Development of an interactive, web-based shared care plan to facilitate the follow-up care of colorectal cancer patients

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Abstract

Introduction A shared model of care between cancer services and primary health care is safe and acceptable and can address the increasing demands on cancer services for long term follow-up. This paper describes the challenges developing an interactive shared care plan for colorectal cancer follow-up care that supports collaboration between the care team and patient. **Methods** A systematic literature review was undertaken to identify web-based care plans for follow-up cancer care that would inform the implementation of a system to share an individualised care plan. We conducted individual consultations with 25 key informants/stakeholders to understand the requirements and challenges of establishing the web-based care plan and to identify the technical options to share the care plan. This was followed by a structured group consultation with 13 key stakeholders to obtain agreement on the model of care and the technical solution to share the care plan. **Results** We identified five web-based shared care plans for cancer follow-up care. These systems supported the creation and/or access to view or share the care plan via internet log-in, email or hard copy. None of the SCP had interactive functionalities to support collaboration and none of the included papers reported formalised models of shared care between cancer services and primary care. The challenges identified included the security, privacy and sharing of patient information between public health services and primary health care and poor integration of clinical information systems. A primary care practitioners' care planning system was selected for the pilot as it addressed the challenge of sharing clinical information between the public health system and external clinicians, partially addressed integration (integrated with the primary care clinical information systems but did not integrate with the cancer centre systems), supported collaboration between the care team and patient and was relatively inexpensive. **Conclusion** Primary care shared care planning systems seem a suitable option for sharing clinical information between a cancer service and primary care practitioners. We plan to evaluate the feasibility and acceptability of this interactive shared care plan to support shared cancer follow-up care.

Background

An estimated 17,004 new cases of colorectal cancer were diagnosed in 2018 and in the last 30 years, the five year survival rate for colorectal cancer increased from 48% to 69% in Australia(1). Hospital based Cancer Services continue to provide long term follow-up care for an increasing number of survivors which is not sustainable.

Sharing long term follow-up care using a care plan between cancer specialists, primary care practitioners (PCP) and other care providers can help address this issue. It has been demonstrated that this model of care is safe and acceptable to patients and providers(2-7), can positively impact on patient attitudes about their health care(8) and does not have different survival outcomes from specialist care(7, 9). The majority of cancer patients have PCPs who are involved in their care but have little role in their long term cancer care and surveillance. Improving communication and support between specialists and PCPs may increase the role of PCPs in managing follow-up cancer care(10).

Information and communication systems can support a shared care model by providing care team members with access to the care plan and a vehicle for collaboration(11). A shared care plan (SCP) system needs to be interactive with multiple user access allowing team members to confirm acceptance of their roles, track that tasks are completed, notify when tasks are due and share information and results(12, 13).

We aim to pilot a follow-up shared model of care for patients who have completed colorectal cancer treatment, using a semi-integrated and collaborative platform in which patients, specialists, PCPs and other care providers interact and share an agreed care plan.

This paper explores the use of web-based SCP systems to support cancer follow-up care, identifies current technologies to share a care plan between a public cancer service and primary health care providers and the challenges getting an interactive SCP to the pilot stage.

Setting

The St George Cancer Care Centre is situated in a public hospital in the South Eastern Sydney Local Health District in the state of New South Wales, Australia. The PCPs in the area are situated within the Central and Eastern Sydney Primary Health Network boundary that has, as one of its aims, to improve the coordination of care.

There is currently no model of shared care between the cancer service and primary health care. Communication between the cancer service and PCPs is limited and usually one way. This may include a letter from the medical oncologist to the patient's PCP that summarises the treatment the patient has received. Conversely, the specialist may receive a PCP Care Plan from the PCP to sign and provide information about the patient's care as a requirement for the PCP to claim the item of service.

The cancer service uses a commercial oncology information system (ARIA® Oncology Information System, Varian Medical Systems, Inc.) which is not well integrated with other District information systems. Patient administrative details are held in a Patient Administration System and pathology and radiology results are captured in two other systems.

GPs use various commercial clinical information systems with the two most common systems being used by 94% of the general practices within the area in which the cancer service is located. Most PCPs are enabled to send and receive secure messages, such as sending referrals and receiving discharge summaries, letters from specialists and pathology and diagnostic results, but this is limited as many specialists and allied health clinicians do not use secure messaging(14).

Methods

We undertook a systematic literature review in accordance with the PRISMA statement(15)., The aim of the review was to identify cancer web-based follow-up care plan systems, their use and functionality, and impacts they had on care. We searched Medline, Scopus, Web of Science, Cochrane and CINAHL using

the following search terms: “informatics” or “internet” and “care plan” and “cancer”. (e.g. Medline search: ((informatics or internet) and (cancer and care plan)). The search was limited to papers published between 2005 and 2018 as currency of the care plan systems was important given we were looking for options that could be currently applicable. Eligibility criteria included that the SCP was for follow-up cancer care and that it was partly or fully web-based, were from OECD countries and in English. All types of research papers and perspectives were accepted as the main priority was to identify cancer follow-up care plans, how they were being implemented and any impacts that had been measured.

Duplicates were first removed and papers were screened by title and abstract and the full articles assessed for eligibility by a researcher (JT). All excluded papers were screened by a second researcher (MH). Data was extracted into a spreadsheet which included author, year, country, a description of the SCP, who created/completed the SCP, study type and results, and impacts of the SCP.

Twenty five key informants and stakeholders were identified by the study’s research team and steering committee members. They included medical oncologists, cancer nurses, GPs, a consumer from the Translational Cancer Research Network, Local Health District integrated care and information and communication representatives, the Primary Health Network (which has responsibility for improving access to primary health services in the district), and a state government eHealth body (eHealth NSW) (16) which was responsible for leading information and communication technology policy and programs for state health services.

Individual consultations were undertaken with key informants/stakeholders prior to the group consultation to understand the requirements and challenges of establishing the web-based care plan and to identify the technical options to share the care plan. Results of the systematic review and individual consultations were used to inform the group consultation discussions and decision-making to determine the best option to create and share the cancer follow-up care plan. . Eighteen key stakeholders were invited to participate in the group consultation. The purpose of the group consultation was to obtain consensus on the approach and scope of the SCP initiative and the best option to share the care plan. The group consultation followed a structured agenda which included the aims, background to the initiative and the systematic review findings, a problem solving session that walked through the functionality requirements and discussed the issues, gaps and challenges that had been identified in the individual consultations, and a group discussion to gain consensus on solutions to address these gaps and issues and the most suitable option. The group consultation was facilitated by a researcher (JT) and a representative from eHealth NSW (JP). Text records and transcripts of the consultations were aggregated and thematically analysed.

An ethics application was not required as this was a service improvement initiative by the South Eastern Sydney Local Health District which met the NSW Health Quality Improvement Ethical Review policy requirements (Quality Improvement and Ethical Review GL2007_20). Group consultation participants verbally consented to the consultation being recorded and were aware that their aggregated contributions would be used for the project and subsequent publications.

Results

Systematic literature review results

Out of 225 papers, seventeen were included that identified five web-based cancer SCP. These were based in the USA (3 SCP), The Netherlands (1 SCP) and one in Sweden (1SCP) which was under development. The Livestrong and OncoLife SCP were the same SCP which had been given different names over time. (See Figure 1 for the PRISMA search flowchart and Additional File 1 for a summary of the included papers).

The papers included feasibility and evaluation studies of the SCP technology (17-19), descriptive studies using SCP data and/or surveys/questionnaires on user satisfaction and participation (20-27), predictive modelling as to who receives a SCP(28), a review on the adherence, advantages and limitations of cancer SCP (29), a review with a focus on nursing practice(30) and a description of SCP systems that were under development at the time(31, 32).

The SCP were usually initiated by physicians/oncologists and cancer nurses. One SCP supported cancer survivors and their families and friends to create the SCP. The SCP was populated using the online responses to survey questions and clinical guidelines(17, 18, 20, 21, 23-26, 28, 30, 33, 34).

There was only one system that reported being integrated with the Electronic Medical Record (EMR) at a cancer centre. Demographics and treatment data were extracted from the EMR into the web-based platform and the final SCP downloaded back into the patient's record in the EMR(17).

Two SCP documents could be shared via internet login(22, 29, 32) while all other SCPs needed to be printed or emailed as a PDF.

There were no papers reporting SCP systems that had interactive functionalities supporting collaboration, coordination and surveillance of care and monitoring of shared care. None of the papers reported formalised models of shared care between cancer services and primary care, although 32% of the survivors who had used one model reported they were receiving follow-up care from an oncologist and a PCP(21) and survivors older than 70 years were more likely to have a primary care provider(33).

Impacts reported in the papers, included that it changed the way survivors participated in health care and improved communication with health providers(20) and was an effective way to communicate(22).

Most survivors using one model planned to share it with their PCPs(18, 20, 23-26). Reasons for not sharing the care plan were that their provider would not care about the plan, they did not feel the plan was relevant to the provider or that the SCP was too long or it would upset the provider(24, 26). In other studies users reported that the SCP was easy to use (18), they were satisfied with the tool(18, 20, 21, 23-

25, 30) and found it useful(19). In one study, survivors who were most likely to receive a SCP were managed by a team and were over the age of 70 years at diagnosis(28).

Key stakeholder consultation results

Twenty five key informants/stakeholders participated in the individual consultations and 13 key stakeholders participated in the group workshop.

Challenges identified to implementing the interactive SCP were mostly governance issues including security, privacy and the sharing of patient information. There were concerns about the security of systems not managed or controlled by the Local District Health Service and uncertainty as to whether electronic clinical information could be shared with PCPs and other external health providers under existing policies and regulations. This was a major challenge given the Local Health District would only provide access to a SCP to their own employees.

Another challenge identified was the lack of incentives for PCPs to participate and engage in cancer shared care under the current fee for service payment system.

It was agreed that the model of care needed to involve PCPs as members of the cancer care team. Patients and their PCPs would be invited to participate by the cancer specialist after a patient's acute cancer treatment was completed.

Our initial thinking was that the cancer specialist would create the SCP and the cancer nurse coordinator would organise and monitor the sharing of care. PCPs would be provided with tasks to monitor reoccurrence, detect other cancers and to manage the late and long term side effects of treatment. Other tasks would address psychosocial issues, lifestyle and other preventive care needs of the patient, such as immunisations. The care team would feedback information after patient visits, indicate when tasks were completed and upload any relevant results into the care plan for the care team to view. A nurse coordinator would monitor that care was being provided and was timely.

Patients would have access to their care plan to self-monitor, report on progress or add their own goals as well as to provide feedback. They could be fast tracked back to the Cancer Service and PCPs could get advice from the cancer specialist through the shared care system or by phone, dependent on urgency.

The technology options identified in the group consultations had to support the model of care, the requirements of the state health system and the needs of consumers and the care team. Some of the identified requirements included that it be scalable to different cancer types and other services and conditions, be consistent and compliant with state and national ehealth and privacy standards, be easy to use, integrate with clinical systems, allow multiple user access, be affordable and able to be implemented relatively quickly for the pilot. It was initially conceived that this system would be hosted

and maintained by the Health District or at the state level by NSW Health. The options identified for sharing the care plan are summarised in Table 1.

Table 1: The advantages and disadvantages of cancer shared care planning options

Options	Advantages	Disadvantages
<p>My Health Record</p> <p>(an online summary of an individual's health record)</p>	<ul style="list-style-type: none"> · Patient controlled · Care team access · View diagnostic and pathology results · Integrated with general practice clinical information systems 	<ul style="list-style-type: none"> · Does not have care plan functionality so needs work around if possible · Not interactive to support collaboration · Not all GP practices are connected to MHR (about 50% in area) · Cancer Information System not integrated with MHR
<p>Secure messaging</p> <p>(Argus, HealthLink and Medical Objects are the main secure messaging systems)</p>	<ul style="list-style-type: none"> · Most GPs have secure messaging installed · Integrated with GP clinical systems 	<ul style="list-style-type: none"> · Not interactive · Version control of the care plan could be a problem · Cancer Service would need to install 3 secure messaging systems to cater for the different systems in general practices that are currently not interoperable with one another · Many allied health services do not have secure messaging installed
<p>HealtheNet</p> <p>(Secure sharing portal connecting a patient's medical history from information systems within the NSW LHDs for clinicians within the health system to access)</p>	<ul style="list-style-type: none"> · Can upload documents from the cancer information system to HealtheNet · Provides access to NSW Health clinicians to view My Health Record · Functionality to send the care plan using secure messaging is possible The SCP could attach as the follow-up action plan to a discharge summary 	<ul style="list-style-type: none"> · Not accessible to external care providers unless they have associate status · Not accessible to patients · GPs cannot send documents back through HealtheNet · Documents can only be viewed · Would require some technical development to send the care plan to GPs through HealtheNet · Does not support collaboration
<p>Web-based cancer care plan creators identified in the literature</p> <p>Oncolife / Livestrong, Passport for Care. The care plan is generated using an algorithm based on responses to a survey</p>	<ul style="list-style-type: none"> · Patient creates and controls the care plan · Passport for Care can be viewed online through the patient log-in · Cancer specialist can upload a Treatment Summary to Passport for Care · Livestrong is integrated with the Epic EMR (Epic is not widely used in Australia but is being implemented at Peter MacCallum Cancer Centre in Melbourne) 	<ul style="list-style-type: none"> · Do not support collaboration between the care team · None were integrated with GP systems · Passport for Care designed for childhood cancers only

Options	Advantages	Disadvantages
Collaborative platforms for businesses (Web or cloud-based systems that support the sharing of information and collaboration)	<ul style="list-style-type: none"> · Supports collaboration · Secure instance could be set up within the LHD firewall 	<ul style="list-style-type: none"> · Challenges around sharing clinical information with clinicians external to NSW Health · There are barriers to the use - requires log-in to a separate system, some difficulty creating and navigating the SCP and time required to set up access rights at the patient level · Not scalable. Only suitable for a small sample of patients as a Proof of Concept
PCP care planning systems (Online services to manage care plans)	<ul style="list-style-type: none"> · Truly interactive and support collaboration between team members and the patient · Integrates with GP information systems · Prompts and notifications included to assist with implementing and monitoring the SCP · Some of these systems are compliant with NSW and Commonwealth standards · GPs can claim the MBS Item for generating or reviewing the SCP · Less expensive than developing a new system · Scalable to other cancers, conditions and services 	<ul style="list-style-type: none"> · Not integrated with LHD information systems · Cancer staff need to interact with the care plan through the web interface · Off the shelf product does not meet all functionality requirements

The first three options (My Health Record (MHR) - national electronic health record, secure messaging and HealtheNet) did not have the functionality to allow fully interactive collaboration between the specialist and primary care clinicians. The care plan could not be shared in an appropriate format in MHR. The care plan could be shared using secure messaging and HealtheNet, but there were barriers to PCPs accessing HealtheNet as access was restricted to state health employees.

The fourth option were the web-based cancer care plan creators identified in the systematic review (See additional file 1 for details on these systems). These provide a useful tool, particularly for patients, to create care plans using algorithms based on the guidelines for follow-up treatment. The main disadvantage of these systems was that in their current state they were not interactive so did not support collaboration, coordination or surveillance of care.

The next option was an off the shelf collaborative platform. These are developed particularly for businesses to share information and collaborate. We set up a care plan in a commercially available

collaborative platform as a proof of concept but were informed that patient information could not be shared using this platform due to the state health privacy and security concerns around the sharing of clinical information with external health providers. Other barriers with using this platform were difficulties with using the system, access and scalability.

Given that sharing information at the Local Health District level with external providers was a problem, we looked to the primary health care sector for off the shelf solutions. A number of PCP care planning solutions were available that were integrated with PCP information systems, supported patient and care team access and were relatively easy to use. Eight of these systems had self-declared compliance with the Commonwealth Department of Health minimum requirements for shared care planning software as part of the Health Care Home trials⁽³⁵⁾ and two of the systems were utilized in the NSW Health Integrated Care trials with varying success. We selected a system based on a set of requirements including compliance (e.g. ISO information security management, mandatory privacy and security legislation and NSW Health standards and guidelines for information management and sharing information, current penetration test), technical requirements (e.g. integrated with PCP systems), functional requirements (e.g. notifications and alerts, supports care pathway, easy to navigate, customisable cancer care plan template), readiness and maturity of solution, scalability and costs to develop and maintain the system.

To utilize PCP care planning systems required a rethink of the care plan pathway (see Figure 2). The process would be initiated by the specialist and providing a treatment summary to the PCP and inviting them to join the shared care team. The PCP would then initiate a standard care plan (for that particular cancer type), upload patient and clinical information (including the treatment summary provided by the oncologist) and provide access rights to the cancer specialist and other providers (eg allied health). The specialist would then review and adjust the schedule of tasks, add in who was responsible and the timeframe for their completion. The PCP (with the patient) would then approve the final care plan and set up patient recall in their practice system. The PCP and oncologist and other team members would notify when their tasks were completed and share other relevant information collected during patient visits. Patients could also notify tasks they were responsible for (eg attending a physical activity program). The cancer nurse coordinator would monitor the patient visits and tasks as an additional check that shared care was being provided and to review the program.

The PCP care planning system would provide a workaround solution to the barrier of sharing clinical information from a state-based health service to external health providers. The PCP would upload the clinical information while the cancer specialist would create the individualised care plan. A disadvantage was that it would not integrate with the cancer service information systems but could have the capacity to in the future.

Discussion

eHealth solutions can enable the coordination of care, the safe sharing of patient information, knowledge and individualised SCP.(36) We identified a gap in the literature on the lack of the use of web-based tools that enable models of cancer shared follow-up care by supporting communication about patient needs and goals, the sharing of clinical information, agreement on the roles and tasks of the care team and surveillance or tracking the completion of tasks.

We found challenges in sourcing an ehealth system for a pilot that was not costly, relatively easy to access and use and met our requirements. While the pilot solution does not meet all the requirements, it does integrate well with PCP clinical systems and provides a workaround for sharing clinical information between the cancer service and PCPs. The care plan creators identified in the systematic review could potentially be part of a web-based shared care plan solution but it would require additional technical development. The issue identified with sharing information between state funded services and external health services was also identified by one of the state's Integrated Care demonstration projects which reported that service providers and patients were fearful and unwilling to share information because of privacy concerns.(36)

The state health service privacy manual for health information states that health information can be disclosed as long as it is directly related to the primary purpose.(37) It could be considered that follow-up care is related to the primary purpose of cancer treatment.

To address security we arranged for the District to undertake a compliance check of the SCP tool and obtained executive approval to use the system.

The SCP system supports PCPs to claim reimbursement through the use of MBS Items for GP Management Plans and Team Care Arrangements which may assist with PCP participation. We also believe if their patient wants to participate in shared care then PCPs may be more likely to agree, particularly if they are supported with education and ongoing communication/links with the cancer service. PCPs need to be confident with follow-up care and feel they are part of the cancer care team. Patients also need to be assured that a shared care arrangement is safe and effective.

In the long term the issue of funding SCP systems will be a challenge given that health providers participating in shared care come from a range of services and jurisdictions. Who will ultimately pay for it? The PCP care planning system we are piloting takes a percentage of each care plan MBS Item generated. We are covering the cost for this in the pilot but in the long term this would be paid by the PCP. Future iterations of the SCP systems will require funding to integrate with the Local Health District information systems and the platform could possibly be managed within the public health system. In the long term, incentives will be needed to support the uptake of ehealth systems (such as SCP) and to minimize any disproportionate costs and savings across the services(36) involved in shared care.

While the SCP system does not address all the functional requirements (such as integration with the cancer service systems) it does offer a work around solution. We are currently evaluating its feasibility and acceptability with patients and clinicians. Our aim is to develop a system that is scalable to other

cancer types, and other services sharing care with primary health care. Using SCP systems that integrate with PCP clinical information systems provides a good starting point for sharing care plans and collaboration between cancer services, PCPs, patients and other care team members. This work will inform other state and national SCP strategies.

Conclusion

Cancer follow-up shared models of care require interactive SCP systems that enable collaboration, coordination and surveillance of care. General practice shared care planning systems seem a suitable option for sharing clinical information between a cancer service and PCPs. We have developed a feasible solution which of course needs further evaluation to determine its impact on work practices both in Cancer Services and primary care and its impact and outcomes for patients.

List Of Abbreviations

ISO International Organisation for Standardisation

PCP Primary care provider

SCP Shared care plan

Declarations

Ethics approval and consent to participate – Participants verbally consented to the group consultations being recorded and were aware that their contributions would be used for the project and subsequent publications. Ethics approval was not required as this was a service improvement initiative by the South Eastern Sydney Local Health District which met the NSW Health Quality Improvement Ethical Review policy requirements (Quality Improvement and Ethical Review GL2007_20).

Consent for publication – Not applicable

Availability of data and materials - The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request

Competing interests - "The authors declare that they have no competing interests"

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- South Eastern Sydney Local Health District, The Inspiring Ideas Challenge 2017;
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- Cancer Institute NSW Innovations in Cancer Control, 2018.

Authors contributions

JT undertook the systematic literature review, conducted, analysed and interpreted the data from the consultations and was a major contributor in writing the manuscript.

MC was a major contributor to developing the study and participated and informed its implementation, was involved in interpreting results and contributed to writing the manuscript.

WL informed the study development and implementation, participated in the interpretation of results, contributed to the consultations and contributed to writing the manuscript.

JL informed the study from the consumers perspective, participated in the consultations and contributed to writing the manuscript.

AD informed the study from the primary health care organisation and information technology perspective, contributed to the project development and writing the manuscript.

JP informed the project from the ehealth perspective, contributed to its development, was a major contributor to the group consultation and contributed to writing the manuscript.

MH was a major contributor to developing and implementing the study, conducting the systematic literature review, interpreting results and was a major contributor to writing the manuscript.

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Additional File

File name: Additional File 1

File format: MS Word

Title of Table: Summary of systematic literature review included papers for web-based cancer shared care plans

Description of data: A summary of the cancer follow-up care plans identified in the systematic literature review findings

Figures

Figure 1

PRISMA search flowchart

Figure 2

Supplementary Files

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- [AdditionalFile1.docx](#)