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University Hospitals Bristol NHS
NHS Foundation Trust

ANALYSIS PHASE CONSOLIDATED FINDINGS REPORT

ON TARGET

ON TARGET: Enhancing the future for young people with cancer

ON TARGET is a service evaluation programme working with patients, the people around them, professionals, charities and local organisations across the South West, to assess the care offered to Teenagers and Young Adults (TYA) with cancer.

Funded by Macmillan Cancer Support, the ON TARGET team have utilised a co-creation approach in order to gain a thorough understanding of the needs and wishes of TYA, and of those who support and treat them. Working in partnership with these groups, the team will now design, pilot and evaluate interventions to improve patient outcomes, increase self-management and reduce future healthcare demands.

Results will be presented to commissioners and health care providers to promote changes which most effectively ensure that “each TYA patient is supported towards re-engagement with life as it would have been without the intrusion of cancer, or as the patient decides to recreate it after experiencing the impact of cancer”.

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1. Summary

ON TARGET seeks to ensure TYA patients are supported towards “re-engagement with life as it would have been without the intrusion of cancer, or as the patient decides to recreate it after experiencing the impact of cancer”. To achieve this goal, and to inform priorities to improve care, views were sought from patients, family/friends/significant others (the ‘patient network’), and professionals. Some of the key themes arising from these enquiries were:

- Amongst the things that matter most to patients are: physical wellbeing; staying motivated; receiving rehabilitation; advice about diet; encouragement to continue activities ‘that matter to me’; life style advice; peer support.
- Patients frequently do not receive the support they would like in areas such as: opportunities for peer support; psychological support; support to their family; advice about education/employment.
- Most patients receive helpful information but the balance, consistency and presentation of information are all important, as is timing and pacing: some patients feel overwhelmed with information load, particularly at diagnosis.
- Over 50% of patients feel that hospital staff need more information/training about working with TYA and about TYA cancer.
- Many patients want information about the role of primary care both during treatment and in Aftercare. Professionals recognise the importance of supporting patients in engaging / re-engaging with GPs at and after diagnosis
- Patients want to know that their family and friends are able to receive information and support but frequently report this is not provided. Patient ‘networkers’ also felt constrained in seeking and accessing support for themselves.
- Almost 50% of the networkers report a high/very high impact of a TYA’s diagnosis on their daily life, and almost 80% recorded adverse effects on their physical wellbeing.
- About one third of patient networkers report an adverse impact of the diagnosis of cancer on their own financial circumstances.
- Overall, professionals value interventions in areas common to all TYA, for example in: maintaining education/work/meaningful activity; finance/housing concerns; managing cognitive effects/fear of recurrence.
- Professionals recognise the need for psychosocial support (including that to parents / partners / siblings); the value of peer support/mentoring; and identified the importance of helping to build resilience.
- Professionals support strategies to facilitate patient ‘self-management’ but opinions vary regarding definition, format, and timing.

The next aim of ON TARGET is to utilise these findings to build and evaluate interventions with patients which address the priorities identified and focus on enhancement to the quality of their life with, and beyond cancer.

2. Introduction to ON TARGET

2.1 Purpose

The analysis phase of the ON TARGET Programme aimed to collect information regarding the Aftercare needs of teenagers and young adults with cancer (TYAs) in the South West of England. Views were sought from three constituencies – from patients, from the family, friends and other individuals who are important to patients during and after their cancer treatment (the patient's network), and from professionals. This document summarises the key findings from this data collection, and its analysis.

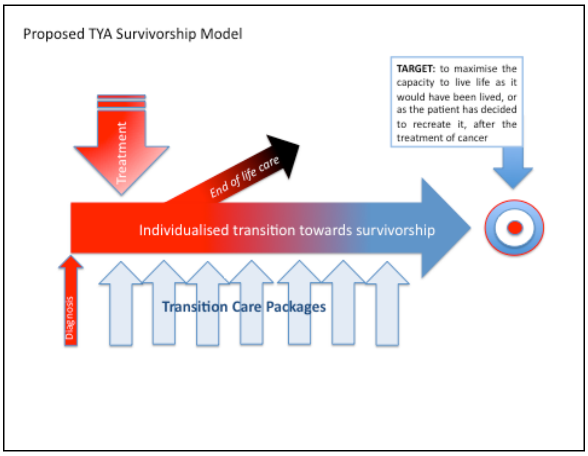
2.2 Background

ON TARGET is a 3 year programme of work intended to assess, and address the Aftercare needs of teenagers and young adults (TYA) with cancer. The programme will develop and evaluate a series of interventions to facilitate and enhance the evolution of a patient's care from its initial focus on the diagnosis of a cancer and its treatment, towards cancer survivorship and the patient's Aftercare needs. The programme is aimed at young people diagnosed between 15 – 24 years with all forms of cancer. The principal objective is to ensure that "each TYA patient is supported towards re-engagement with life as it would have been without the intrusion of cancer, or as the patient decides to recreate it after experiencing the impact of cancer".

Although the programme is directed towards improving the quality of Aftercare / survivorship experienced by patients, interventions introduced to the clinical service offered to TYA patients may also provide a quality enhancement to most other aspects of a patient's 'journey' once the diagnosis has been established and a treatment strategy defined.

A specific aim of the ON TARGET programme is to design interventions that can be applied as early as appropriate in the patient's journey. This is based on the hypothesis that early engagement with strategies that may help adjustment towards survival will best allow young people to re establish the trajectory of their lives.

There will be some young people whose treatment is ultimately unsuccessful and who will therefore transition to an end of life pathway. The scope of ON TARGET does not include the development of strategies to address needs of young people at that stage of their illness but the underlying ethos of the programme includes an assumption that interventions targeted towards survivorship and Aftercare will offer some benefit to all patients, whatever the stage of their illness. The concept for the programme is illustrated in the following diagram:



Based on work undertaken during programme initiation, it was believed that eight work streams would be created during the Design stage, under the following headings:

- Health Risk Assessment, Surveillance and Monitoring
- Healthy Life Style and Physical Rehabilitation
- Education, Employment & Finance
- Psychological and Emotional Wellbeing
- Patient Information
- Peer Support
- Parent, Family and Carer Support
- Informing & Involving Health Professionals / Experts

However, the final choice of work streams on which interventions will be based will be determined by consideration of the outcome of the Analysis Phase.

Lessons learned from the programme will be used to promote and guide the development of Aftercare within the South West TYA service and will also be offered for national dissemination. As the programme is to be delivered in the context of the South West TYA regional network care partnership, it is expected that the work of the programme will extend to engage all clinical teams both at the Principal Treatment Centre and within all designated network care units.

2.3 Programme Methodology

The objectives and scope of the programme were defined during the Initiation Phase of the programme and were reported in a Programme Initiation Document (published January 2012). This document set out an overall structure for the programme, defining the following phases of work:

Analysis: The views of those involved in the TYA service e.g. patients, family, professionals etc, would be sought so that these views can be reflected in the solutions to be proposed and constructed

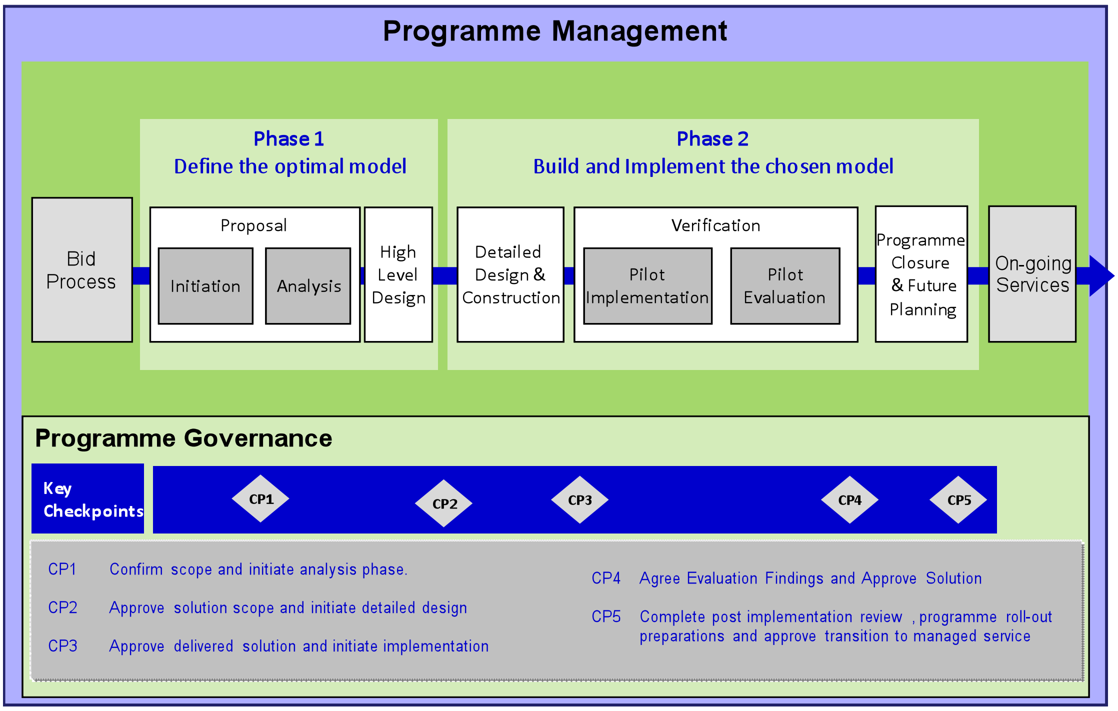
Design: In this phase, solutions to the requirements / expectations documented during analysis will be proposed and agreed as potential interventions.

Construction: Interventions defined in the design phase will be built and prepared for the pilot stage.

Pilot: As far as is possible, each of the interventions will be piloted and evaluated individually prior to the final part of the pilot phase in which there will be an integrated trial of all interventions.

Implementation: The results of the pilot evaluation will be used to define an agreed set of interventions for the on going clinical service.

The progress of these phases, and the governance structure for the programme, are illustrated in the following diagram.



The progress of the programme is reported to a Programme Management Group and, within UH Bristol (the host NHS organisation), to the Trust's TYA Steering Group.

3. Analysis Phase Methodology

3.1 Outline Plan

An outline plan for the Analysis Phase of the programme was summarised in the Programme Initiation Document, and a detailed plan was then generated to achieve the tasks to be undertaken during this phase. A summary of the tasks identified as necessary for the Analysis phase is given below:

a) Patient Participation
  - Identifying the TYA patient cohort
  - Agreeing with the identified patients how best to involve them in participation process
  - Undertaking the patient participation process e.g. questionnaire(s), focus groups etc.

b) Family / Carer Participation (this was later renamed as the "Patient Network")
  - Identifying the family / carer cohort
  - Defining and agreeing the participation process
  - Undertaking the participation process e.g. questionnaire(s), focus groups etc.

c) Professional Participation
  - Agreeing the professionals to be involved
  - Identifying the professionals cohort
  - Conducting the proposed Delphi survey (plus any other agreed participation process)
  - Creating the programme Reference Group

d) Geographic Analysis
  - Identifying the analysis required

  - Confirming the cohort to be analysed
  - Undertaking the analysis

e) Requirements Analysis
  - Establishing the basis for the evaluation of the feedback from patients, professionals etc.
  - All feedback to be compiled and evaluated

f) Other
  - Define the measures to be used to evaluate the success of the programme
  - Identify any tasks that can be done ahead of schedule to deliver support to the existing TYA service.

f) Analysis End
  - Complete the end of phase reports
  - Publish communications to all stakeholders

3.2 Patient Participation

The patient work stream within the Analysis Phase aimed to gather information from TYAs with cancer living in the South West of England regarding their Aftercare needs.

To identify and explore these issues a variety of methods were employed including a questionnaire, semi-structured interviews (1:1) and a focus group.

One of ON TARGET's guiding principles is to ensure that patients, families/carers and professionals are fully involved in the process of assessing and addressing the Aftercare needs of TYAs with cancer. In the case of the work with patients, this was addressed by the use of a Co-creation approach. This shifts the focus from the professionals delivering care to one in which patients themselves are fully engaged in their own healthcare and is an approach that aims to develop a deep and thorough understanding of the complete patient experience. It requires early and consistent engagement with patients in agreeing not only how to respond to any findings, but also how questionnaires, for example, should be designed and built in the first place.

A full report *(Patients' Work stream – Findings Report, January 2013)* provides a detailed account of the work undertaken and presents both the quantitative and qualitative findings.

Initial patient participation was sought to assist in the design and content of a questionnaire. Further assistance was obtained from the Questionnaire Interview and Survey Group (QIS) within UH Bristol. Exploration of the questionnaire findings in more detail was achieved by a focus group and a number of 1:1 interviews.

A limited analysis was undertaken to ascertain if there were major differences between responders and non-responders in terms of age, gender and other demographic variables.

All patients who were contacted were offered the opportunity to express an interest in further work with the programme and to indicate whether or not they wished to receive written feedback on the findings.

3.3 Patient Network Participation

It is recognised that, at the time of the diagnosis of cancer, during treatment, and subsequently, patients gain support from their inner resources, from the professionals involved in their care, and from individuals who have relationships with them outside the healthcare setting. This will include family members, friends, work colleagues, professionals in educational institutions, and others. The diversity of this group creates a challenge both in agreeing a terminology to describe it and in understanding the scope of involvement required if a representative perspective is to be achieved. Considering that most young adults will have significant relationships with individuals outside their family group, the term ‘family and carer’ is inappropriate. For the purposes of the ON TARGET programme, the term “Patient’s Network” was agreed to define the individuals ‘around’ the patient, excluding health and social care professionals.

It is recognised that the diagnosis of cancer in a family member, friend, close work colleague or educational peer has a significant impact on the individual concerned. It may raise anxieties about personal health and vulnerability as well as the more obvious fears for the welfare and future of the young adult concerned; it may challenge or enhance the previous relationship with the patient; and it may raise concerns about the ability to maintain that relationship under changed circumstances. These issues will often generate a need for support to the member of the Patient’s Network him/herself. Part of the benefit of receiving such support is that it may also offer the individual concerned a greater ability to support the patient.

To identify and explore these issues a variety of methods were employed including a questionnaire and semi-structured (1:1) interviews. As it is only the patient who is in a position to accurately define who the key members of their network are at any particular moment, access to this group had to be negotiated by an approach to patients themselves. A small number of patients, identified within the patient cohort, and who had agreed to continue to work with the programme team, were offered the opportunity to distribute a questionnaire to up to six members of their own network. As with the patient questionnaire, further assistance in preparing the questionnaire was obtained from the Questionnaire Interview and Survey Group (QIS) within UH Bristol.

Direct contact with networkers was not sought until questionnaires were returned, at which point an approach could be made to those respondents who had provided contact details and indicated an interest in continuing to work with the programme team. Interviews were also undertaken with a small number of individuals to explore the questionnaire findings in more detail.

A full report *(Patient Network – Findings Report, January 2013)* provides a detailed account of the work undertaken and presents a summary of both the quantitative and qualitative findings.

3.4 Professionals Participation

The professionals work stream within the Analysis Phase aimed to collect information from a wide range of professionals regarding the Aftercare needs of teenagers and young adults with cancer (TYAs) in the South West of England. Professionals’ views were determined by using an online survey, semi-structured interviews (1:1 and telephone) and focused small discussion groups.

Those invited to participate in the online survey were professionals working within health care, social care or education who were known to have an interest in, or to have worked / anticipated working with TYAs; or those with a specialist knowledge in cancer care. All were based in the South West of England.

The professional cohort was identified by members of the programme team and by ‘gatekeepers’ defined as key professionals whose roles allowed them to access and cascade information to a wider range of professionals. For the purpose of the programme these ‘gatekeepers’ included: - Cancer Network Nurse Directors, Cancer Network Lead AHPs, Lead Cancer Nurses, Lead Cancer Clinicians, Lead AHPs, the TCT funded TYA Lead Nurse, TYA Specialist Nurses and a Cancer Centre Manager.

The questions explored in the survey were established using a modified Delphi technique to determine consensus with statements regarding the needs of TYAs and the design of Aftercare interventions. In order to enrich the team’s understanding of the breadth of views held by staff, semi structured 1:1 interviews, telephone conversations, and focused small discussion groups were conducted with professionals throughout the South West. This enabled the programme to gain additional views and opinions, and to hear from those staff who were unable to access the Delphi survey e.g. ward catering staff, portering staff etc.

A full report *(Professionals’ Work stream – Findings Report, December 2012)* provides a detailed account of the work undertaken and presents a summary of both the quantitative and qualitative findings.

As a separate initiative, the programme team convened a Reference Group with a membership representing health and social care structures and voluntary sector organisations. The purpose of the Reference Group is to ensure that the outcomes of the ON TARGET programme are informed and shaped in a wider context and by knowledge of complementary work in other areas. It is also hoped that this will help to ensure that potential stakeholders in the future delivery of the service are engaged at an early stage. Two meetings of the Reference Group have been held to date, involving representatives from 14 organisations outside UH Bristol.

3.5 Geographic Analysis

In addition to the care provided at the Principal Treatment Centre (PTC) at UH Bristol, the model for the TYA service for the South West of England includes the delivery of care by designated Network Care Providers (NCP) across the South West. These are located at six centres:

• Gloucester	Gloucestershire Royal Hospital
• Bath	Royal United Hospital
• Taunton	Musgrove Park Hospital
• Exeter	Royal Devon and Exeter Hospital
• Plymouth	Derriford Hospital
• Truro	Royal Cornwall Hospital

In order to understand how the geography of the South West might influence the distribution of care to patients, and hence the choice of sites for pilot interventions within the ON TARGET programme, an analysis was undertaken to assess travel times for the patients within the cohort used in the Analysis Phase based on the relationship between the post code of their residence and the location of both the PTC and NCP hospitals.

This analysis was undertaken by the South West Cancer Intelligence Service at the South West Public Health Observatory. The reports generated looked at patient density by local authority, travel time to the PTC, and travel times to all NCPs.

3.6 Requirements Analysis

The process of enquiry utilised in the Analysis Phase (questionnaires, focus groups, 1:1 interviews and focused small group discussions) resulted in the collection of a very large volume of data. The methodology chosen to undertake an evaluation of these data was that employed as part of a process known as Requirements Management; this is a methodology characteristically used in systems engineering and software development.

Requirements analysis encompasses the tasks that go into determining the needs or conditions necessary to meet a new or altered ‘product’, taking account of the possibly conflicting requirements (views) of various stakeholders.

The outputs from each of the lines of enquiry generated by the three work streams (patients, networkers and professionals) were first translated into a series of individual findings, i.e. statements that reflected a view on the design of future TYA services. Each individual finding was then converted into one or more statements representing a ‘requirement for change’ (Requirements), i.e. a statement which reflected facts and assumptions that would contribute to the design of an Aftercare service intervention.

The Table below gives two examples of a findings and its derived requirements based on data obtained during interviews with a professional and with a patient, respectively.

SOURCE	**FINDING**	**REQUIREMENT**
Interview with a professional	Pathways are not applied consistently across the South West and there is little evidence that risk stratification is applied to Aftercare	The risk stratification of patients entering Aftercare should be applied consistently across the SW
Interview with a patient	No one ever talked to me about fertility and this was a worry for me. After finishing treatment I got really worried. I rang my research nurse who said my fertility was unlikely to have been affected	Staff working with TYAs should be aware of the pathway for referral on fertility advice

In total, 1764 findings were created across all the work streams from which 3332 requirements were identified. These were reduced to 166 by a process of de-duplication

Each requirement was first assessed as to whether it was considered to be in scope for the ON TARGET programme and, if confirmed, then scored by the team using factors chosen to reflect areas of health policy and practical applicability, using the following criteria:

- Scope (i.e. did the Requirement lie within the agreed scope of the programme)
- QIPPP - benefits considered achievable in areas of Quality, Innovation, Productivity, Prevention & Personalised Care
- Priority for implementation (rated as Must, Should, Could, Would do)
- Difficulty to achieve (rated on a scale from Very Difficult to Very Easy)
- Benefit (rated from None/Very Low to High) both to the patient and to the service.

Each requirement was also allocated to a potential work stream category (e.g. Education & Employment; Psychological & Emotional Wellbeing, etc.) and to an aspect of service function (e.g. Organisation, Process etc).

The purpose of this analysis was to allow prioritisation of requirements within individual work streams and to permit an assessment to be made of, for example, those requirements considered easy to achieve with high direct benefit to patients.

Requirements Management methodology also ensures that an audit trail links each requirement to a final activity used to inform service design.

3.7 Other Work

3.7.1. Support to the TYA Clinical Service

Other work undertaken by the team during the Analysis Phase included support to: the implementation of *realshare*, an on-line social networking resource for TYA cancer patients in the South West; and the design and introduction of a database used to increase the efficiency of the MDaT process and to capture the results of a holistic patient assessment framework (IAM). Both of these are being actively used by the TYA clinical team and map to some of the requirements generated by the ON TARGET programme.

3.7.2. Communication with Commissioners

An ongoing dialogue with commissioners is being maintained so as ensure that the programme prioritises its activities towards those most obviously of higher priority to commissioners of the service.

As part of the processes to be undertaken in the Design Phase, all potential interventions will also be assessed by reference to the principles defined in statements of national policy including the following:

- ‘National Cancer Survivorship Initiative (NCSI): Vision’ (DH, Macmillan Cancer Support & NHS Improvement 2010)
- ‘Improving Outcomes: A Strategy for Cancer’ (DH 2011)
- ‘Living with & Beyond Cancer: Taking Action to Improve Outcomes’ (DH, Macmillan Cancer Support & NHS Improvement 2013)
- Specific publications produced by the Children’s & Young Persons (CYP) Work stream within the NCSI.

3.7.3. Outcome Measures for the Success of the Programme

Work undertaken during the Project Initiation Phase identified a number of provisional outcome measures which might be used to assess the success of the programme. These were defined as follows:

a) The number of patients engaging with the ON TARGET programme each year.

b) Patient experience and satisfaction.

c) Evaluation of quality of life.

**(Improving the management of patients with both mental and physical health needs)*

d) Young people’s perceptions of how well informed they are in making life choices and how appropriately supported in future self-management they feel.

**(Active Support for Self-Management)*

e) Life style choices and behaviours.

**(Primary Prevention)*

f) Educational and employment status

g) The proportion of patients who have treatment summaries and care plans at the end of treatment.

**(Managing ambulatory care sensitive conditions)*

h) The development of systems to collect data on the number of patients in the following categories:

- Those who leave the programme before agreed transition to Supported Self Management where this is considered to be the appropriate model for future care
- Where care is required at other levels of complexity, and the reasons for this (e.g. entry to an end of life care pathway)
- Survivors who move out of the area
- Those who fail to maintain links with the programme or express a wish to leave the programme for other reasons.

(Care co-ordination through integrated health and social care teams)

i) Family / carers' perceptions of the programme and their assessment of patient benefit.

j) Health professionals' perceptions of the programme and their assessment of patient benefit.

** Where shown, these measures were referenced, when possible, to key themes in the publication 'Transforming our Health Care System: Ten Priorities for Commissioners' (Kings Fund 2011).*

Each intervention which derives from the data accrued during the Analysis Phase will be assessed for its ability to satisfy one or more of these criteria

3.8 Publication of Analysis Phase Findings

The programme has a defined communication plan which is reviewed at intervals to ensure that the progress of the programme is appropriately reported to the Programme Management Group (PMG), to the UHB TYA Steering Group and to other stakeholders. Monthly and Quarterly reports are produced and disseminated as agreed by the PMG.

The plan for the Analysis Phase includes the production of a detailed report for each of the three work streams and a report of the Consolidated Findings (this document).

4. Patients' Views

4.1 Initial Patient Participation

In order to ensure that the patient questionnaire reflected TYA views and priorities, patients were involved in its design and content. Patients were approached by members of the TYA clinical team, of whom 27 expressed an interest in working with the ON TARGET team. Six patients confirmed that they would attend a focus group but only 3 participated on the day. Individual interviews were undertaken with a further 4 patients. All were provided with written feedback to ensure that their views had been accurately captured.

This early contact resulted in three specific outcomes.

First, it confirmed the areas that patients felt should be covered by the questionnaire: Physical well being/health; Peer support; Information provision; Psychological & emotional support; Education & employment; Family & friends; Information, education and training about cancer for others.

Second, a large number of suggestions were made about the design and presentation of the questionnaire.

Third, the patients offered helpful suggestions about how the team might most effectively communicate with other TYA patients. Interestingly, the most powerful form of communication was felt to be a letter on NHS headed paper, signed by a senior health professional. Communication by email was not considered by all to be the most effective vehicle although texting and phone calls were seen as good ways to maintain communication.

4.2 Definition of the Patient Cohort

Patients aged between 15-24 years inclusive at the time they were diagnosed with cancer or at its recurrence, and who had been registered through the TYA multi-disciplinary advisory team (MDaT) from 2009 onwards were considered eligible for inclusion in the cohort. Despite a full commitment to inclusivity, in order to ensure no unnecessary distress was caused, the individual circumstances of each patient were assessed before contact was made.

Out of a potential of 204 patients in the TYA clinical service database, 60 were excluded as it was not possible to complete checks on current status within the available time frame and further 36 patients were not included one or more of the following reasons:

- had moved out the area/country
- advised not to contact by their TYA Specialist Nurse
- no longer alive

In total, therefore, questionnaires were sent, by post, to 108 patients . Each questionnaire was accompanied a covering letter and an Expression of Interest (EOI) form, and carried a unique identifier (UID) corresponding to each patient, so it was possible to match completed questionnaires with each the patient via their EOI or UID.

4.3 Response Rate and Characteristics of Respondents

A total of 42 questionnaires were returned, representing a 39% response rate.

The Table below indicates the proportion of patients who responded, by major demographic and diagnostic groups. Whilst caution should be applied to the interpretation of differences in view of the relatively small numbers in each group, fewer older patients (≥ 19 years) responded to the questionnaire.

Characteristics	**% who responded in each group (no responders/total in that group)**
Age	
16 – 18 years	61% (16/26)
≥ 19 years	30% (26/86)
Gender	
Male	48% (22/45)
Female	46% (20/43)
Diagnosis	
Leukaemia/ Lymphoma	42% (16/38)
Brain / CNS tumour	58% (7/12)
Other	33% (19/57)
Residence	
Bristol & Bath	43% (16/37)
Elsewhere	37% (26/71)

To explore the questionnaire findings in more detail, and enrich understanding of patients views, a focus group was held with seven TYA patients and six 1:1 interviews were undertaken with other patients – all chosen from amongst respondents who had also returned an EOI form.

4.4 Key Findings

The key findings have been abstracted from the detailed report and short summaries are presented below under the title of each potential work stream.

Overall, patients rated the following areas as the ‘things that mattered most’ – in each case the individual theme was identified as such by more than 60% of respondents:

- Physical wellbeing
- Staying motivated
- Receiving rehabilitation (e.g. physiotherapy) as an inpatient
- Advice about diet
- Encouragement to continue with activities ‘that matter to me’
- Life style advice
- Support from other young people who have been affected by cancer

In almost all areas, more patients would have liked support than actually received it.

4.4.1. Physical Wellbeing & Health

64% had received some form of support with physical health and wellbeing and 59% of these rated it good or very good. The balance of information provided did not always meet expectations – for example, many patients felt they needed information about exercising safely during treatment but only 12% actually received any kind of physical exercise intervention. Over 30% expressed a specific need for help in staying motivated and being ‘kept on track’ but less than 20% reported receiving support of this nature. Other areas of concern included difficulty in managing physical changes associated with treatment (e.g. weight gain / loss), coping with cognitive changes (brain fog), and skin and hair care. The impact of treatment on sexual function and fertility was not discussed at all by some patients.

4.4.2. Peer Support

64% of patients reported that they had not received any support from people who had had similar experience to themselves but of those who did, over 60% rated it as good or very good. Slightly more patients favoured access to peer support whilst in hospital (21%) than on line or at home / in their local community. Seventeen percent had actually accessed on line support and *realshare*, the South West on-line social networking resource, was mentioned favourably.

4.4.3. Information

Whilst there was a high level of satisfaction with the provision of information – 81% of patients reported receiving information that was helpful to them and 74% rated it as good or very good – almost 1 in 5 patients did not receive any helpful information There were also a number of themes about the delivery as well as the content of information provided. Timing and pacing of information was important and some patients felt overwhelmed with the amount of information they received particularly at diagnosis. The need for information that was personalised, detailed and specific was a strong message and importance was attached to the presence of logos (e.g. NHS, Macmillan, Teenage Cancer Trust) in terms of instilling a sense of trust. Over 40% patients identified that they would have valued information about what they could continue to expect from their GP after the diagnosis of cancer.

4.4.4. Psychological & Emotional Support

Over half (55%) patients reported receiving no psychological or emotional support and 57% of those who did considered it only moderate or not good. The questionnaire asked about eight categories of psychological and emotional support (for example, help in: developing coping strategies, self management tools, coping with worries about recurrence) but delivery of support significantly failed to meet patient aspirations in all eight areas by a factor of at least 2 fold and often more (for example: 46% patients wished for emotional and psychological support in dealing with brain fog but less than 5% were actually offered this). Patient attitudes to emotional and psychological support appeared also to be affected by a reluctance to ask for help and by concern about stigmatisation or being unfavourably judged for failing to cope.

4.4.5. Education & Employment

Half of the patients reported receiving no support with education and / or employment and 43% of those who did rated it only moderate or not good. Overall, only 10% received support for employment issues compared to 31% who received support for education although the exact denominator of those actually in education or work was not known. Patients who had unmet needs in these areas reported it as major source of anxiety. The questionnaire asked about eight categories relating to educational and employment support (for example: help with job market skills, work experience opportunities, support in staying in education) but delivery of support significantly failed to meet patient aspirations by a factor of at least 2 fold (and often more) in all areas apart from support in helping to stay in / return to education.

4.4.6. Support for 'Those Around You'

Sixty one percent of patients said that it would have been helpful / very helpful for them to know that families and / or friends had been getting support, but 55% reported that their families had received no support (and 85% said friends had had no support). Some patients indicated that they were unable to tell family / friends how they were feeling for fear of imposing an extra burden on them, and some suggested that they felt responsible for their family's distress. Many patients described that their diagnosis had profoundly changed existing relationships.

4.4.7. Cancer Information, Education & Training for Others

Over half (57%) patients expressed a view that hospital staff needed more information and training about how cancer impacts young people, and about 25% felt that the same applied to GPs. Lack of trust in GPs, perhaps relating to perceived delays in referral for diagnosis in some cases, was a strong theme and aligned with a previous statement (see section on Information, above) that over 40% felt they would benefit from information about what to expect from GPs in the future. Very few (approximately 10%) indicated a need for more information about TYA cancer to be offered to schools, colleges and universities.

5. Patient Network Views

5.1 Defining and Accessing the Patient Network

The concept of the patient 'network' is not new but nor has it been previously well defined. Most previous work relates to the needs of, and role for, family members but early discussions with patients by programme team members illustrated the diversity of people who support young cancer patients, and the fluidity of those relationships. The following 'overarching' statements were considered to apply:

- Family members and carers are not exclusive in the patients network.

- The patients' network can only be defined by the individual patient. It represents those people who are/were, significant/important to them throughout their experience of cancer and beyond.
- The patients' network can be fluid and changeable with time or situation.
- Each relationship can have a different degree of emotional closeness.
- A diverse range of networker roles may be identified by the patient e.g. sibling, friends, those associated with hobbies / sports etc.

The programme team also recognised that it would be necessary to understand separate but inter related themes – what assistance do those close to young cancer patients require to provide the right support for the patient; and what are the emotional and practical needs of the networkers themselves? The hypothesis being that by addressing the emotional and practical needs of networkers, this will directly reduce some anxiety for patients and also help the networker to support the patient.

Sixteen patients from the original patient cohort who had returned an EOI form (Expression of Interest) indicating their willingness to continue to work with the ON TARGET team were recruited as 'gatekeepers' to a patient network. They were each asked to distribute a questionnaire to members of their own network, and to ask the networker to return the completed questionnaire direct to the programme team. Patients were not asked to tell the team who was in their network or which members of the network they would choose to approach, and no direct contact took place between members of the programme team and the networkers prior to the return of the questionnaires.

Networkers who returned questionnaires were also given an opportunity to complete an Expression of Interest form in which they were able to indicate whether or not they wished to have continuing involvement with the programme.

5.2 Response Rate and Characteristics of Respondents

One hundred and seventeen packs were provided, as requested, to the 'gatekeeper' patients: 28 (24%) were returned. Fifty percent were from family members (32% were parents); 25% from friends, 14% from partners, and 11% from others. The 'other' category included individuals as diverse as: flatmate; spiritual adviser; head of 6th form; and work manager. In total, responses were received from 14/16 patients' networks.

There was a wide age range – 25% of the respondents were aged between 18 -25 years and 25% were aged over 50 years; females (82%) predominated. Additional information was only available for those who also provided an EOI form from which it was clear that respondents came from geographical locations across the South West, and beyond.

In order to explore the questionnaire findings in more detail, individual interviews were held with four networkers, including two parents and two partners.

5.3 Key Findings

Three themes emerged from the questionnaire: 1) what assistance did those close to TYA patients provide; 2) what was the emotional/practical impact on themselves; 3) what did they need to best support the patient? The key findings have been abstracted from the detailed report and short summaries are presented below.

5.3.1. Support offered by Networkers

Almost all (93%) felt they offered patients emotional support; 82% provided practical support, 54% offered advice and information, 43% contributed to physical caring and 36% provided direct financial help. The majority (64%) felt they provided support throughout treatment but 29% considered they had mainly offered it after treatment was complete.

Several networkers acknowledged difficulties in carrying out their role as a supporter – in particular, not knowing what might be best for the patient; dealing with issues despite geographical separation; and in managing their own emotions.

5.3.2. Impact on Networkers themselves

Twenty seven networkers responded to the question “To what extent has the young person’s diagnosis affected your daily life?” – 13/27 (48%) indicated that the impact was high or very high. For most, the impact was greatest at or soon after diagnosis.

Twenty three individuals indicated that the diagnosis had resulted in increased difficulties for them (the networker) in one or more areas of their life: for example, 18/23 (78%) reported effects on physical wellbeing, 9 (39%) on spare time and leisure activities, 8 (35%) on financial circumstances, and 7 (30%) on their ability to undertake everyday household tasks. An impact on relationships such as those with family members, friends and work colleagues was reported by 4 people (17%) in each case.

5.3.3. Networkers own needs

Fifty nine percent (16/27 who replied to this question) admitted that they felt they had needed help to support the patient. Overall 57% received help and 42% sought this themselves.

Ninety percent indicated a need for emotional support for themselves; 75% for advice/information; 55% practical support and 30% financial help. Most networkers (73%) preferred face-to-face guidance and the majority would have liked this from hospital staff but recognised difficulty in accessing this. Several admitted to an anxiety about seeking support for themselves.

Eighty eight percent of networkers had actually received information which they felt was useful to them but many sought information on their own (e.g. on the internet) and were not always able to judge the quality or relevance of what they found. Some, depending on their relationship with the patient, received information directly from health professionals but others relied on the patient to pass information on.

Timeline: networkers emphasised that their need for information and support extended beyond the time of diagnosis and that as treatment progressed they continued to need advice about how to support the patient and how to deal with their own feelings. In particular, the end of treatment did not mark the end of their concerns.

Some networkers indicated that whilst they had received help, this was not always straightforward – for example, being allowed time off work by their employer but on the condition that this was taken as holiday or unpaid leave - and 3 networkers (11%) actually gave up work to help look after the patient. Several referred positively to the contribution of the voluntary sector in providing information, particularly about financial benefits. Themes which emerged about help needed included advice about the best way to provide support (to the patient); how to seek time off work; practical help; and the opportunity to speak to someone else in a similar position.

6. Professionals Views

6.1 Engagement with Professionals

The principal approach used to engage with professionals was by the use of an online survey but semi structured 1:1 interviews and small discussion groups were also utilised.

6.1.1. Online Survey

Those invited to participate in the online survey were professionals working within health care, social care or education who were known to have an interest in, or to have worked / anticipated working with TYAs; or those with a specialist knowledge in cancer care. All were based in the South West of England.

The questions set for the survey were established using a modified Delphi technique to determine consensus with statements regarding the needs of TYAs and the design of Aftercare interventions. Three rounds of questions were circulated and 122/322 (38%) of those to whom the first questionnaire had been sent responded in Round 1. Only those who responded in the earlier round were eligible to receive the questions for the subsequent round. Response rates for rounds 2 and 3 were 59% (72/122) and 75% (54/72) respectively.

Of those who completed all three rounds (n = 54), 30% were nurses, 22% Allied Health Professionals, 19% Hospital Medical Staff, and 6% General Practitioners. In total, thirteen different categories of staff were represented amongst those who responded to the whole survey. This also included: clerical/administrative staff, commissioners, hospital based teachers, health service managers, information/advice centre staff, social services staff, user involvement staff, and youth workers. Eighty five percent worked in the north of the South West region (Gloucestershire, Bristol, Bath, Somerset) and 69% were hospital based. Forty eight percent worked directly with TYA patients for less than 10% of their time and only 19% worked with TYA for more than half their time.

A follow up survey was requested by a small number of staff who had been unable to complete all previous rounds. This single survey included a selection of themes addressed in the three rounds of the main survey. In the event, only 4 out of 15 (27%) responded to the follow up survey.

6.1.2. Semi Structured Interviews and Focused Discussion Groups

In order to enrich the understanding of the breadth of views held by staff, semi structured 1:1 interviews, telephone conversations, and focused discussion groups were conducted throughout the South West. This enabled the programme to gain additional views and opinions, and to hear from those staff who were unable to access the Delphi survey. 97 staff, from a wide range of staff groups, were accessed in this way of whom 46% worked in Devon and Cornwall. This compensated, to some extent, for the lower proportion of staff in these areas who contributed to the Online Survey.

6.2 Key Findings: Online Survey

The key findings have been abstracted from the detailed report. The professionals' consensus view supported a total of 68 out of 70 (97%) statements across the three rounds of the online questionnaire.

6.2.1. Therapeutic Interventions

Agreement was achieved on the value of many therapeutic interventions. Examples included:

- Developing self-management skills

- Building resilience
- Alerting TYAs to the possibility of common cognitive effects resulting from treatment and encouraging them to discuss concerns with their treating team
- Asking patients about education / work; providing information and signposting
- Providing practical help around maintaining appropriate levels of activity during and after treatment
- Providing opportunities to talk about worries for the future e.g. recurrence.

6.2.2. Service Provision

Agreement was achieved on the value of a number of service provision related areas. Examples included:

- Providing opportunities to talk about worries for the future e.g. recurrence.
- Early and continued engagement between the treating team and primary care, particularly when preparing for the end of treatment
- Clarity regarding named key worker and contact options
- Definition and management of key transition periods e.g. end of treatment
- Staff education and training around the unique needs of TYAs
- Support for staff to develop effective relationships with TYAs
- Mechanisms to allow TYAs to provide feedback on their experience of the service they receive.

6.2.3. Commentary

Even though consensus was reached on 97% of statements, there were important messages within the free text comments made by some respondents which both challenged and extended the understanding reached from the consensus statements themselves.

For example, there was consistent support for the introduction of self management; however comments revealed a variety of opinions concerning what was meant by the term, whether it would be suitable for all patients, and at what stage self management should be introduced to patients and their supporters.

Comments made in response to statements regarding ‘assessment’ also highlighted particularly complex issues. First, what is the real value of a prompt/check list to assist staff who treat TYAs less frequently to ask the relevant questions? Second, as there is a choice of assessment formats, consideration needs to be given not only to the selection of the most appropriate but also to the timing of its use. Third, there is a necessity to ensure that assessment produces an agreed action plan. Finally, there was a recognition of the value of a patient’s own ability to self assess.

6.3 Key Findings: Semi-Structured Interviews & Focused Discussion Groups

Thirty separate topics could be identified within the discussions held with individuals and groups of staff. These also covered territory addressed by the consensus statements in the online survey but the content and focus ranged from the general to the very specific (in relation to specific diagnostic groups, geographical locations etc.). Four themes were defined which incorporated much of the overall content.

6.3.1. Structure of the TYA service.

- Equity: for the service to be accessible and relevant to TYAs from every geographical area, and social and economic background
- Planned and effective transitions between services

- Utilising expertise to anticipate and plan for the right intervention at the right time, in the right place – an emphasis, as far as possible, on prevention rather than intervention
- Appropriate clinic settings, with particular reference to providing TYAs with privacy in predominantly older adult waiting areas
- Increased multi-professional interventions, particularly from Allied Health Professionals and Psychology
- Ensuring that TYAs are assisted in navigating the healthcare system

6.3.2. Appropriate interventions.

- Cognitive issues to be recognised, assessed and addressed
- Responding to requests from TYAs for interventions such as exercise programmes, fatigue management, relaxation skills, massage and complementary therapies
- Provision of psychosocial support, peer support and peer mentoring
- Availability of skilled practitioners to facilitate structured group activities
- Provision of support and signposting around education, employment, finance and housing
- Supporting TYAs to continue with activities usually associated with young people e.g. Gap Years

6.3.3. Supporting Partners, Parents and Siblings (the 'Patient Network')

- Particular emphasis on supporting and engaging partners and siblings whose needs may be very different from those typically expressed by parents
- Helping parents and others to model resilience
- Supporting parents and other networkers during times of transition – both those relating to the cancer (e.g. end of treatment) and to normal TYA age events (e.g. leaving home, going to university)

6.3.4. Supporting Staff

- Understanding the time taken to build relationships with TYAs
- Addressing concerns about how to communicate with younger patients
- Addressing concerns about how to work effectively with parents in distress
- Informing how to respond to requests for help with education or employment,
- Confidence in advising and supporting TYAs to continue with valued activities during and after treatment
- To assist the young person prepare for the end of treatment and the future

6.4 Interaction between the Online Survey and Interviews/Discussions

The responses to the survey and the subsequent discussions with professionals began to inform one another as the process of gaining professional views progressed. An example is described below.

In Round 1 of the survey, there was a 97% consensus with the statement "The TYA service should develop a strategy to facilitate the patients re-engagement with primary care to end of treatment". However, 8 out of the 16 comments made in relation to this statement referred to the need to develop a strategy to *maintain* engagement with GPs throughout treatment, as well as recognising the importance of their role when preparing for Aftercare.

During subsequent discussions with members of primary and secondary care services located around the South West, further understanding was gained about the need for improved communication between primary care and treating teams, as well as the type of information which would be most significant when planning for Aftercare.

Quote from a GP: " If I was part of the journey, I would be more helpful to the patient".

7. Geographic Analysis

7.1 Rationale for a Geographic Analysis

An understanding of the needs and views of patients, their networks and the professionals who care for them is central to the design of interventions to meet those needs. However, the delivery of care will be influenced by local resources and by ease of access to possible centres of care. Geographical configuration may therefore be a factor in determining the choice of sites for pilot interventions within the ON TARGET programme.

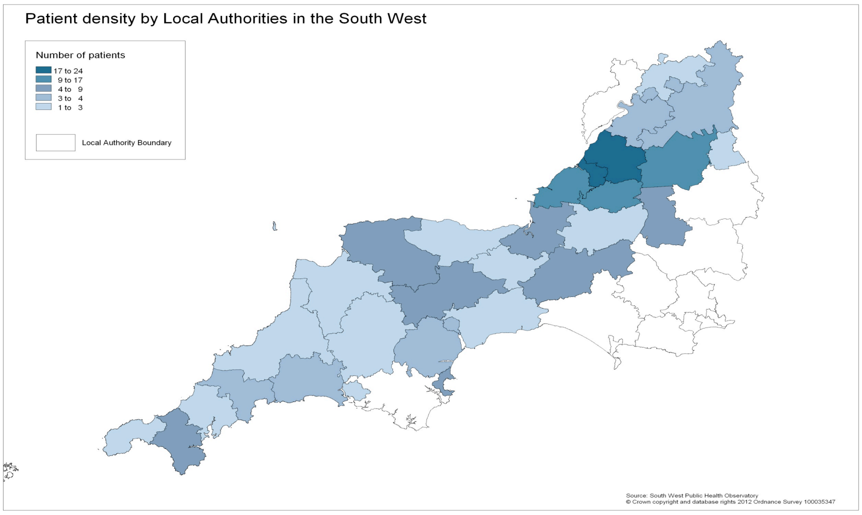
With the support of the South West Cancer Intelligence Service, an analysis was undertaken to assess travel times for the patients within the cohort used in the Analysis Phase. This looked at the relationship between the post code of their residence and the location of both the Principal Treatment Centre (PTC) in Bristol and the Network Care Partner hospitals (NCP – see section 3.5). Travel times were calculated for car journeys and no assessment of travel by public transport was undertaken.

7.2 Travel Times

Travel time was calculated for 146 patients from the TYA database for whom full post codes were available. This showed that 105 (72%) would have been able to access one of the treatment centres within the network (i.e. either the PTC or one of the NCPs) within 30 minutes travel time in each direction, and 137 (94%) would be able to do so within a travel time of 60 minutes. Travel times were, however, noticeably longer for patients living outside the Bristol / Bath area and, in particular, for those in Devon and Cornwall.

Site	% (no.) patients able to access this hospital site within 30 minutes	% (no.) patients able to access this hospital site within 60 minutes
Bristol	40 (58)	64 (94)
Bath	40 (59)	63 (92)
Gloucester	6 (9)	53 (77)
Taunton	5 (7)	42 (61)
Exeter	6 (9)	17 (25)
Plymouth	3 (5)	10 (15)
Truro	6 (9)	8 (11)

The first map shows patient density by local authority region and the second map shows how travel times relate to main routes and to centres of population. This particularly highlights the travel challenges facing patients in North Devon.



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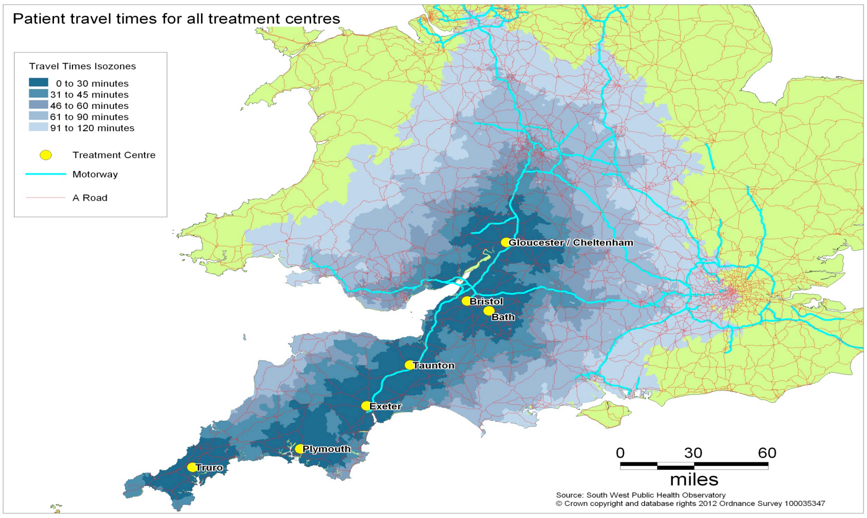

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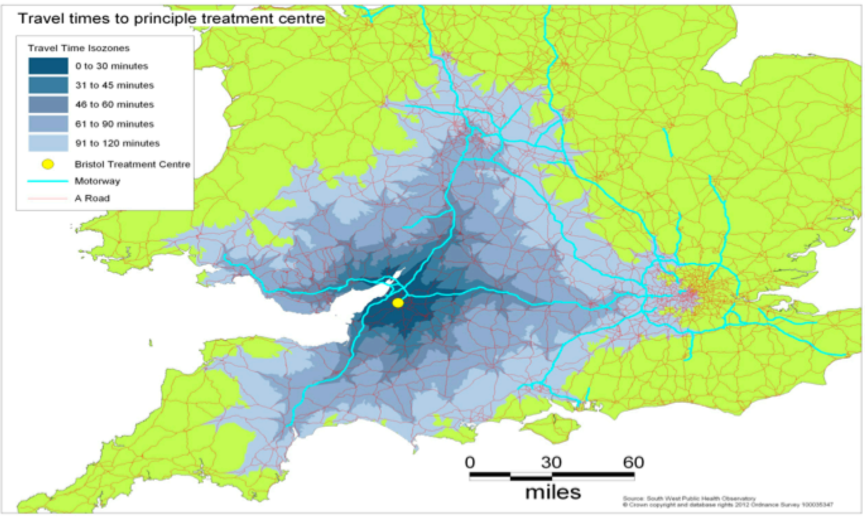
The third map (below) indicates travel times to the PTC for all patients: this illustrates the need for a networked approach to the delivery of care.



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8. Next Steps

The collection of good quality data, in sufficient volume to be seen as representative, and from the perspective of all major stakeholders, is a pre requisite to understanding what TYA patients want and need by way of care. It is important to recognise that some of these findings would be applicable to patients with cancer of any age, and some would apply to all TYA - with or without cancer. The strength of these analyses is, however, that they represent an in depth assessment of TYA cancer patients, their networks and those who provide their care, within a clinical service that is relatively new and which, by virtue of geographical constraints, seeks to deliver care across a network care partnership.

The aim of ON TARGET is now to utilise these data and to build and evaluate interventions for patients which address the priorities identified in this first phase of work and which will focus on enhancing the quality of their life with and beyond cancer.