TRANSFORMING CARE AFTER TREATMENT (TCAT) PROGRAMME

Report on the findings of the NHS Forth Valley

Macmillan TCAT Pilot Project

Nurse Led Follow Up of Prostate Cancer Patients

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1: BACKGROUND:

The Transforming Care after Treatment (TCAT) programme is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities to support a redesign of care following active treatment of cancer. The programme was officially launched by the Cabinet Secretary for Health and Wellbeing in June 2013.

NHS Forth Valley has been successfully developing their "Living with Cancer" agenda since 2008. A key element of this strategy *(Reference 1: Macmillan Cancer Support, 2008)* has been the development of a more person centred model of care. Forth Valley was a pilot site in the UK wide Macmillan Cancer Support "One to One" project. This study was favourably evaluated by both patients and staff and its benefits have been recognised by the recent establishment of a permanent One to One service in Forth Valley.

The learning from the One to One project, especially regarding the use of the Macmillan Holistic Needs Assessment (HNA) Concerns Checklist *(Appendix 1)* informed the planning and delivery of the Forth Valley TCAT project which was to implement a community based Nurse Led model of prostate cancer follow up. Traditional models of long-term prostate cancer care are very much focused on disease status rather than individual patient needs with little or no direct involvement in men in their own management. As such there are no structured attempts to determine whether men have specific needs and requirements beyond the initial diagnosis and treatment of their cancer. The proposed redesign of prostate cancer follow up in Forth Valley provided an ideal opportunity to assess these needs and determine what further interventions might be required in this cohort of men.

2: INTRODUCTION:

The aim of the TCAT programme is to support and enable cancer survivors to live as healthy a life as possible for as long as possible. Integral to this process is the implementation of the four key components of the Recovery Package *(Ref 2: National Cancer Survivorship Initiative NCSI 2012):*

- Holistic Needs Assessment (HNA)
- Treatment Summaries (TSum)
- Cancer Care Reviews (in community)
- Health and Well Being Events

For the purpose of this pilot project NHS Forth Valley concentrated on the HNA and TSum elements only. This report contains the overall findings together with patient and clinician evaluation of both the HNA and the TSum.
The implementation of the electronic TSum was led by NHS Forth Valley eHealth department and a separate report is available. *(Appendix 2)*

3: AIM OF THE PROJECT:

The overall aim of this project was to support men previously diagnosed with prostate cancer to live as well as possible after their diagnosis and treatment.

The main objectives were:

1. To develop a follow up service for patients with prostate cancer that is person centred and meets patients needs and may be a model for prostate cancer follow up service redesign elsewhere in Scotland
2. To ensure each patient has a completed TSum
3. To perform a HNA on all patients attending the clinics and develop individual care plans for all patients, referring or signposting to other agencies as appropriate.

Achieving these objectives will support compliance with 8 out of the 9 Macmillan Outcomes:

- I understand so I make good decisions
- I get the treatment and care which are best for my cancer and my life
- Those around me are well supported
- I am treated with dignity and respect
- I know what I can do to help myself and who else can help me
- I can enjoy life
- I feel part of a community and am inspired to give something back
- I want to die well

Good supported self-management will also provide prostate cancer patients with more information regarding the possibility of recurrence of disease. This includes how to seek help as soon as possible which should facilitate earlier diagnosis of recurrence.

The main purpose of this project was to conduct an audit of this new service and formally evaluate the use of the Concerns Checklist which is the tool of choice being used in Forth Valley to conduct HNA with all patients post treatment, and to implement the completion of Treatment Summaries for all patients with stable prostate cancer.

The anticipated outcomes are outlined below with care being:

- Person-centred
- Aligned to recognised current best practice
- Equitable across Forth Valley with learning from the pilot informing regional and national services
- Clinically effective and efficiently delivered

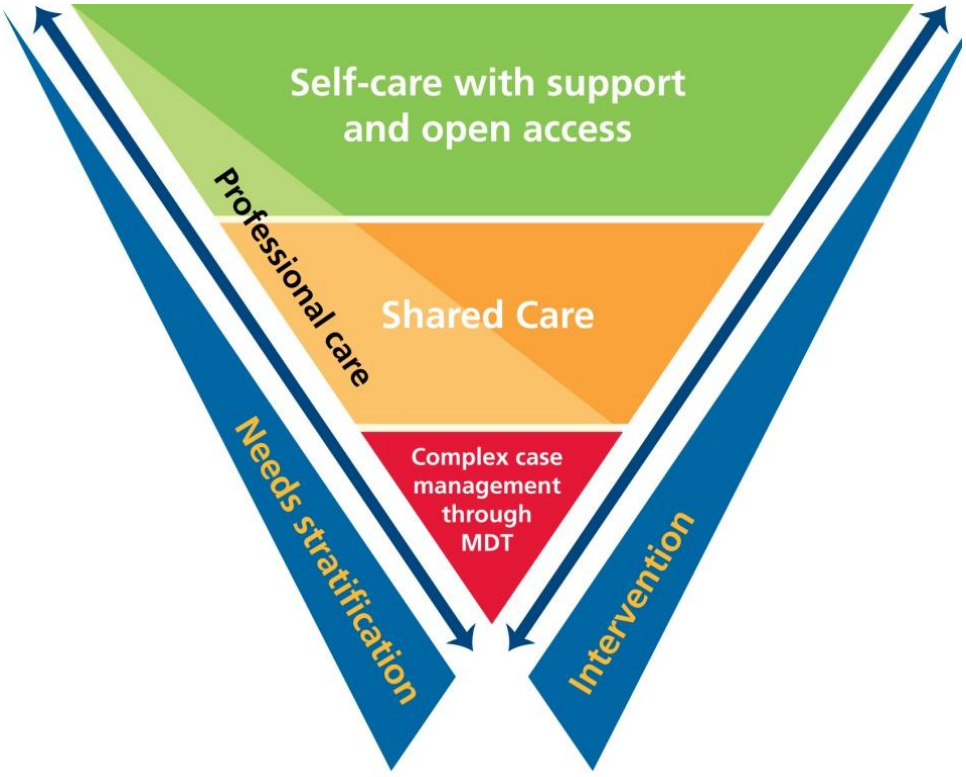
The new model is also designed to:

- Detect and treat recurrent disease as early as possible
- Manage treatment complications
- Provide psychological and supportive care
- Optimise quality of life

The three forms of aftercare are:

- **1 - Supported Self Management** – where patients are given clear information and instruction on how to manage their own care. The required information includes key symptoms and signs to prompt further medical review, clear guidance re frequency of further tests / appointments and appropriate contact details to facilitate re-engagement with service providers if necessary
- **2 - Shared Care** – where patients continue to have face to face, phone or email contact with professionals as part of continuing follow up
- **3 - Complex Case Management** – where patients are given intensive support to manage their cancer and/or other conditions.

Learning from the One to One project has shown that some patients who may be considered suitable for less intensive forms of follow up on the basis of cancer type or stage may actually have high levels of psychosocial needs and dependency. The use of disease specific risk stratification tools in tandem with holistic needs assessment gives much greater precision to the stratification model as illustrated below. Patients will be treated according to which approach is most suitable, and the level of professional input required will vary accordingly. The project was to test the model of nurse led follow up in a group of patients who meet the criteria for level 2 care (requiring regular face to face appointments).



4: PATIENT GROUP:

Prostate cancer is the most common cancer in males, with 3202 new cases diagnosed in Scotland in 2014 (ISD). Fortunately prostate cancer specific mortality has decreased by 11.9% over the past 10 years to 2013 and 5-year survival following a prostate cancer diagnosis has improved from 56.5% in men diagnosed in 1985 to over 85% in men diagnosed in 2010.

Each year approximately 160 men are diagnosed with prostate cancer in Forth Valley. It is estimated there are 1200 men living with prostate cancer locally and of these about two thirds (800 men) could be effectively managed in the community.

In Forth Valley men with stable prostate cancer are followed up at a weekly nurse led clinic within the acute hospital. Clinics are also held once per month in two of the community hospitals. Follow up for these men are as per West of Scotland Cancer Network (WOSCAN) prostate cancer guidelines *(Ref 3: of Scotland Cancer Network (WOSCAN) (2014) Guidelines for Prostate Cancer Follow Up in Primary Care).* All men attending these community hospital based clinics over a six month period were invited to participate in the TCAT study (n=132)

5: METHODOLOGY:

Following consultation with various stakeholders the TCAT Project Nurse developed a letter which introduced the patients to the project *(Appendix 3)* and this was sent to patients 2 weeks prior to their Nurse Led Follow-Up clinic appointment, together with a Macmillan booklet explaining the HNA and a blank Concerns Checklist form which the patients were asked to complete and bring to their clinic appointment.

The men then attended for their usual Nurse Led follow-up clinic appointment with the CNS/Staff Nurse and if they had completed the Concerns Checklist they then had a consultation with the TCAT Project Nurse.

As the project developed and the Urology Specialist Nurses became more competent in the HNA process, the Specialist Nurses began to engage in this process with the men themselves.

During the clinic appointment the patient discussed the concerns they had highlighted on the Concerns Checklist with the Nurse and a care plan was formulated. A copy of the Concerns Checklist and the Care Plan was then given to the patient together with any relevant leaflets.

Three separate strands of data were collected:

- Data required for Edinburgh Napier University
- Data required for the local evaluation
- HNA data – Concerns Checklist data *(Appendix 1)* Care Plan data *(Appendix 4)*

In order to avoid numerous forms being completed by the Nurses, Quality Improvement devised a data collection tool which combined all strands into one A4 data collection tool *(Appendix 5)* Data was collected and stored as per Forth Valley standards and protocols for data protection.
The TCAT Project Nurse and the QI facilitator both agreed that it was important, where possible, to explore the reasons for non participation by the men in the project.
The TCAT Quality Improvement Facilitator devised an Access database into which all data was entered. The monthly data required by Napier University was extracted from this database and submitted.

6: GOVERNANCE:

In accordance with the Service Level Agreement (SLA) a Steering Group, with agreed Terms of Reference was established. The Steering Group was co-chaired by Seamus Teahan and Sandra Campbell. Meetings were planned quarterly but deferred if a planned meeting was not to be quorate. There was no formal Operational Group but regular meetings between key stakeholders occurred to facilitate the progression of the project.

Prior to commencement a Patient Experience project had been undertaken with men affected by prostate cancer. A patient representative was a member of the Steering Group from its inception. In addition to patient and clinical representatives, third sector and social care representatives completed membership of the group. *(List of Steering Group members – Appendix 10)*

The Cancer Advisory Group and the Strategic Cancer Group also received regular updates of the TCAT project.

7: ROLE OF THE TCAT PROJECT NURSE AND THE QI FACILITATOR:

TCAT Project Nurse:

- To implement and develop the TCAT Project for Prostate Cancer patients within the NHS Forth Valley Uro/Oncology Nurse Led Follow up clinics
- To engage with Prostate Cancer patients, informing them of the project and its' benefits
- To introduce and complete the HNA Concerns Checklist (and subsequent care plan)
- To introduce and complete the TSum with patients

Within Forth Valley the TCAT Project Nurse had previous knowledge and experience of providing HNA assessments to cancer patients, obtained through her role within the Macmillan One to One Team. This previous experience proved very useful in the provision of education to the nurses within the Uro/Oncology Team regarding the completion of the HNA Concerns Checklist and subsequent actions to be taken if required.

During the early stages of the TCAT Project, the Project Nurse further developed her knowledge and understanding in relation to prostate cancer through:

- Shadowing the Urology CNS
- Attending MDT meetings
- Meeting with prostate cancer support groups and Prostate Cancer UK
- Meeting with Relationship Scotland

At all times the Project Nurse worked in collaboration with Seamus Teahan and Maureen Hamill (*Uro/Oncology Specialist Nurse Co-ordinator* and also with Sandra Campbell who provided mentorship for the duration of the project.

An adapted Input to Outcomes model was used and shared by the TCAT Project Nurse when attending meetings. The TCAT Project Nurse attended the FV TCAT Steering Group meetings together with the Working Group meetings held in relation to the development of the Electronic Treatment Summary (TSum) for prostate cancer patients which would be shared with GPs.

Quality Improvement (QI) Facilitator:

- Point of reference for external evaluators at Napier University
- Liaise with the local project team, to ensure a local evaluation programme is identified, implemented and reported. This included undertaking and reporting the outcomes of audits, patient, carer and staff engagement and or focus groups, process mapping and any other improvement methodologies required to support the team
- Overall responsibility for data collection, analysis and reporting

Throughout the project the QI Facilitator worked in close collaboration with the TCAT Project Nurse. The QI Facilitator had responsibility for the implementation of the processes required to ensure robust data collection and analysis for both the local and national (Napier University) evaluations. This involved designing data collection tools, analysis systems, and advising on the most appropriate methods for patient, carer and staff engagement.
The QI Facilitator attended the FV TCAT Steering Group meetings together with the Working Group meetings held in relation to the development of the Electronic Treatment Summary (TSum) for prostate cancer patients which would be shared with GPs.

8: CHALLENGES EXPERIENCED DURING THE PROJECT:

- Two members of the CNS team were on long term leave over the course of the project. This reduced the time available for teaching and slowed dissemination of HNA and TSum utilisation particularly in the earlier part of the project.
- Due to unexpected absences detailed above there was increased pressure on clinic time. Clinic templates are currently being reviewed to examine feasibility of increasing appointment time in these follow up clinics.
- Work on health and social care integration pressurised social care representation on the Steering Group. Though attendance at meetings was sporadic towards the end of the project, good lines of communication remained open.

9: PATIENT ENGAGEMENT AND EVALUATION:

- A National Patient Evaluation questionnaire was developed by Napier University and was sent to the men by post *(Appendix 6)* with a stamped addressed envelope, allowing the completed evaluation forms to be returned directly to Napier University.

- A local Forth Valley Patient Evaluation was undertaken by the TCAT Project Nurse (for both HNA and Treatment Summary) *(Appendix 7)*

- A local Forth Valley Staff evaluation was also undertaken *(Appendix 8)*

- The TCAT Steering Group included a patient representative who had prostate cancer.
  Comments were sought from him regarding the project, including his thoughts and opinions on the information/leaflets etc. provided to men at their TCAT Nurse Led clinic appointment

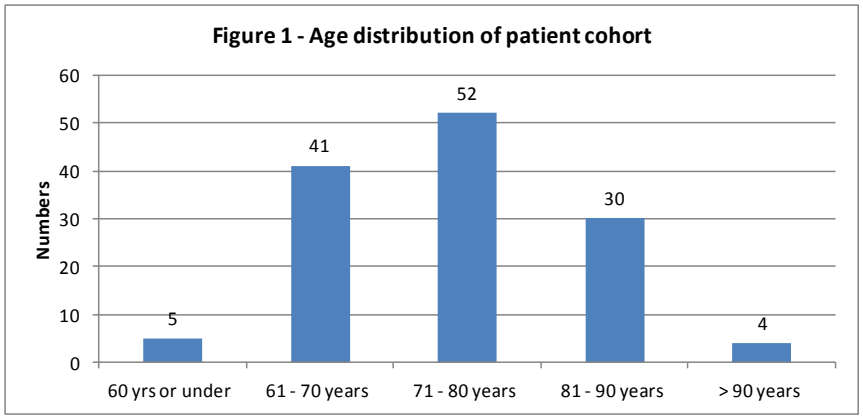
- The TCAT Lead Clinician, Project Nurse and TCAT Quality Improvement Facilitator also engaged with the local FV Prostate Cancer Support Group and demonstrated the project to those members attending. It is worth noting that none of the men who attended this particular meeting had been involved in the project.

Examples of comments made by participants at the local support group:

- This is a great project to improve the aftercare for men like us
- I would like to complete a HNA – think it prompts you to think about things and to open discussions and raise concerns/issues you may well keep to yourself
- Having a copy of your treatment summary sounds a good thing
- My husband has had prostate cancer for years, he and I would have benefited from something like this early on
- Always feel the Nurses at the follow-up clinic are so busy, so I would never have thought to raise some of the things that are on the concerns checklist. I have just learned to live with them

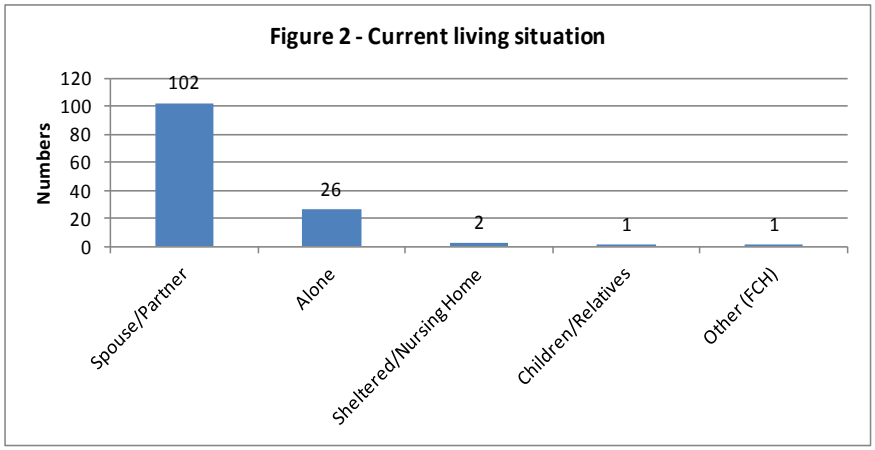
10: DISCUSSION: *(See Appendix 9 for full data analysis)*

The peak incidence of prostate cancer diagnosis in Scotland is in men aged 65-69. The age distribution noted in this follow up study *(Figure 1)* reflects this peak and estimated survival following diagnosis and is likely therefore to be representative of prostate cancer follow up patterns across Scotland.



The mean age of this cohort was 74.6 years (range 55-93)

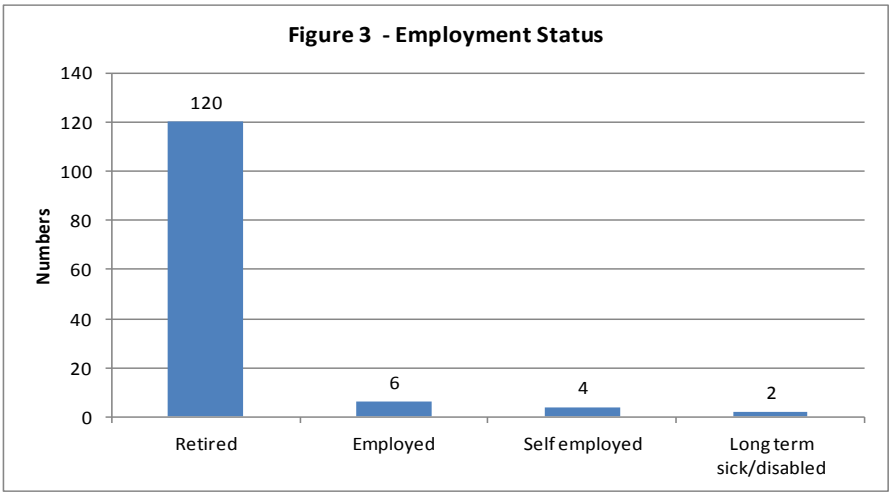
More than three quarters of men in this study lived with a spouse or partner *(Figure 2).* This may be one of the reasons this group managed so well as the beneficial effects of close family support are well recognised a key element in coping strategies following a cancer diagnosis. *(Reference 4 Macmillan Cancer Support 2014)*



As shown in *(Table 1)* the overwhelming majority of men attending these clinics were of white Scottish ethnic background. This finding reflects the population demographic in Forth Valley in this particular age group.

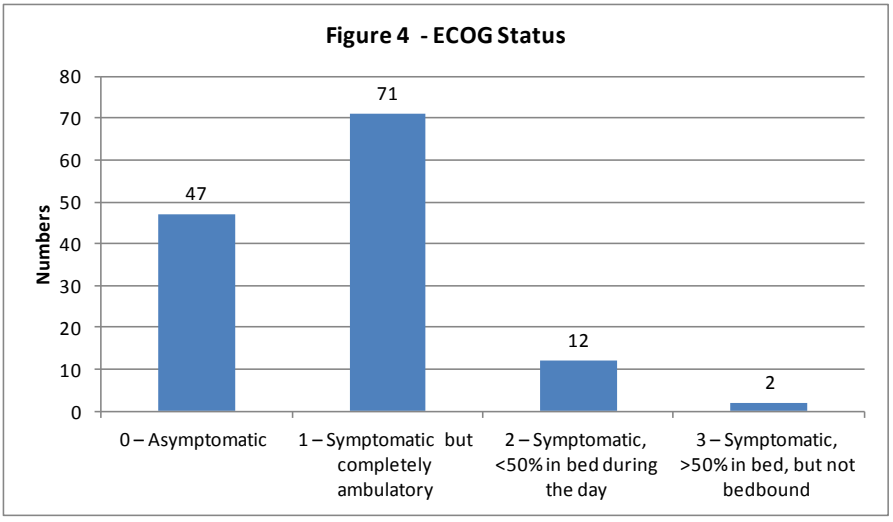
Table 1 - Ethnicity	**Number**
White Scottish	130
White Other *(Welsh)*	2
Total	**132**

Given the age profile of this follow-up cohort the finding that more than 90% of men in this group had retired was not surprising. *(Figure 3)*



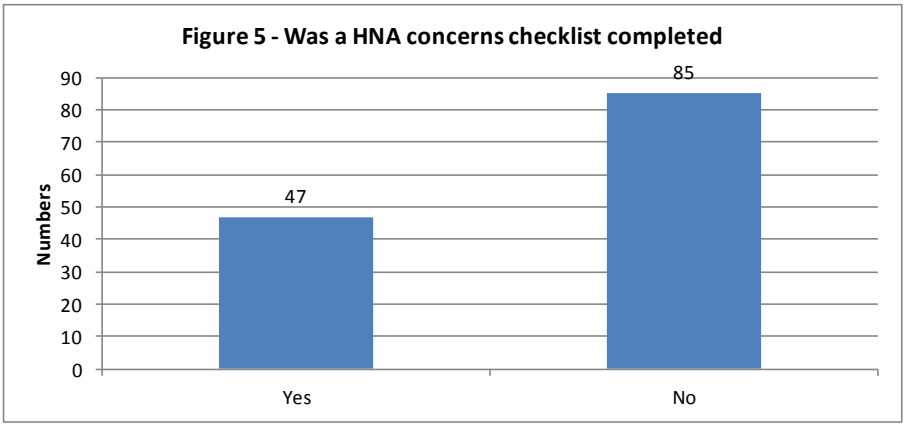
The potential financial impact of prostate cancer diagnosis and treatment for cancer may be less significant than other cancers diagnosed during someone's working career and may explain the relatively low incidence of financial/housing concerns reported in this study. This contrasts with other cancers such as breast where many more are in employment and therefore face higher levels of distress around financial issues and may actually have contributed to the lower level of the completion of the HNA. *(Reference 5 – Macmillan Cancer Support (2011), Stressed and Strapped: Cancer Patients Take Financial Hit*

Ninety percent of men in this cohort were either entirely asymptomatic or had minimal symptoms in relation to their prostate cancer (ECOG performance status 0 or 1 – Figure 4*).*



This implies good or reasonable health despite the diagnosis of prostate cancer and that the majority of men remained independent in relation to activities of daily living.
This was expected as these community-based clinics were developed to manage men with stable prostate cancer and/or low risk disease.

One third of men in this study group chose to complete the HNA Concerns checklist *(Figure 5).*

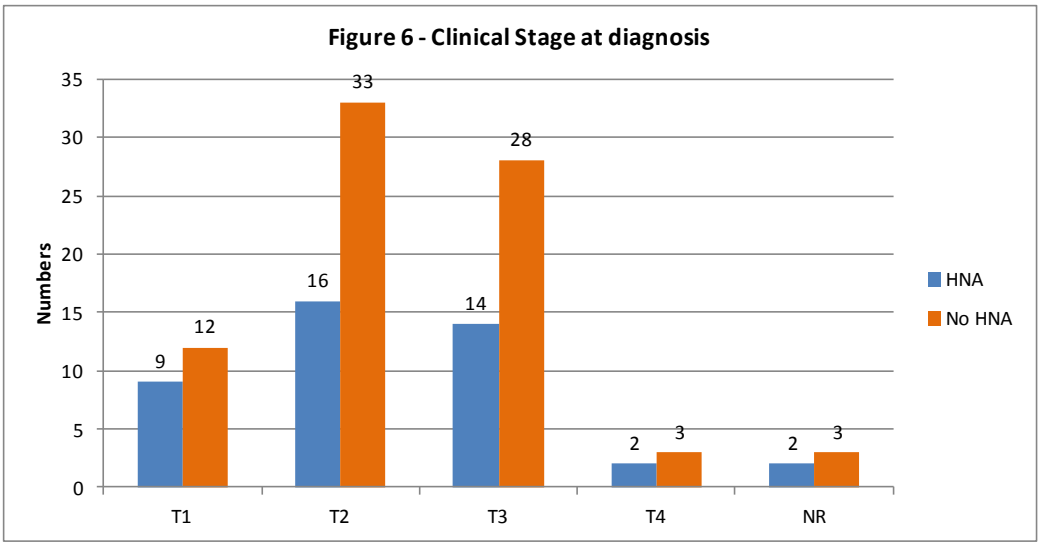


Though at first glance this was a dissappointing response rate, 64 of those 85 men who did not complete the checklist specifically stated they had no concerns. The remaining 21 patients gave 'other' reasons for not completing the Concerns Checklist.

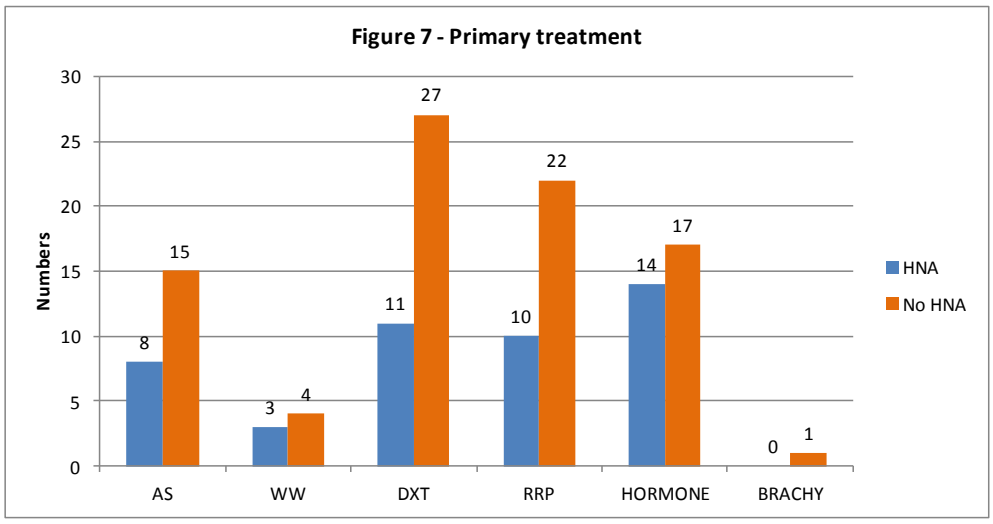
Examples of 'other' reasons (n=21) for not completing the HNA were:

- "Don't want to see anyone else"
- Declined - no specific reason given
- Did not wish to "waste nurse's time"
- "What use is that for me, I'm 5 years down the line"
- Refused to take part
- Feels 'not appropriate'
- Metastatic prostate cancer, declined and states that he has good support

Though it would have been impossible to control and match stage at diagnosis between those who choose to complete a concerns checklist and those who did not, nonetheless both groups were very similar in relation to stage at diagnosis as demonstrated in *(Figure 6).*



Similarly both groups were well matched in relation the proportions choosing active surveillance (AS), radiotherapy (DXT) and radical retropubic prostatectomy (RRP) as can be seen in *(Figure 7).*



A higher proportion of patients managed by watchful waiting (WW) and primary hormone therapy completed a HNA but it is impossible to determine if this was due to ascertainment bias or chance given the design of the study.

The 'National Cancer Survivorship Initiative' – Macmillan Holistic Needs Assessment (HNA) Concerns Checklist *(Appendix 1)* is a self assessment document in which the patient can highlight any concerns that they have.

6 categories of concerns have been described:

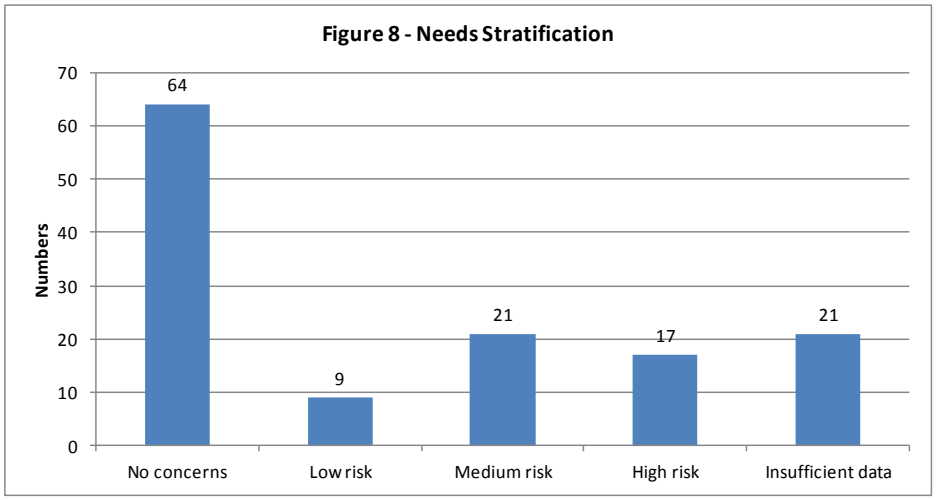
- Physical
- Practical
- Family/relationship
- Emotional
- Spiritual or religious
- Lifestyle or information needs

Based on the level of need, patients were stratified into three groups *(Table 2)*

Table 2 - Patient's level of concern (1-10) on completion of HNA (n=47)	**Number of patients**	
1	5	**Level 1 (0-3 mild)**
3	4	
4	8	
	17	
5	8	**Level 2 (4-6 moderate)**
6	5	
7	3	
	16	
8	8	**Level 3 (7-10 significant)**
9	1	
10	5	
	14	

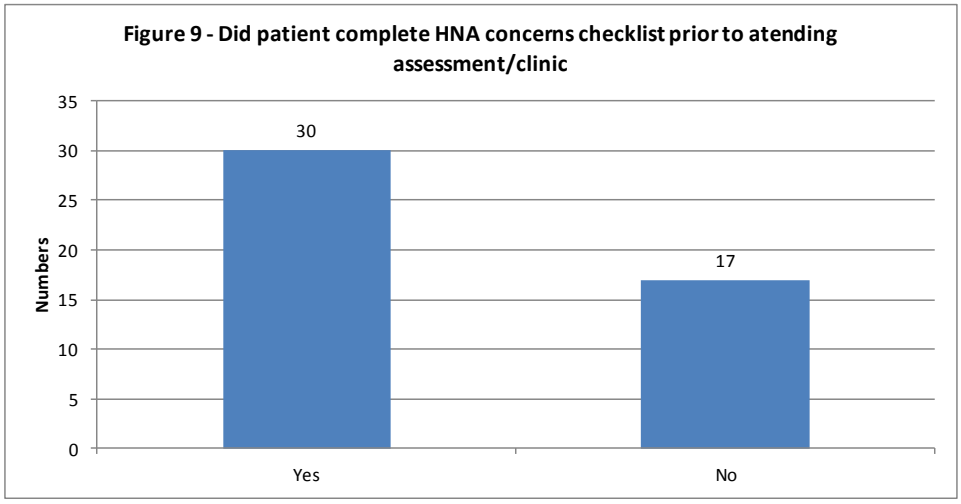
- Those who may be able to lead their own management given adequate support (Mild = Supported Self Management)
- those who may be able to partially self-manage with input from generic/specialist teams (Moderate = Shared Care)
- those men with ongoing complex specialty needs who require ongoing input from secondary or tertiary services (Significant = Complex case management)

For the purposes of risk stratification we combined the HNA data with the feedback given at the initial consultation when 64 additional men reported “no-concerns”. (Figure 8)

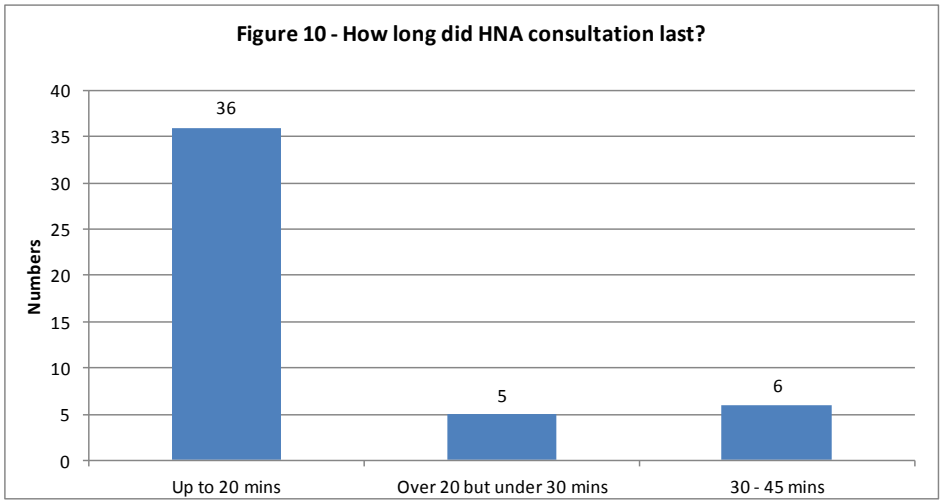


- 73 patients were categorised as having no or low level concerns and are potentially suitable for Supported Self Management
- 21 patients were categorised as requiring Shared Care
- 17 patients were categorised as requiring Complex Case Management
- There were insufficient data on the remaining 21 patients to categorise appropriately

The 47 patients who completed the HNA Concerns Checklist were seen in the Nurse Led prostate cancer Clinic by either the TCAT Project Nurse or a member of the Urology Specialist Nurse Team. Though none of these men had previous experience of the Holistic Needs Assessment tool, almost two thirds completed the checklist successfully prior to coming to the HNA consultation. (Figure 9)



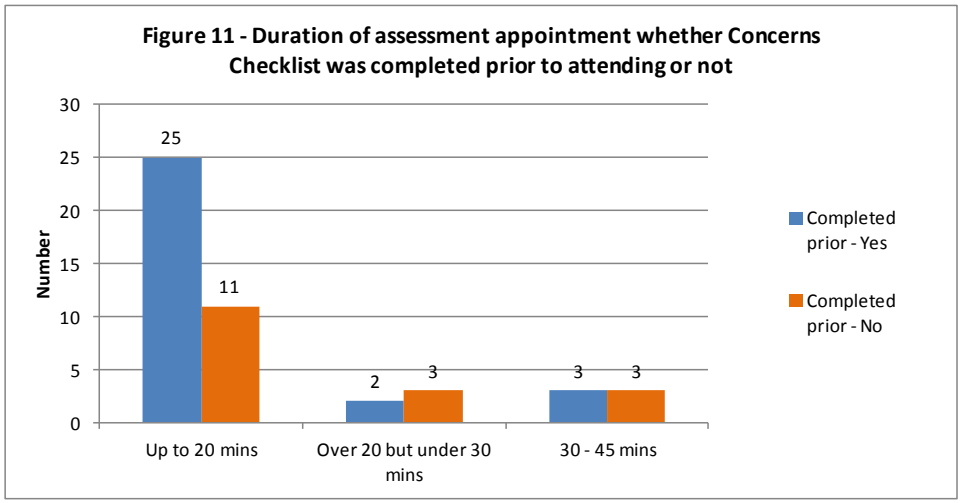
For the majority of these patients the HNA consultation itself took less than 20 minutes *(Figure 10).* It is often considered that HNA may be a time consuming intervention when in reality it is a very effective way to ensure person centred care.



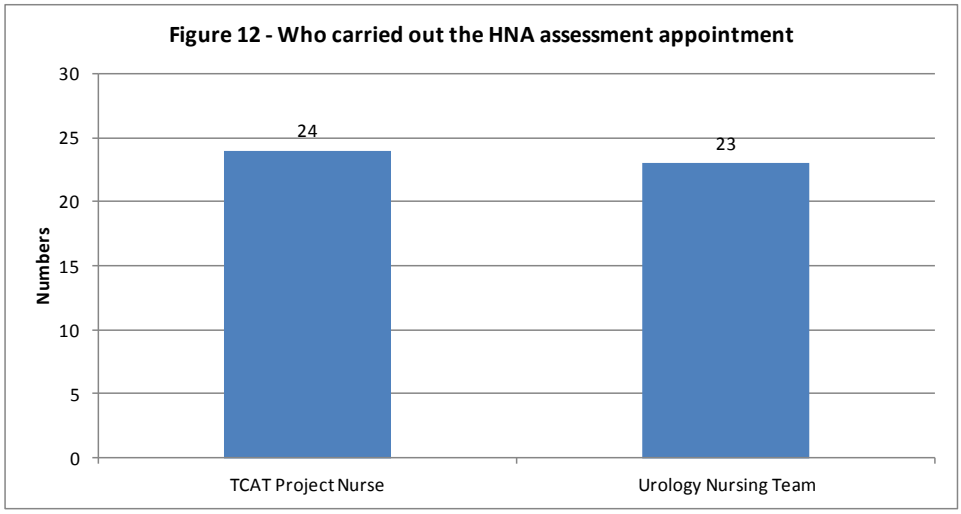
Though it is important to acknowledge that the nurse in this project was highly experienced in conducting these assessments, a similar amount of time was required by other members of the nursing team to conduct the assessments later in the project. *(Table 3)*

Table 3 - Appointment duration = Up to 20 minutes	TCAT Nurse	Staff Nurse	CNS
Completed prior - Yes	13	8	4
Completed prior - No	3	4	4
Appointment duration = over 20 but under 30 minutes	TCAT Nurse	Staff Nurse	CNS
Completed prior - Yes	1	0	1
Completed prior - No	3	0	0
Appointment duration = over 30 but under 45 minutes	TCAT Nurse	Staff Nurse	CNS
Completed prior - Yes	1	0	2
Completed prior - No	3	0	0

For a minority of the patients the consultation took between 20-45 minutes and it was noted that 9 out of the 11 men had significant/complex or moderate concerns though 2 had mild concerns. Even if the Concerns Checklist had not been completed by the patient prior to attendance, the consultation may in most cases still have taken less than 20 minutes. *(Figure 11)*

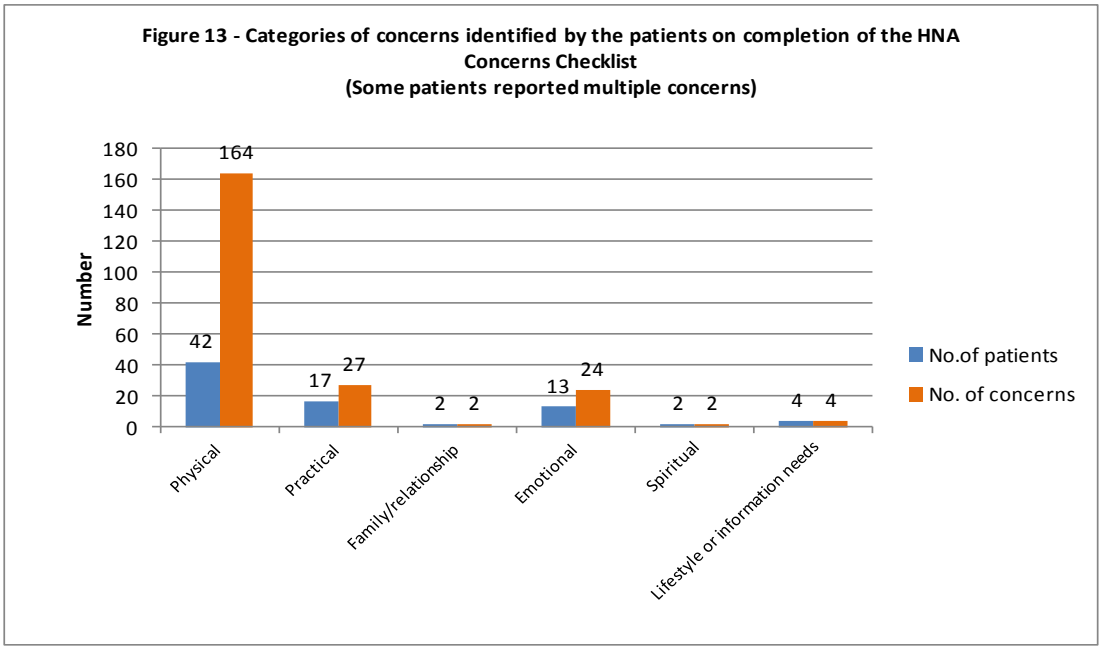


The majority of the HNA consultations were undertaken by the TCAT project nurse in the earlier part of the project but as the project matured more of these assessments were undertaken by the urology nursing team *(Figure 12).*

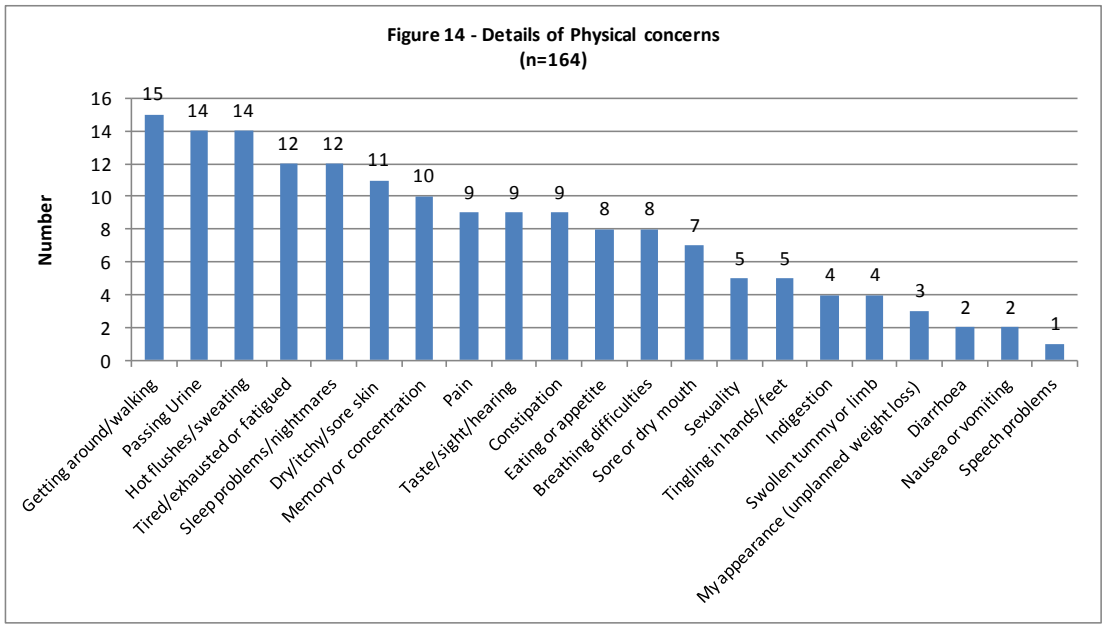


There were no appreciable differences in the length of consultation irrespective of nursing grade as previously demonstrated in Table3. This suggests the necessary skills needed to administer and interpret the tool are readily learned and outcomes are independent of previous specialist prostate cancer experience.

All 47 men completing a HNA identified various concerns. *(Figure 13)*



Physical concerns were common and many men reported more than one physical symptom *(Figure 14).*



Interestingly many of the concerns identified were quite generic and not necessarily associated with the cancer diagnosis and may reflect the age profile of this group of men.

Despite the prevalence of physical (42/47), practical (17/47) and emotional concerns (13/47), formal referral to specialist health or social services was not necessary in the majority of cases. In total 13 of the 47 men were referred onwards from the prostate cancer Nurse Led Clinic *(Figure 15 and Table 4)*

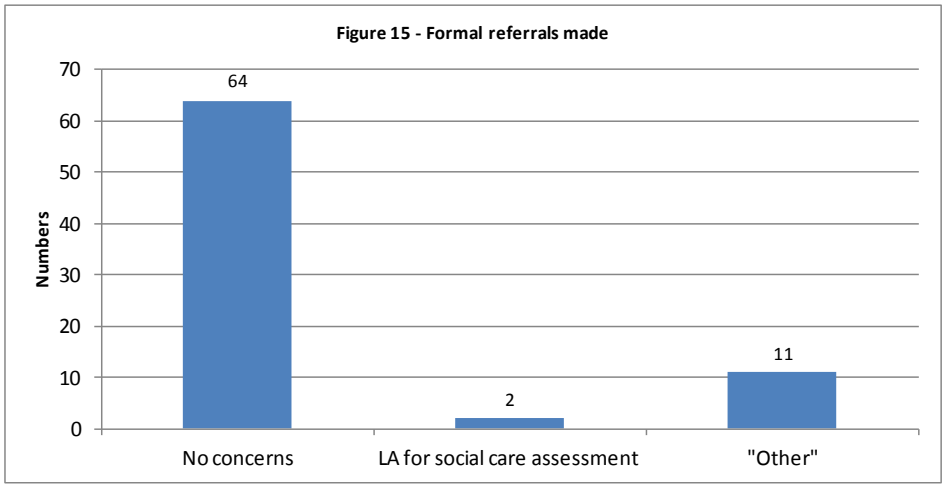
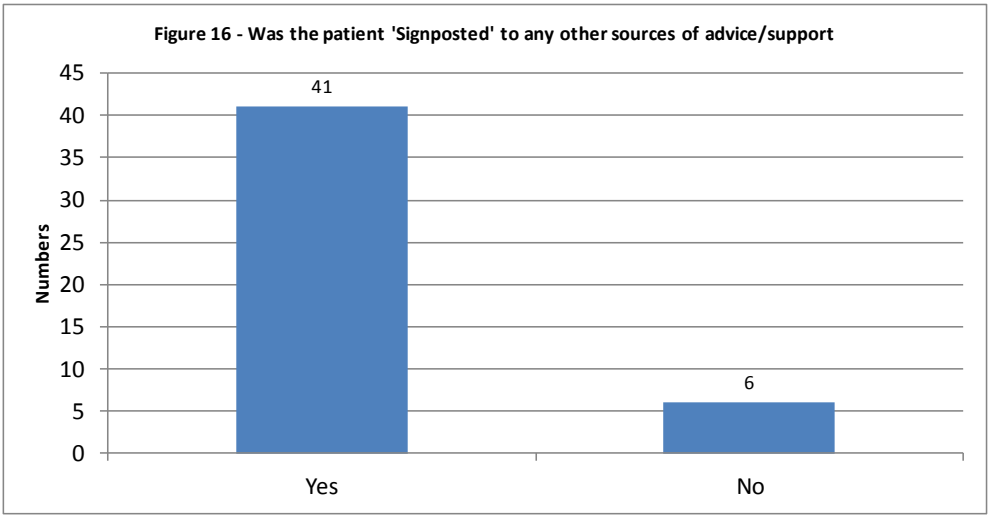


Table 4 - If yes (n=11):-	**Number**
Patient's own GP	8
Referred to NHS specialist cancer service	2
NHS in general (non cancer)	1
Specialist benefits-financial advice agencies	1
Total	**12**

NB-1 patient was formally referred to both their GP and NHS in general (non cancer) service

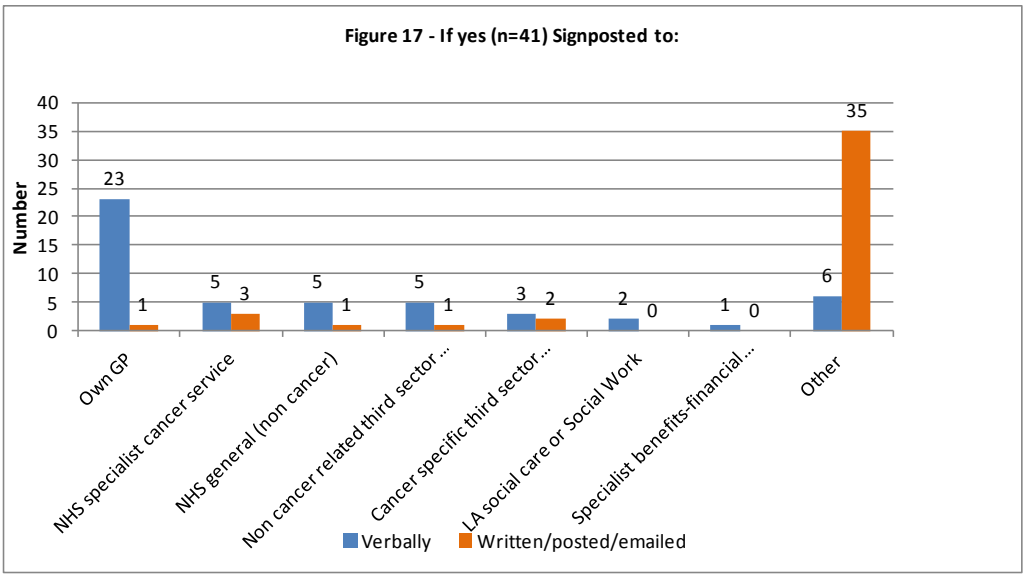
8 of the 13 men were advised to seek review appointments with their own GP. In the majority of cases (6/8) this was to have a recommended medication prescribed. These men frequently commented they would have requested an appointment with their GPs were it not for the pre-arranged follow up.
Two of the 47 men completing a HNA were referred to social care for formal assessment and possible further intervention and another man was referred to the specialist financial advice team.

41 of the 47 men were “signposted” to other organisations or individuals who may have been in a position to offer further advice or support *(Figure 16).*



This option was chosen on the basis of a lower level of need and following discussion with the client. The organisations included prostate cancer support groups, health and wellbeing clinics, physical activity and fitness groups etc.

Additional information / self help leaflets were also utilised in this setting. *(Figure 17)*



11: CONCLUSION:

This project has provided the foundation for the transformational change to support the follow up management of prostate cancer patients in the community.

Our data demonstrate that community based prostate cancer follow up is feasible and safe in men with stable and or low risk prostate cancer. In our experience the majority of men in these categories had minimal or no symptoms related to their cancer and 73/132 reported either no or minor concerns only.

These data have potentially very significant implications for follow up planning as on the basis of this information more than 50% men currently being followed in secondary care could potentially be discharged from routine follow up if adequate support networks were in place. In addition those deemed suitable for shared care have many generic needs rather than needs specifically related to their cancer management and may be suitable for follow up in a multidisciplinary context rather than in a specialist cancer clinic. There remain a group of men who need ongoing complex care and specialist care and this group are possibly best managed with ongoing secondary care.

The use of a holistic needs assessment tool and treatment summaries was broadly welcomed by patients and readily incorporated into routine clinical practice. In the short term at least additional time is required to successfully adapt this approach. However, the skills required are readily learned and transferred. Holistic needs assessment facilitates very precise and truly patient centred care and used in tandem with treatment summaries provide patients and carers with the tools required to confidently self manage their conditions.

The short time frame of study in this project has not allowed us to assess the longer-term impact of this model on subsequent patient satisfaction, clinical outcome and resource utilisation. We plan however to continue with this approach given the very favourable feedback to date from patients and other stakeholders.

We have already introduced treatment summaries at a much earlier stage in men's pathways and not as originally conceived as an "End of Treatment" tool. In addition we are also working with other specialist teams to spread the learning from this project to other areas and encourage HNA use at earlier stages (and repeatedly) of patient management.

The challenge of an ageing population and improved cancer survival mandates a radically different approach to follow up and we believe the approach adopted in this study offers a realistic and sustainable alternative to current follow up models in prostate cancer care.

12: REFERENCES:

1: Macmillan Cancer Support (2008), The Cancer Survivorship Agenda https://be.macmillan.org.uk/be/p-231-the-cancer-survivorship-agenda.aspx

2: National Cancer Survivorship Initiative (2012) The Recovery Package, http://ncsi.org.uk/what-we-are-doing/the-recovery-package/

3: West of Scotland Cancer Network (WoSCAN) (2014) Guidelines for Prostate Cancer Follow Up in Primary Care, http://www.woscan.scot.nhs.uk/managed-clinical-networks/nhs-woscan-primary-care-homepage/nhs-woscan-primary-care-guidelines/

4: Macmillan Cancer Support (2014), Loneliness damaging the lives of 400,000 people living with cancer, new research shows http://www.macmillan.org.uk/aboutus/news/latest_news/lonelinessdamagingthelivesof400,000peoplelivingwithcancer,newresearchshows.aspx

5: Macmillan Cancer Support (2011), Stressed and Strapped: Cancer Patients Take Financial Hit

http://www.macmillan.org.uk/aboutus/news/latest_news/stressedandstrappedcancerpatientstakefinancialhit.aspx

6: Oken M, Creech R, Tormey D, et al. Toxicity and response criteria of the Eastern Cooperative Oncology Group. *American Journal of Clinical Oncology.* 1982;5:649-655.

Appendix 1

National Cancer Survivorship Initiative – Concerns checklist Holistic needs assessment

Identifying your concerns

Patient's name or label

Discussed by:

Date:

Designation:

Contact details:

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

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

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

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

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

Family/relationship concerns
- ☐ Partner
- ☐ Children
- ☐ Other relatives/friends

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

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

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

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

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

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NHS Improvement

Appendix 2

NHS Forth Valley
eHealth Programme Office

TSum: Cancer Treatment Summaries

End of Project Report

Version: 1
Author: Suzanne Millar
Issue Date:29/01/2016

Document Management

Version History

Version No:	Date	Author	Details of Changes included in Update
0.1	29/12/2015	Suzanne Millar	First draft
0.2-0.4	30/12/2015-21/01/2016	Suzanne Millar	Minor updates to formatting etc
0.5	22/01/2016	Suzanne Millar	Inclusion of comments from eHealth manager
0.6	26/01/2016	Suzanne Millar	Inclusion of comments from P Baughan & guidance about logging calls on Altiris
1	29/01/2016	Suzanne Millar	Final version

Distribution

Version No:	Date	
0.1	05/01/2015	S Teahan, P Baughan, C Salvador
0.2-0.4	Not circulated	
0.5	22/01/2016	S Teahan, P Baughan
0.6	Not circulated	
1	29/01/2016	Cancer Treatment Summaries Project Group, Scott Jaffray, Stephen Nelson and Mary Cameron

Document Location

This document is stored in the following location:
V:\eHealth\Programme Office\eHealth Project Files\eHealth Projects current\CATS\Phase 2\Project Documents\3 Close

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7. Outstanding Issues/Risks/Tasks 7
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1. Purpose of Document

This document reviews the performance of the cancer treatment summaries project implementation against the objectives detailed in the project initiation document.

2. Background

The overall purpose of this project was to deliver a new IT system to produce cancer treatment summaries at key stages in a patient's cancer journey. This collaborative work was funded by Macmillan Cancer Support and aimed to provide a solution that could be adopted by other NHS Boards.

The end result of this project is that a new IT system has been developed which allows users to build up treatment summaries and transmit these electronically. NHS Forth Valley has been sharing its work with other Boards and interested stakeholders. The project had a distinct timeline with the end product available for use within NHS Forth Valley in August 2015. System use commenced in July 2015 with treatment summaries being sent from then.

3. Achievement of Project Objectives & Deliverables

The project's objectives and deliverables identified pre-project were:

Objective/ deliverable	Achieved
A facility to assign patients to a cancer pathway	Yes
Electronic availability of these for all recipients e.g. GPs, district nurses	Yes
Functionality to print out treatment summaries	Yes
Summaries will be built up over time as the patient goes through their cancer journey	Yes
Summaries can be printed, saved and transmitted at different times	Yes
Monthly group meetings	Yes
Remit of the group	Yes
Project Initiation Document (PID)	Yes
Requirements documentation	Yes
Developer estimation of work	No
Technical documentation	Yes
Macmillan Cancer Support branding applied to project documentation	Yes

Cancer treatment summary facility which is separate from CATS	Yes
Develop new name for system	Yes
Test version of new system with link to **test** SCI Store	Yes

4. Benefits

The benefits outlined in the PID were:

Expected benefit	Achieved
Empowerment of patients with cancer to understand their cancer treatment and to know when and how to see further held	Yes
Reduced paper/ postage and printing costs*	No
Wider access to the information as summaries will be held in EDMS	Yes
Quicker receipt of information to recipients	Yes
Compatibility with mobile devices will ensure the product is future-proofed if mobile working is adopted**	Yes
Improved visibility and management of patient information	Yes
Improved patient safety via electronically retrieved demographics (i.e. from SCI Store)	Yes

*The expected benefit of reduced paper/postage and printing costs cannot be considered to have been achieved as no exercise was undertaken to baseline current costs of postage etc.

** The system has been used on a Windows Dell Venue Pro 11 tablet computer and a Surface Pro 3 device. These run Internet Explorer 11 and Windows 8.1*.

5. Performance Against Scope/Time/Budget

Time	The project was delivered on time however the time spent on project management by eHealth far exceeded the initial estimate. This was a result of close working and engagement with the developer to ensure that the project was delivered on time. Whilst this was essential to ensure project success, it resulted in excessive time being spent on the project which had not been anticipated.
Budget	The project came in on budget despite the increased input from eHealth as additional effort required was absorbed by NHS FV eHealth
Scope	The scope of this project as defined in the project initiation document was: "*Cancer Treatment Summaries will be developed within the scope of the*

	Macmillan Cancer Support treatment summary template. It will be possible to create a treatment summary for all patients with cancer in Forth Valley. Access to the system will be required at the following hospital sites: Forth Valley Royal Hospital, Stirling Community Hospital (SCH), Falkirk Community Hospital (FCH) and Clackmannanshire Community Healthcare Centre (CCHC) The project stayed within its original scope, however there were no practical applications of the tool at SCH, FCH or CCHC. Some alterations were also made to the original Macmillan template based on local requirements/feedback.

The number of treatment summaries sent were impacted early on due to commencing system use over the summer of 2015. Approximately 4-5 weeks of time was lost due to key users being off on annual leave at the same time in July & August 2015.

There was variable use of the system by clinical users. Whilst some clinical users embraced the system at the start of the project and generated treatment summaries from the project's start date, other users did not utilise the system to the same extent. This is likely to be due to the different rates which individuals accepted this change and the introduction of a new process in their area.

6. Ongoing Resource Requirements

The resource requirements after project close will be:

	Resource requirements
System Owner	The system owner is Mr Seamus Teahan, consultant urologist and clinical lead for cancer services.
System Administrator	Day to day system administration tasks will be done by Charlie Salvador until a system administrator has been assigned to TSum.
Project Manager	Suzanne Millar will continue to provide consultancy and support until the end of March 2016. After this date, the project manager will not take forward any work related to the project.

7. Outstanding Issues/Risks/Tasks

The project manager provided support to manage issues, risks and tasks during the project's duration.

Outstanding Task	Owner	Description
System Administration (Task)	Cancer Advisory Group	The CAG will be responsible for taking forward discussions with IT management to ensure there is a system administration resource and support for the system when the developer is not available
System Upgrade (Task)	Suzanne Millar /Charlie Salvador	Final system upgrade to implement outstanding fixes
Project support (Risk)	Cancer Advisory Group	There is a risk that, without some support from eHealth, tumour groups may not use the system without out guidance/ engagement

8. Disaster Recovery and Business Continuity

Business continuity will be managed by users returning to paper and following existing local processes to complete patient information. No formal disaster recovery or business continuity plans have been completed.

9. Quality Review

The system functions as per the requirements of the project i.e. *"..the establishment of a Macmillan Forth Valley Treatment summaries project within the Forth Valley area"* (extract from the Macmillan grant agreement letter).

10. Training Evaluation

Training was delivered on a one-to-one basis by the project manager. This approach was manageable due to the low number of users and was an opportunity for ongoing business analysis. An eHealth trainer/ facilitator developed a user guide to support users. This will be the only eHealth resource for future training i.e. no trainers/facilitators will carry out system training.

11. Lessons Learned

No formal lessons learned exercise has been taken.

12. Conclusion and Recommendations

In conclusion, NHS Forth Valley has developed a system which not only produces a cancer treatment summary but also interfaces to three other systems, generates a point-in-time PDF treatment summary document and transmits this electronically to recipients.

Key recommendations for moving forward and embedding into organisational use are:

- The Cancer Advisory Group assumes responsibility as the governance route for embedding the system within Forth Valley
- The Cancer Advisory Group identifies local clinical champions to promote and encourage use amongst tumour groups
- The Cancer Advisory Group develops standard operating procedures (SOPs) for system use and business continuity.
- Involvement of eHealth project manager and system developer for post project consultancy until **end of March 2016**
- Any future development of the system will be a new project and will need to be resourced appropriately and managed as a new project.
- This project may facilitate future development/ integration of MDT functionality for the organisation

13. Post Project Review

A post project review meeting will be convened in February/March 2016. A minute will be circulated but no actions will be taken forward. Following this meeting, the project team will be disbanded and there will be no further meetings or input from the project manager. There will be no further development as the project is now finished.

14. Appendix A – End of Project Checklist

	Y	N	N/A
System Management/Security			
System Owner identified	Y		
System Administrator identified		N	
Cover for System Administrator identified	Y		
System Security Policy complete	Y		
Secure Operating Policy complete	Y		
Standard Operating Procedures complete (*to be completed by service)*		N	
Privacy Impact Assessment complete	Y		
Business Continuity documented ((*to be completed by service)*			N/A
Database registered *(TSum registered on 07/01/2016)*	Y		
Training and Support			
Responsibility for training identified (online user guide)	Y		
Project			
Lessons Learned Report		N	
All outstanding benefits have an identified owner			N/A
All outstanding risks have an identified owner	Y		
All outstanding issues have an identified owner			N/A
All outstanding tasks have an identified owner	Y		
All project deliverables delivered		N	
End of Project Report	Y		
Post Implementation Review meeting to be arranged	Y		

15. Appendix B – Logging calls on Altiris

Any problems or issues with TSum **must** be logged on the IT Helpdesk's online system as a *Service Fulfilment* request. An option for *TSum: Cancer Treatment Summaries* has been included in the drop down lists for *System Administration*

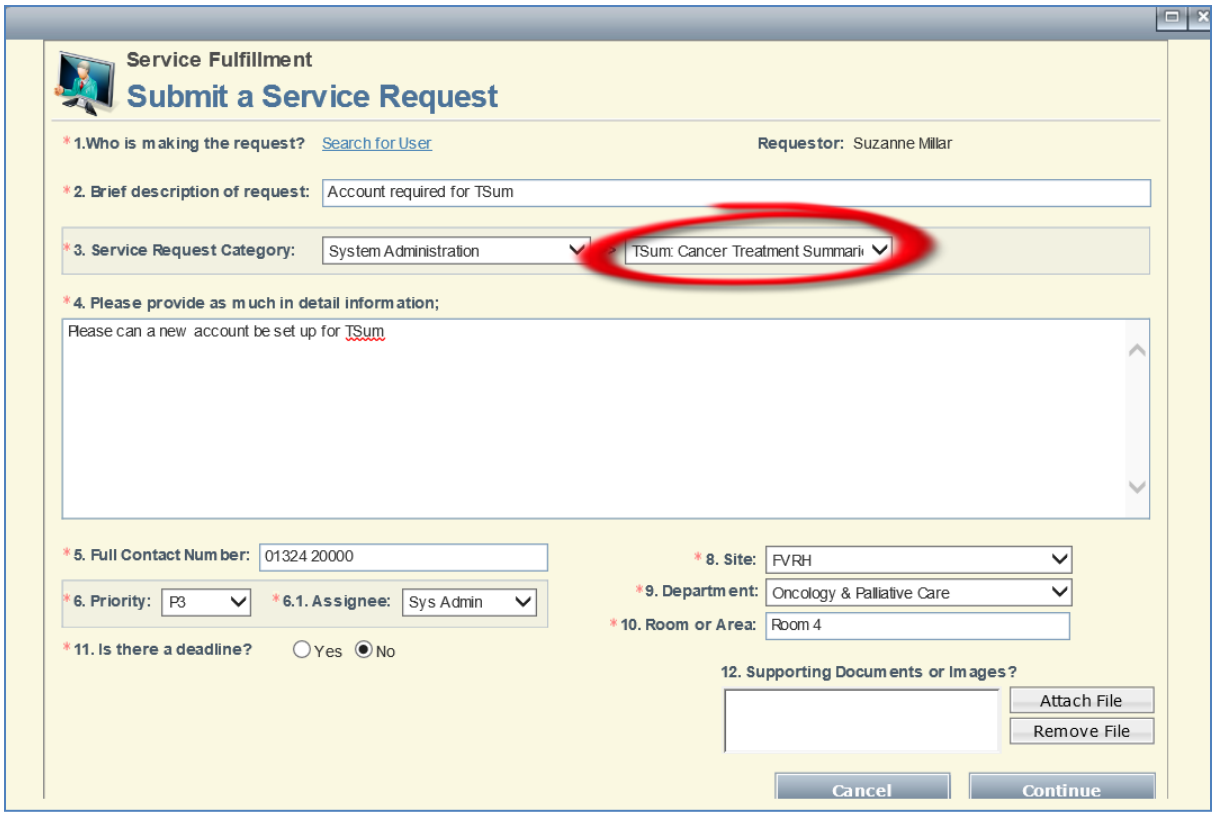

Figure 1- Logging a call for TSum on IT Helpdesk

Appendix 3

Forth Valley Royal Hospital
Stirling Road, Larbert
FK5 4WR
01324 566000

Carseview House
Castle Business Park
Stirling
FK9 4SW

Date:

Dear Mr

Your Appointment at Prostate Cancer Follow Up Clinic

NHS Forth Valley is working in partnership with Macmillan Cancer Support to redesign the follow up care of prostate cancer patients. This is in line with a key objective of the Scottish Government, Transforming Care After Treatment (TCAT). It will involve a new way of assessing the needs of patients to enable a patient centred approach to provide appropriate information and care. You will continue to be seen in the clinical setting as before, however your assessment will be slightly different. You will be asked to complete a concerns checklist prior to your appointment in order that all your concerns can be properly identified and discussed.

A Macmillan leaflet on assessment and care planning is enclosed for your information together with a checklist of concerns called "Identifying Your Concerns" for you to complete before your appointment. Please read the leaflet which gives you ideas of the types of concern you may have and then if you do have any, you can go on to complete the checklist. The checklist gives you the opportunity to think about your needs and agree a plan of care with our team. It would be helpful if you could mark a score from 1 to 10 by the side of each concern, number 1 being the lowest and number 10 the highest level of concern you have.

Please bring the checklist with you to your next appointment where you may also meet our Project Nurse to discuss your concerns.

You are not obligated to complete this form and should you choose not to do so this will not affect your future prostate cancer follow up. If you would like to discuss this further prior to your appointment please do not hesitate to contact the team on 01324 566889.

Yours sincerely

Maureen Hamill
Uro-Oncology Specialist Nurse Co-ordinator

Jane Niblo
Macmillan Project Nurse Prostate Cancer

Appendix 4

National Cancer Survivorship Initiative – Concerns checklist

Care plan

Patient's name or label

Completed by:

Date:

Designation:

Contact details:

Level 1: Score 0–3 Mild concerns

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

Level 2: Score 4–6 Moderate concerns

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

Level 3: Score 7–10 Significant concerns

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

Overall score on the scale:

Main concerns	Score	Description of concern	Plan of action

Copies sent to:

Next review due:

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Appendix 5

(V2) TCAT Pilot Project Prostate Cancer

This form should be completed at time of clinic follow up ***Today's clinic date*** ___/___/____ *Data ID* _____

Identifier: *ID label* *Please include CHI No.*											
Gender	Male ☐	Female ☐		Age at 1st contact	_____ yrs						
Date of 1st attendance at TCAT clinic project/service	____/____/_____			Postcode		SIMD 2012 Rank Vigintile:					
Cancer Type				Date of original Diagnosis	___/___/_____						
Stage of cancer	Primary ☐			Secondary ☐		Not known ☐					
Ethnic Group	White Scottish ☐	White Irish ☐	White other ☐	Mixed ☐	Indian ☐	Pakistani ☐	Chinese ☐	Asian other ☐	African/ Caribbean/ Black ☐	Other ☐	Not known ☐
Current Living	Alone ☐	Spouse/ partner ☐	Children/ relatives ☐	Friends ☐	Sheltered/ Nursing Home ☐	Not known ☐	Other ☐	If other -			
Economic Activity	Employed ☐	Self employed ☐	Unemployed ☐	Retired ☐	Student ☐	Looking after home/family ☐	Long term sick/disabled ☐	Not known ☐			

ECOG Performance Status	
Fully active, able to carry on all pre-disease performance without restriction	☐
Restricted in physically strenuous activity / ambulatory/ able to carry out work of a light/ sedentary nature e.g. light housework, office work	☐
Ambulatory and capable of all self-care but unable to carry out any work activities – up and about > 50% of waking hours	☐
Capable of only limited self-care, confined to bed or chair > 50% of waking hours	☐
Completely disabled. Cannot carry out any self-care. Totally confined to bed or chair	☐
Dead	☐
Not known	☐

Initial PSA		**Current** PSA level			
Initial T category		**Secondary** treatment			
Initial Nodes		**Further** treatment			
Initial Mets		**General Health**	Lower Urinary Tract Symptoms (IPSS)		
Initial Gleason score			Other symptoms e.g. bone pain		
Initial Treatment			Quality of life		

Side effects of treatment			
Hot flushes	☐	Fatigue	☐
Incontinence	☐	Osteoporosis	☐
Impotence	☐	Rectal bleeding (radiotherapy)	☐
Other	☐	If other:	

Assessment		
No evidence of disease ☐	Stable ☐	Progression ☐

Treatment Plan			
Continue current plan ☐	Change plan ☐	Refer to Consultant ☐	For investigations ☐

Next follow up			
1 month ☐	3 months ☐	6 months ☐	1 year ☐

Are bloods required at next follow up?	Yes ☐	No ☐
Has a Cancer Treatment Summary been completed/updated	Yes ☐	No ☐
Has a HNA concerns checklist been completed *(if yes please continue overleaf)*	Yes ☐	No ☐
If no – reason		
Signature of who has completed:		

Holistic Needs Assessment

Date of HNA consultation	____/____/_____
Did the patient complete the HNA before the assessment consultation/appointment ***e.g. at home or in clinic waiting area***	Yes ☐ No ☐
Who took the HNA assessment consultation *(write in)*	

How long did the assessment/consultation last	< 20 minutes ☐	>20 but <30 minutes ☐	30-45 minutes ☐	46 – 60 minutes ☐	>1 hr ☐	Don't know/can't remember ☐
Where did the assessment/consultation take place	Patient's Home ☐	Hospital In-patient ☐	Hospital out-patient ☐	Other ☐	If other - specify	
Has the patient completed a TCAT related HNA before	Yes ☐	No ☐	Don't know/can't remember ☐			
If yes how many times before today (write in)	Once ☐	Twice ☐	Three times or more ☐			
Is the patient still receiving treatment	Yes ☐	No ☐	Don't know/can't remember ☐			

Overall HNA Concerns Checklist Score (1-10)

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Risk Stratification

Level 1	Level 2	Level 2
Score 0-3 **mild** concerns ☐	Score 4-6 **moderate** concerns ☐	Score7-10 **significant** concerns ☐

Individual element score:	Physical concerns score	
	Practical concerns score	
	Family/Relationship concerns score	
	Emotional concerns score	
	Spiritual/Religious concerns score	
	Lifestyle/Information concerns score	
Care Plan completed:	Yes ☐	No ☐

Formal referral/s to other service/s

Local Authority (LA) for Social care assessment	☐	Vocational support/back to work specific agencies	☐
NHS Specialist Cancer Service	☐	Local TCAT projects – Health & Wellbeing events/activities	☐
Macmillan One to One	☐	Cancer specific 3rd sector organisation/charity	☐
Patient's GP	☐	Other 3rd sector organisations/charity	☐
NHS General (non cancer service)	☐	Other	☐
Other LA service e.g. housing/leisure etc	☐	If other – specify	
Specialist benefits/financial advice agencies	☐		

Signposting to other sources of advice/support *(only informing or directing the patient)*

	Given verbally only	**Written information given at consultation or posted/ emailed after**
NHS Specialist Cancer Service	☐	☐
Macmillan One to One	☐	☐
Their own GP	☐	☐
NHS General (non cancer service)	☐	☐
LA Social Care/Social Work	☐	☐
Other LA service e.g. housing/leisure etc	☐	☐
Specialist benefits/financial advice agencies	☐	☐
Vocational support/back to work specific agencies	☐	☐
Local TCAT projects – Health & Wellbeing events/activities	☐	☐
Cancer specific 3rd sector organisation/charity	☐	☐
Other 3rd sector organisations/charity	☐	☐
Other (1) write in -	☐	☐
Other (2) write in -	☐	☐
Other (3) write in -	☐	☐

Appendix 6

NHS FORTH VALLEY
THE TRANSFORMING CARE AFTER TREATMENT (TCAT) PROJECT

You have recently attended the Urology/Urology Oncology Transforming Care after Treatment (TCAT) clinic.

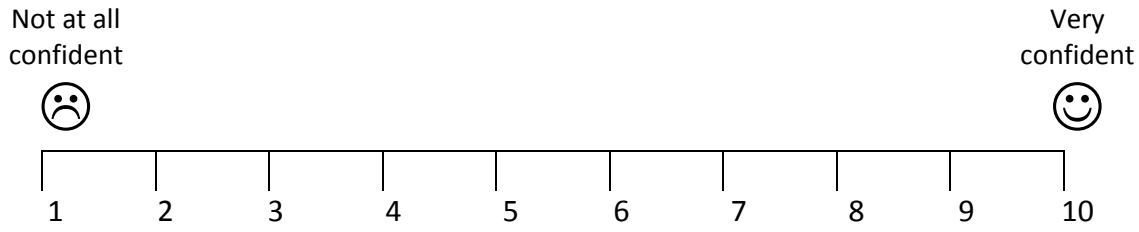
We are evaluating our service and are seeking your views on the difference this service has made to the lives of the people who use it. By giving us your feedback we can understand your experiences better and identify how we can improve our service.
It will only take a few minutes to complete. The information you provide is anonymous and will be treated confidentially.

1. **Are you male or female?**

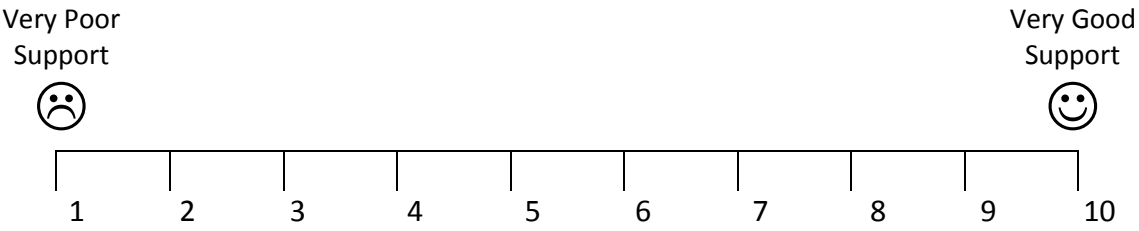
☐ Male
☐ Female

2. **What type of cancer are you or were you treated for _____(please write in)**

3. **As a result of attending the TCAT clinic how confident are you that you can now manage your condition by yourself? Here "managing" means understanding ways to cope and knowing where to seek help if needed.**



4. **Overall, how would you rate the support you received from the TCAT clinic? Here 'support' includes any appointments, advice, information or being referred to or signposted to by the clinic.**



TCAT: Patient Feedback Form

5. **Please describe what you <u>valued</u> the most about this clinic.**

_____
_____
_____
_____

6. **Do you have any ideas /comments about improving the clinic?**

_____
_____
_____
_____

7. **Thinking about the support provided at the TCAT clinic to what extent were your needs met in relation to the following?**

a) <u>Managing side effects/consequences of treatment?</u> (Tick one box only)

☐ Needs were met completely
☐ To some extent
☐ Not at all
☐ I did not want/need this type of support
☐ I did not see this as part of this service's job/role
☐ Don't know/can't remember

b) <u>Knowing where to seek help if you need it?</u> (Tick one box only)

☐ Needs were met completely
☐ To some extent
☐ Not at all
☐ I did not want/need this type of support
☐ I did not see this as part of this service's job/role
☐ Don't know/can't remember

c) <u>Understanding who to ask for help if you need it?</u> (Tick one box only)

☐ Needs were met completely
☐ To some extent
☐ Not at all
☐ I did not want/need this type of support
☐ I did not see this as part of this services; job/role
☐ Don't know/can't remember

d) Awareness of support available to your family/carers? (Tick one box only)

☐ Needs were met completely
☐ To some extent
☐ Not at all
☐ I did not want/need this type of support
☐ I did not see this as part of this services; job/role
☐ Don't know/can't remember

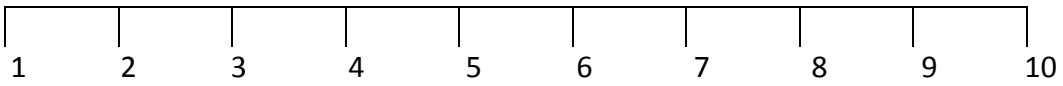
e) Knowing about other support services or groups you could use? (Tick one box only)

☐ Needs were met completely
☐ To some extent
☐ Not at all
☐ I did not want/need this type of support
☐ I did not see this as part of this services; job/role
☐ Don't know/can't remember

8. Thinking about this clinic. To what extent do you agree with the following statements?

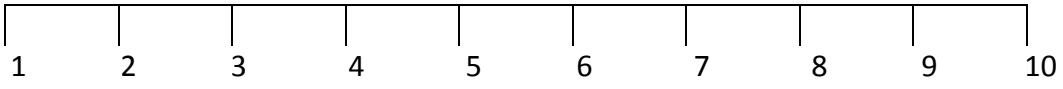
a) I was passed around from person to person without getting the support I needed

Strongly DISAGREE Strongly AGREE



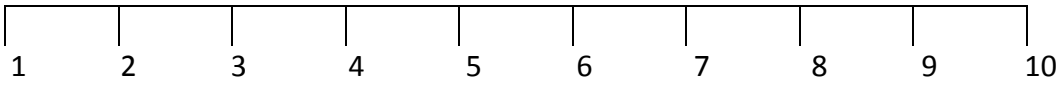
b) It helped me to get other services and help, and to put everything together.

Strongly DISAGREE Strongly AGREE



c) I have been involved in decisions about my care.

Strongly DISAGREE Strongly AGREE

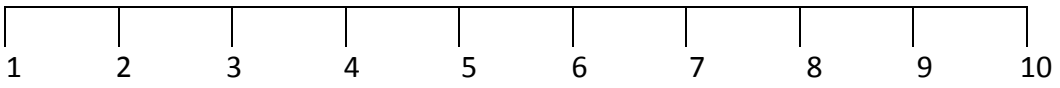


9. We are interested in how much MORE confident you feel to manage potential concerns you may have.

Here "managing" means understanding ways to cope and knowing where to seek help if needed.
For each of the following, that are relevant and applicable to your situation, please *circle* the number that corresponds with your level of confidence as a result of attending the TCAT clinic.

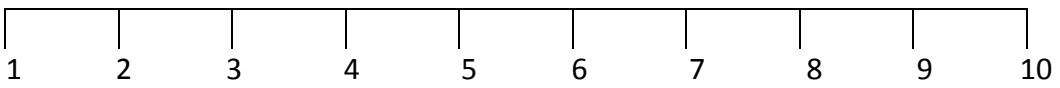
a) To manage my physical condition

Much less confident ☹ No Change Much more confident ☺



b) To manage practical concerns such as shopping, housework and travel

Much less confident ☹ No Change Much more confident ☺



c) To manage any financial concerns

Much less confident ☹ — No Change — Much more confident ☺

1 2 3 4 5 6 7 8 9 10

d) Getting back to work

Much less confident ☹ — No Change — Much more confident ☺

1 2 3 4 5 6 7 8 9 10

e) To manage family/ relationship issues

Much less confident ☹ — No Change — Much more confident ☺

1 2 3 4 5 6 7 8 9 10

f) To manage my lifestyle for example diet and level of physical activity

Much less confident ☹ — No Change — Much more confident ☺

1 2 3 4 5 6 7 8 9 10

g) To manage any emotional concerns

Much less confident ☹ — No Change — Much more confident ☺

1 2 3 4 5 6 7 8 9 10

h) To manage any spiritual or religious concerns

Much less confident ☹ — No Change — Much more confident ☺

1 2 3 4 5 6 7 8 9 10

10. Did the TCAT clinic give you any information or contact details for OTHER relevant support or information services you could make contact with/use? (Tick one box only)

☐ Yes
☐ No
☐ Don't Know/Cannot remember

11. If YES, please list the other support agencies or services you have actually made contact with or used **as a result of attending the TCAT clinic.**

_____
_____
_____
_____

Date completed: _____ Thank you

Project Number		Patient Number	

Appendix 7

PATIENT EXPERIENCE
TELEPHONE EVALUATION
MACMILLAN TCAT PROJECT
NURSE LED FOLLOW-UP CLINIC PROSTATE CANCER

DATE OF TELEPHONE INTERVIEW ____/____/_____

CONTACT NO. _____

INTERVIEWING **Patient** ☐ **Carer** ☐

SURNAME: _____ **Project ID No. 109 -** _____

CHI ☐☐☐☐☐☐☐☐☐☐

SECTION 1: **THIS PATIENT HAS COMPLETED A HOLISTIC NEEDS ASSESSMENT (HNA) CONCERNS CHECKLIST** ☐

SECTION 2: **THIS PATIENT HAS A TREATMENT SUMMARY** ☐

SECTION 1: HOLISTIC NEEDS ASSESSMENT (HNA)

No.	Question/	Consideration	Response
1	Did you find completing the concerns checklist and sharing your concerns with the TCAT/Specialist Nurse of benefit to you?	*e.g. what did they get out of sharing their concerns with someone*	
2	Had you raised any of these concerns to anyone prior to highlighting them on the concerns checklist and discussing them with the TCAT/Specialist Nurse?	*e.g. GP, Consultant, CNS etc*	
3	Can you tell us what you valued most about being able to discuss your concerns with the TCAT/Specialist Nurse	*e.g. having the opportunity to share/discuss your concerns if no-one had raised these issues with you before*	
4	Do you feel that your concerns were discussed and acted upon at the most appropriate time for you in your cancer journey?	*e.g. would it have been more beneficial to have discussed these concerns earlier in your journey*	
5	Do you feel that you have benefited from: • any onward referrals made • any signposting to other support services • any information leaflets given to you	*e.g. finances, info leaflets, or just being able to talk to someone about your concerns*	
6	Do you feel that you would know where to go for any help/support that you might need in the future?	*e.g. GP, CNS, Macmillan One to One team*	
7	General comment on completing and discussing your concerns using the Macmillan National Cancer Survivorship Initiative - Concerns Checklist		

SECTION 2: TREATMENT SUMMARY (TSum)

No.	Question	Consideration	Response
1	Do you understand the content of your treatment summary?		
2	Have you shared/discussed it's contents with anyone	e.g. NOK/GP/Hospital Consultant/CNS/Family member	
3	Do you think that having your own personal copy of the 'Treatment Summary' and being able to share this with others is of benefit to you and other health care professionals		
4	What do you feel works well in having a copy of your Treatment Summary		
5	What do you feel doesn't work so well		
6	What could we do differently to make the Treatment Summary work better for you		

PATIENT EVALUATION FINDINGS

PATIENT EVALUATION OF COMPLETING <u>THE HNA CONCERNS CHECKLIST</u>:

(23 respondents = 49% response rate)

1: Did you find completing the concerns checklist and sharing your concerns with the TCAT/Specialist Nurse of benefit to you? *(Total respondents = 23)*

Yes x 21
Examples of comments:

- I got quite a good deal of benefit from it
- It was really beneficial as pain was reassessed. Furthermore, an assessment was undertaken for equipment, aids and outdoor handrails
- It was good to be able to talk to someone in a different way
- It was comforting and let me know about things I previously didn't know existed

No x 2
Comments:

- Not certain that it was of benefit to me
- If I thought I had a real concerns, I would have discussed further

2: Had you raised any of these concerns to anyone prior to highlighting them on the concerns checklist and discussing them with the TCAT/Specialist Nurse? *(Total respondents = 23)*

No x 18
Yes x 5 (all 5 patients had previously raised their concern/s with their GP)

3: Can you tell us what you valued most about being able to discuss your concerns with the TCAT/Specialist Nurse

Examples of comments:

- Usually I would keep this to myself but completing the checklist brought it out into the fore and up for discussion. It was really nice that the Nurse listened to me.
- You actually came at things from a different angle. Made me think about things that were under the surface and I was maybe trying to block out
- Just that all the help given to me was really helpful and how easy it was to talk to you
- Talking to someone who is actually aware of my situation and is understanding of it
- Talking about my concerns, since then have had a new shower installed
- What I valued was you told me things that I didn't know and I learned from it. A very useful exercise
- It made me more aware – there were things on the concerns checklist that were concerning me
- Feel 100% better now that it is out in the open

4: Do you feel that your concerns were discussed and acted upon at the most appropriate time for you in your cancer journey?

Yes x 12
No, earlier would have been better x 8

Additional comments:

- Depends on the circumstances, now is probably as good a time as any. I have had cancer for so long.
- My concern was very personal; and it was up to me to raise
- I was always in the position that I was prepared for prostate cancer as both my father and uncle died from it.

5: Do you feel that you have benefited from: any onward referrals made, any signposting to other support services, any information leaflets given to you

Yes x 15
Comments:

- I am now in touch with the carers centre and will contact the District Nurse if and when required
- My GP is now going to send me to see the vascular surgeon to see if it helps
- Doctor gave me medication and this has really helped
- The information and leaflets given to me were very useful

8 patients did not respond to the question or stated that is was not applicable to them

6: Do you feel that you would know where to go for any help/support that you might need in the future?

Yes x 22
1 patient did not respond to the question

7: General comment on completing and discussing your concerns using the Macmillan National Cancer Survivorship Initiative - Concerns Checklist

- *I was happy to complete the concerns checklist and I feel this would be beneficial to people newly diagnosed*
- *It took a lot off my mind filling in the Concerns Checklist. It's a private thing and I don't want everyone to know my business, so it was very helpful*
- *I am sure going through the Concerns Checklist would benefit people who have to face this*
- *No problem for me filling out the Concerns Checklist – happy to do so.*

- *The Concerns Checklist is an excellent tool. My Grandad has excellent family support and we went through the Concerns Checklist with him. In all honesty we were surprised at some of his responses. I hope this service will continue as patients have different needs throughout their journey and require follow-up. Appreciate we are lucky to have specialist palliative care in-put from the Hospice.*
- *Wife helped to fill out and she felt this was really beneficial*
- *The concern about sex was in the back of my mind and you made me and my wife talk about it - I might never have talked about it*
- *Again, quite enlightening because it made me think – I would probably never have thought about and raised some of the concerns on the list*
- *I hadn't filled out the concerns checklist prior to my appointment – glad that the CNS asked me the question*

PATIENT EVALUATION OF THE <u>TREATMENT SUMMARY (Tsum)</u>

Did you understand the content of your Treatment Summary?

- Yes
- Wife says 'yes' – we are both happy
- I understand Prostate Cancer, PSA and Gleason score – but don't understand staging
- Yes – however, I am not very well at the moment, my PSA is rising

Have you shared or discussed its' contents with anyone? e.g. NOK/GP/Hospital Consultant/CNS/Family member

- My wife
- My GP
- No
- No response from the patient

Do you think having your own personal copy of the 'Treatment Summary' and being able to share this with others is of benefit to you and other health professionals?

- Yes I think it makes you have ownership of it. And the GP having a copy is very useful
- Yes, it is definitely a good idea
- It is a good thing – I can check it for reference
- Good idea. However, at the moment I feel that the less I know the more I can cope

What do you feel works well in having a copy of your Treatment Summary?

- Having a copy of my Treatment Summary gives me ownership and I think the document itself looks very good
- I had to go to the doctor recently and the doctor had a copy. I thought this was a really good idea
- The more information I have the better
- No response from the patient

What do you feel doesn't work so well?

- Can't think of anything
- No response from the patient x 3

What could we do differently to make the Treatment Summary work better for you?

- Would have liked to have had it earlier – I was diagnosed in 1997
- Could have it sooner – rather than later
- No response from the patient x 2

WE ARE MACMILLAN. CANCER SUPPORT

NHS Forth Valley

Appendix 8

TCAT
PROSTATE CANCER NURSE LED FOLLOW UP CLINICS
EVALUATION OF COMPLETING THE HNA CONCERNS CHECKLIST AND THE TREATMENT SUMMARY

NHS Forth Valley is currently participating in a pilot project funded and led by Macmillan Cancer Support which aims to 'Transform Care after Treatment' (TCAT) for prostate cancer patients.

This pilot project has 2 elements:

1: The completion of a Holistic Needs Assessment Concerns Checklist
2: The completion of a patient 'Cancer Treatment Summary' (TSum)

It is planned that these documents will be completed/updated at important stages throughout the patient pathway and/or where a patient has undergone significant treatment or changes are made to their treatment. In order to evaluate the HNA Concerns Checklist and the Cancer Treatment Summary, your feedback is important. Please could you spend a few moments considering the points below and reply with your thoughts/ comments.

Designation:

TCAT Project Nurse ☐
Urology/Oncology CNS ☐
Urology/Oncology Staff Nurse ☐
Other ☐ If other – specify _____

I have completed a HNS Concerns Checklist for a follow up prostate cancer patient ☐

I have completed a Treatment Summary for a follow up prostate cancer patient ☐

COMPLETION OF THE HOLISTIC NEEDS ASSESSMENT (HNA) CONCERNS CHECKLIST

1	What do you feel are the benefits for the patient of completing the concerns checklist?	
2	What do you feel are the benefits for you as a nurse to completing the concerns checklist with the patient?	
3	Do you feel that by completing the HNA Concerns checklist the patient is now raising issues that they may not have previously discussed/raised?	
4	What impact if any, has completing the Concerns Checklist with the patient made on your workload?	
5	What if anything could be done to enhance the completion of the Concerns Checklist?	

COMPLETION OF THE CANCER TREATMENT SUMMARY (Tsum)

1	What if anything could be done to enhance the patient's Cancer Treatment Summary: *E.g. additional fields for information, changes to layout/formatting etc.*	
2	What do you feel is the value to the patient of having a copy of their treatment summary?	
3	What impact if any, has completing the Treatment Summary made on your workload?	
General comment on the TCAT Project:		

STAFF EVALUATION - HNA and TREATMENT SUMMARY: (TSum)

What do you feel are the benefits <u>for the patient</u> of completing the HNA concerns checklist?

- Enables the patient to talk and focuses the conversation on previously unmet needs they may not have previously raised, thus enabling them to self manage
- Gives the patient an opening to discuss any concerns they may have
- Highlights any issues/concerns the patient may not have raised otherwise

What do you feel are the benefits <u>for you as a nurse</u> to completing the HNA concerns checklist with the patient?

- Enables me to demonstrate patient centred care in documentation
- Ensures we are not focusing on medical condition alone. Ensures we are treating patients holistically
- Allows me to discuss concerns patient may not have previously raised

Do you feel that by completing the HNA concerns checklist the patient is now raising issues that they may not have previously discussed/raised?

- Yes definitely so and this is evidenced by patient experience comments
- No, but I feel it gives structure to the conversation
- Yes, they might have previously been unable/embarrassed to discuss certain issues

What impact, if any, has completing the HNA concerns checklist with the patient made on your workload?

- Having previous experience in completing the HNA with patients in their own home, it was nice to see how the process could be further streamlined in a clinic environment. It was helpful for me to see that the process can indeed be performed in less than 15 minutes
- There has been a definite increase in our workload. However, the positive from this is that we have reviewed our clinic times to allow time to complete the HNA with patients
- Initially appointment times were breached as forms were new, therefore took longer to complete. Clinic times have now been altered

What if anything could be done to enhance the completion of the HNA concerns checklist?

- Can’t think of anything x 3

What if anything could be done to enhance the patient's Cancer Treatment Summary? *(e.g. additional fields for information, changes to layout, formatting etc)*

- Not aware of anything at the moment. My opinion may change once I have been using Tsum longer
- Can't think of anything at the moment x2

What do you feel is the value to the patient of having a copy of their Treatment Summary?

- I usually go over the completed Tsum with the patient. Good to explain stage and grade of disease (surprising how many had forgotten this). Patients have commented that it is helpful knowing what side effects/signs to be aware of
- Enables patients to self manage their condition by having all available information which is pertinent to their cancer in a succinct and understandable format. This also helps primary care practitioners such as GPs involved in their care, to be more informed about the patient's condition, thereby more able to manage/treat their patients
- Patient is aware of any changes from clinic visit and this is reiterated with the Tsum

What impact if any, has completing the Treatment Summary made on your workload?

- Initially time consuming when locating historic information on pathology, treatment etc. However, the process is less time consuming now with the introduction of the clinical portal
- This has had an impact on our workload but changing the clinic template has helped. Newer cases are easier as information is linked with TCAT
- Initially took longer but has become quicker

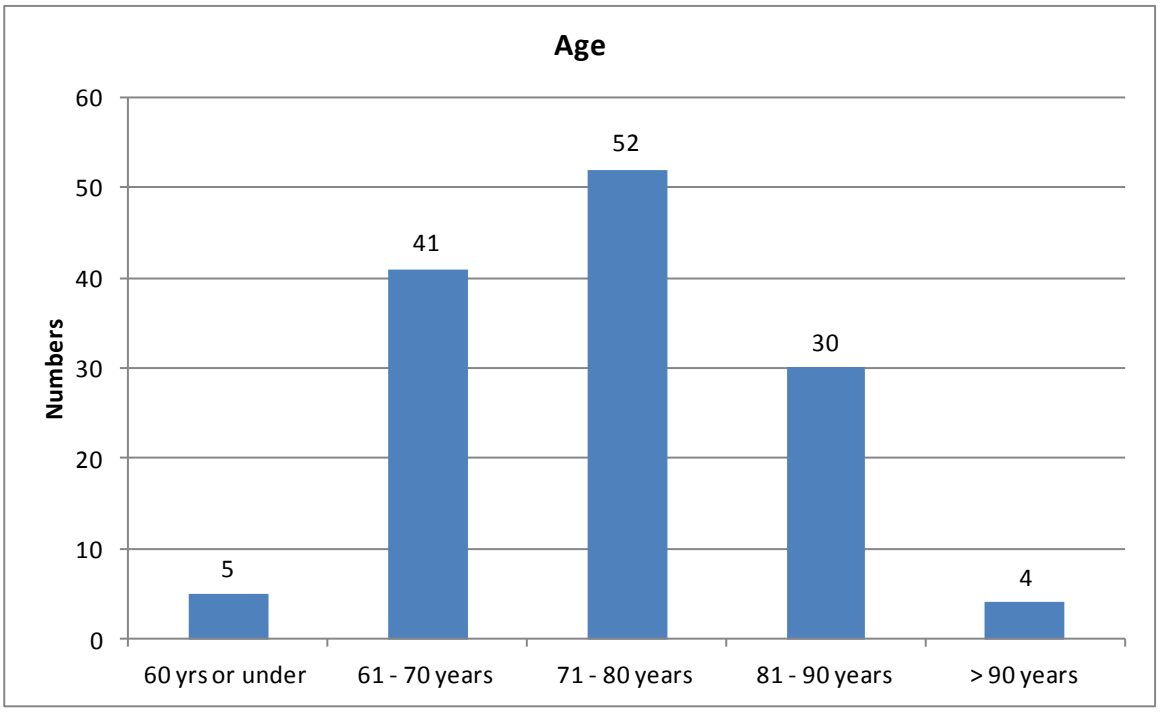
General comment on the TCAT Project

- Good experience having the TCAT Project Nurse, she brought a different perspective coming from Primary Care
- I thoroughly enjoyed working in secondary care with the Uro-oncology Nursing Team. This gave me a huge insight into how the Oncology Unit works. However, I feel the TCAT project has been too short and I would have liked more time to provide additional education and support for the Urology Nurses. I am pleased that I was able to attend meetings in relation to the Treatment Summary and thereby influence some of it's content

APPENDIX 9:

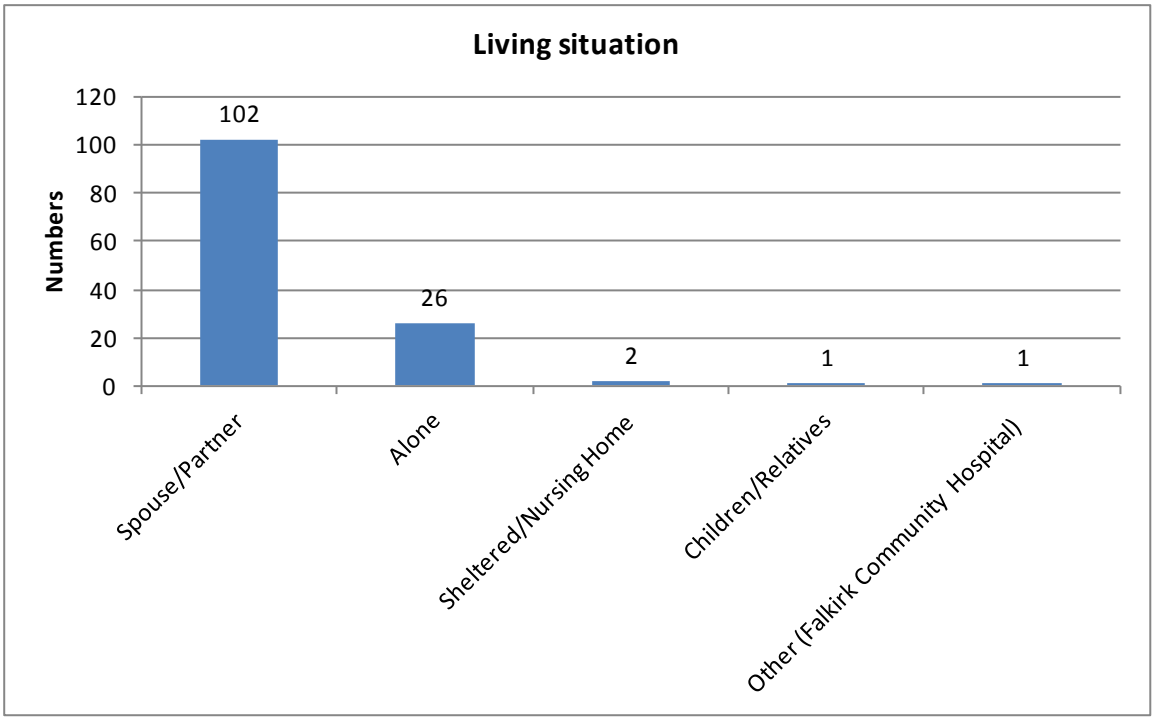
DATA ANALYSIS – Demographic and clinical data were collected on all 132 men invited to participate in the study.

Graph 1 Age of patient at first contact with TCAT Project



The mean age of this cohort was 74.6 years (range 55-93)

Graph 2: Current living situation

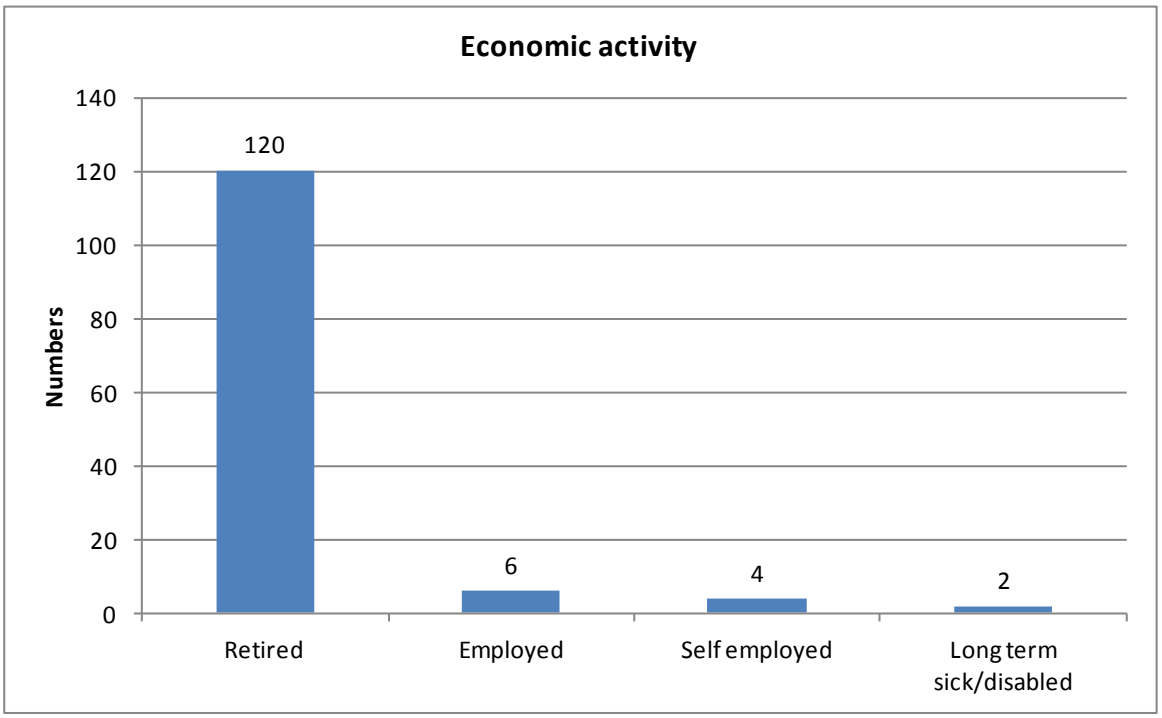


The majority of men in this study lived with a spouse or partner. Loneliness is recognised as a significant factor in poorer outcomes for patients with cancer. *(Macmillan cancer support, 2014)*

Table 1 – Ethnicity

Ethnicity	Number
White Scottish	130
White Other *(Welsh)*	2
Total	**132**

Graph 3: Economic activity



This contrasts with other cancers such as breast where many more are in employment and therefore face higher levels of distress around financial issues and may actually have contributed to the lower uptake of the completion of the HNA. *(Ref 5: Macmillan Cancer Support, 2011)*

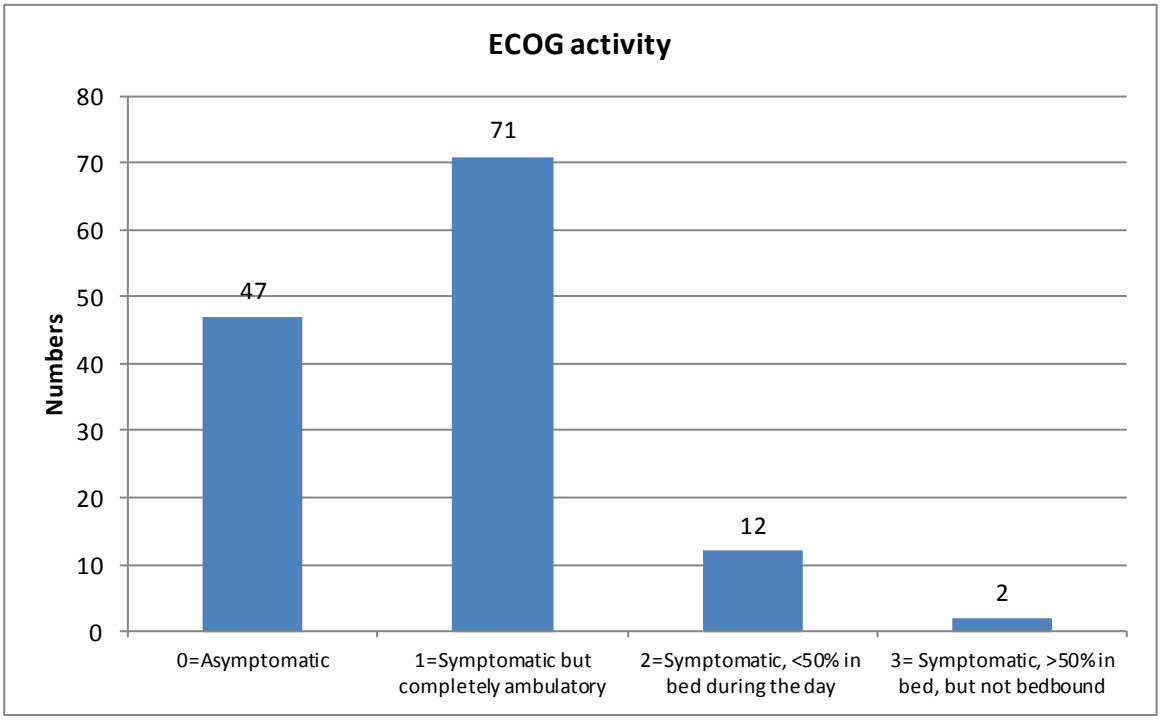
ECOG Performance Status

The ECOG (Eastern Co-operative Oncology Group) Scale of Performance Status describes a patient's level of functioning in terms of their ability to self-care, daily activity, and physical ability (walking, working, etc.).

The score published by Oken *et al.* in 1982, runs from 0 to 5, with 0 denoting perfect health and 5 death. *(Oken et al, 1982)*

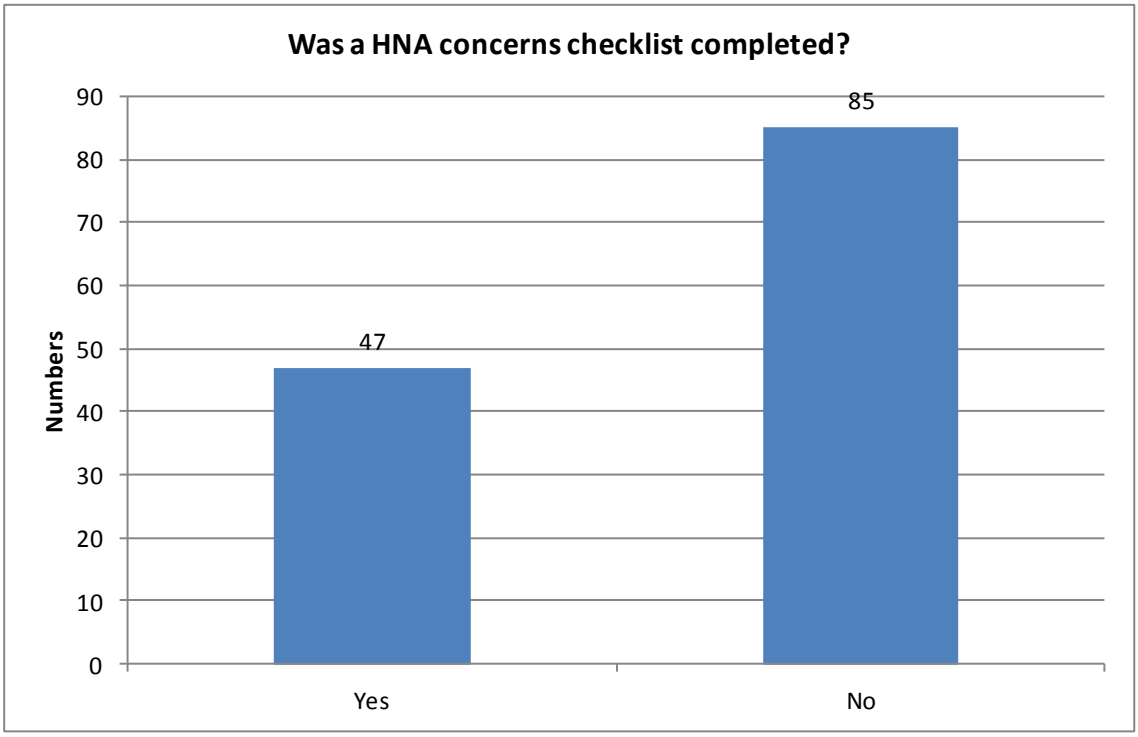
- **0 – Asymptomatic** *(Fully active, able to carry on all pre-disease activities without restriction)*
- **1 – Symptomatic but completely ambulatory** *(Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature. For example, light housework, office work)*
- **2 – Symptomatic, <50% in bed during the day** *(Ambulatory and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours)*
- **3 – Symptomatic, >50% in bed, but not bedbound** *(Capable of only limited self-care, confined to bed or chair 50% or more of waking hours)*
- **4 – Bedbound** *(Completely disabled. Cannot carry on any self-care). Totally confined to bed or chair)*
- **5 – Death**

Graph 4: ECOG Performance Status



Almost 90% (n=118) of men in this study were either entirely asymptomatic or completely ambulatory. This implies good or reasonable health despite the diagnosis of prostate cancer and that the majority of men remained independent in relation to activities of daily living

Graph 5: HNA Concerns Checklist completion rate

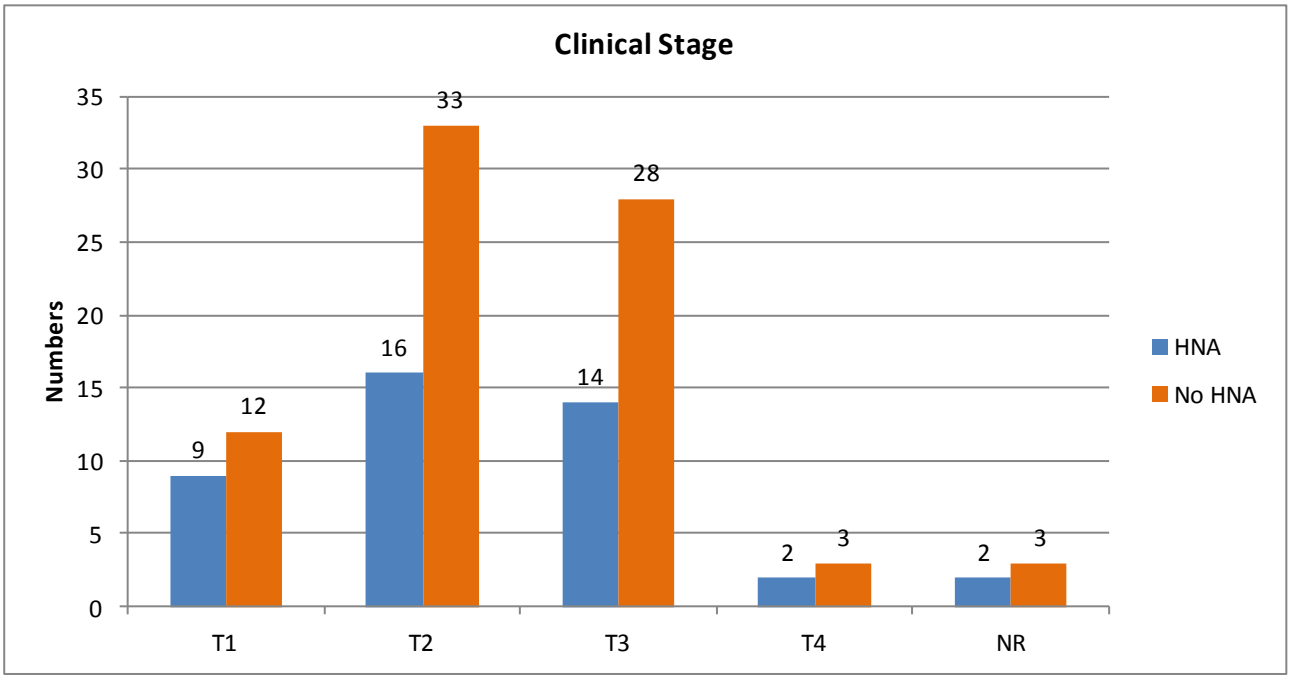


Of the 85 patients who did not complete the HNA, 64 of them specifically stated that they "had no concerns"

Examples of 'other' reasons (n=21) for not completing the HNA were:

- "Don't want to see anyone else"
- Declined - no specific reason given
- Did not wish to "waste nurse's time"
- "What use is that for me, I'm 5 years down the line"
- Refused to take part
- Feels 'not appropriate'
- Metastatic prostate cancer, declined and states that he has good support

Graph 6: Clinical Stage at Diagnosis



Explanation of Cancer Staging:

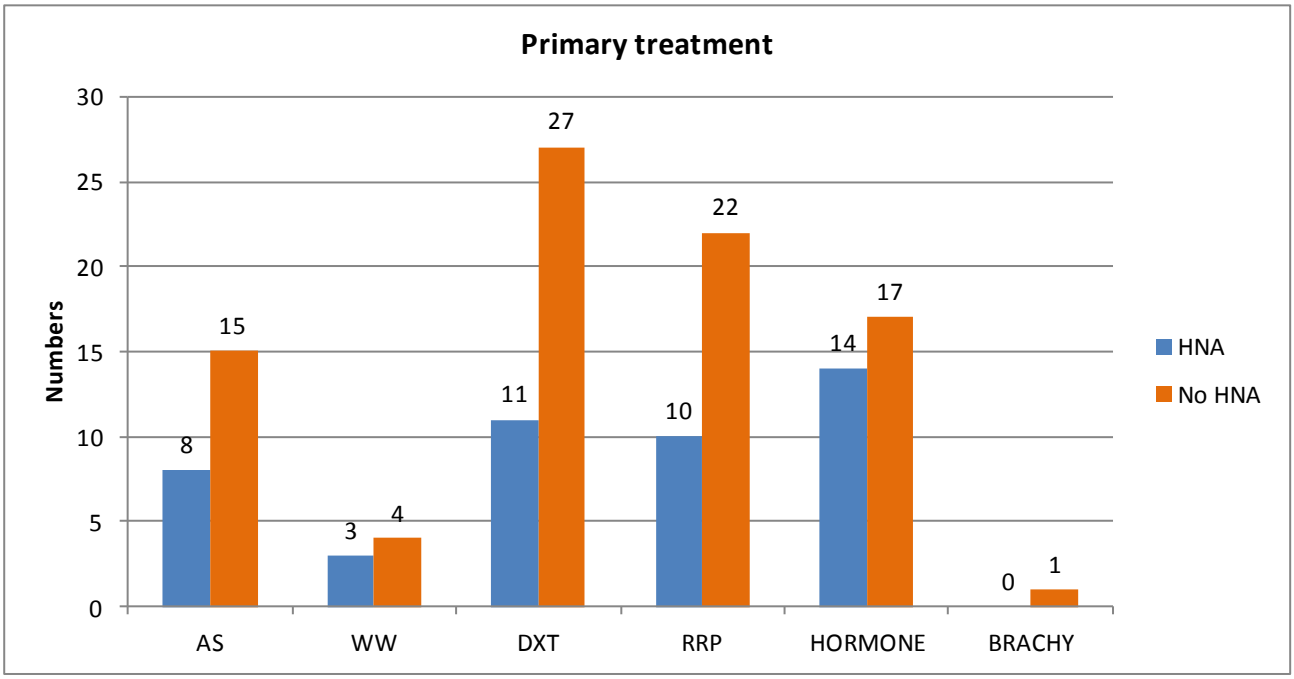
- **T1 (stage 1)** usually means that a cancer is relatively small and contained within the organ of origin

- **T2 (stage 2)** usually means the cancer has not started to spread into surrounding tissue but the tumour is larger than in stage 1. Sometimes stage 2 means that cancer cells have spread into lymph nodes close to the tumour. This depends on the particular type of cancer.

- **T3 (stage 3)** usually means the cancer is larger. It may have started to spread into surrounding tissues and there are cancer cells in the lymph nodes in the area

- **T4 (stage 4)** means the cancer has spread from where it started to another body organ. This is also secondary or metastatic cancer

Graph 7: Primary Treatment Following Diagnosis



Explanation of Primary Treatments

AS	=	Asymptomatic (Active surveillance)
WW	=	Watchful waiting
DXT	=	Radiotherapy
RRP	=	Radical Retropubic Prostatectomy
HORMONE	=	Hormone therapy
BRACHY	=	Brachy therapy

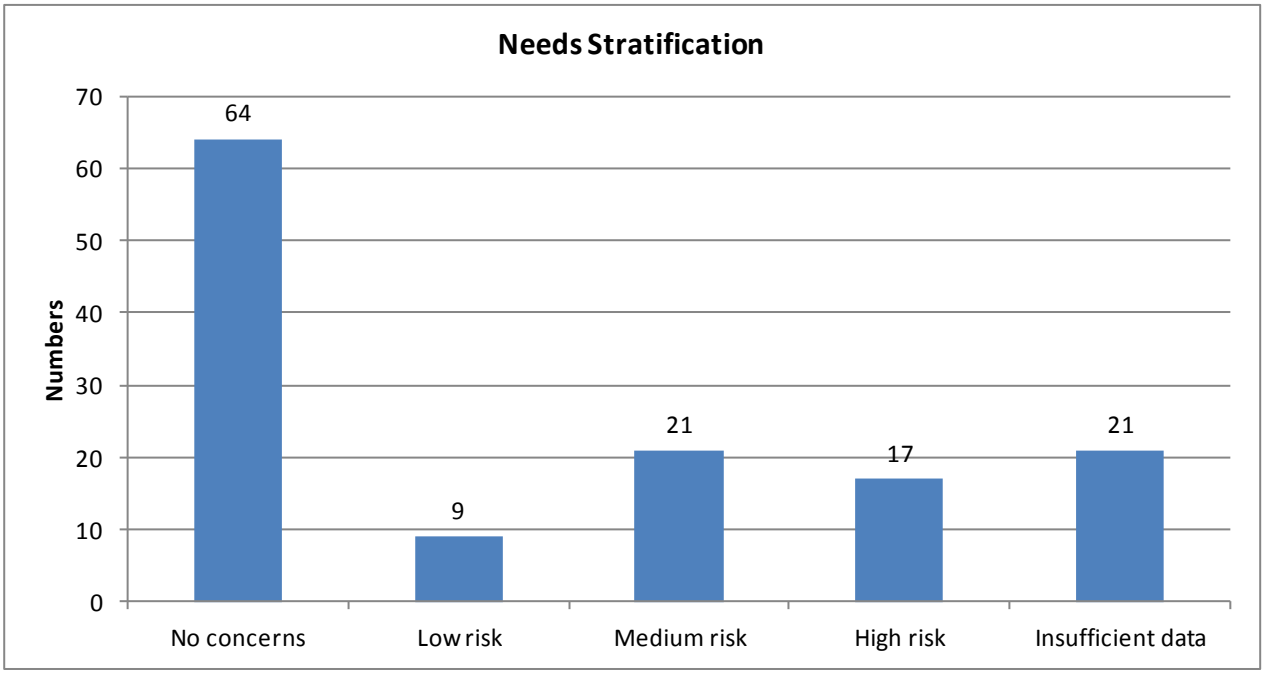
Similarly both groups were well matched in relation the proportions choosing active surveillance (AS), radiotherapy (DXT) and radical retropubic prostatectomy (RRP) as can be seen in (Graph 7). A higher proportion of patients managed by watchful waiting (WW) and primary hormone therapy completed a HNA but it is impossible to determine if this was due to ascertainment bias or chance given the design of the study.

Table 2: Patient levels of concerns

Score of patient's overall level of concern (1-10) on completion of the HNA concerns checklist (n=47)	Number of patients	
1	5	Level 1 (0-3 mild)
3	4	
4	8	
	17	
5	8	Level 2 (4-6 moderate)
6	5	
7	3	
	16	
8	8	Level 3 (7-10 significant)
9	1	
10	5	
	14	

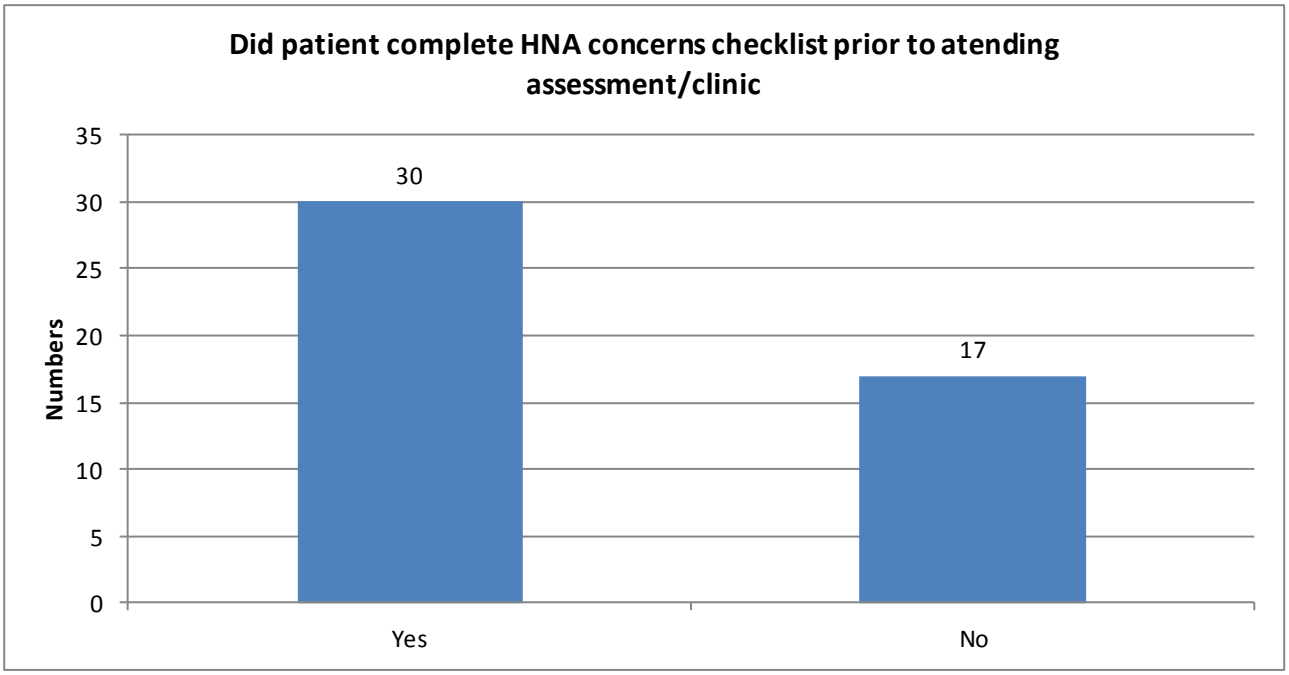
For the purposes of risk stratification we combined the HNA data with the feedback given at the initial consultation when 64 additional men reported "no-concerns" and 21 patients gave 'other' reasons for not completing the HNA

Graph 8: Needs Stratification



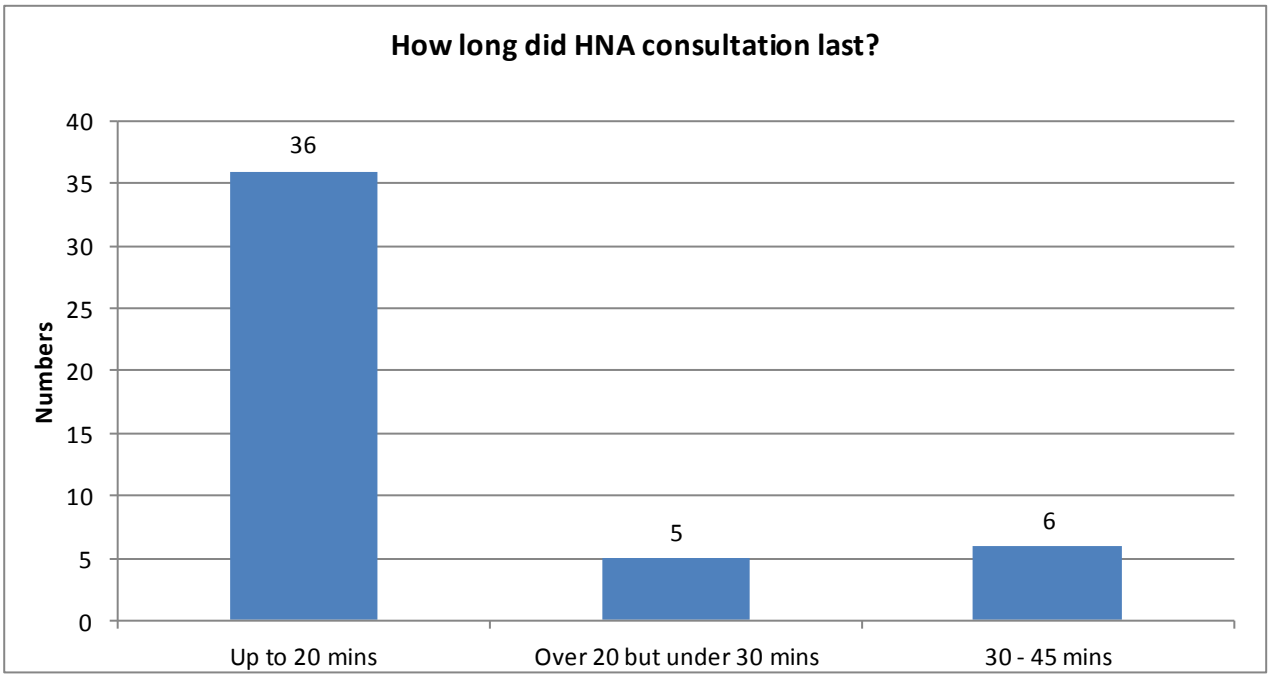
- 73 patients were categorised as having no or low level concerns and are potentially suitable for Supported Self Management
- 21 patients were categorised as requiring Shared Care
- 17 patients were categorised as requiring Complex Case Management
- There were insufficient data on the remaining 21 patients to categorise appropriately

Graph 9: Did the patient complete the HNA Concerns Checklist prior to attending the assessment/clinic appointment



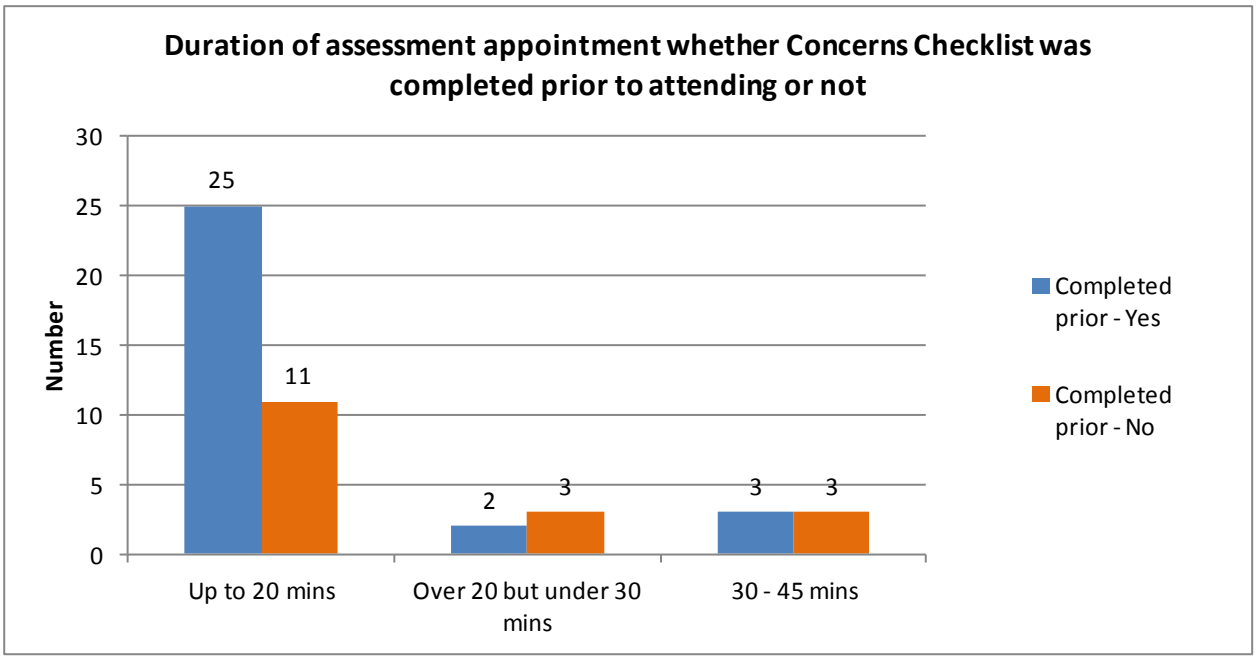
30 patients completed the HNA Concerns Checklist themselves prior to being seen at the clinic. The remaining 17 patients completed the Concerns Checklist with the Nurse during their consultation.

Graph 10: How long did the HNA assessment consultation last?



36 of the HNA Assessment consultations took less than 20 minutes, with 5 taking between 20-30 minutes and 6 taking between 30-45 minutes.

Graph 11: Did the patient completing the Concerns Checklist prior to attending the clinic appointment, make any impact on the duration of the appointment?



Even if the Concerns Checklist has not been completed by the patient prior to attendance, the consultation may in most cases still take less than 20 minutes.

Graph 12: Who carried out the HNA Assessment appointment?

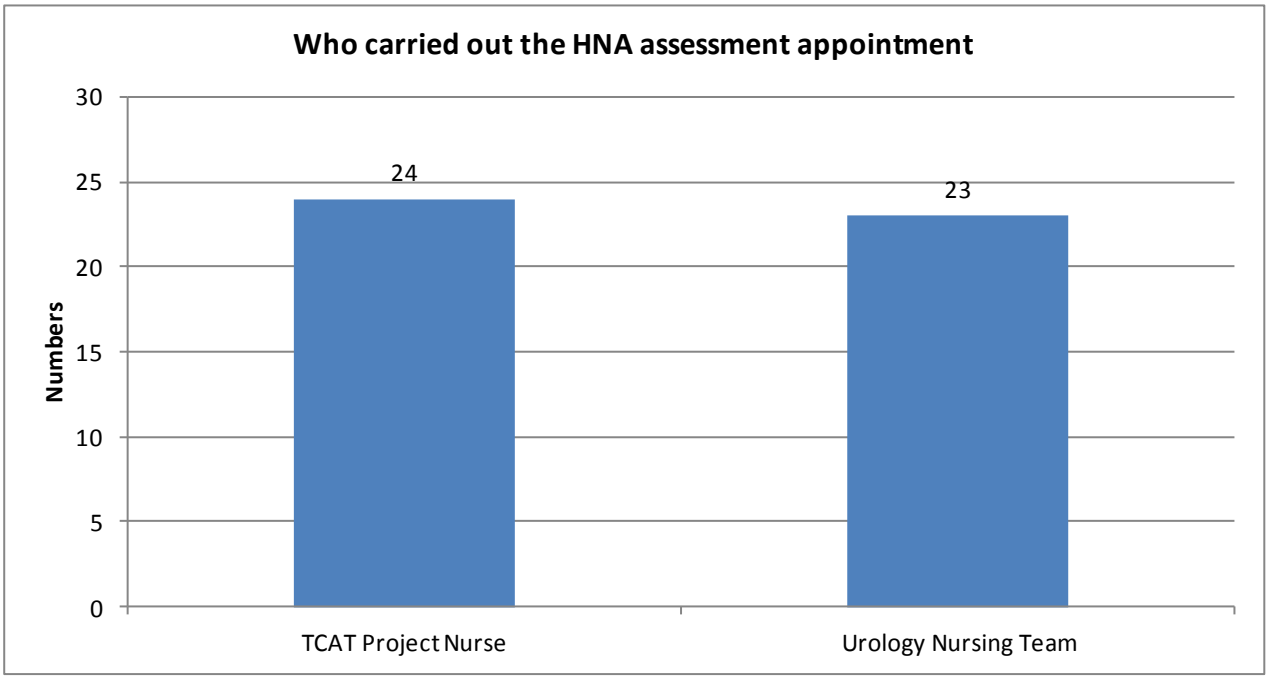


Table 3: Did the discipline of the staff member undertaking the assessment and if the concerns checklist had been completed prior to attending the clinic have any impact on the duration of the appointment?

Appointment duration = Up to 20 minutes	TCAT Nurse	Staff Nurse	CNS
Completed prior - Yes	13	8	4
Completed prior - No	3	4	4
Appointment duration = over 20 but under 30 minutes	TCAT Nurse	Staff Nurse	CNS
Completed prior - Yes	1	0	1
Completed prior - No	3	0	0
Appointment duration = over 30 but under 45 minutes	TCAT Nurse	Staff Nurse	CNS
Completed prior - Yes	1	0	2
Completed prior - No	3	0	0

It appears that there is no discernible difference in the length of consultation depending on who took the appointment

Graph 13: As a result of the HNA assessment was the patient formally referred to the Local Authority for social care assessment, or any other formal referrals made?

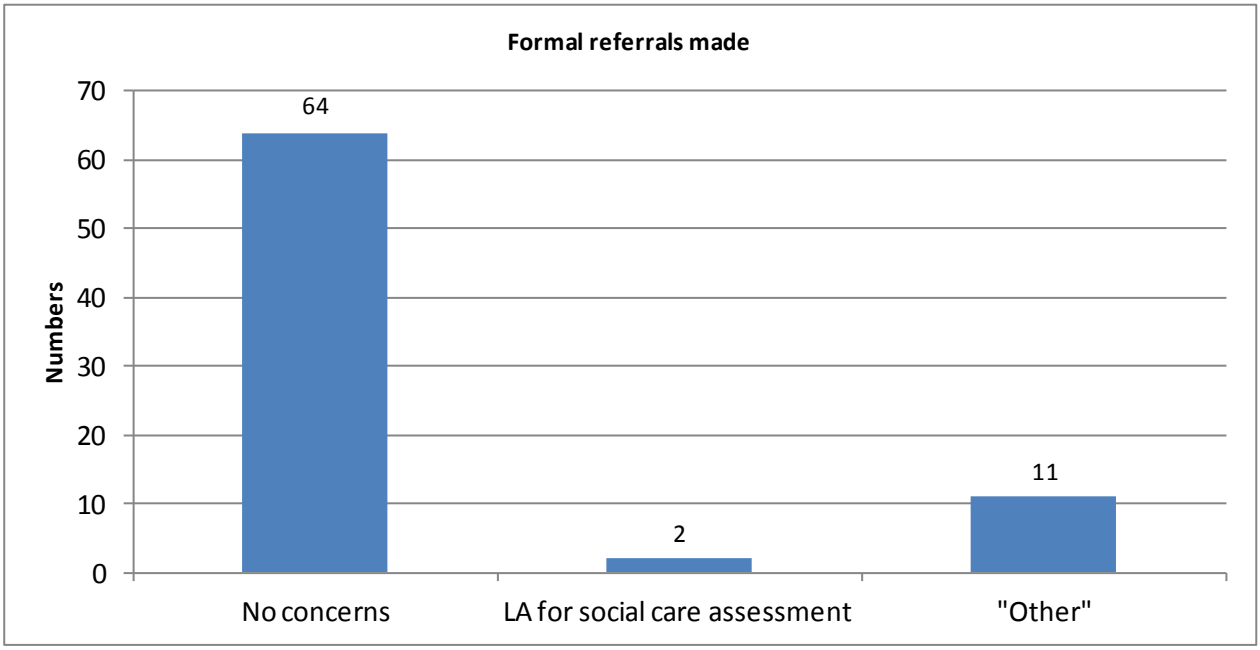


Table 4 - below identifies where these 11 patients were referred to

If yes (n=11):-	**Number**
Patient's own GP	8
Referred to NHS specialist cancer service	2
NHS in general (non cancer)	1
Specialist benefits-financial advice agencies	1
Total	**12**

NB-1 patient was formally referred to both their GP and NHS in general (non cancer)service

Examples of 'formal referrals'

One man was formally referred to his GP due to circulatory concerns. GP since checked bloods and he was found to have a Vitamin B12 deficiency.

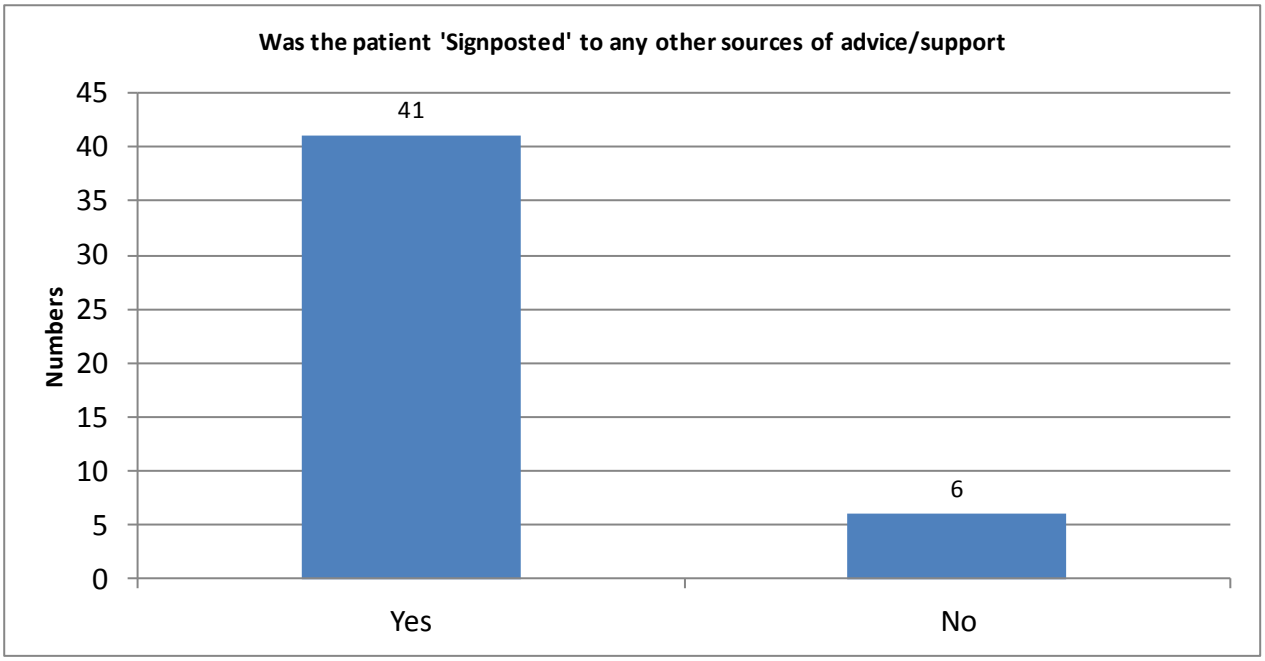
Anti-cholinergic medication was suggested for another man who had high concerns over frequency of passing urine. Again, referral was made to GP for prescription for medication.

Another three referrals were made to GP in relation to medication for erectile dysfunction. Referral was made to GP for prescription in relation to medication for proctitis as this man was suffering from rectal bleeding.

One man scored high for financial concerns as was struggling to pay his bills and felt he did not have enough money to live, he was referred to Macmillan long term conditions for a benefits review.

Graph 14: Was the patient 'Signposted' to any other sources of advice/support?

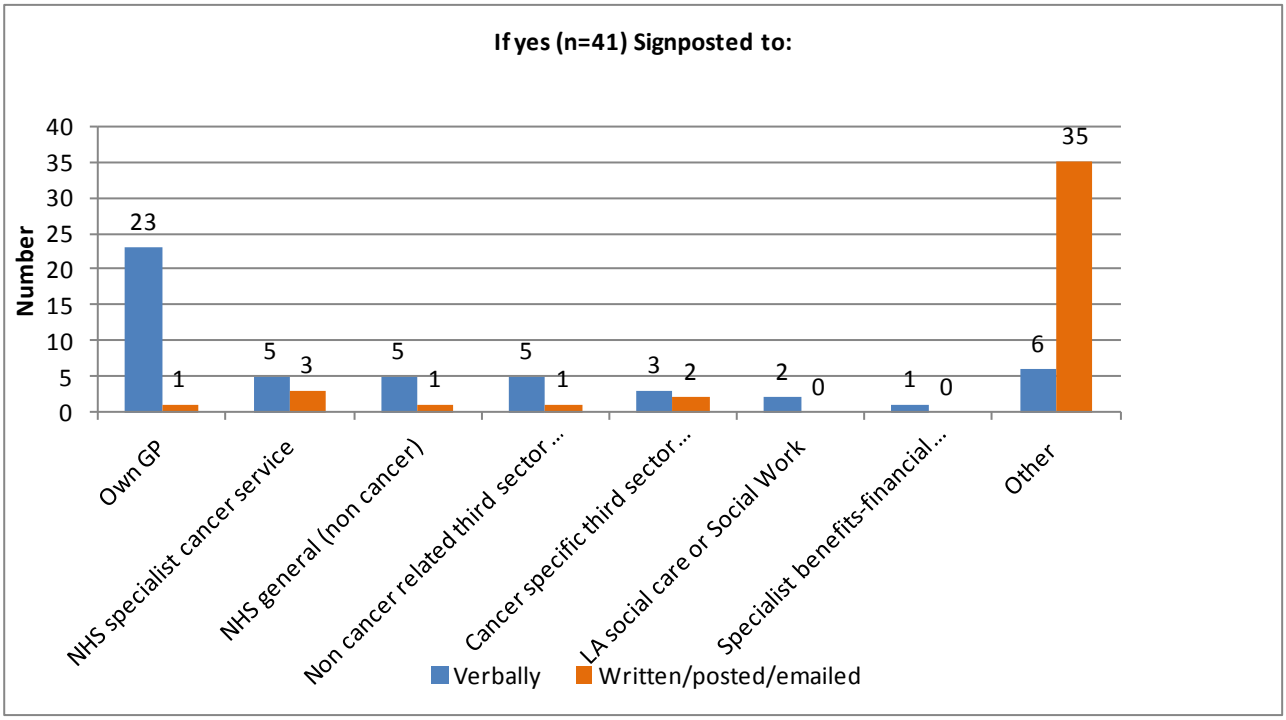
By signposting we mean ONLY informing or directing a patient to organisations or individuals who could provide advice/support if the patient contacted them independently/referred themselves to them.



41 patients were 'signposted' to other sources of advice/support. (Fig 14)

Graph 15: Where were patients signposted to?

Where were patients signposted to and how was the information given. (verbally or written/posted/e mailed). Patients may have been signposted to more than 1 or multiple source/s of advice/support



Examples where the Signposting was to 'other' - verbal or written signposting:

- Macmillan leaflets e.g.
  - Coping with fatigue
  - Healthy eating
  - Get active – Feel good
  - Money matters
  - Travel insurance
  - Talking about cancer

Men were signposted to various 3rd sector services such as:

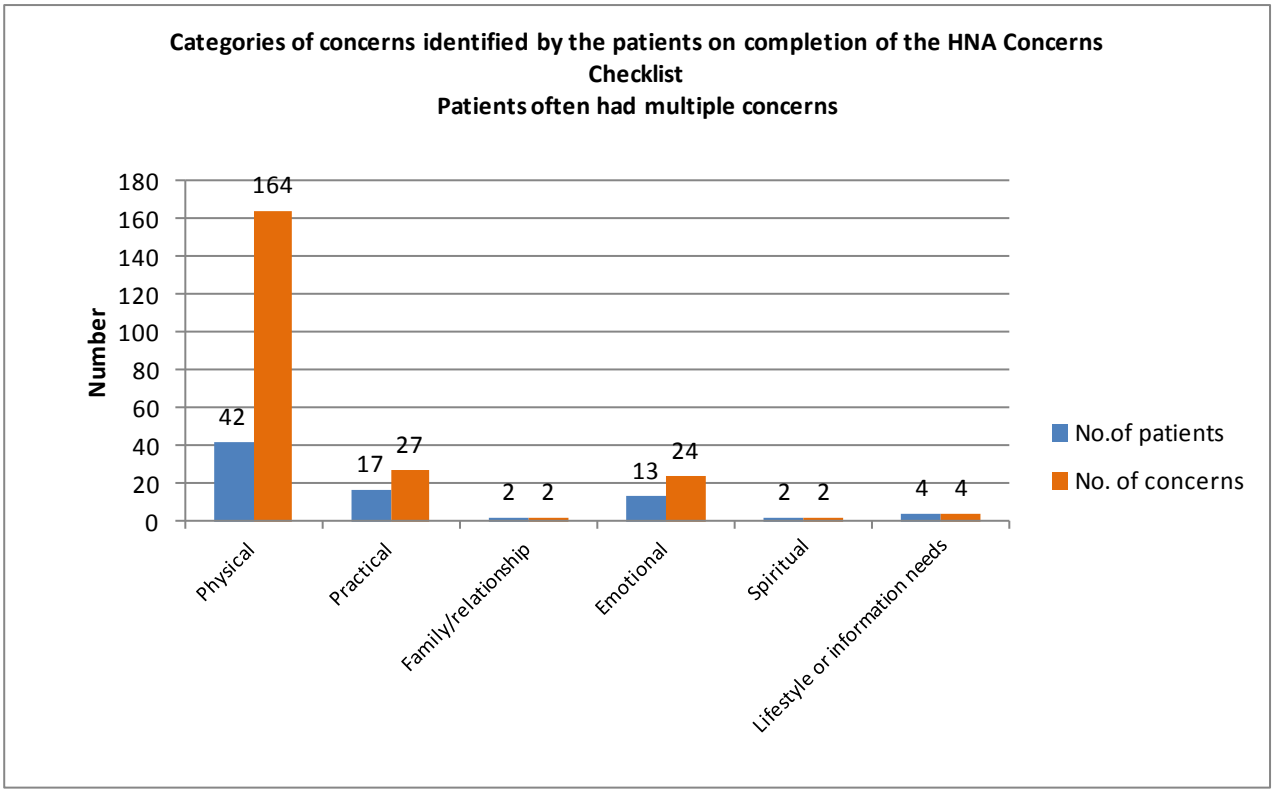
- Prostate Cancer Support Group
- Relationship Scotland
- Health and Wellbeing Clinics
- Living It Up
- Yoga chair based exercise programme
- Active Forth
- Walking Groups
- Befriending Services
- Drop In for Coffee (Macmillan One to One Project)

Further examples:

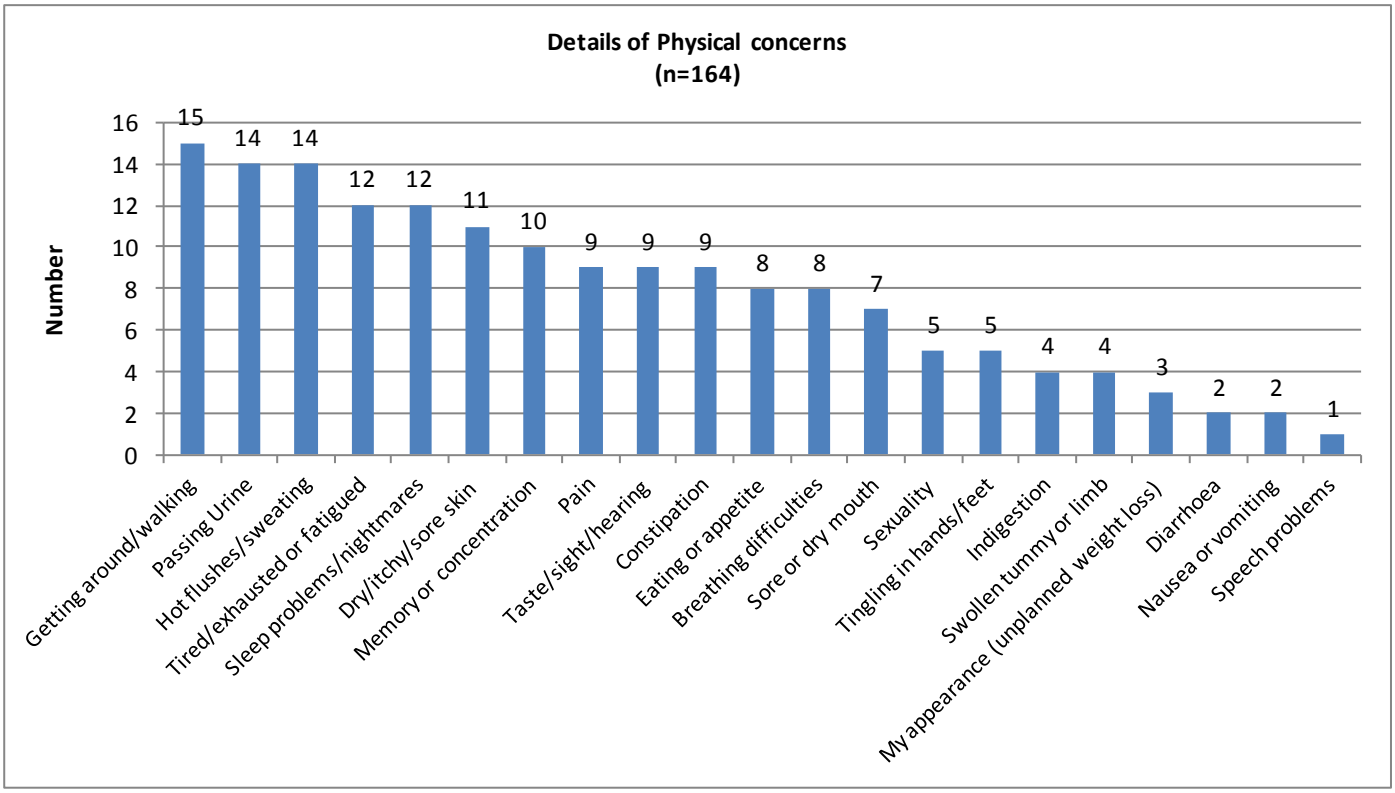
Three men scored high for caring responsibilities. This was in relation to caring for their wives (two with dementia and one with mobility problems). The men were reassured and signposted to the

carers centre. The role of the district nurse was also described in order that they could provide an assessment for their wives and make necessary arrangements as appropriate for carers, equipment, etc, should the need arise.

Graph 16: Breakdown of the type of concerns identified by the 47 patients who completed the HNA Concerns Checklist



Graph 17: Physical concerns highlighted by the 42 patients who stated they had physical concerns



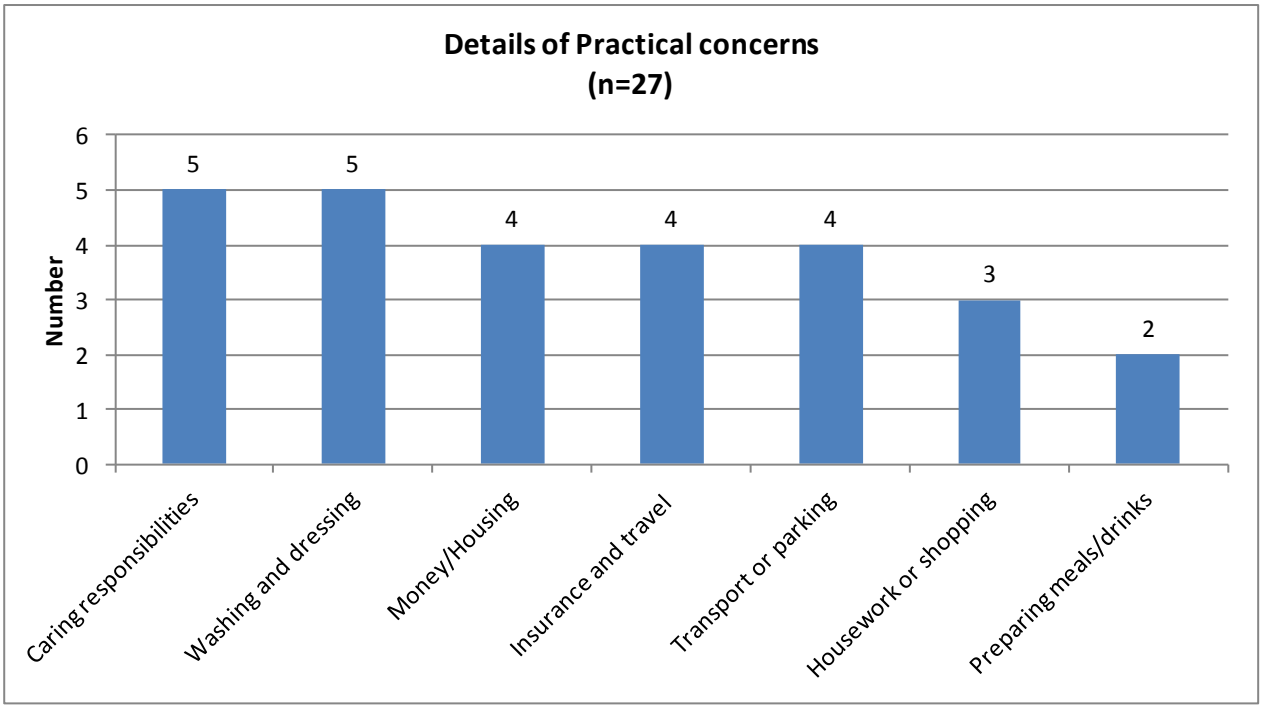
It is worth taking into consideration the age range of these patients with regard to mobility concerns.

The highest physical concern indicated by the men was noted to be getting around/walking (15 men, 32%), which could in some instances be attributable to age with the average age being 75.

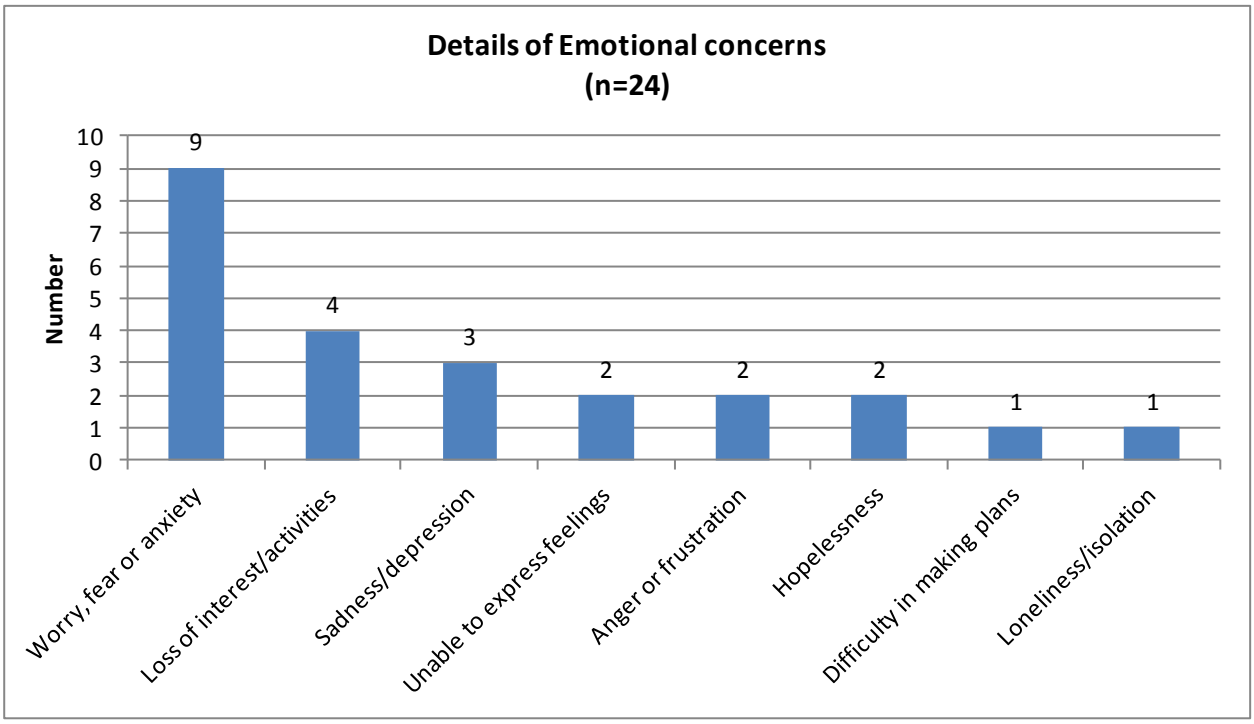
Other examples of interventions included:

- two men were formally referred to a local physical exercise programme
- reassurance regarding cancer related fatigue (Macmillan leaflet on coping with fatigue)
- discussion re breathlessness (Macmillan leaflet on managing breathlessness)
- general advice on fluid balance and caffeine intake
- general discussion and advice regarding healthy sleep patterns and signposted to appropriate websites
- discussion re sexual health and interventions to help rectify erectile dysfunction

Graph 18: **Highlights the various types of practical concerns highlighted by the 17 patients who stated they had practical concerns**



Graph 19: **Highlights the various types of emotional concerns raised by the 13 patients who stated they had emotional concerns**



Examples of interventions:

Most of the concerns were in relation to worrying about PSA rising and cancer progressing. The nurses acknowledged these concerns and reminded them that they were being monitored. One man was formally referred to Macmillan One to One Team and a few were signposted to this service.

Table 6:

Details of Lifestyle or information needs	**No.**
Support Groups	1
Exercise and Activity	1
Sun protection	1
Diet and nutrition	1
Total	**4**

Table 7:

Details of Family/relationship concerns	**No.**
Partner	1
Children	1
Total	**2**

Table 8:

Details of Spiritual concerns	**No.**
Loss of faith or other spiritual concern	2
Total	**2**

APPENDIX 10

TCAT Project Steering Group

Membership

Forename	***Surname***	***Designation***
Paul	*Baughan*	*Lead Cancer GP*
John	*Burns*	*Patient Representative*
Sandra	*Campbell*	*Nurse Consultant for Cancer & Palliative Care (Co-Chair)*
Catriona	*Cockburn*	*Falkirk District Council*
Maureen	*Dryden*	*Stirling / Clacks Council*
Maureen	*Hamill*	*Urology/Oncology CNS*
Nici	*Hills-Lyon*	*Macmillan Cancer Support*
Monica	*Inglis*	*Clinical Governance*
Carole	*Jones*	*Falkirk District Council*
Tom	*Kane*	*MCN Manager, West of Scotland Cancer Network*
Tom	*Kane*	*Patient Representative*
Gordon	*McLean*	*Macmillan Cancer Support*
Maxine	*Michie*	*Finance*
Craig	*Millar*	*Prostate Cancer UK*
Jane	*Niblo*	*TCAT Project Nurse*
Mary	*Orzel*	*Cancer Services Manager*
Betty	*Paterson*	*Macmillan Quality Improvement Facilitator*
Susie	*Porteous*	*Clinical Psychologist*
Margaret	*Ramsay*	*Cancer & Palliative Care Facilitator*
Diane	*Sharp*	*District Nursing Team Leader*
Seamus	*Teahan*	*Urologist (Co-Chair)*
Seamus	*Teahan*	*Consultant Urologist (Co-Chair)*
Margaret	*Welsh*	*Regional Project Lead, TCAT, WoSCAN*
Sandra	*White*	*WoSCAN Clinical Lead for TCAT (Cancer)*
Jennifer	*Wilson*	*Oncology Manager*
Robert	*Young*	*Patient Representative*