ABSTRACT

Background: Providing coordinated care remains a challenge for cancer services globally. There is a lack of consensus in the literature about what constitutes successful coordinated care.

Purpose: This study aimed to define and prioritise a set of consensus-driven success factors that can lead to coordinated care.

Methods: A mixed method approach was used that included literature review, a broad call for submissions from relevant stakeholders and a priority setting process based on a modified Nominal Group Technique.

Results: Thirty articles that related to success factors in coordinated care were identified in the literature. Twenty submissions were received from a broad range of stakeholders. From these sources, a set of 20 success factors was derived. Seventy stakeholders attended a series of workshops across New South Wales (NSW), Australia, to review and prioritise these 20 success factors against significance and measurability. Clear consensus was reached on prioritising two success factors linked to improving coordinated care from first presentation to diagnosis and ensuring that patients are routinely screened for physical and supportive care needs. Other highly-ranked factors included the need for a comprehensive care plan and that patients at higher risk for disjointed care are identified.

Conclusions: This study defines and prioritise a set of success factors regarding to coordinated care in cancer. These success factors will be used to guide the development of interventions targeting improving coordinated care as well as supporting the development of new funding models based on performance indicators derived from these factors.

**INTRODUCTION**

How to best coordinate cancer care remains a key challenge for health services globally 1-3. Across many types of cancer, there is evidence that care is poorly coordinated resulting in fragmented care, unnecessary stress and increased morbidity 4. A variety of interventions have been adopted by health services to improve coordinated care including: introduction of cancer care coordinators and patient navigators 5-7; implementation of treatment care pathways and plans8; screening of patients for physical and psychological distress 9; multidisciplinary cancer care teams 10 and application of electronic communication tools 11.

Despite the wide variety of approaches taken to improve coordinated care, gaps remain in empirical evidence pertaining to the effectiveness and impact of coordination strategies. One of the greatest challenges is a lack of conceptual clarity for a broadly accepted definition of care coordination 12,13. A literature review conducted by McDonald et al 13 identified more than 40 definitions of care coordination. While the authors of this study propose a common definition for care coordination, the emphasis of an extensive list of available definitions highlights a lack of common understanding for shared discourse and research. This only adds confusion to an already a complex process involving multiple players who deliver multimodal interventions typically dispersed across health services. Further consequence includes a lack of common reference for consensus raising processes that seek to better understand components of coordinated cancer care and the development of measures to gauge the impact of these care components.

Globally, providers are faced with increasing performance scrutiny, with growing requirements to justify service provision, inclusive of coordination of care interventions. This has led to considerable interest from multiple stakeholders, such as funders, accreditors and governing agencies, who seek valid indicators for the measurement of care quality, including care outcomes. The American Society of Clinical Oncology (ASCO) notes the growing number of long-term survivors of cancer to be a success story, but acknowledges that now greater focus is required on transitions in care and coordination with other providers 14. In the report addressing the state of cancer services in America (2014), ASCO emphasises the need to engage primary care and advanced practice providers in coordination of care, as well as making reference to new payment models that reward care coordination services.

In the state of New South Wales (NSW), Australia, funding for coordinated care in cancer has been historically linked to funding care coordinator positions. While cancer care coordinators clearly provide valuable services 5,7, there is considerable inequity in the distribution of cancer care coordinators across institutions and tumour streams 5. The Cancer Institute NSW, a government-funded statewide cancer control agency, has recently changed its funding model from one that focuses on roles to one that links funding to improving performance in key areas across the cancer system. To support this transition, funding for coordinated care is progressively being linked to meeting a set of Key Performance Indicators (KPIs). Such calls exemplify the widespread transitions in services that call for reliable measures of care coordination.

In addition, There have been a number of indicator development efforts associated with care coordination, including those not specific to cancer care 15, those focused on a particular tumour stream 3 and others targeted at a specific stage of the cancer journey 16.

To support their iterative KPI development process, the Cancer Institute NSW commissioned the University of Sydney to identify and prioritise a set of key ‘success factors’ to represent a broad set of statements that collectively describe successfully coordinated cancer care from a patient, health professional and systems perspective. The aim of this study was to document and prioritise success factors for coordinated care based on significance and measurability that can be used to guide the development of a set of coordinated cancer care KPIs. The term success factor is used to describe how successful coordination of care can be described which is a necessary precursor to the development formal KPIs

**METHODS**

A systematic process was used to define a set of success factors (Figure 1). This included: a review of the literature; a broad invitation to stakeholders to submit their own success factors; and a series of workshops to prioritise these success factors against the criteria of significance and measurability.

Figure 1 about here

## Literature review

A literature review was undertaken to identify existing success factors for coordinated cancer care. As there is no definitive definition of coordinated care in cancer, a wide variety of search terms were used across coordinated care, integrated care and chronic disease to identify potential success factors. The literature search was conducted using MEDLINE and SCOPUS between 1946-2014 which included up to the commencement of the project. The search terms in Table 1 were applied across both databases.

Table 1 about here

In addition to the three searches, reference lists of relevant references were crossed-checked for further articles, and the related documents function was utilised within the database. Further, Google Scholar and Google were searched using a combination of the above search terms to identify further research articles or grey literature. The titles and abstracts of articles or executive summaries of grey literature documents were reviewed by two authors (SY, AH) for relevance. Any discrepancies in inclusion or exclusion of articles were addressed by three authors (SY, AH, TS) until a consensus was reached. Articles were included if they made reference to factors or performance indicators of cancer care coordination, achieving best practice for coordinated care in cancer, measuring coordinated care, barriers to coordinated care and strategies for improving coordinated care. Relevant research articles or grey literature documents were identified and included in the review process (See Figure 2).

**Figure 2 about here**

**Developing coordinated care ‘success factors’ in cancer**

While no literature was found that specifically referred to the term ‘success factors’ for coordinated care in cancer, a number of key references and documents were identified that included aspects of successfully coordinated care from a variety of perspectives including the patient, health professional and organisation. Two members of the research team extracted these examples to form a series of succinct statements or ‘success factors’ (SY, AH). This process was independently cross-checked by a third member of the team (TS). A matrix of these success factors was developed that linked the factors to the one or more references from which they were drawn. An interactive process of document review and refinement of success factors was undertaken by consensus processes including five authors (SY, AH, TS, DM, NR) until saturation of factors in the literature was reached.

## Inclusion of stakeholder perspectives on successful coordinated care in cancer

A list of key stakeholders was identified by the Cancer Institute NSW leadership team and invited by email to electronically submit their perspectives about what they considered to be factors that contributed to improved coordinated care. Key stakeholders included cancer care coordinators, Cancer System Innovation Managers (CSIMs), Directors of Cancer Services, specialist nurses, clinical managers and consumers (including patients and caregivers). The email provided a background to the project, a set of domains of coordinated care (which consisted of broad areas of coordinated care commonly referenced in the literature, such as provision of timely information) and examples of potential success factors. A template was included for stakeholders to provide suggestions about what may be regarded as outcomes of successfully coordinated care as well as examples of how these might be measured. Success factors and examples of indicators identified through stakeholder submission were merged into the matrix. Where stakeholder suggestions could not be incorporated into success factors drawn from the literature, they were included as standalone items.

## Refining success factors

A consensus driven process was undertaken by the research team and Cancer Institute NSW to refine the list of success factors to reduce duplication, remove factors not clearly linked to coordination of care and refine wording of success factors. This involved two face-to-face meetings attended by the three members of the research team (SY, DM and TS) and two representatives of the Cancer Institute NSW. At these meetings each success factor was discussed and consensus was reached on its final inclusion, consolidation if agreed a duplicate or deletion if it was considered to be not linked to coordinated care.

## Priority setting workshops

A set of success factors was subjected to a prioritisation process previously developed by Sydney Catalyst researchers in an implementation science program of work in lung cancer 17,18. This priority setting methodology involves a modified Nominal Group Techniquewith individual and group ratings of success factors against pre-determined criteria. This methodology was well suited to this program of work as it harnesses individual judgements and the interactive discussions of key stakeholders to gain insights and determine the extent of consensus for priority items.

*Workshop activity 1 - Individual ratings*

Participants were presented with the success factors and provided the opportunity to seek clarification, discuss and debate the factors and provide suggestions for improvements.

A matrix table (see Figure 3) using a Likert rating scale from 1-5 was provided to each participant; they were asked to rate each success factor against two criteria of significance and measurability from 1 ‘agree least’, to 5 ‘agree most’. Significance was defined as ‘most likely to impact on patient outcomes’ and for measurability, that a ‘Key Performance Indicator could be developed that could be *feasibly* measured and reported on across cancer services’. During this step, participants were asked to consider and allocate scores based on their individual judgements and were also given the opportunity to provide further comments or suggestion relevant to each success factor.

Figure 3 about here

*Workshop activity 2 - Focus group priority setting activity ‘Significance’*

Following the completion of the individual matrix, participants broke into one or two groups depending on participant numbers, providing further opportunity for group discussion and debate of the success factors. A ‘dotmocracy’ approach was used to capture the group’s priorities and highlight areas of consensus 19. Using their individual ratings as a guide, each group member was asked to identify and share what they considered to be their top four success factors, according to significance. Each participant’s priorities were captured with a star placed next to each of their top four identified priorities. If two groups were used, the groups then re-convened and ‘dotmocracy’ charts were compared and combined to determine whole group consensus and priorities for success factors considered to be the most significant.

*Workshop activity 3 - Focus group priority setting activity ‘Measurability’*

Participants again broke into one or two groups and repeated activity 1 for the criteria of measurability. The groups re-convened if needed and charts combined and compared to determine whole group consensus and priorities considered to be the most measurable in cancer services.

*Workshop Activity 4- Discussion and group consensus*

Following the priority setting activities, the charts were combined and reviewed to collectively identify factors that rated highly in terms of both significance and measurability. This provided further opportunity to discuss, debate, and determine whether whole group consensus could be achieved.

*Evaluation*

A brief online evaluation survey was developed and disseminated to all workshop participants. The survey consisted three questions that asked participants to rank on a 1-5 Likert scale: 1) that they had the opportunity to contribute to discussion during the workshop; 2) that the success factors were relevant; and 3) that they found the prioritisation process useful.

The research team recorded participant’s feedback at each workshop and convened immediately after each workshop to consider how the feedback informed the success factors selected by the participants.

**RESULTS**

## Scoping literature review

Thirty studies and reports were identified and used to develop the success factors for coordinated care. Results included a range of peer reviewed articles, government reports, position statements of cancer control agencies, and clinical and quality care guidelines 1-3,8,12,15,16,20-42.

## Inclusion of stakeholder perspectives for successful cancer care coordination

A total of 20 submissions were received from stakeholders both metropolitan and rural representing 13 local health districts from across NSW (8 submissions were from metropolitan and 12 from outer metropolitan or rural). Success factors included in the submissions were grouped according to common themes, along with any included examples of indicators.

## Refining success factors

A total of 48 success factors were identified through the review of literature and stakeholder input. This was refined to the set of 20 success factors. This set of 20 success factors was used in the priority setting process at each workshop.

## Priority setting workshops

### *Quantitative data*

Seventy key stakeholders from across all NSW local health districts attended one of six priority setting workshops. Of those in attendance, 25% were from regional, rural or remote areas. A range of stakeholders attended each workshop dependant on availability. In general, this included as a minimum, cancer care coordinators at each site, the CSIM and a representative of the relevant leadership team. A dedicated workshop was held with 8 consumers selected by Cancer Council NSW. Consensus was said to be reached when a success factor was rated as a priority by over one third of all workshop participants for both significance and measurability (this value was seen to provide clear across a heterogeneous stakeholder group).

Two success factors stood out as priorities with consensus reached at four of the six priority setting workshops. These identified success factors were:

1. ‘Patients receive timely and appropriate care on the pathway from first presentation to diagnosis and to commencement of treatment’
2. ‘Patients are routinely screened for physical, psychological and supportive care needs using validated tools and referred to required services in an appropriate and timely manner.’

Two success factors were identified as potential second tier priorities with consensus reached at three of the six priority setting workshops. These success factors were:

1. ‘All patients have a comprehensive care plan that is created jointly by patients, family and health professionals and that is documented, accessible by relevant care providers and patients and maintained over the course of their care.’
2. ‘Patients at elevated risk for disjointed care and poorer outcomes (e.g. Culturally and Linguistically Diverse (CALD), Aboriginal & Torres Strait Islander) are identified and systems are in place to ensure care is appropriately managed and coordinated.’

Consensus was not clearly reached on other success factors

### *Qualitative data*

Reflection on feedback resulted in the combining of a number of success factors, ultimately leading to refinement of the presented set of 20 success factors to a final set of fourteen. (see Table 2).

Table 2 about here

It was discussed that Identifying key time points along the care pathway was vital but particularly challenging in primary care. This led to success factor 1 being expanded to include time to diagnosis, time from diagnosis to treatment and time from diagnosis to supportive care, as described by others 44,45.

The need for distress and symptom screening being vitally important was highlighted but it was acknowledged that it needs to include both planned and unplanned screening activities. The latter was particularly important in reducing unplanned admissions to Emergency. Success factor 13 was adjusted accordingly.

Treatment and follow up care plans were considered very important, however, it was recognised that development of a single comprehensive care plan is ideal but perhaps unachievable for all patients. Success factor 6 was modified to indicate that more than one plan could be used along the care trajectory.

Much discussion occurred around Success Factor 5 that referred to identifying patients at elevated risk of poorly coordinated care. While this factor was ultimately not prioritised, almost all participants agreed that this factor was central to increasing the efficiency, effectiveness and equity of access to coordinated care. It was highlighted that what may make a patient at risk of poor coordination included a wide range of issues including location, cultural, physical, family and caregiver related issues.

It was discussed at length that every patient needs a key contact at all times during their care journey. However, it was also acknowledged that that it is not feasible for all patients to have a coordinator, nor does everyone perhaps need one. It was suggested that appropriate screening of ‘at risk patients’ may alleviate this issue.

The role of the general practitioner in the care team was frequently raised. Participants concurred that while there may well be benefits in having GPs included in Multi Disciplinary team (MDT) meetings to support coordinated care, logistical issues such as time coordination made it extremely difficult to achieve. Stakeholders referred to just one successful example that involved a GP in a rural location attending a MDT meeting on behalf of other local GPs and reporting back.

Participants raised concerns around the potential load that may fall on cancer care coordinators and other health professionals in regard to monitoring performance and that this load should be kept to a minimum through automation of data collection so it does not distract from clinical care. Care coordinators identified a lack of opportunities to collaborate and recommended establishing a network of coordinators within the State.

Participants identified a need for a ‘universal’ electronic/IT system for data collection/reporting and communication/sharing of information between members of the care team and many felt that a majority of success factors were dependent on the implementation of quality health data systems.

*Evaluation survey*

A brief online evaluation survey was developed by the research team and disseminated to all workshop participants. The survey evaluated how the workshops were run, how relevant the success factors were and how useful participants found the prioritisation process.

Twenty six of the 51 workshop participants completed the survey (51%). Nearly all (96%) respondents either ‘strongly agreed’ or ‘agreed’ that they had the opportunity to contribute to discussion during the workshop. All respondents either ‘strongly agreed’ (62%) or ‘agreed’ (38%) that the success factors were relevant and respondents either ‘strongly agreed’ (50%) or ‘agreed’ (46%) that they found the prioritisation process useful.

Approximately two thirds (62%) of respondents either ‘strongly agreed’ or ‘agreed’ that the workshop provided them a better understanding of the changing funding model for coordinated cancer care suggesting that further information dissemination and stakeholder engagement would be beneficial.

**DISCUSSION**

This study presents for the first time success factors for coordinated care in cancer, bringing together the key elements that are reported disparately across a wide body of evidence. We have tested these factors with a diverse group of key stakeholders that includes consumers, clinicians, policymakers and managers using a validated methodology (the Nominal Group Technique) to prioritise these factors according to significance and measurability.

Two success factors in coordinated cancer care were prioritised by study participants. The first was that patients receive timely and appropriate care on the pathway from first presentation to diagnosis, throughout the journey to commencement of treatment, and beyond treatment to follow-up care, survivorship and end of life. This is in line with previous research conducted by Walsh et al who identified seven key components to care coordination, including access to and navigation through the healthcare system and delivery of services in a complimentary and timely manner [1]. Many tumour streams have considerable variation in patient pathways and timeliness of care from first symptom to treatment. This is especially the case in cancers with high morbidity and mortality, such as lung and ovarian cancers where timely treatment needs to occur over a shorter, more rapid timeframe 46. With regards to the patient journey beyond treatment, the American Society of Clinical Oncology’s statement on achieving high-quality cancer survivorship care includes acknowledgement of the need for greater coordination of care as the growing population of cancer survivors transition back to primary care 47.

The second prioritised success factor related to patient screening for psychological, physical and supportive care needs. Again, this is in line with previous research findings that identified needs assessment of each patient's physical, psychological and supportive care requirements to be a key element of care coordination1. However, while screening for issues such as psychosocial distress is becoming more widespread and staff are generally positive about screening to help them care for their patients 48, there remains a lack of evidence on the effectiveness of supportive screening and the impact on improving patient outcomes or patient experience 49. Studies have revealed limited use of screening tools, with cancer care professionals expressing reservations about their application in routine practice and well documented challenges associate with time pressures, handling both the clinical and emotional aspects of care, the perception of not having appropriate skills and poor access to psychological and supportive care services 50. Concern has also been raised about the potential impact on services, including ensuring adequate psychosocial staff to support a potentially increased need 48. Issues relating to the systematic identification of patient needs and establishing clear referral pathways need to be addressed if effective psychological, physical and supportive care is to be provided.

The second tier priority identified in this study that patients should have a defined care plan along their treatment pathway is also supported in the literature 20,27,33,34. Once again this factor presents significant challenges in broad implementation as qualitative data gathered during the prioritisation process would indicate that treatment plans are infrequently used and are challenging to keep up to date. Further work is needed to define what key elements constitute a treatment plan and when in the treatment pathway plans are best developed and communicated to the patient and GP.

The literature review provided concise overview of best available evidence relevant to the factors of successful coordination of cancer care. Recent studies, published following commencement of the consensus process contribute further to the evidence base of relevant consensus studies in cancer care coordination 3,51,52 and the impact of care coordination approaches on the quality of care and patient experiences 53.

In this study, patient-reported measures of successful coordination of care were considered in the analysis of the literature and consumers of cancer care were active participants in the consensus process. While others have developed tools for capturing measurements of patient experiences 54, including tools for oncology outpatients 55 and for patients to measure cancer care coordination during the treatment phase of the cancer journey 32, results suggest a need for greater attention on tools aimed at measuring patient experiences of cancer care coordination across the continuum, inclusive of measures of physical and psychosocial care needs.

An unexpected outcome of the workshop series was the establishment of a network of care coordinators and exchange of emails across workshops. This reflected the enthusiasm of stakeholders to be able to benchmark different approaches to care coordination across services as well as share experiences.

This study identifies priority factors in the coordination of cancer care to inform future indicator development activities. The results of this study informs not only the Cancer Institute NSW policy concerns, including investments in cancer care services, but also provides valuable insights on priorities that can inform future quality improvement and research activities more broadly.

Limitations of this study include the lack of literature available with regard to specifically defining factors relating to successfully coordinated care. The lack of a common definition of coordinated care means that it is more challenging to seek consensus across participants, as participants may attribute different meanings to the term ‘coordinated care’. The Cancer Institute NSW provided the initial list of stakeholders and this convenience sample may not represent the views of all oncology health professionals in NSW. For instance, while oncologists were included, it is possible not all specialties were canvassed. This includes challenges with obtaining input from specialties such as radiation oncology. However, the project team went to considerable lengths to engage a wide variety of participants in the six workshops. Therefore, we consider that a wide range of views were represented for the final analysis.

In conclusion, this work identifies success factors for coordinated care that are significant in terms of impact on patient outcomes as well as being measurable. These factors lay a strong foundation for the development of (Key Performance Indicators) KPIs that can be used to link funding with performance. An initial set of KPIs is under development by the Cancer Institute NSW that link to the top two success factors. This project was successful in engaging stakeholders in a priority setting process that has obvious implications for future adoption of KPIs into service delivery.

**Table 1**

|  |  |
| --- | --- |
| Search | Terms |
| 1 | (cancer) OR (neoplasms) AND (care coordination) OR (coordination of care) OR (continuity of care) AND (success factors) OR (quality indicators) |
| 2 | (cancer) OR (neoplasms) OR (chronic illness) OR (chronic disease) AND (care coordination) OR (coordination of care) OR (continuity of care) OR (integrated care) OR (care integration) AND (success factors) OR (quality indicators)]; |
| 3 | (measurement OR measuring OR measure) OR (evaluation OR evaluate) OR (assessment OR assess) AND “care coordination” AND cancer |

## Table 2 – Final success factors in coordinated cancer care

|  |  |
| --- | --- |
| 1 | Patients receive timely and appropriate care on the pathway from:* First presentation to diagnosis
* Diagnosis to commencement of treatment
* From treatment to follow-up care, survivorship and end of life
 |
| 2 | Patients are screened (routinely and as required) for physical, psychosocial, supportive care and practical assistance needs using validated tools where available and referred to required services in an appropriate and timely manner. |
| 3 | Patients have timely referral and allocation to a key contact person to assist with the coordination of their care. |
| 4 | Patients receive best practice care defined by clinical practice guidelines or a clinical pathway for each tumour group |
| 5 | Complex presentations and patients at elevated risk for disjointed care and poorer outcomes are identified and systems are in place to ensure care is appropriately managed and coordinated. |
| 6 | All patients have comprehensive treatment and follow up plans that take into account patient and caregiver needs and preferences, are documented, accessible and revised over the course of the patient’s care. |
| 7 | Transfer of patient information and care between members of the multidisciplinary care team, including allied health, primary and community care providers, is timely, appropriate and takes into account patient and caregiver preferences. |
| 8 | Patients, families and caregivers receive timely, relevant and appropriate information at key points along their care trajectory; this may include information regarding diagnosis, prognosis, intention of treatment (e.g. curative/palliative) and survivorship. |
| 9 | Patients are aware of and have access to practical assistance and financial entitlements as appropriate (e.g. transport and accommodation). |
| 10 | Patients, caregivers and families know who to contact for information at different stages during their care trajectory. |
| 11 | All patients are considered for discussion at an MDT meeting in a timely manner and exclusions are guided by protocols. |
| 12 | The roles and responsibilities of each health care professional involved in the patient’s care are understood and communicated to the patient and all members of the multidisciplinary care team. |
| 13 | Side effects of disease and treatment are managed in a timely and appropriate manner by the care team to reduce unnecessary visits to ED and hospital admissions. |
| 14 | Patients receive timely screening and referral to palliative care services. |

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Figure 1. Methodological approach



**Figure 2: Systematic retrieval and exclusion of articles for review**

**Medline and Scopus**

(1947-2014)

**Search 1:**

Title and abstract review of 17 references.

2 refs

**Article reference list & related articles**

**Search 2:**

Title and abstract review of 52 references.

**Search 3:**

Title and abstract review of 44 references.

1 ref

3 refs

**6 refs**

**5 refs**

**22 refs**

**Google Scholar & grey literature**

**Total:**

**33 references**

## Figure 3: Grid analysis matrix

|  |  |  |
| --- | --- | --- |
| **Criteria****Success Factor** | **Significance*****Most likely to impact on patient outcomes*** | **Measurability** ***What indicators set against this could be potentially measured?*** |
| 1. Patients receive timely and appropriate care on the pathway from first presentation to diagnosis and to commencement of treatment. |  |  |

|  |  |  |  |
| --- | --- | --- | --- |
|  **Agree Least**  |  |  |  **Agree Most** |
|  **1**  |  **2** |  **3**  |  **4**  |  **5**  |