

# National Cancer Survivorship Initiative (NCSI)

## Assessment and Care Planning

### Lessons Learned

**Aim of Project:** To test the introduction of self-assessment and care planning for patients had completed their initial treatment for cancer and were now living with and beyond their diagnosis of cancer.

**NHS Improvement Role:** To co-ordinate on behalf of the NCSI the testing of assessment and care planning tools and methodologies within 11 test communities. Tribal Group Consultancy were appointed by the NCSI ACP work stream to undertake a quantitative and qualitative evaluation of this testing work.

**Background:** The 11 Test Communities (TCs) appointed in November 2009 were asked to test two new processes over a period of 6 months from January to June 2010

1. Assessment and Care Planning (ACP) at the end of initial treatment
2. Treatment Record Summaries (TRS) at the end of initial treatment

A few other test communities from the first wave sites also tested the ACP and TRS and where appropriate the findings from these sites are referred to in this report. This report is purely about the ACP elements. A separate report summaries the learning from the TRS.

Sites were provided with an ACP framework produced by the NCSI that included a range of templates to help initiate test and evaluate holistic needs assessment and care planning. Whilst the use of the tools provided in the framework was not prescriptive the expectation was that the core principles and elements outlined within it were incorporated into the approach adopted by each test community. The majority of the sites opted to test alternative tools to the one provided. In the majority of sites the ACP process was Clinical Nurse Specialist (CNS) led.

### Data Collection Methodology

Data for this report was derived from Test community final case study reports and from the comprehensive evaluation report produced by Tribal<sup>1</sup>. The latter involved pre and post intervention surveys (data was limited for this element) and focus groups on 11 sites with 128 people interviewed including doctors, nurses, project managers, administrative staff, patients and carers.

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<sup>1</sup> Assessment and Care Planning Final Report Executive Summary. Louw G Tribal Group August 2010

A total of 213 patients completed a questionnaire dealing with issues relating to quality of life, physical activity, self confidence, how they feel about the HCP looking after them, information they received and the ACP process itself.

## Quantitative Data Findings.

- 138 of 208 (66%) respondents provided comments that showed a reasonable quality of life.
- 170 out of 202 (84%) did not currently participate in any form of regular physical exercise
- Patients were most confident in doing tasks and activities needed to manage their health condition and least confidence in keeping the fatigue caused by their disease from interfering with their normal activities.
- 96% agreed that their HCP listened to them, showed interest in their problems and answered their questions.
- 79% of those who received information found it easy to understand and 92% felt it to be the right amount of information.
- One patient felt the quality of service was poor and 88% thought the care excellent or very good.
- 64% did not have a care plan (prior to testing the ACP).

There were 36 responses to the second survey and these have been matched to the first responses (i.e. before ACP) Whilst numbers are low patients and not statistically significant patients who responded were found to more content with life, less likely to be worried about their cancer returning, more likely to be able to manage their condition and a greater proportion strongly agreed that the HCP asked appropriate questions.

## Lessons learned

### What worked well?

- **For patients**
    - The overwhelming response by patients was positive. Some praised the CNSs for eliciting issues not previously voiced. For some patients the realisation that their lives could return to 'normal' became possible through this ACP discussion.
    - 78% of patients felt able to discuss their future care needs and 57% patient have identified that following an ACP they feel more confident in their ability to plan for the future.
    - Some patients identified that the ACP process was important to them as it improved their feeling of well being, gave them confidence in the system, helped them to think about life after cancer and prepare to get back to life.
    - Some patients identified that the ACP helped them to discuss their fears related to a recurrence of the disease and helped to relieve their anxiety.
    - Patients interviewed liked to have their ACP completed by a clinician who knew them and liked appreciated a private and confidential location for this
    - Patients and clinicians found the Distress Thermometer (used in 10/11 sites) a useful tool, however it was how the tools are used and communicated that made it relevant and useful to people
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- Patients told us they enjoyed the opportunity and time to discuss their needs however some did not like completing forms and filling in questionnaires.
- Identified issues that would not have been addressed otherwise
- One organisation outside this group has been evaluating the impact of telephone assessment and support over the 6-9 months following completion of treatment. The interim evaluation found patients very satisfied with this model of care.
- **For staff**
  - Nurses enjoyed 'having permission' to spend protected time with patients at the end of treatment to discuss their needs and help plan their care. They found the experience very positive and that it gave a clearer picture of whole patient.
  - Staff recognized the clear benefits of the ACP discussion for patients and place the patient more in control of their care. It provided a good monitoring process and was useful for screening and trouble shooting.
  - It was useful to use a tool to facilitate the discussion and not use the opportunity as simply a tick box exercise.
  - Staff identified that the process improved team working and communications in particular where it was combined with the generation of the Treatment Record Summary for the GP.
  - Telephone assessment received positive and negative feedback. Some staff preferred telephone assessments as they were quick and easy, with the ability to refer to the tools and guide notes whilst speaking to the patients.
  - Clinicians felt that the completion of a self assessment questionnaire prior to the consultation helped to focus the discussion on specific needs of the patients and therefore a resulted in a more productive outcome of the consultation for both staff and patient

#### **What didn't work well?**

- **For patients**
    - For some patients a telephone assessment was disliked preferring a face to face discussion with the HCP. Most HCPs also preferred this approach.
    - Some patients did not enjoy completing the self assessment tool at home preferring to do so in the hospital clinical setting where HCP were more immediately available to discuss and support. A few preferred to opportunity and time to discuss issues of concerns with their family first
    - Some patients found that the prompts within the self assessment made them consider and in some cases worry about issues not previously thought about.
    - The ACP framework tools provided by NCSI for testing were found to be over complex, repetitive and poorly constructed. They were time consuming for both the patient and staff to complete and were a distraction from the focus of the discussion around providing education and support to patients as they enter the follow up period.
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- There were some comments raised by patients that the assessment process focused more on the past rather than preparing for the future.
  - Some concerns were raised that the process was too long and prescriptive especially where there were only a couple of issues raised where support was required.
  - **For staff**
    - Identification of patients at the end of treatment was often impossible to ascertain prior to the OP visit (ie from PAS). Given this position the timing of the ACP discussion either meant the patient had to wait to see the CNS after the consultation with the doctor was complete (ie had an extended hospital visit) or an additional appointment was arranged to see the CNS for this discussion.
    - Lack of recognition and support from other members of the multidisciplinary team around the use and potential value of the ACP to improve the patient experience.
    - Implementing the introduction of ACP had a significant impact on CNS resources and for many this meant that testing was only possible with a limited number of patients. Few Trusts were able, in the timescales required, to review CNS job plans and set up dedicated clinics to undertake these discussions.
    - Some sites spent considerable time selecting and amending the assessment tools with less time looking at how to develop a care plan derived from that screening discussion
    - For some sites there was a lack of resources and these included inadequate space to speak with patients in privacy and lack of access to IT/computer support to enable the production, copying and transfer of the completed assessment and care plan or treatment record summary. This meant that patients often experienced delays in receiving their care plan.
    - To comply with Peer Review the CNS is required to be present in clinic for breaking bad news discussions with patients. For this reason CNS resources are targeted at those in treatment rather than those who have completed treatment and are entering follow up period.
    - For some staff, especially the less experienced, training in how to conduct an ACP was limited and therefore ACP discussions were less productive than they could have been
    - Staff found that addressing physical and practical needs was relatively straightforward however other issues such as family relationships, spiritual matters, anxiety that were more difficult to handle and some staff, especially the less experienced, found this complex and difficult to manage.
    - The term 'Distress' incorporated in the title of the Distress Thermometer was disliked by several sites who changed the name to a suitable alternative for use at the end of treatment where the focus was on recovery and well being.
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## Recommendations arising from the testing work

### Choice

- Patients need to be offered and encouraged to participate in a care plan discussion at the end of treatment and at other key points in their journey. If they do not wish to participate at that time, it is their choice not to do so. The offer should be recorded in the case notes.
- Patient need to have greater control over the process and have access to self assessment tools at any point in the care pathway.

### Timing of ACP

- Feedback for patients and staff strongly suggested that the ACP needs to commence at the time of diagnosis where a number of concerns and issues can be alleviated rather than wait, for what can be many months until treatment is complete. What is required beyond diagnosis is simply a review of that care plan to ensure any new needs or issues are addressed.

### Tools

- The purpose of any self assessment tool is to identify the main issues affecting the patient at that time. The emphasis needs to be directed towards the generation of a clear concise plan that addresses current needs and also a plan of care (appointments, tests etc ), promoting healthy lifestyle issues such as smoking cessation, diet and exercise and recording any additional signposting and support required.
- Use the Distress Thermometer or equivalent as a high level screening tool and use other more in depth tools e.g. HADS where this would benefit the discussion and outcome
- Trusts might consider patient held folder/diary in which a copy of the care plan, treatment summary, test request forms, clinic letters, advice leaflets can be held. Careful planning for this is required to ensure they remain 'live' documents and offer real value to the patient
- Organisations contemplating the use of ACPs are advised to explore tools currently used in their Trust or Network as use of the same tools throughout the patient journey would provide a more consistent approach.
- Organisations should make available to HCPs a local directory of services, how to refer, times of access etc
- The use of touch screen or electronic technology to record self assessments was not tested with these test communities however is about to be tested in two of the first wave sites

### Training and support

- Additional training may be required for some staff. This may require more than the 'Advanced Communication Course' already available. Although there were differences in opinion as to how much or what training is necessary it appears that more motivational skills training would be of benefit along with other skills such as telephone interviewing.
- Clinical support systems offer benefit to HCPs in supporting them to undertake difficult and challenging discussions with patients and carers.

### Capacity Planning

- Prior to establishing an ACP service a review of resources (time, space, IT support, administrative time) should be undertaken to ensure capacity is in place. Adding this activity to the current workload without freeing up appropriate capacity may prove detrimental to sustainability and spread
  - Where a nurse led clinics were established, appointments slots of 45 mins seemed to be the optimum length allowing 30 mins per patient with 15mins to complete any documentation
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