provided to share learning and help support staff.

Learning Outcomes

Demonstrate knowledge of the implications and impact of chronic illness and long-term survivorship

Recognise and demonstrate when and how to refer appropriately to other professionals and agencies

Gain confidence and practice in holistic needs assessment and effective care planning

Describe the principles of rehabilitation, self-management and lifestyle interventions for improving quality of life in those affected by cancer

Within TCAT and beyond, the debate around the role and profession of assessors is wide ranging and covers work planning issues of specialism vs generalist, the extent of need for clinical input post treatment, management of risk and recurrence signs, efficiency, value for money and patient expectations and acceptability. Over the last decade a number of reports have offered guidance to practitioners providing a HNA and through this identified skills and competencies. (See Box 2).

Box 2: Examples of Guidance for holistic needs assessors

A guide for professionals providing holistic needs assessment care and support planning. Macmillan Cancer Support (November 2016)

Holistic needs Assessment for people with cancer. A practical guide for healthcare professionals. National Cancer Action Team (2011)

Holistic needs assessment and care planning. Sharing Good practice. Macmillan Cancer Support (Winter 2012)

Innovation to implementation: stratified pathways of care for people living with or beyond cancer. A 'how to guide'. NHS Improvement Cancer (2012)

Most recently, Macmillan Cancer Support considered the core skills for assessors are in the fields of communication and problem solving[xi]. The national and local evaluation findings support this by illustrating the dynamic, interactive and reactive aspects of the HNA and care planning processes. Assessors have to detect concerns, deal with them, at times within the consultation itself and/or then direct PABC to appropriate services and support.

Taking 'action' as a result of an HNA is also therefore dependent on individual assessor's awareness of and the availability and accessibility of local support and information services. Specifically, TCAT has highlighted that holistic needs assessors must have an understanding of and access to services and resources to deal directly with or signpost/ refer for both physical and emotional/psycho social concerns. For example, for the most frequently reported concern of "tired/exhaustion or fatigue", assessors must know how to address this within the consultation if necessary and the availability of relevant local support services. To do this well requires an effective implementation infrastructure.

Implementation Infrastructure

At a very basic level the required infrastructure for assessors is a current directory of local organisations and community based resources. It is important for this list to be updated and embedded into practice.

At a more strategic level, those involved in implementing HNAs in hospitals or community hospitals must put in place broader service infrastructures and partnerships to enable assessors to support an effective transition of the patient.

The national evaluation indicates that when implementing HNA it is important to acknowledge that the assessor is only one of many 'partners' in a supported self-management approach. As such, the assessor alone cannot address all of a patient's concerns – but needs trusted colleagues and partner agencies contributing to the implementation of the whole support pathway. **Practitioners and service commissioners must construct an internal and external HNA implementation infrastructure to support the processes and actions of the assessor.**

Going forward it could be insufficient and ineffective to merely categorise, implement or evaluate HNA solely within the delivering sector or service, the cancer type of the recipient, or the profession of the assessor. It is suggested that to do so, perpetuates a segmented silo' d sequence of standalone, one off -assessments of people affected by cancer. The 11 TCAT projects have implemented HNA in 3 different single host settings. These are broadly defined as within hospital, in the community or in primary care. See Table 6.

Table 6: Host setting of HNA Implementation

Hospital	Primary Care	Community
NHS Borders	NHS Lanarkshire	NHS Lothian/ Westerhaven
NHS Tayside		Fife HSCP
NHS Lothian		Midlothian HSCP
NHS Ayrshire & Arran (EofT)		NHS Ayrshire & Arran (HWBC)
NHS Fife (melanoma)		Renfrewshire HSCP
NHS Forth Valley		

To maximise the potential of the HNA it is critical to understand and consider the connectivity and inter dependence of potential operational decisions and actions on the patient, the delivering service or department and wider organisation/agency and its partners. **The future delivery of HNAs must be implemented in the context of the whole cancer journey, the whole recovery package and the whole person.**

Figure 3: The importance of a holistic implementation of HNA
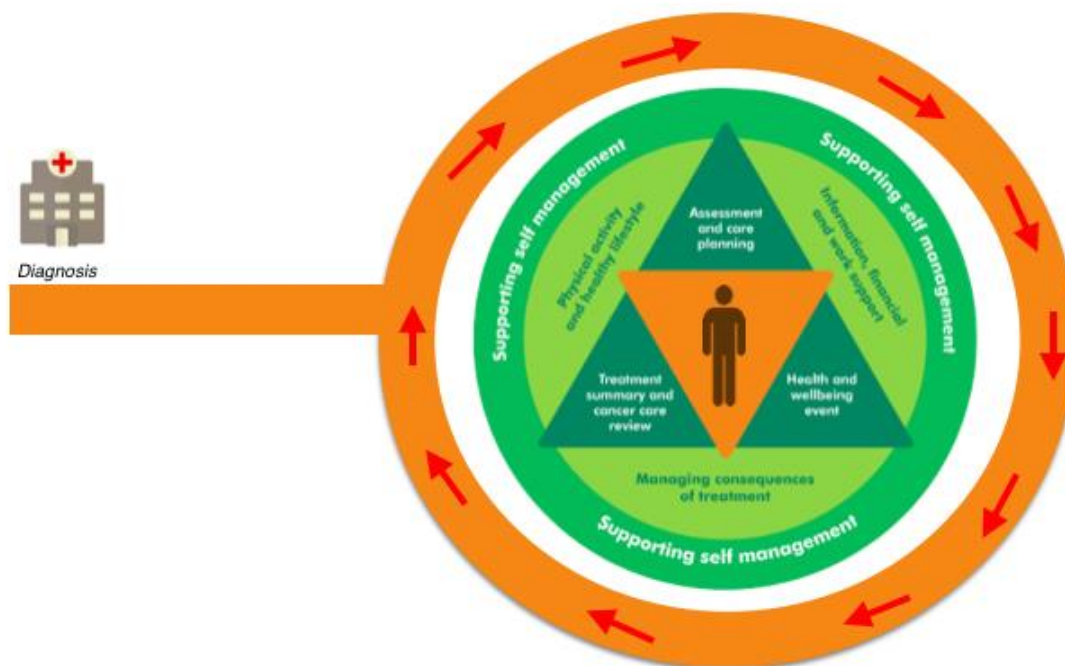
If conceptualised as a journey - the care plan that results from the HNA process is the map. However, to date much of the analysis and evaluation of HNA practice is targeted at quantifying concerns, their broad domain and level of reported concerns. Yet a key aspect of the means to concern reduction is the resulting care plan. Most care plans will include referring or signposting PABC to a range of agencies that they have to

navigate across and within traditional sectoral providers. **The content and utility of care plans resulting from assessments must be evaluated and their contribution to improved outcomes identified and assessed.**

Informing service responses: Interpreting and using what the assessed tell us

Patient Feedback and Outcomes

The patient experience of HNA was reported positively by all 11 local evaluations. In particular, high levels of satisfaction and acceptability were universally reported in relation to overall satisfaction with the service and the extent to which needs were met. Also of note from the synthesis of local evaluations is the high number of PABC who agreed strongly with the statement that the intervention had improved their confidence to manage their concerns by themselves.

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 'snap shot' 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.

If a robust evidence base for HNA and care planning is to be built up, it is inadequate to rely on one-off reporting on the extent of agreement with a range of affirmative, non-validated statements. Many TCAT projects did not collect baseline data, which undermines the extent to which a project can take credit for observed and measurable changes.

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.

Analysing Concerns Data

From the 11 projects reported within this Bulletin, data on the number and type of concerns reported by 1,291 PABC is available. Table 7 looks at the average number of concerns those assessed reported.

Table 7: Concerns reported by project

Project	Number of people assessed	Average number of concerns per person of all those assessed	Average number of concerns if reported 1 or more	Number of people assessed reporting 'no concerns'
NHS Fife (dermatology)	115	1.13	3.71	80
NHS Tayside	284	2.02	3.90	137
NHS Ayrshire & Arran (EofT)	161	4.2	5.8	38
NHS Forth Valley	47	4.72	/	0
NHS Borders	31	4.74	5.65	5
NHS Lanarkshire Phase 2	248	5.0	6.07	41
NHS Ayrshire & Arran (HWBC)	146	5.95	6.94	21
NHS Lothian	61	6.61	6.95	3
Renfrewshire	80	9	9.24	1
Fife Phase 2	29	9.52	/	0
Midlothian	42	10.12	/	0
NHS Lothian/Westerhaven	47	10.23	10.45	1

Table 8 below shows the most frequently reported concerns by those assessed within hospital, primary or community based projects.

Table 8: Most frequently reported concerns by project

MOST FREQUENT	COMMUNITY BASED						HOSPITAL BASED					PRIMARY CARE
	Westerhaven	Fife	Midlothian	NHS Lanarkshire	Renfrewshire	NHS Ayr (HWBC)	NHS Ayr (EofT)	NHS Lothian	NHS Fife (melanoma)	NHS Forth Valley	NHS Tayside	NHS Borders
↓	Tired, exhausted or fatigued	Tired/Exhausted or Fatigued	Tired, exhausted and fatigue	Tired, exhausted or fatigued	Tired/exhausted and fatigue	Tired/exhausted and fatigue	Tired/exhausted and fatigue	Tired/exhausted and fatigue	Worry, fear and anxiety	Getting around (Walking)	Tired, exhausted or fatigued	Tired, exhausted or fatigued
	Worry, fear or anxiety	Getting around (Walking)	Worry, fear or anxiety	Pain	Sleep problems/nightmares	Worry, fear and anxiety	Hot flushes	Worry, fear and anxiety	Exercise and activity	Passing Urine	Diarrhoea	Worry, fear or anxiety
	Complementary therapies	Exercise and activity	Sleep problems/nightmares	Worry, fear or anxiety	Hot flushes	Hot flushes	Sleep problems/nightmares	Hot flushes	Sleep problems/nightmares	Hot flushes	Getting around (walking)	Eating or appetite
	Sleep problems/nightmares	Worry, fear or Anxiety	Memory and concentration	Breathing difficulties	Worry, fear or anxiety	Sleep problems/nightmares	Memory and concentration	Tingling in hands and feet	Tired/exhausted and fatigue	Tired/exhausted and fatigue	Dry, itchy skin	Breathing difficulties
	Money or housing	Loss of interest/Activities	Exercise and activity	Eating or appetite	Pain	Pain	Pain	Sleep problems/nightmares	Sun protection	Sleep problems/nightmares	Pain	Partner
	Pain	Sadness or Depression		Sleep problems/nightmares	Exercise and activity	Memory and concentration	Worry, fear or anxiety	Sadness or depression	Eating or appetite	Dry, itchy skin	Passing urine	Getting around (walking)
	Support groups	Money and Housing		Getting around (walking)	Tinging in hands/feet	Tingling in hands and feet	Tingling in hands and feet	Dry, itchy skin	Hot flushes	Memory and concentration	Constipation	Transport or parking
	Exercise or activity	Anger or frustration		Sore or mouth	Loss of interest/activities	Weight loss	Sore or Dry Mouth	Memory and concentration	Dry Skin	Constipation	Sleep problems/nightmares	Children
	Eating or appetite	Pain		Partner		Complementary therapies	Getting around (Walking)	Getting around (Walking)	Memory and concentration	Worry, fear or anxiety	Tingling in hands and feet	Sleep problems/nightmares

Analysis of this table provides evidence and insight that have implications for how HNAs are implemented and also the scale and type of post assessment responses that PABC will require. For example:

- There is some indication that lower numbers of concerns are reported by PABC when the HNA is conducted within what has been termed a routine model of HNA
- Higher average number of concerns per patient were reported by community based projects
- In seven of the 11 projects being tired, exhausted and fatigued was the most frequently reported concern. Related to this is the high placing of concerns about sleep problems/nightmares.
- Among the hospital based project where CNS are assessors, higher up the list are more physical /symptomatic concerns such as hot flushes, dry mouth, diarrhoea and constipation.
- HNAs carried out (a) closer to diagnosis/end of treatment and/or (b) by a CNS or nurse specialist are associated with higher reporting of physical/medical related concerns.
- Shown in a different colour are the <u>lifestyle or information needs</u> identified by some patients. It is important to distinguish these from 'concerns' as the reporting of issues within this domain will require a different service response from, for example, more physical concerns such as pain or mobility. Of note is the recurrence of this 'need' reported by PABC within community based projects.

At this stage of the national evaluation it is not possible to determine the main drivers of these indicative findings. They could include not only the type of cancer, but also the timing of the assessment (close to treatment), the profession of the assessor (a CNS/nurse specialist), or the location of the assessment (Hospital or primary care setting) where it could be supposed that PABC would more naturally expect physical/medical issues to be dealt with.

In relation to interpreting and using what PABC tell us a number of issues are of importance when considering the evidence base for new services for people living with and beyond cancer. These are discussed below.

Firstly, the implications of analysing aggregated concerns data are important. Such a high level of analysis is less valuable to service commissioners than a detailed interrogation of individual concerns. For example, physical concerns numerically dominate the checklist so have a greater chance of being the most frequently reported area of concern. Of more use is the knowledge that within the domain of physical concerns – the most frequently reported issue is that of being "tired, exhausted or fatigued".

Secondly the concerns listed are not 'exclusively' those of people 'after treatment'. Rather they are an amalgam of those at many and all stages of individual cancer journeys. All data must therefore be interrogated within the context and circumstances

from which it was derived In addition, a better understanding of how the inclusion or exclusion of those reporting no concerns affects the figures on prevalence of concerns is required.

Thirdly it remains questionable how informative the over collation of concerns data is to service commissioners. For example, it is possible to calculate that within the hospital based projects a total of 699 had an overall average of 3.1 concerns. However, within this, individuals with PABC reported their concerns ranging from none to 47 – the maximum number of concerns that can be reported on the concerns checklist.

Using the number of concerns as a baseline to determine overall prevalence and changes (a drop) in reported concerns is a useful proxy outcome measure. Yet the over collation of concerns data may mask enduring concerns and fail to identify where scarce resources should be targeted. The learning from TCAT illustrates that there is more value in focussing attention and resources on understanding the specific *nature* of reported concerns and on how they can be reduced or resolved.

To illustrate the analytical benefit of more detailed interrogation of the concerns data resulting from HNAs we present data from one project. High level of analysis demonstrates a statistically significant drop in the mean number of concerns (p=0.000) between Time 1 (12.79 mean number of concerns) to 5.24.

In the following tables we compare the number of concerns (Table 9) and the nature of concerns (Table 10) reported by a matched sample of 33 patients at the first HNA (Time 1) and the subsequent HNA (Time 2).

Table 9: Concerns by domain, Time 1 and Time 2

Concern Domain	Time 1	Time 2
Physical	176 (41%)	114 (66%)
Practical	53 (12%)	11 (6%)
Family/ relationship	15 (3%)	7 (4%)
Emotional	104 (24%)	31 (18%)
Spiritual or religious	25 (6%)	6 (3%)
Lifestyle or information	59 (14%)	4 (2%)

Table 10: Most frequently reported concerns, Time 1 and Time 2

Time 1	Time 2
Tired/ Exhausted or Fatigued	Tired/ Exhausted or Fatigued
Getting around (Walking)	Getting around (Walking)
Exercise and activity	Pain
Worry, fear or Anxiety	Sleep problems/ Nightmares
Loss of interest/ Activities	Worry fear or anxiety
Sadness or Depression	Memory or concentration
Money and Housing	Constipation
Anger or frustration	Eating or Appetite
Pain	Hot Flushes/ Sweating
Difficulty making plans and support groups	Anger or Frustration

Looking first at physical concerns it is evident that numerically the 33 patients report fewer concerns within this domain (from 176 at Time 1 to 114 at Time 2). However, the percentage of physical concerns as a proportion of all concerns reported increases (from 41% at Time 1 to 66% in Time 2). Presenting the data as a 'proportionate change' illustrates a different finding to say for example percentage decrease in reported domain. (in this example it would be a decrease of 36%). Table 9 highlights that the most prevalent concerns overall are that of being tired/exhausted or fatigued and problems getting around (walking). These are potentially the most enduring/unmet - at both time points they remain at the top of the list

For lifestyle or information needs it can be seen that they accounted for 14% (n=59) at Time 1 and only 2% (n=4). Table 10 provides some explanation for this – with the third most reported concern at Time 1 (exercise and activity) and money and housing – the seventh most reported not being evident at Time 2.

Despite the qualifications and recommendations for use, given above, as a result of TCAT, we now have an increased understanding of the scale and nature of the concerns PABC have. Further enhanced practice and improved patient outcomes will however only result from the appropriate interpretation and analysis of what PABC tells us is concerning them and using it as a basis to meet the identified needs.

It is now incumbent on practitioners and service providers to interrogate both the locally and nationally, derived data on reported concerns and use it as a basis for the planning and provision of effective post assessment responses. To do this requires better insight into the impact the different approaches to implementing HNA actually has on short and longer term patient outcomes.

Macmillan Cancer Support commissioned a realist evaluation of HNA and care planning as part of the national evaluation of TCAT. This work is ongoing. By utilising a realist evaluation approach this work is focussing upon exploring in more depth relevant outcomes from patient, practitioner and service perspectives. In addition, as this approach seeks to establish what generates the outcomes (by interrogating both

context and mechanisms) this work has greater potential to produce findings that are more generalizable and transferable.

Conclusion

In common with other long-term conditions, the provision of effective and sustainable cancer survivorship services requires reform of the planning, delivery and performance of health and social care services. This is needed to ensure appropriate use of resources, improved outcomes for patients and carers, support for self-management and an overall and ongoing shift in focus from treating the disease to supporting general health and wellbeing.

As a result of the testing and piloting work funded by TCAT programme there are now evidenced demonstration case studies and local exemplars of how HNAs can be implemented. This Bulletin presents the evidence and learning to date from the national evaluative perspective on the implementation of holistic needs assessment (HNA). By disseminating what is known as a result of the programme and through sharing important lessons practitioners and service commissioners can use the knowledge to optimise implementation in their areas and with relevant partners. These evaluation findings illustrate some of the challenges facing service commissioners and practitioners.

TCAT has provided Scottish evidence that implementing HNA need not limit itself to one prescriptive delivery model. The various design and implementation approaches of local TCAT projects have demonstrated that holistic assessment and care planning for people affected by cancer is not an off the shelf intervention. The resulting key lesson is that when implementing HNA it is critical to understand and consider the connectivity and inter dependence of implementation decisions on processes experienced by PABC and subsequent short and longer term outcomes. For example, when and why the assessment takes place will have implications for who carries out the assessment, who is assessed, where and what happens next for the patient. The answer or decision to when the assessment takes place for example, will have implications for who carries out the assessment and where and of course why.

Improved patient outcomes, impact and related costs and benefits are related to and dependent upon how HNAs are designed and implemented. To be truly effective the implementation of HNA has to be approached as the sum of its parts. Not all parts will be within one service, sector or department.

For the benefits of HNA to be maximised, it cannot continue as isolated pockets of good practice. **The 'holistic' nature of the intervention cannot be restricted to the assessment process alone. It must in it its implementation, delivery and evaluation transcend sectoral and service boundaries**.

APPENDIX ONE: DATA SOURCES

The content of this Bulletin draws on the work of 11 completed local TCAT projects who utilised the Patient Concerns Checklist as an assessment tool. A summary of each project is presented in Appendix 3.

Phase 1	Phase 2
NHS Borders	NHS Lothian/ Westerhaven
NHS Tayside	Fife HSCP
NHS Lothian	Midlothian HSCP
NHS Ayr	NHS Lanarkshire
NHS Fife (melanoma)	Renfrewshire HSCP
NHS Forth Valley	

The data sources are summarised in Table 1 and are:

- Pre and post implementation focus group discussions with the eight local projects Steering Groups (n= 48 individuals).
- Review and synthesis of the local project evaluation findings and available from each by April 2018.
- Analysis, of available data from local patient surveys that used the ENU Feedback Form.
- Nationally specified data sets collected from local projects relating to a total of 1,291 HNAs. See Box 1. This has been collated, reviewed and re-analysed by Edinburgh Napier University for a national perspective.

Table 1: Data sources

Project	Available HNA data sets (n)	Post TCAT Feedback Form (n)	Pre TCAT Feedback Form (n)	Focus Group Discussion (pre & post)
NHS Lothian	61			x
NHS Borders	31	9		x
NHS Forth Valley	47	29		x
NHS Fife (Dermatology)	115			x
NHS Tayside	284	85		x
NHS Ayrshire & Arran (E of T)	161			x
NHS Ayrshire & Arran (HWBC)	146			x
NHS Lothian/ Westerhaven	47	13		
Fife HSCP	29	32	57	x
Midlothian HSCP	42			
NHS Lanarkshire	248	77		
Renfrewshire HSCP	80	47	62	x

Readers should note the following in relation to the quantitative data:

- The HNA data presented here relates only to individuals for which all three data sets were was available to ENU (see Box 1). Therefore the totals of HNA assessment will not equate to the total number of patients assessed by each project overall.

- Data from the project in NHS Ayrshire and Arran occurs twice. All 3 data sets were available for patients who attended the TCAT Health and Well Being Clinic. In addition, concerns data only was available for patients gathered by CNS at the end of treatment clinic. Where relevant this is presented.

Box 1: Description of specified data – which was included in analysis if all 3 data sets were available

> **Core Data:** is collected for all the patients/clients/users of TCAT services/interventions across the whole programme in Scotland and provides basic demographic information. It includes for example, cancer type, age and living situation.
>
> **HNA Processes and Actions:** is a data sheet used to record key aspects of the assessment undertaken, regardless of the HNA tool used, such as profession undertaking the assessment, location, length, referral and signposting activity.
>
> **Concerns Checklist:** is a record of the identified concerns and overall concern level/score of individuals within the TCAT programme who locally completed a HNA using the Concerns Checklist tool only

Analysis

All qualitative data and local evaluation reports were subjected to thematic analysis[xii]. Transcripts of interviews and group discussions were firstly listened to and read to check the accuracy of the text and then coded using the software, QSR NVIVO. This was then verified independently by other members of the team for consistency and interpretation. All quantitative data was reviewed for accuracy and omissions. The Research Fellow worked with the statistician and local projects to ensure the submission and analysis of only robust data. The data was analysed using Excel and SPSS.

Further detail of the overall national evaluation work strands can be found in the Baseline and Interim reports and accompanying Technical Appendix (on request from TCAT@napier.ac.uk).

APPENDIX TWO: CONCERNS CHECKLIST

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.

1 _____ 10

Lowest — Highest

WE ARE MACMILLAN. CANCER SUPPORT

(DH) Department of Health

NHS
NHS Improvement

Concerns Checklist   Version 1   April 2015

APPENDIX THREE: SUMMARY OF PROJECTS

Fife - Health and Social Care Partnership

This project offered people with cancer a Local Area Coordinator (LAC) who met them and talked through the HNA to establish their needs and wants before they jointly agreed a care plan. The LAC helped the person access the support they needed. Patient feedback was very positive.

NHS Ayrshire & Arran

This project offered people who had finished cancer treatment an HNA followed by support to deal with their wider emotional, financial and practical needs. The project resulted in patients reporting fewer concerns in many areas. It is now being rolled out within the health board.

NHS Borders

This project highlighted the need for better care and support for patients in Hawick, and has now been rolled out across NHS Borders. The project found gaps in care after treatment for cancer, with patients often not knowing what to expect, what to look out for or who to contact.

The project met their needs by offering people an HNA and care plan. It also held Health and Wellbeing Events and created a service directory.

NHS Fife - Skin cancer

This project offered people with skin cancer personalised medical follow-up, a care plan and other support. Most people found the new approach helpful in meeting their needs.

NHS Forth Valley

This project offered men who had finished treatment for prostate cancer, an assessment of their support needs, alongside help dealing with their emotional, financial and practical needs. The results suggested a significant proportion of men attending follow-up appointments in hospital after the end of their treatment could be supported to self-manage.

NHS Lothian – Westerhaven

This project aimed to empower people to optimise their well being after cancer treatment, whether they needed help to return to normal life or support as they entered the palliative phase of their illness. Patients who had completed their cancer treatment - as well as their carers - were offered an HNA and care plan in Wester Hailes Medical Practice.

NHS Lothian - Secondary care

This project offered patients with breast, gynaecological, anal, rectal and lung cancer an HNA and care plan, alongside the opportunity to attend a recovery clinic with a cancer nurse. The project saw a drop in the number of concerns reported by patients between their first and second assessment. Positive feedback was received from patients.

[NHS Tayside](#)

This project offered people with cancer an HNA and care plan, and an invite to a Health and Wellbeing event. Afterwards just over half said they felt confident to be able to self-manage their condition.

[Midlothian Council - Living Well After Treatment Project](#)

The Midlothian Living Well After Treatment project offers people with cancer, their family and carers HNAs and care plans, followed by help finding the right support and information to meet their needs.

[NHS Lanarkshire – Cancer reviews in Primary Care: The role of practice nurses](#)

This project involves practice nurses using the HNA and care plan to conduct Cancer Care Reviews. The aim is to empower patients to access the range of local support and self-management options available, while also proving the effectiveness of practice nurses conducting Cancer Care Reviews.

[Renfrewshire Health and Social Care Partnership](#)

The project offers people with cancer assessments of their needs and supports them to access community services.

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