



Wessex
Strategic Clinical Networks

An evaluation of the progress made towards the implementation of treatment summaries for cancer patients across Wessex

Final Report

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1. SUMMARY OF PROGRESS

Introduction and Context:

This report details an evaluation of the implementation of treatment summaries for cancer patients across the Wessex Deanery, encompassing Hampshire, Dorset and the Isle of Wight. The service evaluation commenced at the end of September 2015 and this report presents the progress made towards the implementation of cancer treatment summaries (CT) across the Wessex Deanery and service users' experiences of receiving the TSs from two NHS Trusts in the catchment area. The survey results present the progress that has been made in the first six months of implementation and include descriptive data relating to the progress and process of implementation. The qualitative findings from an analysis of service user experience are presented and the findings from the evaluation are discussed in the context of national policy and the wider literature.

Remit of the Project:

A mixed method approach has been utilised, following the Logic Model for Evaluation (HM Treasury, 2011). The purpose of this evaluation is to monitor the progress and process of the implementation of treatment summaries (TS) as part of a key work stream identified by the WCSCN (2014).

The project aims are:

1. To identify the progress that has been made towards the implementation of treatment summaries between April 2015 and September 2015 in acute trusts in the Wessex Deanery.
2. To identify factors that have influenced the process and progress of the implementation of treatment summaries in the above Trusts.
3. To evaluate the experiences of service users who have received care from acute Trusts in Wessex Deanery between April 2015 and September 2016.

Method:

- Stage 1 of the project included a survey of lead cancer nurses in the chosen localities to determine the progress made towards the implementation of treatment summaries.
- Stage 2 involved the use of interviews and focus groups to describe cancer survivors' experiences of receiving a treatment summary. Ethical approval for the evaluation has been obtained from Bournemouth University and the project met the criteria for service evaluation in IRAS.

Key Findings

Questionnaire:

1. Between April and September 2015 three of the participating Trusts had provided treatment summaries for patients with colorectal and breast cancer. Of those an average of 49% of colorectal patients and 62% of breast cancer patients received a treatment summary.
2. Qualitative comments from four of the participating Trusts indicated that from the spring of 2016 treatment summaries were being introduced for patients with prostate, head and neck, brain and skin cancers.

3. A number of challenges were identified by staff involved in implementing TS and these included: limited staffing resources, lack of availability and accessibility of IT systems, lack of clarity over patient selection and documentation, lack of clarity over staff engagement and expectation of roles.
4. Driving forces identified included the recognition of leaders with vision who engaged with staff, multidisciplinary involvement and collaboration, education and updates, positive feedback and perceived benefits identified by patients and colleagues.

Service user evaluation:

1. Not all participants could remember receiving a treatment summary and when they were given close to completion of the treatment episode some service users appeared overwhelmed by the volume of information they had received while others were able to select out key information and this appeared to be related to whether or not they had previous experience of receiving cancer services.
2. Service users who remembered having a TS had a clear understanding of its purpose and thought they were a useful source of key information that could be shared with their family and other professionals although for some the technical terminology appeared confusing.
3. Service users experienced a good integration of care between the members of the cancer team in secondary care. However from their perspectives, they saw no integration between primary and secondary care and had not anticipated that there would be in the majority of cares. Those with co-morbidities did however question if there should be stronger communication links between the patient, primary and secondary care services.
4. The quality of care received from the cancer service teams was consistently praised and service users recognised the collaborative effort made.
5. The TS does appear to provide a focus point for sharing information between service users and their significant others and appeared to support service users in the self-management of their survivorship.

Conclusion and recommendations

This service evaluation has been conducted at a very early stage of service implementation and as such the findings can only represent a snapshot of the early transition phase. For the participating Trusts, treatment summaries are becoming an integral part of the care for cancer survivors with evidence that feedback from GPs and service users is positive. Service users' experiences of receiving treatment summaries has been positive however some participants couldn't remember receiving one, when this happened it was associated with receiving large amounts of information at a time when it was difficult to absorb what was happening. Service users also recognised that their care and support came from secondary care rather than primary care following completion of a treatment episode. Key drivers and lessons learnt from this early evaluation can be used to guide future development and these have been presented as recommendations for further development.

In summary key recommendations at this stage include the following:

1. For clinical staff to continue to identify where ambiguities in operational definitions of treatment episodes, treatment summaries and patient selection exist and agree a way forward.
2. To review the coding and usability of electronic data systems and digital communication.
3. To identify examples of good practice in relation to leadership and engagement and share this information with others.
4. To engage clinical staff in the provision of education and updates
5. To continue to monitor feedback from service users including patients and primary care staff.
6. To support continuing multidisciplinary engagement in secondary care and more engagement with primary care.

2. INTRODUCTION AND CONTEXT

Introduction:

This report details an evaluation of the implementation of treatment summaries for cancer patients across the Wessex Deanery, encompassing Hampshire, Dorset and the Isle of Wight. The service evaluation commenced at the end of September 2015 and this report presents the progress made towards the implementation of cancer treatment summaries (CT) across the Wessex Deanery and service users' experiences of receiving the TSs from two NHS Trusts in the catchment area. The survey results present the progress that has been made in the first six months of implementation and include descriptive data relating to the progress and process of implementation. The qualitative findings from an analysis of service user experience are presented and the findings from the evaluation are discussed in the context of national policy and the wider literature. Recommendations are made and summarised at the end of the discussion section.

The purpose of this report is to present a summary of the key findings from the evaluation, highlighting the challenges met during treatment summary implementation as well as the progress made. Recommendations are made to support future development and evaluation.

National and policy context:

A projection of the number of people living in England with cancer in 2012 is 1.8 million and by 2030 this figure is estimated to be over 3 million (Independent Cancer Task Force, 2015; Macmillan Cancer Support, 2012). There is evidence however that many people who survive cancer struggle with the consequences and side effects of treatment and often have unmet needs that could have been either avoided or managed more effectively (Treanor et al, 2013; Santin et al, 2012; Armes et al, 2009). In 2013 the UK National Cancer Survivorship Initiative (DH, Macmillan Cancer Support & NHS Improvement) set out updated actions and guidance to improve the outcomes of this client group. One such intervention included the implementation of treatment summaries that could be used as part of an integrated package of care for cancer survivors. The use of treatment summaries continues to be supported and the Independent Cancer Task Force (2015) has recommended that the treatment summary should be an integral part of a specified cancer recovery package for every person with cancer in England by 2020.

Treatment Summaries as a key work stream for the Wessex Cancer Strategic Clinical Network (WCSCN):

Treatment summaries are a key component of survivorship and provide information in an accessible format to support early recognition of cancer consequences by patients and primary care workers enabling early intervention (Wessex Cancer Strategic Clinical Network, WCSCN, 2014). The WCSCN go on to recommend the use of treatment summaries as a core part of the communication process between the providers of secondary care, the patient and primary care providers. The use of treatment summaries is seen as an important step forward towards improving information and continuity of care for cancer survivors.

When treatment summaries were piloted by the National Cancer Survivorship Initiative (2010) nationally across eleven test communities in 2009 they were received positively both in primary and secondary care. This finding was reinforced locally by findings from focus groups of cancer survivors where they valued the importance of having detailed, bespoke information that they could share with their GP about their individual treatment and on-going cancer care (Airey and Moxham, 2015).

The adoption of treatment summaries as part of standard care in England is still in the early stages of implementation and, based on the findings of the National Cancer Patient Experience Survey (NCPES), continues to be identified as an area for further development and improvement by Quality Health (2014). The findings revealed that when service users were asked if they had received a written assessment and care plan as part of their care, only 22% of patients reported that they did (Quality Health, 2014). This was in contrast to 89% of respondents who said that their overall care was excellent or very good. These national findings were consistent and comparable with the findings for the acute NHS hospital Trusts in the Wessex Deanery area (Quality Health, 2014) and more widely by findings in the USA (Klemanski et al, 2016; Hewitt et al, 2005).

In response to the findings produced by Quality Health in 2014, the implementation of treatment summaries, as part of the National Cancer Survivorship Initiative Recovery Package (2014), was agreed as a key work stream for the WCSCN work programme (WCSCN, 2014). This project is part of the Department of Health (DH) domain 3 work stream which is focussed on, 'Helping people to recover from episodes of ill health or following injury' (DH, 2010).

Definition of Treatment Summary:

For the purpose of this report, a treatment summary can be described as a tool to improve communication between cancer services, the patient and primary care (Smith and Thompson, 2013). The Treatment Summary will be provided by healthcare professionals working in secondary care and differs from a standard discharge summary in that it is much broader in its remit and should contain the information listed in Table 1 (Macmillan, 2014; National Cancer Survivorship Initiative (NCSI) (2010).

Table 1: Information provided as part of a Cancer Treatment Summary (Macmillan, 2014; NCSI, 2010)

| Information provided as part of a Cancer Treatment Summary |
|--|
| Date of diagnosis |
| Diagnosis |
| Staging information |
| Treatment aim |
| Summary of treatment and relevant dates |
| Possible treatment toxicities and/or late effects |
| Alert symptoms that require referral back to a specialist team. |
| Secondary care on-going management plan |
| Required GP actions in addition to the cancer care review. |
| Summary of information given to the patient about their cancer and future progress |
| Additional information including issues relating to lifestyle and support needs |
| Useful contact numbers |
| Other service referrals made |
| DS 1500 application completed (a form to apply for specific benefits if terminally ill) |
| Prescription charge exemption arranged. |

Treatment summaries and Local Clinical Commissioning Groups:

Treatment summaries have been included in seven out of nine local Clinical Commissioning Groups' (CCGs) commissioning intentions for 2014-2015, following guidance from the WCSCN (2014) that all cancer patients should receive at least one treatment summary. In addition work has been undertaken to ensure treatment summaries are included in CCG contracts for 2015-2016 either as a quality incentive scheme (CQUIN), as part of a service development and improvement plan. The CCGs (2014) who have shown an intention to include in contracts for 2015-2016 are:

- Dorset
- Fareham and Gosport
- Isle of Wight
- North Hampshire
- North East Hampshire and Farnham
- Portsmouth
- South East Hampshire
- Southampton
- West Hampshire

The acute NHS Trusts in the Wessex Deanery that are included in this contract are:

- Dorset County Hospital NHS Foundation Trust
- Hampshire Hospitals NHS Foundation Trust
- Isle of Wight NHS Trust
- Poole Hospital NHS Foundation Trust
- Portsmouth Hospitals NHS Trust
- Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust
- University Hospital Southampton NHS Foundation Trust

This report focuses on the progress made towards the implementation of treatment summaries in the Wessex Deanery as part of their quality improvement plan and includes data collected from September 2015 to October 2016.

3. EVALUATION METHOD

A mixed method approach has been utilised, following the Logic Model for Evaluation (HM Treasury, 2011). The purpose of this evaluation is to monitor the progress and process of the implementation of treatment summaries as part of a key work stream identified by the WCSCN (2014). The date of policy implementation was April 2015 and the timing of data collection within the first 6 months of implementation is consistent with the use of a process evaluation that describes and measures initial challenges and driving forces that influence the progress of implementation (HM Treasury, 2011).

Aims:

The project aims are:

1. To identify the progress that has been made towards the implementation of treatment summaries between April 2015 and September 2015 in acute trusts in the Wessex Deanery.
2. To identify factors that have influenced the process and progress of the implementation of treatment summaries in the above Trusts.
3. To evaluate the experiences of service users who have received care from acute Trusts in Wessex Deanery between April and September 2016.

Scope and Design:

The evaluation includes a two stage mixed method approach.

Stage 1: includes a survey of lead cancer nurses in the chosen localities to determine the progress made towards the implementation of treatment summaries and relates to project aims 1 and 2.

Stage 2: Service users from a variety of sites have been invited to take part in focus groups at locations that are convenient to them. The focus groups will consist of a minimum of 4 participants up to a maximum of 10. The option of face to face or telephone interviews will be available for cancer survivors who wish to take part but who are unable to attend on the date specified.

Ethical approval and Trust permissions:

This project has been considered by IRAS to be service evaluation and does not require ethical approval under the NHS Research Governance Framework. The evaluation is however subject to local Trust information governance approval. Permission to access the sample sites are being obtained through the Trusts' Information Governance/ Audit teams and the lead cancer nurses in each Trust. To date 6 of the 7 acute Trusts have given permission for stage 1 of the study to take place and two Trusts have given permission for stage 2 to commence. Because the project involves undertaking interviews and focus groups with vulnerable groups the research team sought ethical approval through Bournemouth University and this was obtained in September 2015.

Sampling Strategies:

Stage 1: The lead cancer nurses from the 7 acute trusts contracted to implement treatment summaries have been selected by the WCSCN as the people best placed to complete the survey based on their strategic knowledge of cancer care in the their trust.

Stage 2: The Trusts included in a case-study approach will be selected according to the following criteria:

- The Trust will be part of the sample group included in the Wessex Deanery population.
- Cancer survivors will have received treatment in that locality during the evaluation period

Participants for the focus groups and interviews will be selected using purposive sampling with the guidance of lead nurses working in the case-study Trusts. A participant information sheet and consent form will be provided in advance of data collection to allow a cooling off period.

Access to Trusts and permission to collect data:

- Permission to access Lead Cancer Nurses in each Acute Care Trust was agreed and supported by Wessex Strategic Clinical Networks in July 2015 and this provided an opportunity to pilot the survey for stage 1.
- Permission to access the Trusts in order to collect data has taken longer and after obtaining ethical approval in September 2015, permission to access 6 of the 7 trusts has been granted. The findings represent data obtained from the six participating trusts.

Pilot study and testing of the survey tool:

A pilot questionnaire was developed based on the requirements of the funders and available literature (WCSCN, 2015; Rechis et al, 2014; Jabson and Bowen, 2014). The questionnaire was tested with the lead cancer nurses in two Trusts in the Wessex Deanery during July 2015. Of the Trusts who agreed to take part in the pilot study, one was based in a rural area (Trust A) and one in an urban setting (Trust B). Data were collected during a face to face interview using the pilot questionnaire as a guide.

The data from the pilot survey revealed that, at the time of collecting the data Trust A and Trust B were at different stages of progression towards the implementation of treatment summaries:

- Trust A described their progress as going through a staged implementation plan that facilitated gradual increase in the number of cancer diagnostic related groups being included as the project expanded. Trust B described being at a very early stage of implementation and were not able to identify which diagnostic related groups were included in the implementation plan at that stage.
- At this early stage factors that appeared to affect the progress of implementation related to:
 - staff attitudes and motivation
 - stakeholder involvement in the change process
 - funding and support
- There also appeared to be inconsistency in:
 - The definition of a treatment episode
 - when a treatment summary should be provided
 - who provides the treatment summary
- There was an indication that data on the number of patients who have received treatment summaries may not be available in all Trusts due to proposed changes in the way the clinical coding data is stored and the transition from paper based data to an electronic data base.

Based on the findings of the pilot survey the following amendments to the questionnaire have been made:

- Three questions have been added to the questionnaire including:
 - How do you define the term “treatment episode” in your Trust?
 - Are there any factors that have inhibited the progress of treatment summary implementation?
 - Are there any factors that have driven the use of treatment summaries forward?
- Each question in the survey is followed by a request to include further information if relevant.

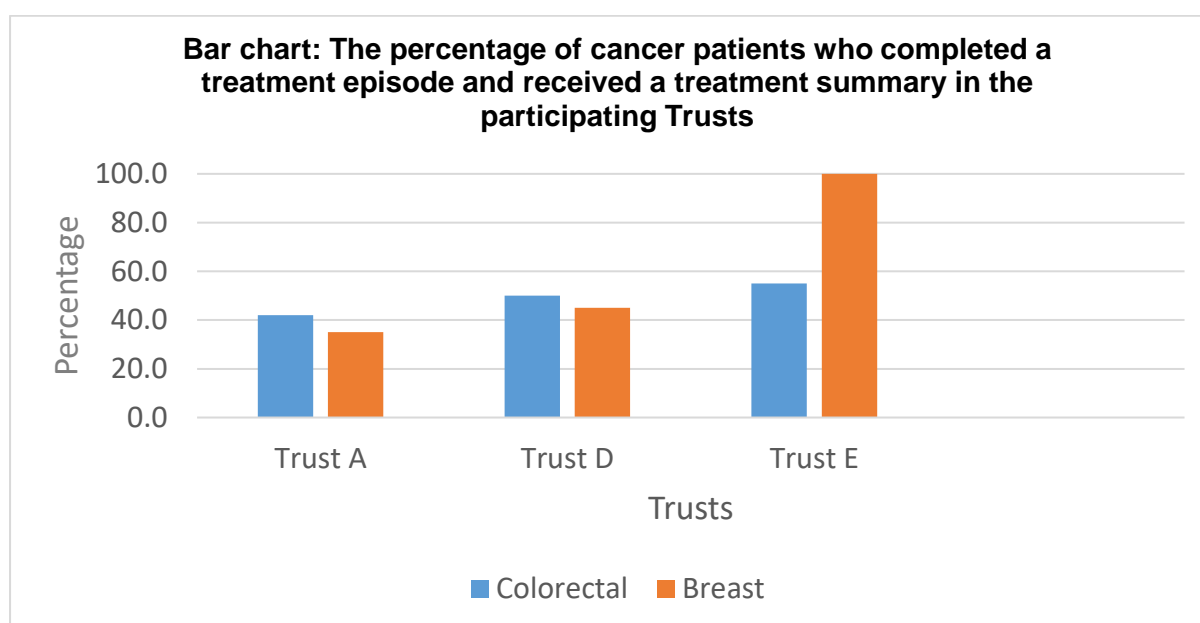
A full version of the questionnaire is available in Appendix A.

4. FINDINGS

4.1 Survey Results:

The provision of treatment summaries between April and September 2015

The bar chart below provides a summary of the percentage of cancer patients who received a treatment summary based on the data available for the period between April and September 2015. Of the six Trusts included in the study, three Trusts were able to provide data for this period, two of the trusts provided numerical data while the third presented their data as percentages.



In **Trust A** the number of patients with colorectal cancer who completed a treatment episode between April and August 2015 was 54 and of those 23 (42%) received a treatment summary. For patients with breast cancer, 81 patients completed a treatment episode with 29 (35%) receiving a treatment summary.

In **Trust E**, 180 patients with colorectal cancer completed a treatment episode with 100 (55%) receiving treatment summaries. Also 300 patients with breast cancer completed a treatment episode with 100% of patients receiving a consultation record (treatment summary) after each episode of treatment including post-surgery, post radiotherapy and post chemotherapy (Please see Table 2).

A third, **Trust D** provided an estimated percentage of the number of colorectal patients who had received a TS as 55%, with less than 50% of breast cancer patients receiving a TS.

The remaining groups did not know or did not specify numbers but did offer qualitative comments to explain this.

- In **Trust A**, no data relating to treatment episodes for prostate and other cancers were available for the time period April- August but from February 2016 patients with prostate cancer completing a treatment episode will receive a treatment summary.
- In **Trust D** electronic treatment summaries were introduced at the end of 2015 for patients receiving treatment for breast, head and neck, colorectal, brain and skin cancers. In April 2016 patients receiving treatment for lung and prostate cancers will also receive treatment summaries.
- **Trust E** did not specify a plan for rolling out treatment summaries to other specialities but they did note that some specialities such as haematology already use treatment summaries for some patients as part of their care pathway.
- In **Trust F** the respondent recognised that TS are not yet available as part of the patient's electronic care record and that this had made collation of figures difficult. This is being recognised and addressed at a regional level.
- Other qualitative comments in this section related to the following:
 - Patients receiving palliative care will not be provided with a TS
 - TS are more likely to be used where follow-up care is nurse led
 - The template for the TS provided is not always clinically appropriate for the patient's care.

These findings are summarised in table 2.

Definition of a treatment episode and provision of treatment summaries:

At the time of data collection there appeared to be some differences of opinion around what denotes a treatment episode and how this relates to patients receiving a treatment summary.

For example:

*Treatment summary is completed by the team in each of the specialities and will be given to the patient at the end of the treatment package. Some patients in colorectal speciality will receive a treatment summary at the end of each stage.
(Trust A)*

Reference is made to the term "treatment package" as being different to a "stage" of treatment. This statement was further qualified when reference was made to some individuals who receive a treatment summary at the end of a "package" of treatment that included several treatment episodes, rather than at the end of each "stage" of specialist treatment. It was also recognised that some patients may receive combination treatment and that where this occurs it is defined as one treatment episode. Trust A for example, referred

to patients with colorectal cancer who receive one treatment summary at the end of the treatment package when the person's care is transferred to primary care. They also identified that treatment summaries for some people receiving complex care were individually tailored to the person's treatment journey.

In Trust D the timing of TS provision is related to the cancer type. However as a general rule the TS is provided at the end of a treatment episode at the first follow-up appointment. This could be between 6 weeks and 6 months post treatment.

In Trust E a treatment episode was defined as being aligned to an episode of specialist care along a patient's cancer experience:

Whilst this has never been articulated I think that most would define the term treatment episode as an episode of care along an individual patient's cancer experience which requires expert clinical care. (Trust E)

The example used to illustrate this referred to an individual receiving treatment for breast cancer that may have three episodes of treatment including: surgery, radiotherapy and chemotherapy. This interpretation was reinforced by staff in Trust D where colleagues interpreted an episode of treatment as a single modality of treatment such as hormone treatment, surgery or adjunctive treatment- each one being a treatment episode. One respondent defined a treatment episode as a "treatment pathway" explaining that a TS would be given at the end of the surgical pathway, for example. They described treatment summaries being individually tailored to the patient care pathway with completed summaries being provided at different times along the pathway.

The findings therefore suggest that each Trust and /or area of cancer speciality has defined a treatment episode to be consistent with the package of care provided and that decisions are made about when a TS is provided according to cancer type, interventions provided and the patient's progress.

Table 2: The number (n) and percentage of cancer patients who completed a treatment episode and received a treatment summary in the participating Trusts

| Trust | Cancer Type | Completed episode (n) | Received summary (n) | Received summary (%) |
|----------|--------------------------|-----------------------|----------------------|----------------------|
| A | Colorectal | 54 | 23 | 42% |
| | Breast | 81 | 29 | 35% |
| | Prostate | 0 | 0 | 0 |
| C | <i>No data available</i> | | | |
| D | Colorectal | Not specified | Not specified | 50% |
| | Breast | Not specified | Not specified | < 50% |
| | Prostate | Not specified | Not specified | Not specified |
| E | Colorectal | 180 | 100 | 55% |
| | Breast | 300 | 300 | 100% |
| | Prostate | 125 | 0 | 0% |
| F | Colorectal | Not known | Not known | Not known |
| | Breast | Not known | Not known | Not known |
| | Prostate | Not known | Not known | Not known |
| G | <i>No data available</i> | | | |

People and processes involved in the format and completion of the TS

In **Trust A** for people experiencing colorectal cancer, the individuals who complete the treatment summary are either the consultant or the nurse. For people with breast cancer, there is a different system in that a nurse administrator has been employed to complete and provide treatment summaries. The treatment summaries are then delivered to the patient in person with a letter sent to their address. At the moment the patient's GP also receives a

copy of the letter but work is being undertaken to explore the feasibility of emailing the letters to both the patient and GP where appropriate.

In **Trust D** the TSs are given to the patients by the clinical nurse specialist in each speciality, a copy is also placed in the patient's hospital notes for use by the multidisciplinary team.

In **Trust E**, for patients with colorectal cancer the treatment summary may be completed by either the consultant, specialist registrar or the clinical nurse specialist. For patients with breast cancer it may be completed by the consultant or radiotherapist. Patients received their treatment summaries in person but no reference is made to how or whether the information is sent to the patient's GP.

In **Trust F**, again the clinical nurse specialist gives the patient their TS after liaising with the medical team. Patients are provided with a paper version and a copy is sent to the GP.

The most frequently used format at the time of data collection was a standard treatment summary template.

Factors that have challenged the implementation of treatment summaries:

Analysis of the qualitative data collected from the survey revealed that the staff had experienced a number of challenges to implementation across the Trusts and these included the following themes:

- Resource challenges
- Availability and accessibility of information technology (IT) systems
- Lack of clarity over patient selection and documentation
- Role expectations and staff engagement

Table three summarises the themes supported by quotes from the respondents.

Table 3: Challenges encountered when implementing treatment summaries

| Theme | Quotes from respondents |
|---|--|
| Resource challenges | <ul style="list-style-type: none"> Limited staff time and pressure of workload (<i>Trust A</i>) Staffing shortages, especially qualified nurses, nurse staffing vacancies in the specialities (<i>Trust A</i>) Time (<i>Trust E</i>) Asking more of the CNS without providing an increase in resources (<i>Trust F</i>) There are increasing numbers of patients being diagnosed with cancer (<i>Trust F</i>) |
| Availability and accessibility of IT systems | <ul style="list-style-type: none"> IT (<i>Trust E</i>) The interface between the IT systems of primary and secondary care (<i>Trust F</i>) The difficulty associated with extracting data on TS from the electronic data base (<i>Trust F</i>) We work around our IT systems rather than them working for us (<i>Trust F</i>) |
| Lack of clarity over patient selection and documentation | <ul style="list-style-type: none"> Lack of knowledge and clarity over who treatment summaries are aimed at (<i>Trust E</i>) Lack of knowledge and clarity about what contributes a patient treatment summary (<i>Trust E</i>) During the targeted time frame there was a lack of a coherent system and consistency around regional implementation (<i>Trust D</i>) Lack of clarity over what is the correct paperwork (<i>Trust E</i>) I believe there is too much confusion with regards to treatment summaries (<i>Trust E</i>) |
| Role expectations and staff engagement | <ul style="list-style-type: none"> An expectation that this is a “nursing” i.e. CNS job/role/requirement leading to a lack of medical staff engagement (<i>Trust E</i>) Unrealistic expectations (<i>Trust F</i>) Implementation basically down to the CNS (<i>Trust F</i>) |

Factors that have driven forward the use of cancer treatment summaries and ideas for future development

Analysis of the qualitative data collected from the survey revealed that the staff had recognised some factors that had driven forward the implementation of treatment summaries and that where they been implemented there had been perceived benefits. Some respondents also identified ideas that could be considered when planning the future development of the service. All together six themes were identified and they include:

- Targets
- Leaders with vision who engage all staff
- Education and updates
- Multidisciplinary involvement and collaboration
- Positive feedback and perceived benefits
- IT systems

Table four summarises the themes supported by quotes from the respondents.

Table 4: Factors that have been perceived to have driven forward the implementation of cancer treatment summaries and ideas for future development

| Theme | Quotes from respondents |
|--|--|
| Targets | <ul style="list-style-type: none"> • Awareness and need to comply with CQUINN target (<i>Trust A</i>) • The need for national targets (<i>Trust F</i>) |
| Leaders with vision who engage all staff | <ul style="list-style-type: none"> • Individuals within the organisation who see their value and worth and attempt to share the vision and a lead who has the time to drive the initiative forward (<i>Trust E</i>) • Leadership by lead nurses, doctors and cancer service management team (<i>Trust A</i>) |
| Education and updates | <ul style="list-style-type: none"> • Our cancer services manager was promoted and delivered a focused awareness campaign to staff about the initiative (<i>Trust A</i>) • The CNS to have input into the education of district nurses for undertaking cancer reviews (<i>Trust D</i>) • Combined education sessions between primary and secondary care (<i>Trust D</i>) |
| Multidisciplinary involvement and collaboration | <ul style="list-style-type: none"> • An increase in clinicians' involvement (<i>Trust D</i>) • Multi-clinical involvement (<i>Trust D</i>) • Greater collaboration between the participating Trusts across Dorset (<i>Trust D</i>) |
| Positive feedback and perceived benefits | <ul style="list-style-type: none"> • Staff motivated and enthusiastic and can see the value in this initiative, benefits to patients and the wider MDT such as GPs (<i>Trust A</i>) • Better care and communication for patients (<i>Trust A</i>) • GPs in the locality have provided positive feedback on the initiative (<i>Trust A</i>) • Patients have fed back positively on the benefits of receiving the TS (<i>Trust A</i>) • The clinical team see the benefit and value of TS from the patient perspective and this increases commitment (<i>Trust F</i>) |
| IT systems | <ul style="list-style-type: none"> • There is a need to improve IT systems linking primary and secondary care (<i>Trust D</i>) • To be able to email GP surgeries (<i>Trust D</i>) • The development of an electronic treatment summary that links with other systems (<i>Trust D</i>) |

4.2: Findings from service user experience data

Two Trusts agreed to take part in the service user evaluation of treatment summaries, trusts A and D. Data were collected using one focus group of four people and two face to face interviews. Service users were selected and contacted by the lead cancer nurses on the basis that they had all received a treatment summary following an episode of treatment. Service users who took part in the study included people with colorectal cancer, breast cancer and head and neck cancer. Some family members were invited to take part in the study in situations where the service user felt more comfortable with them present. A further three service users who agreed to take part in the study were unable to attend and declined to be interviewed by telephone. Analysis of the data revealed five themes developed from 11 categories and these are included in the table five.

Table 5: Themes and categories related to service user experience of cancer treatment summaries

| Themes | Categories |
|--|---|
| 1. Timing and delivery of treatment summaries | <ul style="list-style-type: none"> • Knowing or not knowing if I have had a treatment summary • When the treatment summary was received measured by days of treatment completion, weeks or months after the treatment episode • How the TS was delivered- by post or by hand |
| 2. Purpose of the treatment summary | <ul style="list-style-type: none"> • Alerts to side effects and symptoms • Who is the treatment summary for the patient or the professional? |
| 3. Integration of care | <ul style="list-style-type: none"> • Integration of information between primary and secondary care • Focus on providing support from secondary care as the first point of call |
| 4. Quality of care | <ul style="list-style-type: none"> • Feeling fortunate • High quality care |
| 5. Family centred care | <ul style="list-style-type: none"> • Sharing with the family • Being a team |

In the theme: **timing and delivery of treatment summaries** some service users couldn't remember receiving a treatment summary even when a sample template was shown to them. For example one service user from Trust D described:

*I didn't receive anything like that, at least I don't remember ...
I only finished my treatment a few weeks ago*

Another service user from Trust D had a different story:

Oh I've had loads of leaflets ... sheets of paper telling me what will happen...

Both of these participants had treatment for head and neck cancer and had completed a treatment episode at approximately the same time however, neither felt that receiving the treatment summary was significant at the time. One service user in Trust D had received a treatment summary following a treatment episode for breast cancer and was very clear about when she received it and by whom:

*The treatment summary came when I was discharged from hospital...
I was discharged with it.*

A service user in Trust A who had received treatment for colorectal cancer also clearly remembered receiving his treatment summary and went on to explain that he wasn't expecting it at all:

It would be useful to be informed when you're discharged that you'll get a TS.

The timing and delivery of the TS also varied considerably among the service users with one participant receiving his 6 months after his treatment episode, while others were either posted or talked through and given out by specialist nurses at the point of discharge. This finding is consistent with the survey data. Service users who received their TS between two to six months after their treatment episode described how their "*mind was more capable of taking things in*". One service user said:

... there were two cancer nurses trying to talk me through things but it wouldn't stay in, trying to all absorb that, what I needed was a tape recorder!

For some service users, their latest treatment episode was following a reoccurrence of their cancer and they appeared to be more receptive to the information given, saying that they had a better idea of what to expect. From this evaluation it appears that not all participants could remember receiving a treatment summary and when they were given close to completion of the treatment episode, some service users appeared overwhelmed by the volume of information they received while others were able to select out key information and this appeared to be related to whether or not they had previous experience of receiving cancer treatment.

In theme two: ***purpose of the treatment summary*** those service users who acknowledged receipt of their treatment summary were able to describe what they thought it was for and stressed that it was to alert them to the symptoms and side effects of their cancer and the treatment they had received. They also stressed the importance of knowing who to call if they were concerned or needed advice. In Trust A the service user stated:

The information is very clear about the procedure, but I already knew that because the surgeon had told me... it reinforced what I already knew.

Some service users felt the treatment summary was more for the professionals than for them:

There's a lot about the cancer itself and its growth rate some people may not appreciate what that means. What's a DS1500 application? I don't know what that means?

You should have two forms, one for the patient and one for the professional.

One service user who had comorbidities raised the question about whether treatment summaries may be useful for other patient groups living with chronic conditions so that people could have a better understanding of what was happening and where to go for help. All service users agreed that the information available from a treatment summary could be and was used to share information with their families.

Overall service users who remembered having a TS had a clear understanding of the purpose of a treatment summary and thought they were a useful source of key information that could be shared with their family and other professionals although for some, the technical terminology appeared confusing.

In theme three: **integration of care** all service users and family members interviewed shared the view that the treatment summary was related to the relationship they had with the cancer specialist team (secondary care). None of the service users who participated in the study had engaged with their GP following their treatment episode and were not fully aware of what the GP had been told. Some service users noted that they were not given a discharge letter to take to their GP so had no need to attend the surgery. In Trust A one service user who completed his treatment six months before had not had any contact with his GP:

The hospital has been fine but I've not had anything from my GP at all.

In Trust D three service users knew what the ongoing treatment plan from the hospital was but had not considered going to see their GP:

It's all to do with the hospital, I see my GP once a year for blood tests because it's the only way I can get them done. I don't even go to the surgery for my repeat prescriptions.

Service users described feeling safe and secure because they could contact the specialist team if they had any problems rather than go to their GP.

In summary the findings demonstrated good integration of care between the service user and the cancer team in secondary care. However from the service users' perspectives they

saw no integration between primary and secondary care and had not anticipated that there would be in the majority of cases. Those with co-morbidities did however question if there should be stronger communication links between the patient, primary and secondary care services.

In theme four: **quality of care** all the service users praised the quality of care they had received and the accessibility of staff in the specialist cancer units. Some service users saw themselves as being:

... in a privileged position because we do receive a lot of information and the system works.

In summary the quality of care received from the cancer service teams was consistently praised and service users recognised the collaborative effort made.

In theme five: **family centred care** all service users recognised the importance of family in their treatment and recovery. One service user identified that he and his wife were a team:

We have coped with it quite well haven't we....? It was a joint thing, we did it together.

One service user who received radiotherapy explained:

They let me keep the mask, all the family wanted to see it, especially the grandchildren.

Another service user described:

When my hair started to grow back my grandson came over to me and stroked my head and said- Ooh it's just like the cat's fur. ... it makes it easier when you can talk about it with the family.

All service users described sharing all the information they had received, including the treatment summary, with their family “*my wife reads everything!*” Interestingly there was considerable family interest when service users were invited to participate in the evaluation and this led to some family members being part of the evaluation process.

In summary one significant feature of the TS was that it appeared to provide a focus point for sharing information between service users and their significant others and appeared to support service users in the self-management of their survivorship.

5. DISCUSSION

The first aim of this evaluation was to determine the progress made towards the implementation of treatment summaries received by patients between April and August 2015 across the Wessex Deanery. In this evaluation ambiguity around the definition of a treatment episode has impacted on the ability to compare findings across Trusts. This was further complicated by the use of the term “treatment package” which relates to the whole package of care provided at the point where care is transferred from secondary to primary care. According to Smith and Thompson (2013) a treatment episode relates an acute treatment phase, with a treatment summary provided at the end of each phase. This should also be an integral part of the holistic needs assessment and care planning and the cancer care review in primary care. The relationship between the definition of a treatment episode and the provision of a treatment summary does seem to be an area for future discussion and clarification for the accuracy and benefit of future audits.

Recommendation 1:

For clinical staff to continue to identify where ambiguities in operational definitions of treatment episodes, treatment summaries and patient selection exist and agree a way forward.

In relation to progress made towards implementation, the findings suggest that patients who fall into the colorectal and breast cancer groups were in receipt of treatment summaries although not all patients experiencing a treatment episode received a treatment summary. The percentage varied according to Trusts but overall uptake for colorectal cancer patients across the Trusts included was 49 %. For breast cancer the overall uptake was higher at 58%. This finding must be viewed with caution however because of the ambiguity of interpretation between definitions of a treatment episode.

Recommendation 2:

To review the coding and usability of electronic data systems and digital communication.

These results can be considered to be very positive when compared with findings from international studies on the implementation of treatment summaries. For example in USA the average uptake is between 31-38% with colorectal and breast cancer specialities as early adopters (Jabson, 2015; Rechis et al, 2014; Jabson and Bowen, 2013; Sabatino et al, 2013). This comparison should be considered with caution however due to the different definitions

of treatment summaries used and the timing of the evaluation which occurred 4-5 years after the publication of national USA guidelines, compared to 1-2 years in the UK. Nevertheless in spite of endorsements from key stakeholders, the uptake of treatment summaries in the USA for cancer survivors in the last 10 years is less than 50% (Klemanski et al, 2016; Rechis et al, 2014; Jabson and Bowen, 2014).

The second aim of this survey was to identify factors that have influenced the process of implementation. The challenges identified in the findings can be summarised as: resource challenges including: time, staff skill mix and documentation; role expectation and staff engagement; availability and accessibility of information technology (IT) systems; and lack of clarity over patient selection and documentation. These findings are similar to findings identified in the literature. For example in a systematic review of care plan preferences of cancer survivors and health care providers by Klemanski et al (2016), they identified that issues and barriers to implementation of care plans and treatment summaries included: debates about who should complete them, the time and cost involved, lack of consensus over format and concerns about sustainability of provision. Klemanski et al (2016) concluded that the provision of treatment summaries and care plans is strongly based on the principle of beneficence rather than rigorous evidence and that more work is required in order to explore the relationship between treatment summaries, care plans and patient outcomes.

Recommendation 3:

To identify examples of good practice in relation to leadership and engagement and share this information with others.

In relation to service user experience, the UK, outcome data on the benefits of treatment summaries for cancer patients has yet to be demonstrated due to the early stage of implementation across the UK nations. The qualitative findings from this evaluation however do highlight that positive feedback from service users and GPs in primary care on the benefits of treatment summaries acts as a motivator for clinical staff to continue their commitment and enthusiasm for the continued implementation of TS. Similarly multidisciplinary involvement and collaboration was seen as a positive factor in the implementation of treatment summaries, along with visionary leadership, education and updates; and IT systems that are fit for purpose. These findings are similar to studies that have identified factors that positively influenced the implementation of service improvement and clinical guidelines in health care settings (Jun et al, 2016; Rajasekhar et al, 2016; Ebben et al, 2015; van de Steeg et al, 2014; McCluskey et al, 2013; Abrahamson et al, 2012).

These have included: positive feedback from service users and perceived improvements in the quality of care have improved the motivation and engagement of clinical staff involved; leadership and engagement; education and updates and effective management of resources.

Recommendation 4:

To engage clinical staff in the provision of education and updates.

In this service user evaluation however several participants could not remember having a treatment summary, saying that they felt overwhelmed with information at a stressful time. Those who have previous experience of having cancer and those who had their TS several months later appeared to see the benefits of the TS. The timing of delivery for the treatment summary, up to six months after completion of the treatment episode, highlights what Brown et al (2016, p196) describe as an *“important teachable moment at the end of treatment”* In their study of 19 colorectal cancer survivors in the UK, they found that participants who had received information at the end of a treatment episode benefited from increased information provision about treatment consequences at a later stage and this supported increased patient empowerment and self-management. Brown et al’s (2016) study also highlights the uniqueness of cancer survivor’s experiences and while one survivor is willing to engage with the support systems available this may not be reflected in a wider population of survivors with different needs. In this evaluation some of the service users preferred to seek support in the family rather than through cancer support groups, while others actively engaged in all the support and activities that were offered.

For the participants in this study the treatment summary provided a reminder of the information received as part of the discharge planning process and provided a resource for sharing information with their families. This finding is consistent with findings from a study by Blanch-Hartigan et al (2015) who found that in a study of 359 cancer survivors , where 34.5% had received treatment summaries, there was a positive correlation between the receipt of a treatment summary and improved patient centred communication and perceived quality of care. However in this evaluation all service users had received a treatment summary and all described receiving high quality care although there appeared to be no direct link between the two factors.

Recommendation 5:

To continue to monitor feedback from service users about their experiences of receiving treatment summaries.

The question of what should be in a treatment summary and to whom it should be directed was raised by participants in stage one of the evaluation and continued to be issue for the service users in stage two. According to Smith and Thompson (2013) the TS was designed to improve communication between cancer services and primary care, however for some service users the technical information included in the TS did not always make sense.

Recommendation 6:

To support continuing multidisciplinary engagement in secondary care and more engagement with primary care.

The National Cancer Survival Initiative in 2013 proposed that a greater collaboration between primary and secondary care can provide a risk stratified approach to supporting cancer survivors through the short and long term consequences of cancer treatment. In this evaluation the findings suggest that from the service users' perspective there is still a divide between specialist support and support available via GPs in primary care. Service users are still contacting specialist services when they can rather than communicating with their GP. According to Walter et al (2015) following an online survey of GPs in England they found that GPs have a potentially important role in caring for people following cancer treatment and that timely use of cancer treatment summaries could enhance communication between secondary care providers, primary care and cancer survivors. However in this evaluation service users preferred to contact the cancer services rather than their GP.

6. CONCLUSION AND RECOMMENDATIONS

This service evaluation has been conducted at a very early stage of service implementation and as such the findings can only represent a snapshot of the early transition phase. For the participating Trusts, treatment summaries are becoming an integral part of the care for cancer survivors with evidence that feedback from GPs and service users is positive. Service users' experiences of receiving treatment summaries has been positive however some participants couldn't remember receiving one, when this happened it was associated with receiving large amounts of information at a time when it was difficult to absorb what was happening. Service users also recognised that their care and support came from secondary care rather than primary care following completion of a treatment episode. Key drivers and lessons learnt from this early evaluation can be used to guide future development and these have been presented as recommendations for further development.

In summary key recommendations at this stage include the following:

7. For clinical staff to continue to identify where ambiguities in operational definitions of treatment episodes, treatment summaries and patient selection exist and agree a way forward.
8. To review the coding and usability of electronic data systems and digital communication.
9. To identify examples of good practice in relation to leadership and engagement and share this information with others.
10. To engage clinical staff in the provision of education and updates
11. To continue to monitor feedback from service users including patients and primary care staff.
12. To support continuing multidisciplinary engagement in secondary care and more engagement with primary care.

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