

**Transforming Care After Treatment**

**Realist Evaluation of Holistic Needs Assessment and Care Planning**

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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.

## EXECUTIVE SUMMARY

This report sets out the findings of a Realist Evaluation (RE) of Holistic Needs Assessment (HNA) and Care Planning for people affected by cancer (PABC). The overall aim of the work was to:

Increase insight into mechanisms of HNA and Care Planning to provide better understanding of processes, assessor skill sets & remits, settings, and delivery of HNAs and Care plans, allowing evidence-based decision-making to improve outcomes and experiences.

The overarching question of all Realist Evaluations is “what works, for whom, in what circumstances and why?” The work required to answer this question was approached in three phases.

Phase 1: Establishment of programme theory for HNA and Care planning

- The articulation of the initial ‘programme theory’ is a critical first step in RE. It serves to make explicit the assumptions of the intervention about how and why it was expected to generate the set objectives.

Phase 2: Exploration and documentation of local programme theories to establish ‘candidate theories’ or ‘theory areas’ that will be interrogated

- The local programme theories of the six study sites were identified and additional, local outcomes of the intervention identified. From this ‘candidate theories’ or candidate, ‘theory areas’ were defined. Candidate theory /theory areas have to be ‘testable’. Once defined, they are ‘unpacked’ to discover how, more specifically, the intervention actually does work.

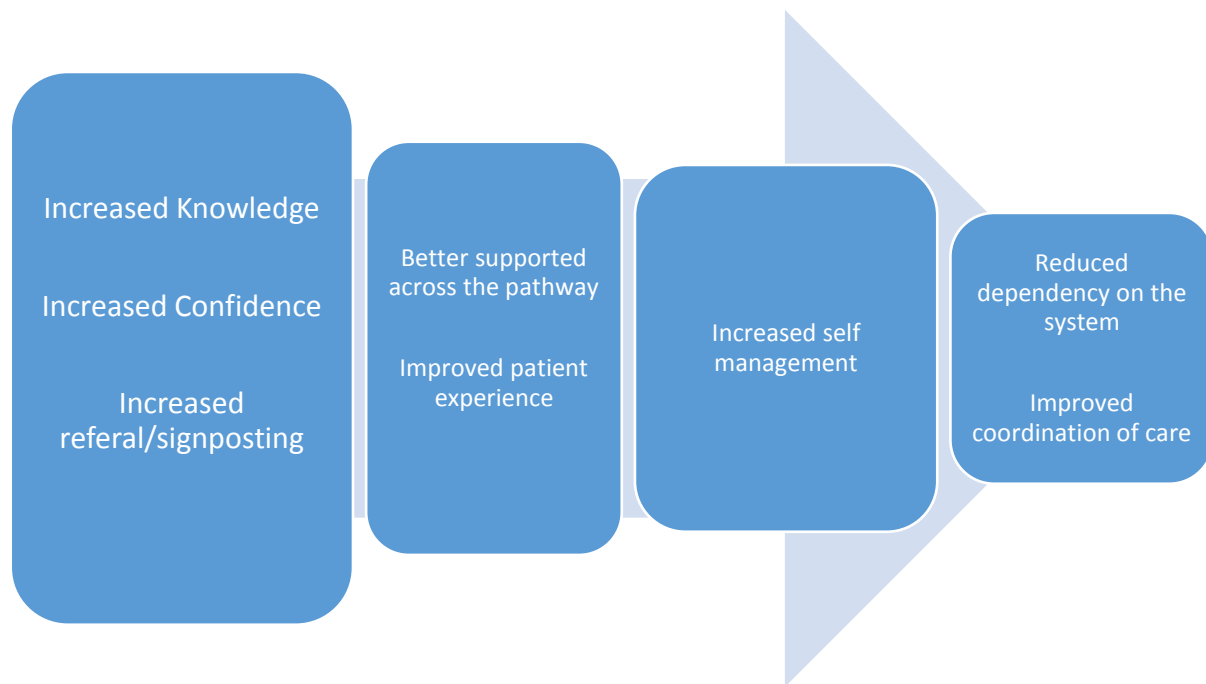
Phase 3: Theory testing and refinement

- RE requires the pursuit of ‘ontological depth’ to identify and explore what it is exactly about an intervention that makes a difference. Interrogating what happens ‘below the water line’ provides more detailed insight into what actually generates outcomes. In making a difference the function of ‘mechanisms’ are critical. During theory testing and refinement, mechanisms are looked for and their relationship to an outcome explored. That is how they work and what specific contexts ‘trigger’ or ‘fire’ them into action. Mechanisms can of course also be ‘latent’. This occurs when the context within which they are present, fails to trigger them sufficiently.
- The results of RE (the refined theories) are set out at a middle range of ‘abstraction’. The positioning of the evaluation findings at this level is assisted further by framing it within ‘substantive theories’ of health and social behaviour. This assists with the ultimate pursuit of transferability, generalisability or ‘portability’ of the findings.

## ***Properties and outcomes of HNA and Care planning***

This work has increased understanding of the inner workings of HNA and Care planning by detailing out the aimed for outcomes and their interplay and by explicating the properties of the intervention that may affect its impact.

### ***Outcomes***



### ***Properties***

1. Holism is fundamental as is the presumption that it will be patient led
2. The raison d'être of HNA and Care Planning is to assist recovery/living well with and beyond cancer
3. HNA is a process involving interaction between patient and assessor and a discussion is the main vehicle of this
4. The assessment itself and the assessment process are assumed to have causal properties. As such both can/could be both an outcome and a mechanism
5. Outcomes are dependent not only on the role of the assessor but also upon the response of the assessed (during and after the intervention)

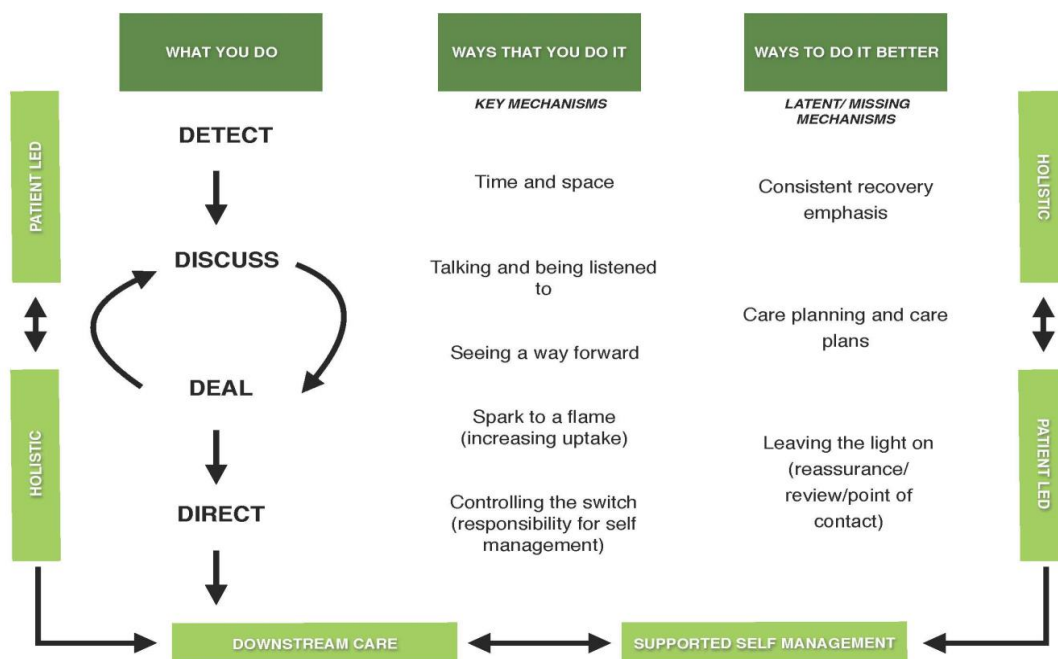
Realist Evaluation (RE) seeks to better understand, identify and evaluate why complex interventions succeed or fail in order to inform spread, replicability and sustainability of effective interventions. RE provides a way of explaining in more detail how the outcomes of an implementation are actually achieved. This knowledge can be used to enhance the likelihood of success when implemented in other areas.

To understand the optimum conditions for the effective implementation of HNA and Care Planning, a realist approach proposes that: outcomes (results, changes, improvements) of an intervention are generated by mechanisms (intervention resources, ideas, how the implementer and recipient react to these through response/reasoning) that are activated in specific context. This explanatory way of describing causation is presented as a formula or Context, Mechanism, Outcome Configuration (Pawson & Tilley, 1997).

Context + Mechanism = Outcome

The findings indicate how the implementation of HNA can be optimised. This is achieved by working to ensure the consistent and effective ‘triggering’ of the identified key mechanisms. When triggered effectively these mechanisms will increase the impact of the intervention short term by improving the patient experience and longer term - facilitate increased self management and reduced demands on the system.

The key findings and recommendations are presented below using this heuristic and in summary in the diagram below.



## Conclusions and Recommendations

**The concerns checklist is an important tool for detecting and legitimising concerns and its continued use is recommended**

The evaluation found that the use of a concerns checklist as an HNA tool did assist the patient in reflecting on and identifying their concerns within the offered holistic framework. This primarily held true for patients who completed the list in advance of the assessment appointment as once 'introduced' into the assessment process patient reporting and identification of holistic concerns could be 'corrupted' by the actions or processes of the assessor.

**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**

The duration of HNA, that is the length of the appointment (*mechanism*) has an impact on the patient's experience. PABC appreciated not feeling under pressure during the assessment because of perceived or real time constraints of the assessor and this made the experience a more positive one (*outcome*). In addition, the length of appointment was seen to affect patient led and holistic assessment fidelity (*outcome*).

**Any future patient reported outcome/experience measure of HNA and care planning must include that PABC felt that they have had the opportunity to talk about their concerns and report consistently that these were actively listened to.**

Being 'allowed' or afforded the opportunity to talk to an assessor (*mechanism*) 'at some length' (*context*) who is actively listening (*mechanism*) is of critical importance to how a HNA and Care Planning is implemented. Talking was reported to be, not just the means to outcomes, but a positive 'end' in itself for PABC.

The combination of 'patient talks/assessor listens' (*mechanism*) and the length of the HNA (*context*) provided 'reassurance' (*outcome*) to PABC in that what mattered to them had been verbalised and heard (*mechanism/outcome*) in an environment where they had 'time and space' (*mechanism*) to benefit fully from the process.

**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.**

If an assessor's role in the assessment process is not exclusively to conduct an HNA, (for example if HNA is combined with surveillance/medical follow up) that is they have two or more roles, there is a risk that the desired holistic, recovery focussed assessment and process is not or cannot be fully implemented.

**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.**

Ensuring a patient led/holistic assessment can be less likely to be realised earlier on in a patient's cancer journey (during treatment, immediately post treatment) when functional/medical issues may rightly be at the forefront of both the patients' and the assessors' minds. Analysis of concerns data revealed that HNAs carried out closer to diagnosis/end of treatment and/or by a CNS are associated with higher reporting of physical/medical related concerns such as hot flushes, dry mouth, diarrhoea and constipation.

The holistic focus of the assessment may be more vulnerable if carried out during treatment or within weeks of completion if physical concerns or functional issues experienced by a patient are dominating their life

The findings of this RE identified two key mechanisms within HNA and Care Planning, that if operating will increase the likelihood of service uptake. These relate to the PABC understanding, from diagnosis, their own role and responsibilities on the route to recovery (control of the switch) and the need for reassurance and reinforcement of recovery focussed messages and actions (leaving a light on).

**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).**

Throughout the cancer journey the point of contact does not necessarily require a face to face consultation, it could be achieved through telephone contact or the development of recovery emphasising Apps and other forms of electronic communication. Both reassurance and reinforcement cannot be at a singular point in the recovery pathway. Concerns change over time and are enduring in nature. Therefore 'leaving the light on' through the provision of a point of contact and Care Plan review is especially important in the care after treatment of PABC.

**The utility of Care Planning and Care Plans must be further evaluated and enhanced**

The content of Care Plans was extremely wide-ranging, indicating a high level of variation in practice This RE found that this critical mediating mechanism, the one that should in theory link the assessment to the longer term 'self-management' actions of PABC is latent or weak.

To generate positive outcomes from Care Planning and Care Plan co-production, it is critical for the intervention to actually contribute to an increase in self-management acts. Aimed for outcomes are generated also through the assessor consistently

working with the patient to clarify both their roles in recovery and to support the PABC to assume a greater level of control post assessment.

In addition, the following areas of **service piloting and broader research** are recommended:

- 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.
- Piloting of technology based interventions to increase the impact of key reinforcement and reassurance mechanisms.
- A needs assessment of required training and mentoring to support optimal implementation of HNA and Care Planning.

## Purpose and background

This report sets out the findings of a Realist Evaluation (RE) of Holistic Needs Assessment (HNA) and Care Planning for people affected by cancer (PABC). It formed a major work strand of the overall national evaluation of the Transforming Care After Treatment Programme (TCAT) carried out by Edinburgh Napier University.

Many piloted approaches to HNA have their roots in the UK work of the National Cancer Survivorship Initiative (NCSI, Department of Health, 2010). This was a partnership between the Department of Health (England and Wales) and Macmillan Cancer Support. In January 2010, a “National Cancer Survivorship Vision” was published promoting HNA as a key component, of the whole Recovery Package to support people living with and beyond cancer. However, currently there is limited evidence on the effect different implementation or design approaches may have on patient experiences and outcomes, resource use and sustained and informed ‘good practice’ (Carlson, 2012).

Macmillan Cancer Support therefore commissioned this RE to further inform and progress evidence-based practice of HNA and Care Planning. The overall aim of the work was to:

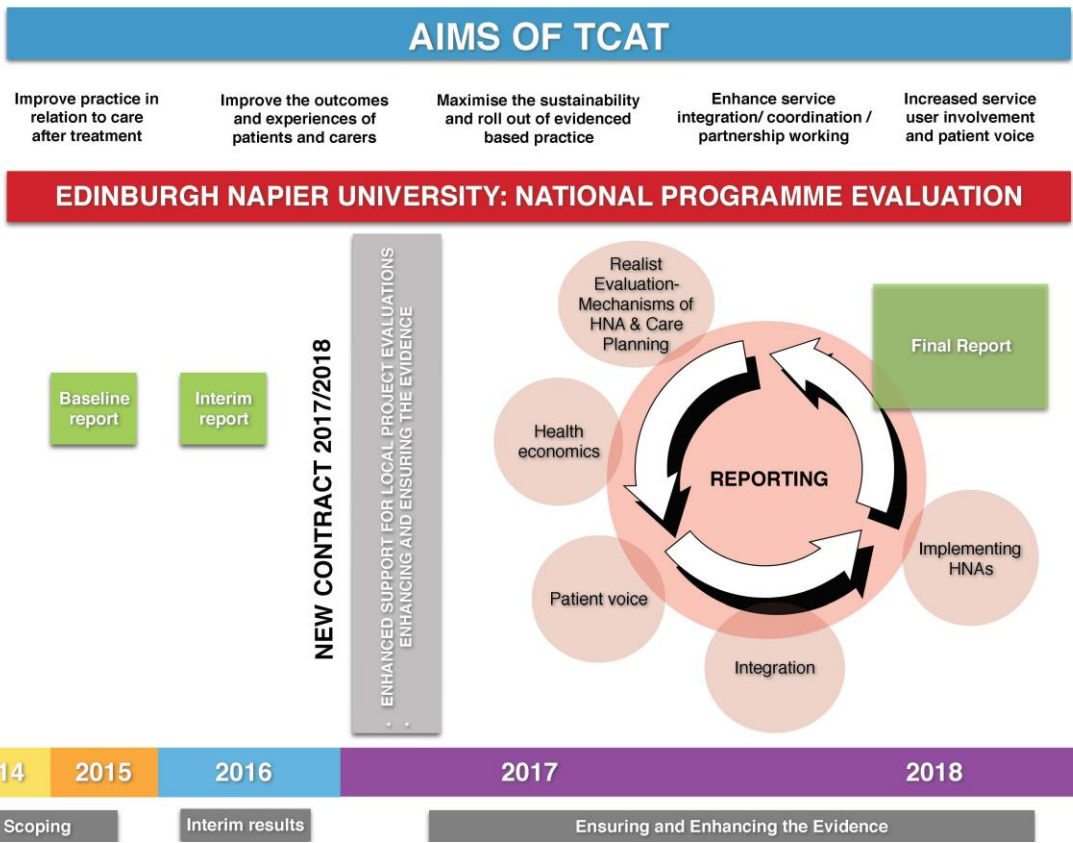
Increase insight into mechanisms of HNA and Care Planning to provide better understanding of processes, assessor skill sets & remits, settings, and delivery of HNAs and Care Plans, allowing evidence-based decision-making to improve outcomes and experiences.

The findings of the RE are presented as a standalone report. They are related to the evaluation findings presented in the Baseline (2016) and Interim (2017) reports, and the Final Evaluation Report (November 2018). It is part of a suite of topic specific Evidence and Learning Bulletins, prepared by the national evaluation team.

- 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

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.





## Methods

Realist Evaluation (RE) seeks to better understand, identify and evaluate why complex interventions succeed or fail in order to inform spread, replicability and sustainability of effective interventions. RE provides a way of explaining in more detail how the outcomes of an implementation are actually achieved. This knowledge can be used to enhance the likelihood of success when implemented in other areas.

To understand the optimum conditions for the effective implementation of HNA and Care Planning, a realist approach proposes that: outcomes (results, changes, improvements) of an intervention are generated by mechanisms (intervention resources, ideas, how the implementer and recipient react to these through response/reasoning) that are activated in specific context. This explanatory way of describing causation is presented as a formula or Context, Mechanism, Outcome Configuration (Pawson & Tilley, 1997).

$$\text{Context} + \text{Mechanism} = \text{Outcome}$$

The focus of this RE is solely upon HNA and Care Planning. It was designed to elicit better understanding of processes, assessor role and remit, settings and delivery

systems. It is acknowledged that HNA and Care Planning is only one component of the Recovery Package, which as a whole has “collective aims” (Mahler, 2018). This work focuses on outcomes of most relevance to HNA and Care Planning as a standalone intervention. It focussed on shorter-term impacts and intermediate/process outcomes of the intervention rather than on longer-term indicators such as quality of life or health and well-being. The detailed reasons for this, such as data control and comparison insufficiency are set out in the Bulletin – The Measurable Outcomes of TCAT. Moreover, the timing of the qualitative fieldwork within this time-limited study resulted in participants only being able to reflect and comment on shorter term and intermediate outcomes.

The overarching question of all Realist Evaluations is “what works, for whom, in what circumstances and why?” The work required to answer this question was approached in three phases.

#### Phase 1: Establishment of programme theory for HNA and Care Planning

- The articulation of the initial ‘programme theory’ is a critical first step in RE. It serves to make explicit the assumptions of the intervention about how and why it was expected to generate the set objectives.

#### Phase 2: Exploration and documentation of local programme theories to establish ‘candidate theories’ or ‘theory areas’ that will be interrogated

- The local programme theories of the six study sites were identified and additional, local outcomes of the intervention identified. From this ‘candidate theories’ or candidate, ‘theory areas’ were defined. Candidate theory /theory areas have to be ‘testable’. Once defined, they are ‘unpacked’ to discover how, more specifically, the intervention actually does work.

#### Phase 3: Theory testing and refinement

- RE requires the pursuit of ‘ontological depth’ to identify and explore what it is exactly about an intervention that makes a difference. Interrogating what happens ‘below the water line’ provides more detailed insight into what actually generates outcomes. In making a difference the function of ‘mechanisms’ are critical. During theory testing and refinement, mechanisms are looked for and their relationship to an outcome explored. That is how they work and what specific contexts ‘trigger’ or ‘fire’ them into action. Mechanisms can of course also be ‘latent’. This occurs when the context within which they are present, fails to trigger them sufficiently.
- The results of RE (the refined theories) are set out at a middle range of ‘abstraction’. The positioning of the evaluation findings at this level is assisted further by framing it within ‘substantive theories’ of health and social behaviour. This assists with the ultimate pursuit of transferability, generalisability or ‘portability’ of the findings.

A key feature of RE is the linking of 'new knowledge' to relevant, previously conceived social theories to enhance the credibility and plausibility of the findings and explanation as to what generates outcomes. Although, as is usual in many RE reports, the findings are not related 'directly to the theory – but have been informed by them.

It was determined that the utilisation of Meleis Transition Theory (Meleis, 2000) for the HNA and Care Planning intervention, offered the greatest 'fit' for the analysis and reporting processes (See Box 1). The overall framework and concepts of Transition Theory correspond well to the lived experiences of PABC. Having a cancer diagnosis is often described as a 'journey' or a pathway with different stages or events and stages. Macmillan Cancer Support recommend that HNA and Care Planning is offered at what they term 'key transitions'. In the evaluation of HNA and Care Planning a frame of reference informed by Transition Theory enhanced the explanatory power of the findings overall.

Other authors have identified transition as a key concept in cancer care and experiences. For example, the work of Merluzzi (2016) indicates that as a person moves into survivorship phase post-treatment, their need for support and the type of support required will also change. Rancour (2009) investigated the move from treatment to 'survivorship' and recommended that positive interventions are enhanced by an awareness of the impact of a patient's transitioning. Kralik (2006) proposes that if health and social care professionals have an understanding of transitions, they can deliver a more holistic approach to care.

## Box 1: Meiles Transition Theory

At the heart of Transition Theory is how to ensure 'healthy transitional environments and processes'.

- A transition is signified by a change in 'role' and the patient is viewed, not as an unconnected person or disease, but in terms of their relationship to a network of significant others (which will include health and social care services)
- Changing roles will require new skills the person may not possess - referred to as Role Insufficiency. Role insufficiency is exacerbated by not being prepared for the transition and 'anticipatory preparation' will facilitate a positive transition experience.
- This skill 'deficit' can be compensated for and reduced, with new role appropriate skills acquired via the provision of processes (of which communication is a key one) or intervention provided by others – referred to as Role Supplementation.
- Role supplementation can be preventative or therapeutic and a major aspect of supplementation takes the form of occurs through the clarification of roles

The following aspects of Transition Theory have been critical to its role as an explanatory platform for HNA and care planning:

- Encompasses the temporal nature of HNA and Care Planning – transitions occur over time and not in one place in time
- Has cross sector and multi – profession applicability
- Acknowledges that the person and their circumstances should be viewed holistically. Offers insight into the importance of the roles of the patient and provider and how they interact and change
- Offers a framework within which to analyse, interpret and understand better the meaning of 'increased and supported 'self-management'

These concepts and theoretical frameworks acted as both a guide and prompt to further analysis and exploration.

To enhance the practical application of the insight gained, a number of analogies are employed in describing the mechanisms identified. By evoking commonly, used expressions where appropriate the findings can be more readily used to enhance implementation, develop practice and inform new, more nuanced training materials.

## Sources

This is a mixed methods study based on six local TCAT Projects<sup>1</sup>. The evaluation utilised nationally specified data derived from these local TCAT projects and a review and synthesis of their local project evaluations. Table 2 shows the main methods utilised over the last three years and the additional fine testing fieldwork applied within the RE.

**Table 1: Fine Testing Methods by local site**

	Ayrshire & Arran Phase 1	Tayside Phase 1	Midlothian	Renfrewshire	Fife Phase 2	Lanarkshire Phase 2
1:1 patient interviews	7/23	5/22	5/17	9/46		
Care Plan review	x	x	x	x		
Interviews with assessors individual / focus groups	1	5	2	2	2	10
Programme papers and Logic Model	x	x	x	x	x	x
Expression of interest documents and approved applications	x	x	x	x	x	x
Pre implementation group discussions	x	x		x	x	x
Post implementation group discussions	x	x		x	x	

<sup>1</sup> Published protocol can be accessed here (<https://doi.org/10.1186/s12913-018-3373-6>).

## THEORY DEVELOPMENT (PHASES 1 and 2)

The process of HNA and Care Planning is defined as;

*“a process of gathering and discussing information with the patient and/or carer/supporter in order to develop an understanding of what the person living with and beyond cancer knows, understands and needs. This holistic assessment is focused on the whole person; their entire well-being is discussed – physical, emotional, spiritual, mental, social, and environmental. The process culminates when the assessment results are used to inform a care plan.”* (NCSI, Department of Health, 2010).

Box 2 below sets out the Initial Programme Theory for the implementation of HNA and Care Planning.

### Box 2: Initial programme theory of HNA and Care Planning

IF a holistic assessment is focused on the whole person, their entire well-being—physical, emotional, spiritual, mental, social, and environmental (*context*), through a process of gathering and discussing information (*resource mechanism*) with the patient and/or carer/supporter an understanding of what the person living with and beyond cancer knows, understands and needs is developed (*reasoning mechanism*) and the results are used to inform a care plan (*a mechanism and an outcome*) THEN patient experiences and outcomes (health and wellbeing, self-management) will improve and demands on health services will be reduced. (*longer term outcome(s)*).

### Local programme theories

Within TCAT, there was heterogeneous implementation of HNA. Holistic needs assessment of people affected by cancer were undertaken in different health and

social care settings, by different professions, for a range of reasons and at a variety of points on the patient's journey. HNA and Care Planning, within TCAT, was deemed to have universal applicability. That is, it was assumed, that variation in implementation (such as when an assessment takes place) would not result in significantly different patient outcomes. Box 3 provides details of the implementation approach of the study sites.

### **Box 3: Local implementation of HNA and Care Planning**

1. As part of routine care, a Clinical Nurse Specialist or specialist nurse in cancer in a hospital out-patient setting conducts an HNA with people at the end of active treatment for colorectal cancer
2. As part of an additional 'after treatment service' a non-health professional in a community setting offers /invites patients with breast cancer to attend an appointment for an HNA 8 weeks after the completion of active treatment
3. As part of routine care a practice nurse in a GP Surgery, offers /invites patients with any cancer to attend an appointment for an HNA to all patients within 6 months of receiving a diagnosis of cancer.
4. As part of an additional 'after treatment service' patients with any cancer at any stage of their cancer journey to attend an appointment for an HNA in a community setting if they self-refer or are referred by a health or non-health professional. (2 study sites)
5. As part of an additional 'after treatment service' a Clinical Nurse Specialist or specialist nurse offers/invites patients with any cancer at any stage of their cancer journey to attend an appointment with a non-health professional for an HNA in a community setting

## **Resulting candidate theories**

As a result of Phase 1 and 2, four significant candidate theories were configured.

1. If a patient completes the concerns checklist in advance of the appointment (context), the holistic needs assessment and care planning is patient led (mechanism resource) resulting in the concerns addressed during the process being of priority for the patient and not those of the practitioner taking the assessment (mechanism reasoning) and the patient experience will be positive (outcome) with referrals and signposting more targeted to the individual (outcome)
2. If the HNA and care planning process emphasises recovery/moving on after treatment for cancer (context) then the patient will be made aware of their role in recovery (mechanism) and a better understanding of their need to increase their self- management activities (mechanism/outcome) which may reduce their dependency on the system (outcome)
3. If the HNA and care planning process provides a patient with individualised knowledge and/or offers referrals/signposting to relevant support services/resources (context) then the patient will be more equipped to deal with their concerns (mechanism) and more likely to increase their own self-management activities (outcome)
4. If a patient's experience of attending HNA and care planning service is a positive one (context) this positivity engenders a feeling of being better supported across the cancer pathway (mechanism) and results in the patient feeling more confident in their ability to increase their self-management activities (outcome)



## THEORY TESTING

Testing of the candidate theories began with an exploration of the properties of the intervention across the study sites and the characteristics of the implicit, desired HNA and Care Planning outcomes. This was done by making explicit the visible implementation variables, identifying 'assumptions' about what is meant by 'working' (i.e. what are the indicators of success/outcomes) and explicating what it is about the intervention (inherent properties) that the theory suggest is key to achieving success/outcomes.

The complexities and nuances of the outcomes and processes of HNA and Care Planning were identified. The resulting level of specification of the way in which the intervention 'works' increased insight and understanding required to enhance implementation.

### *Understanding Outcomes*

Listed below are the eight patient outcomes of HNA and Care Planning of the national and local theories.



- Increased knowledge
- Increased confidence
- Increased self-management
- Improved patient experience
- Feeling better supported
- Increased referral/signposting
- Improved coordination of care
- Reduced dependency on the system

Taken individually and together these outcomes are multi-dimensional, inter-related and non-linear. In addition, some are, largely, sequential, and somewhat hierarchical. Also implicit in the initial and local theories is a degree of 'cumulative benefit' and

contingency – that is achieving one outcome may be dependent on a different outcome being achieved first.

The intended outcomes and their potential dependencies on one another are illustrated below as a possible 'critical path'. Illustrated in this manner it is clearer to see that relevant outcomes of HNA and Care Planning encompass indicators of the actions of the assessor, that is what the individual assessor does (for example, increase referral/signposting).

It is also evident that some outcomes are dependent on interaction and input from other professionals and agencies – over and above that of the assessor /care planner and the patient themselves (for example coordination of care).



### ***Properties of HNA and Care Planning***

Making explicit all the inherent properties is key to increasing understanding of the inner workings of HNA and Care Planning.

- Holism is fundamental as is the presumption that it will be patient led
- The raison d'être of HNA and Care Planning is to assist recovery/living well with and beyond cancer
- HNA is a process involving interaction between patient and assessor and a discussion is the main vehicle of this

- The assessment itself and the assessment process are assumed to have causal properties. As such both can/could be both an outcome and a mechanism
- Outcomes are dependent not only on the role of the assessor but also upon the response of the assessed (during and after the intervention)

### ***Surface level implementation variables***

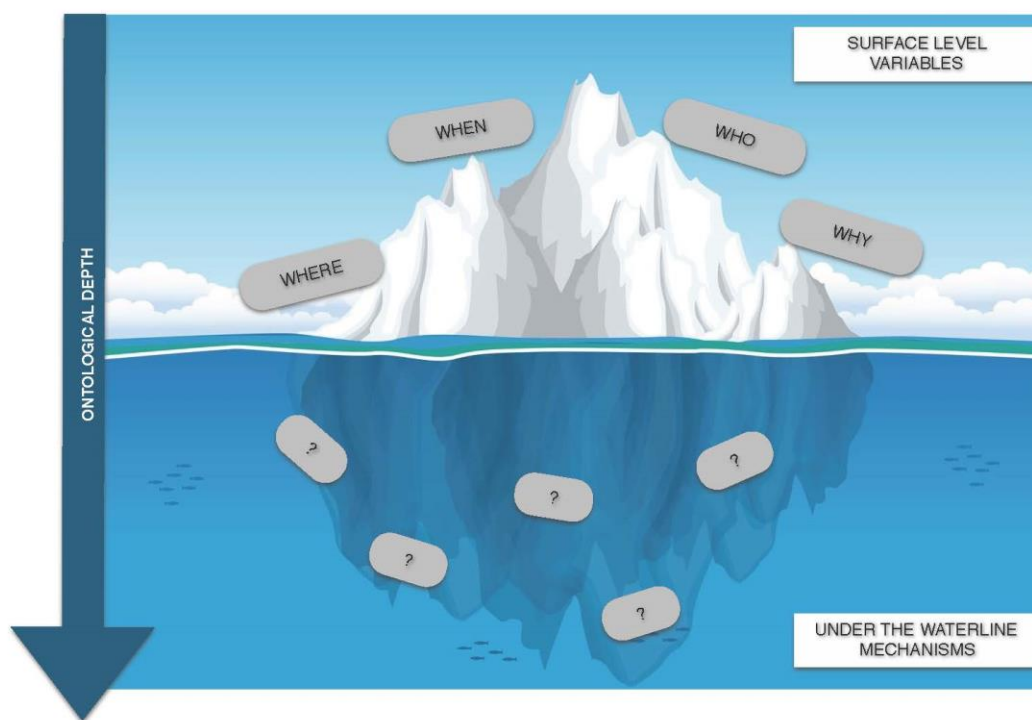
Three implementation variables were identified across the study sites. Defined at a fairly 'high level of conception' they were determined to be the profession of assessor (who), location (where) and timing of the assessment (when). Further work during 2017, targeted at the implementation of HNA and Care Planning identified a fourth delivery variable - that of the priority reason for implementing an HNA (why).

- Routine: This relates 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

The next stage of the RE identified the key causal mechanisms that generate outcomes. Mechanisms are the critical, active components of the intervention that operate 'below the surface'. The ontological insight provided by RE is often therefore illustrated as an iceberg<sup>2</sup>.

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<sup>2</sup> See for example Dr Justin Jagosh, Centre for the Advancement of Realist Evaluation and Synthesis



## Key causal mechanisms of HNA and Care Planning

The following section of this report presents the identified mechanisms one at a time. However, their cumulative and collective properties must be borne in mind. In addition, it is important to reiterate that these mechanisms only generate outcomes if triggered or 'fired' by the context within which they have potential.

### *Time and space*

The priority reason (routine or recovery) for implementing HNA and Care Planning affected 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. In contrast, a negligible number (less than 2%) of 'recovery' HNAs took this time, with a high percentage of recovery HNAs (80%) recorded as having taken over an hour. In these projects, no pre-determined length of appointment was set. Among those who experienced a recovery-focussed HNA many reported that it was the first time in their cancer journey that they had been given adequate time for a consultation or meeting.

*And having the opportunity to talk about some of the issues that I was going through, that in itself was helpful, ..... I haven't really had anyone, that I could*

*sit down and say, these are the issues for me. And you go to a GP, he's got about two minutes for you. And they don't really have time for you to talk in any depth about how things are affecting you. So I guess, having the opportunity to talk to somebody for longer than five minutes was a good thing. (Patient 20)*

*"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 (Patient 2)*

*"because sometimes you just need to speak. They've not been given that opportunity. They go to the doctors and within five minutes they're out" (Assessor)*

The duration of HNA, that is the length of the appointment (*mechanism*) has an impact on the patient's experience. PABC appreciated not feeling under pressure during the assessment because of perceived or real time constraints of the assessor and this made the experience a more positive one (*outcome*). In addition, the length of appointment was seen to affect patient led and holistic assessment fidelity (*outcome*).

*"You have to get the HNA done by somebody who has the space and time, to be able to kind of get the whole story, rather than just the clinical" (Assessor)*

*"I got the (HNA) meeting down to an hour and I think it would be very challenging to get it down to half an hour. We have to identify what is the purpose of this meeting and do we want it to be holistic?" (Assessor)*

### **Talking and being listened to (patient talks/assessor listens)**

HNA and Care Planning is delivered and received through dialogue, through discussion and the interaction of the assessor and the assessed. Key to increasing the likelihood of generating a positive experience for the PABC (*outcome*) may however, be the balance of this two-way communication.

*"X listens, and doesn't interrupt when you're mid through a conversation, which a lot of people may well do. But no, X is a very good listener, a very active listener. X does look, X makes eye contact all the time, so you know what you're saying actually goes in, and it's not just a blank face that you're talking to." (Patient 1)*

*“I said to the to the CNS you’ll need a drink of water after that with all the talking you’ve done”...I didn’t get a word in edgeways” (Patient 23)*

Being ‘allowed’ or afforded the opportunity to talk to an assessor (mechanism) ‘at some length’ (context) who is actively listening (mechanism) is of critical importance to how a HNA and Care Planning is implemented. Talking was reported to be, not just the means to outcomes, but a positive ‘end’ in itself for PABC.

*“Probably it released quite a wee bit of stress on me, I would turn round and say...and it's talking to somebody that...well I obviously don't want to talk to my family about certain things, do you know what I mean, so it gave me the opportunity to kind of express myself, whether it went anywhere or not, at least I was able to release that to be honest”. (Patient 24)*

*“I think sometimes, they're just, they're looking for reassurance. And just the fact that you talk about it, and they get an explanation as to maybe why they're feeling like that, and they're quite happy with that, you know. So they don't necessarily officially get on a bus and go somewhere for it, you know, they just need a little bit of reassurance that it's okay, and it's not a problem.” (Assessor)*

The combination of ‘patient talks/assessor listens’ (*mechanism*) and the length of the HNA (*context*) provided ‘reassurance’ (*outcome*) to PABC in that what mattered to them had been verbalised and heard (*mechanism/outcome*) in an environment where they had ‘time and space’ (*mechanism*) to benefit fully from the process.

### **Seeing a way forward**

An HNA can provide PABC with knowledge (*mechanism*) and a feeling of support (*mechanism/outcome*) that can help them see a way forward to living well with and beyond cancer (*outcome*),. Actually seeing a way forward, (*context*) results in PABC feeling more confident (*mechanism/outcome*) to address some of their concerns themselves and seek out alternative sources of support, thereby reducing their dependency on the system (*outcome*).

*“Well, I think it kind of shows you the way forward. I think at the time when X 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” (Patient 19)*

*“I was given direction on how to try and solve some of my concerns” (Patient 1)*

*“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, because I don’t feel my life is anything like the quality it was before I had the treatment”. (Patient 2)*

*“I don’t know, I feel like I’m standing in nowhere, and grasping for support. And I need somebody to guide me, to lead me, in which way, the direction. And when those support for me, to be not feeling alone, and empty, and depressed in a way, you know, and focus on my health. So it was a good experience”. (Patient 5)*

‘Seeing a way forward’ (*mechanism/outcome*) is contingent on the increased knowledge and awareness of sources of support provided by the HNA process (*context/mechanism*). When implemented optimally an HNA can not only show PABC the way forward (*mechanism*) but also be of greater benefit if it can also ‘light the way’ (*mechanism*).

*“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” (Patient 15)*

*“were able to indicate resources I was not aware of. So the extent that they helped, they improved the amount of knowledge that I have about services and people who are out there to assist. And putting me onto things that I didn’t know about. I didn’t know about (local charity) for instance, I’d never heard of them” (Patient 20)*

Referrals and signposting are a means of lighting the way (*mechanism*) for PABC on their recovery pathway and the stronger the level of ‘illumination’ the more confident a person feels on this journey. Although the number of referrals is not an indication of their level of appropriateness or subsequent impact, regression analysis ( $R^2$  of 0.259) illustrated that the implementation of HNA as a recovery or routine model of care had a significant effect ( $p=0.000$ ) on referral rates. For PABC who received a routine HNA 12.6% received a referral, compared to 57.9% of those whose HNA was recovery orientated.

Overall recovery orientated HNA and Care Planning resulted in a higher number of recorded signposting destinations for the PABC. However overall the number of concerns (and type) and overall level of concern of a PABC did not have a significant effect on the signposting rates. Variation in the scale and destination of referral practices was also evident.

This suggests that the actions of the assessor may be directed towards and therefore restricted by what services are available in a PABCs local community and also by which services the assessor is most closely connected to traditionally.

### **Care Planning and Care Plans**

The term HNA is most often used as a short hand for 'HNA and Care Planning'. Within the theory and its original vision, HNA was synonymous with Care Planning. This RE has found that this critical mediating mechanism, the one that should in theory link the assessment to the longer term 'self-management' actions of PABC is latent or weak. There are strong indications that Care Planning and an effective Care plan are 'missing mechanisms' in the delivery of HNA and Care Planning. This was found in both the routine and the recovery-focussed interventions.

Within guidance for HNA and Care Planning there is a low level of specificity of how the Care Planning process and the Care Plan itself should be delivered. In a 22 page guide for professionals providing holistic needs assessment care and support planning, (Macmillan Cancer Support, 2016) content relating to care planning is limited to three aims and a short description.

- *To document the patient's concerns identified within the HNA*
- *To summarise the required actions of both the professional and patient*
- *To resolve or reduce anxiety levels for the concerns raised.*

*"The care or support plan should include what the patient can do too. This should be supported by up-to-date information on local resources like healthy lifestyle projects, benefits advisors, support groups and programmes to encourage independence. The purpose of the care plan is to support the patient"*

An effective Care Plan will fulfil two critical functions. Firstly, to support self-management activity through PABC co-production and ownership of the plan. Secondly, a Care Plan must support individual action and solutions and not be just a record of a discussion. The patient interviews however found limited evidence of either of these functions. Patients had vague if any memory of an actual 'plan' and none could provide examples of how they had used the document post assessment.

*Patient: "Erm, I don't know if we had it written down. But X did say, right, so what is the plan, you know, for the, say it was the stopping smoking, what is the plan. And at first the plan was, I was gonna go to the doctor, right. So, there was a plan, kind of, but I don't know if it was a written down plan"*



*Interviewer: "You didn't take anything home, or anything"?*

*Patient: "No" (Patient 4)*

*Patient: "yeah, I'd forgotten about that. I mean, I just cleared out a lot of stuff, because you get so much information that's not tailored to you, you know. And that's maybe a bit of an issue. Where's my blooming care plan. I've just gone through to the bedroom, where there's a load of stuff.....Care plan, da, da. There we go. Oh, I've got two care plans. Now, there it is there...identifying your concerns. So is that what you mean"?*

*Interviewer: "Yes, yeah".*

*Patient: "There we go. So, eating and drinking, indigestion .... So I had three things on my care plan, yeah. Continue taking, remain...so I mean, that's not something that I had to do differently, you know, on the plan of action. It's continue things, and consider adding in new things. But yes, no, so it's all pretty straightforward" (Patient 7)*

The content of Care Plans was extremely wide-ranging, indicating a high level of variation in practice. At one end, a Care Plan consisted of only two words - "See GP" and at the other end it was a three-page letter. This set out in detail what had been discussed, what the assessor had committed to do (e.g. send leaflets in post, make a referral) and what the PABC had committed to do (e.g. phone GP, attend leisure centre).

To generate positive outcomes from Care Planning and Care Plan co-production, it is critical for the intervention to actually contribute to an increase in self-management acts. Aimed for outcomes are generated also through the assessor consistently working with the patient to clarify both their roles in recovery and to support the PABC to assume a greater level of control post assessment.

### **Spark to a flame**

The review of Care Plans found that the content of most plans was dominated by the recording of the fact that downstream Care agencies had been suggested. Assessors have a key role in *directing* PABC to appropriate, local sources of support. However it was unclear how the HNA and Care Planning process maximised the possibility of actual uptake of appropriate support services (the spark to the flame). In achieving the aims of HNA and Care Planning the uptake and utilisation of services and support outwith the NHS, post assessment, is the crucial mediating mechanism. The findings indicate that the energy currently being put into the detection of concerns via the

administration of HNA is not matched by that required to actually resolve or alleviate them (Care Planning and Care Plan). Meeting unmet needs is largely contingent on the availability and quality of the services and support (not the assessment) (Carey, 2012).

TCAT projects have demonstrated that the stronger the referral link between the assessor and the receiving support service, the brighter the route to recovery can be illuminated for PABC. PABC whose experience of HNA and Care Planning had been recovery focussed and hosted in the community discussed during interview at greater length the services they had attended post assessment. This illustrated that if routes to 'downstream care' are more visible and illuminated, PABC are more likely to attend.

Increasing uptake of services by PABC is crucial but of course complex. Issues of timing, service availability, local access and motivation will all play a part in a person's decision to attend a service.

The findings of this RE identified two key mechanisms within HNA and Care Planning, that if operating will increase the likelihood of service uptake. These relate to the PABC understanding, from diagnosis, their own role and responsibilities on the route to recovery (control of the switch) and the need for reassurance and reinforcement of recovery focussed messages and actions (leaving a light on).

### ***Control of the switch***

From the interviews with assessors, it was evident that there was understanding and appreciation that their role in HNA and Care Planning was one of initiating, encouraging and to some extent, supporting PABC to self-manage. If PABC are more prepared to have this control and actually expect to be given this responsibility early on in their cancer journey, they can more readily adapt and accept their new role in recovery as one that encompasses self-management (Hebdon, 2018).

Assessors described how they had to work to ensure the patient had 'control of the switch' and that as an assessor, they were not exclusively responsible for how brightly or dimly lit a person's route to recovery could be.

*"So, it's, you know, asking them what they think they can do to alleviate it, and if they don't particularly have any suggestions then discussing any ideas that I've got and then letting them know what's available locally that could help, you know, if it is emotional concerns we've got counselling services, or if it is weight gain we've got all the weight management classes. So, it's really just kind of getting them to sort of adopt a degree of responsibility for their own care, but also, you know, supporting them in the meanwhile." (Assessor)*

Assessors, during the interviews described the necessity to evolve away from the traditional role of the fixer in 'what they did to patients or for them'. The descriptions below illustrate that the role of the 'holistic' assessor required re-formulating to ensure a 'self-management' promoting mind set (context). It was through this that PABC can assume a greater control of the switch.

*"Especially in the early days, I felt, what am I actually doing for this person? I really, you know, they'd be in maybe 40 minutes, and I used to think, what have I actually done, what have I helped them with, here"* ( Assessor)

*"I just felt it was, I should be doing things, but you're actually not, it's just being, is facilitator the right word"* (Assessor)

*"from the point of view that it's not really about us, it's about the patient, you know. So I think it's more a case of us learning to sit back and let the patient...take control of it, you know. Which is probably a turnaround from the way that we all used to do things. We used to guide the conversations. So it's taking your time, and keeping yourself out of the conversation, to allow them to lead it."* (Assessor)

*And I've realised now, that if that's mainly what it is, listening, and letting them talk, then that's fine, 'cause that's still helpful, I hope. But I think you're just always, I just always think I should be trying to do more and I don't always know what that more is, sometimes.* (Assessor)

*"The model is not one that we've traditionally used. We've gone in, sort of, to fix it all for somebody and make it better. And I think it's been quite an adjustment to think, well actually no, we need to step back here and see what you come up with yourself, and what would be useful, and what you're prepared to do, or not do, and what you feel able to do, and ready for, and all these kind of things."* (Assessor)

In some contexts, the use of the HNA tool, the Concerns Checklist was viewed as having an impact on how a patient perceived their level of responsibility. For some the intervention itself was seen to work to retain 'control of the switch' with the assessor

*Assessor 1 : Yes, I think the approach is like the...that's not really self-managing when they come in and they tick boxes and hand it to you, to solve that.*

Assessor 2: *...thought, my understanding was, that the whole object of this, transforming care after treatment, with the HNAs, is to empower that patient, to move on and manage some of their symptoms.*

Assessor 3: *Yeah, and it is.*

Assessor 4: *Yes, take ownership, rather than...but doing that, is difficult/*

Assessor 2: *But you're right, the minute they tick that box, they come into the [service] thinking that you're going to sort that.*

Assessor 4: *Yeah, to fix it.*

Assessor 2: *So there's a mixed sort of message, there.*

### **Leaving the light on**

For PABC, HNA and Care Planning was found to be, in itself reassuring (*outcome*) and also a 'new' context. Attending an HNA provided reassurance (*mechanism*) as it demonstrated to them that 'someone was there' to support them (*outcome*) and that this person had relevant knowledge to do this well (*context*). This finding resonates with a key statement from one of the core stakeholders in 2015. They described their vision for the design, implementation and delivery of the HNA and Care Planning as one in which "they should feel as though somebody really has got their interest at heart and is a go to person for them if they've got doubts or issues" which was further described and shown by the patients quotes from the interviews:

*"And I feel that TCAT, I wasn't, I feel that I wasn't alone after all, knowing that there's somebody there to give me support." (Patient 5)*

*"it was just knowing somebody was there in the background if any problems had arisen, I think was the good thing," (Patient 12)*

Reassurance (*outcome*) 'on the day' however needs to be sustained and reinforced over the proceeding weeks and months. Linked to 'knowing someone is there' mechanism there is potential value in PABC having a point of contact from diagnosis. This role could review Care Plans 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*).

Throughout the cancer journey the point of contact does not necessarily require a face to face consultation, it could be achieved through telephone contact or the development of recovery emphasising technology. Both reassurance and reinforcement cannot be at a singular point in the recovery pathway. Concerns change over time and are enduring in nature. Therefore 'leaving the light on' through the provision of a point of contact and Care Plan review is especially important in the care after treatment of PABC.

Providers who continue to design delivery primarily or exclusively around answers to organisationally driven questions such as "who, where and when will an HNA be done" will not achieve the desired outcomes.

The findings illustrate that the 'role' of the assessor in HNA and Care Planning is critical to its successful delivery.

### **The role of the assessor - Ensuring holistic, patient led assessment and Care Planning**

In this final section of findings, attention turns to the fundamental premise of HNA and Care Planning – that of patient led holistic practice. It presents what has been uncovered about timing and the role of the assessor and considers how these principles are best assured and protected during implementation and delivery.

The evaluation found that the use of a concerns checklist as an HNA tool did assist the patient in reflecting on and identifying their concerns within the offered holistic framework. This primarily held true for patients who completed the list in advance of the assessment appointment as once 'introduced' into the assessment process patient reporting and identification of holistic concerns could be 'corrupted' by the actions or processes of the assessor. The quote from the assessor below was a typical description of how the checklist assisted concern detection.

*"And I think the tool helped, we would normally send it prior to the appointment, so people would have time to discuss it with family or friends, or just even have that time on their own to really think about it, and prepare for the session. So I think, you know, the fact that the tool was very sort of wide reaching, it was truly holistic, in that it covered sort of all aspects of life that people might not necessarily think was a problem. And then, when we interviewed people they said, you know, I never really thought about my spiritual needs, or about these needs, but you know, having seen it on the form. So it kind of encouraged people, really, to kind of look at all aspects of life. And I think having the form prior to the appointment helped a lot". (Assessor)*

During interview patients were asked if filling out the concerns checklist had helped them identify concerns in different areas of their life.

*“I think it did make it helpful because it focussed, it focussed your mind onto the things. It helped me to focus on what if anything was really troubling me.” (Patient 25)*

*“And it made me target, although before I came and met [Assessor], I didn't realise, really, that I had things to confront or whatever. It wasn't until I had seen the tick list, and we went over it, that I realised, well there are a few issues in my life that I want to get sorted out.” (Patient 4)*

*“Because it's only when you're actually faced with a list of stuff, that you actually think, hey, shit, that's me there, I've got that. Because often, some of the things you don't think about. You just think it's you as the way you are. And it doesn't always sort of leap out and actually scream, this is abnormal, it's not normal. So having it all in one place... it was good because I could quantify it” (Patient 20)*

*“Yes in a way. I found it actually more useful to me in some ways to say, yeah, this is what I...you don't always sit down and, kind of, prioritise or try and put in some order the things that are concerning you. You just know you feel pretty low about life generally. But when you actually see things that have been, kind of, described in specific terms about this aspect or that aspect of how you're coping, it does make you...it did make me, kind of, think in those terms as well what was the most difficult thing I was finding to cope with.” (Patient 2)*

The checklist helps PABC see that their concerns were not unusual. Seeing a concern the PABC was experiencing, written on the concerns checklist, provided some with a feeling of legitimacy (*mechanism*) in relation to their own concern and was therefore reassuring (*outcome*).

*“I think it's a useful tool for patients, because ....so lets them see that it's ok to feel this way. If this is on the list other people must feel negative or be worried or anxious or loss of faith or things like that, so it lets them see, oh, if this is on the list this might be a possibility, so maybe they'll be less hard on themselves for having negative feelings.” (Assessor)*

Moreover, as the checklist was to inform an appointment/consultation during which, what was selected on the form, would be addressed this could provide 'permission' to patients. This feeling of 'having permission' related not only to having a concern but more importantly to being permitted to 'present' them for discussion. This in turn improves the detection of concerns (*outcome*) and a feeling that they are or could be supported to address them (*outcome*).

*“you’re letting them know that you’re interested in their spiritual needs, their financial needs and how they’re worried about their family and things like that” (Assessor)*

*“I felt that it opened up discussions that they probably wouldn’t have initiated”...they didn’t know that that was allowed...you get to the end of the discussion they would say, you know hen if that wasn’t written down I don’t know if I would have spoke to you about it” (Assessor)*

A key aim of implementing HNA and Care Planning is to ensure that the concerns addressed during the assessment are those that are actually of priority to the patient and not those of the practitioner taking the assessment. It was found that both a patient led and a ‘holistic’ response could be impacted on by the role of the assessor and the assessor’s response to the identified concerns.

If an assessor’s role in the assessment process is not exclusively to conduct an HNA, (for example if HNA is combined with surveillance/medical follow up) that is they have two or more roles, there is a risk that the desired holistic, recovery focussed assessment and process is not or cannot be fully implemented.

*“if it's a long term condition, it's not related to your cancer, you know, if it's anything we can help you with, signpost it, and give them a quick explanation..... And so in terms of the long term condition aspect, and then you filling in that holistic needs assessment, you're looking for the cancer related ones, that you can respond to”*

*“we have to be quite strong bringing it back to, right, ok, it’s your breast cancer treatment that we are trying to discuss here. Not constipation that you’ve had for 20 years”*

If the assessor prioritises or focusses on cancer related issues, to the exclusion of reported wider, holistic concerns it may mean that the patient’s agenda is not central to the assessment.

*“Yeah, I've found, some people have used it, not just relevant to their current cancer diagnosis, and treatment, and side-effects. They've ticked things that refer to longstanding ill health, or issues they've got. So they're still issues that they're concerned with, but they're not their current cancer, it's nothing to do with their current cancer diagnosis. So, some people just tick a lot, and I think some people don't want to tick very much..... we still do that as part of the whole, or holistic thing. But it's not always to do with their current illness” (Assessor)*

*“Yeah. I mean, the questionnaire was great and it was a way of putting points across and asking things. But like I say, I had one concern and it didn’t get*

*dealt with, so then you...so...so it's like, well okay, well they asked but then they didn't really get too much involved with it" (Patient 8)*

The professional discipline of the assessor was also seen to impact on holism and the extent to which a truly person-led assessment was conducted. There may be a tendency for a nurse to naturally prioritise medical concerns.

*"I think you pick up initially the things that you know are going to be related to their treatment...the symptom ones (on the first column) are the first ones you come to" (Assessor)*

*"because as a nurse you will be in front of the NMC (Nursing and Midwifery Council) if you didn't pay attention to a clinical symptom and act upon it..you're not gonna be in front of the NMC if you forget an HNA" (Assessor)*

To some extent, ensuring a patient led/holistic assessment can be less likely to be realised earlier on in a patient's cancer journey (during treatment, immediately post treatment) when functional/medical issues may rightly be at the forefront of both the patients' and the assessors' minds. Analysis of concerns data revealed that HNAs carried out closer to diagnosis/end of treatment and/or by a CNS are associated with higher reporting of physical/medical related concerns such as hot flushes, dry mouth, diarrhoea and constipation.

The holistic focus of the assessment may be more vulnerable if carried out during treatment or within weeks of completion if physical concerns or functional issues experienced by a patient are dominating their life.

*.."cause I had finished my treatment but I had my review appointment in the January and after that I think you're just still, sort of, ploughing on in your head. I felt it was quite soon afterwards to, kind of, know how you were going to feel, if you know what I mean. Sort of, come out of treatment and you think everything will be fine and you are fine and then I think it's something that maybe could have been a wee bit later" (Patient 14)*

*"Where I think if it was a wee bit further out of your treatment, and I think that's when it then...it, kind of, hits you. I think that's...when I had that appointment, it was maybe too early for me to say that I was struggling. I wasn't, you know...'cause I think you're just, sort of...oh I don't know. Just...my mindset at that point...you were, kind of, relieved to be away from hospital appointments and doctor's appointments. I think that's the, kind of, day you're waiting for. But then I think, as I say, had it been maybe May or June, I might have ticked things differently" (Patient 19)*



*Patient: "So I remember thinking it was maybe a bit early for the TCAT when I went. But certainly I was out of hospital so it would be October, was it maybe March, February or March time maybe?"*

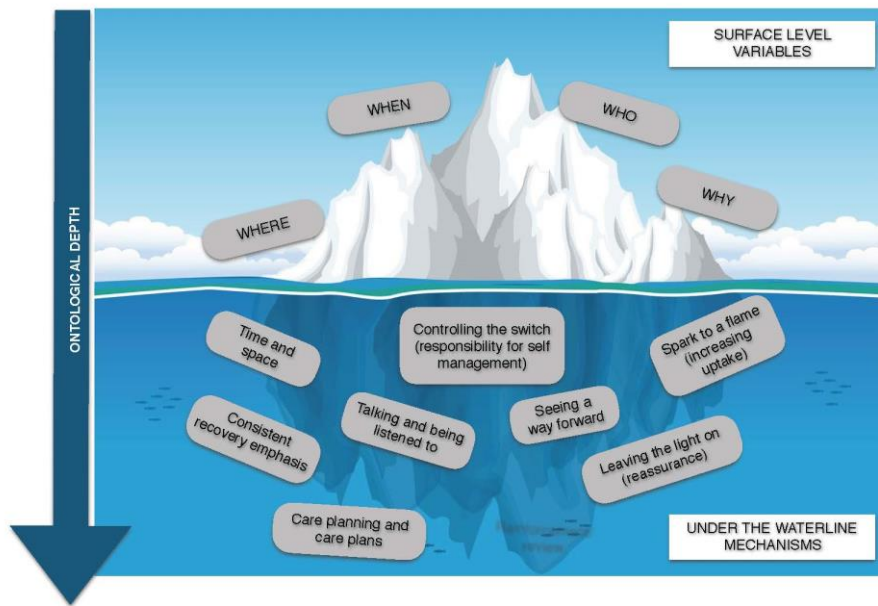
*Interviewer: And what made you think it was a bit early?*

*Patient: Well, because I hadn't finished the treatment to be honest. Because I knew the ileostomy I had was a temporary one, so I was going to be going through further surgery with some of the same trauma and sort of patterns as the first operation". (Patient 25)*

Overall then, when considering 'when' an HNA should be conducted it appears that an HNA can be delivered too early in a PABC pathway, but never too late. Ensuring that PABC have access to an HNA and Care Planning from the right person, with the right skills at the right time, may require a more fundamental shift in thinking and delivery of overall care after treatment to ensure PABC can live well with and beyond cancer.

## **Conclusions**

Eight causal mechanisms of HNA and Care Planning have been identified by this RE. They operate below the surface to generate outcomes. The findings indicate that the provision and commissioning of HNA cannot just be about what is done. The implementation of HNA and Care planning must be optimised to maximise the benefit of this crucial intervention for PABC.



The analysis undertaken to refine the candidate theories has provided transferable and generalizable insight into the optimal implementation contexts for implementation, improved understanding of how HNA and Care planning can generate outcomes in different contexts.

Two broad 'refined theories' are proposed as a result of this work.

1. If an HNA and the resulting care plan prioritises 'recovery/moving on' AND action post assessment on the part of the PABC, AND is delivered from diagnosis by an assessor with a remit solely for HNA, who is embedded in or with strong links to the PABC's locality and community assets, who also has the skills to listen well and can offer time and space, THEN the PABC can talk about their concerns (not just identify them) resulting in them feeling more reassured, more supported and confident to use the knowledge and contacts provided to increase self-management.
2. If the assessor provides individualised knowledge and referral/signposting destinations and is available from then on as a point of contact, providing care plan reviews, the role of the PABC in their own recovery is reinforced which may enhance the likelihood of increased self-management, increased uptake of downstream care and result in more sustained benefit from the intervention.

In presenting these as singular, linear refined theories or 'context + mechanism = outcome' configurations, there is a danger in over simplifying and delineating the insight provided in this report.

The diagram below presents the interplay of the identified causal processes of HNA and Care Planning. That is the non-linear, multi-dimensional, multi-function properties of the relevant mechanisms, contexts and outcomes of HNA and Care Planning are illustrated.

### Interplay of causal processes and outcomes of HNA and Care Planning



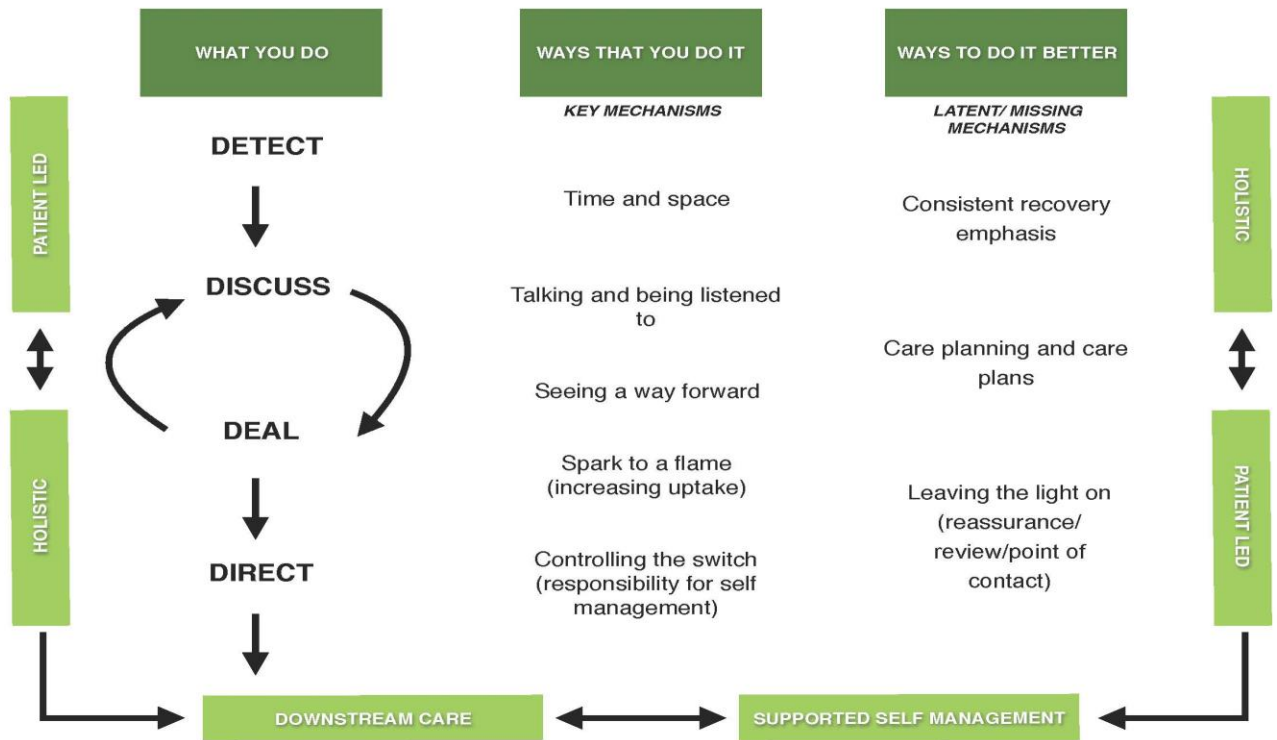
Service commissioners, practitioners and educators/trainers must acknowledge and address the dynamic yet nuanced interplay of timing, patient circumstances, receptivity and availability of services to ensure the end justifies the means. HNA and Care planning is a means to an end - that of reducing concerns, supporting self-management and reducing demands on the system.

## Recommendations

The findings indicate overall the ways in which the implementation of HNA has to be optimised. This is achieved by working to ensure the consistent and effective 'triggering' of the identified key mechanisms. When triggered effectively these mechanisms will increase the impact of the intervention short term by improving the patient experience and longer term - facilitate increased self management and reduced demands on the system.

The key findings and recommendations are presented below using this heuristic and in summary in the diagram below.

- The concerns checklist is an important tool for detecting and legitimising concerns and its continued use is recommended
- As time and space 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
- Any future patient reported outcome/experience measure of HNA and care planning must include PABC must feel they have had the opportunity to talk about their concerns and report consistently that these were actively listened to
- 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
- 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 role of Practice Nurses and the wider primary care team offer most potential
- The utility of care planning and plans must be further evaluated and enhanced



In addition, the following areas of **service piloting and broader research** are recommended:

- 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.
- Piloting of technology based interventions to increase the impact of key reinforcement and reassurance mechanisms.
- A needs assessment of required training and mentoring to supports optimal implementation of HNA and Care planning.

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