



Silver Chain

Evaluation of the Silver Chain Community Palliative Care Service Western Sydney – Social Impact Investment

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PAXON GROUP

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EXECUTIVE SUMMARY



Executive Summary

Community Palliative Care Service

The Community Palliative Care (CPC) service is one of the first health based social impact investment (SII) program in NSW developed in partnership with Silver Chain Group, Western Sydney Local Health District (WSLHD), NSW Health (Ministry of Health), and the NSW Office of Social Impact Investment.

The service delivers enhanced community-based palliative care 24/7 in the home providing clinical care, practical support for daily activities, support for families and carers and bereavement support. The service was designed for (but is not confined to) people in their last three months of life and supports clients to die in the place of their choice. The service commenced on 1 July 2017 and provides palliative care to eligible residents within the WSLHD catchment area.

The evaluation

Paxon Group was commissioned by Silver Chain to provide an independent evaluation of the service over a period of seven years (2017 – 2024).

The purpose of the evaluation is to assess the implementation, effectiveness and cost effectiveness of the CPC service. This evaluation report is the first Implementation Evaluation Report and reports on the initial implementation of the service and the provision of services to the first cohort of participants between 1 July 2017 to 30 June 2018. It reports achievements and learnings to date and identifies opportunities to improve service delivery.

An interim evaluation will be provided in February 2022 with the final evaluation report is to be submitted in February 2025.

Methodology

The methodology for the evaluation has included the development of a Program Logic and Evaluation Framework, ethics application and baseline data collection and analysis. The baseline data collection involved site visits, stakeholder interviews, client and clinician surveys, review of aggregated program data, and review of service delivery data and comparison with national palliative care benchmarks.

Key Findings

Finding	Description
The CPC service has been established and operating in the WSLHD region	<p>The implementation and commencement of the CPC service was enabled through the Joint Development Phase undertaken by the program partners (May 2015 – June 2016).</p> <p>Preparation to commence services was undertaken over a short period of 7 weeks from approval to operational commencement.</p> <p>Key challenges revolved around staffing and recruitment of the service within the short implementation timeframe.</p>
Referral processes target the eligible cohort	<p>In 2017/18, a total of 840 eligible referrals were received resulting in 806 clients admitted to the service. 96% of eligible clients agreed to be were admitted to the service.</p> <p>The 806 admitted clients was short of the of the predicted cohort target 929 for the first year of operations.</p>
WSLHD minimum referral requirements were not achieved in 2017/18	<p>The 589 eligible persons referred from WSLHD in Year 1 to the service fell short of the agreed minimum referrals by 131 for Year 1 (18.1%).</p>

Finding	Description
Clients/Carers have reported a positive level of satisfaction with the service	Overall clients/carers reported a positive level of satisfaction with the CPC service. Survey respondents characterised the care provided by the CPC service as being compassionate and respectful for the patients and families with support provided across the full spectrum of illness, dying, death and bereavement.
Service targets a person's choice to die in their preferred place	For the 2017/18 client cohort, 70% died in their place of choice other than a hospital (home, residential aged care, palliative care facility), with 57% of clients able to die in their home environment supported by family/carers and the CPC service team.
Strong established JWG relationships in place	Overall, both the JWG, WSLHD and Silver Chain reported positive working relationships with each other, and the current level of palliative care services being delivered in Western Sydney as a positive outcome for clients and health care sector in general.
Local clinician and stakeholder relationships are developing	<p>Clinician stakeholder relationships are developing with mixed levels of satisfaction found with the CPC service implementation, and service delivery.</p> <p>Opportunities to deepen these relationships and expand connections with external GPs, aged care services and other health care organisations and clinicians should be explored as the CPC service matures.</p>
Staffing recruitment and capacity development impacted on first year service delivery outcomes	The ability to attract experienced community-based palliative care clinical staff remains an ongoing risk for the CPC service. The short preparation period from service approval and announcement to commencement of the services in July 2017 impacted on the initial recruitment strategies that may have enabled the service to be staffed at a high capacity in the early stages of the implementation.
The CPC service has adapted the service model to address service delivery requirements	Silver Chain and WSLHD have responded to service and operational learnings in the first year to adapt the model and processes including the introduction of share care governance, increasing the onsite medical FTE, and representation of the CPC service in WSLHD committees.
CPC service experienced a small, but not statistically significant reduction in NWAU	Clients in the CPC service experienced a small, but not statistically significant reduction in NWAUs when compared to the counterfactual control group. Review of avoided bed days, compared to the control group, found that CPC service clients had a greater number of hospital bed days in the three months before death.
Use of avoided NWAUs does not cover all the costs associated with delivery of palliative care services for the control group	The use of the avoided NWAU as the primary outcome measure does not factor for all costs associated with the delivery of palliative care services in an LHD. Direct cost comparison between control group and intervention group has limited value at this stage of the evaluation.

Recommendations

On the basis of the preliminary findings, we recommend the following actions for the CPC service:

1. Silver Chain and WSLHD to continue to work on relationship building at the local WSLHD clinician level through education and information sessions on the CPC service's capacity and outcomes.
2. Silver Chain to consider strategies to improve communication and information sharing between WSLHD clinicians and the CPC service clinicians to ensure that client palliative care needs (including complex care requirements) are met in a timely and responsive manner.
3. Silver Chain and WSLHD continue to support education and awareness amongst local community clinicians/community care providers of the SII model for delivering palliative care services to the community.

**PART A –
OVERVIEW OF SERVICE
AND EVALUATION**



1 Introduction

1.1 Community Palliative Care Services in NSW

Palliative care is an essential component of modern health care services and an increasingly important part of the wider health and social care systems. Palliative care is healthcare and support for people with a life-limiting illness, their families and carers. It is provided by (or informed by) professionals who specialise in palliative care.

'End-of-life' care is provided to people in their last few weeks of life in which a person with a life-limiting illness is rapidly approaching death. The person and their carer's needs are typically higher at this time. This phase of palliative care is recognised as one in which increased services and support are essential to ensure quality, coordinated care from the health care team is being delivered. This takes into account the terminal phase or when the person is recognised as imminently dying, death and extends to bereavement care.

Hospital based and community delivered palliative and end of life care in NSW is diverse and devolved. Community palliative care has historically been delivered in NSW through Local Health Districts (LHDs) via an outreach model of care. Under this system, LHDs decide how to deliver services that meet local needs under service agreements with the Ministry of Health.

Palliative care services depend on the person's needs and what is available in their area. Specialist LHD palliative care teams support other care services, including GPs, allied health clinicians and hospital staff in the overall network. The private, not-for-profit, community and voluntary sectors also provide care.

How this works in practice varies. For some patients, their GP and other non-specialist providers will fully support them. As care is provided based on need: many patients are cared for by GPs and non-specialist providers because these providers can fully meet their needs. For others, a palliative care specialist (LHD/hospital based) will manage their care and coordinate other services. As palliative care often involves a range of clinicians and service providers, linkages and relationships between these clinicians are critical.

In recent years, NSW Health through LHDs has introduced a range of additional funding initiatives to enhance palliative support to clients (eg last days of life home support packages). These services complement and link with existing LHD community palliative services and aim to reduce inappropriate use of scarce acute and sub-acute hospital bed capacity and community nursing resources, as people are supported to die at home. Under this model, care services are provided by third party community care organisations (eg Hammond Care, Silver Chain), and care coordination remains with the LHD palliative specialist team.

1.2 Social Impact Investment – New Community Palliative Care Model

In April 2017, the NSW Government through the Health Administration Corporation and Silver Chain Group (Silver Chain) signed an Implementation Agreement (IA) for the first social impact investment (SII) in the Australian health sector. The SII was designed to:

- target a reduction in the National Weighted Activity Unit (NWAU) for palliative patients through the delivery of community palliative care services;
- increase access and services for palliative care for the community;
- provide people with increased options to die in their place of choice; and
- improve the patient's quality of life during their last phase of life.

The SII funds the CPC service in Western Sydney being delivered by Silver Chain in partnership with Western Sydney Local Health District (WSLHD). Under the agreement, when the service achieves agreed social outcomes, this generates significant social and economic benefits. These benefits allow better utilisation of scarce health resources for the government while improving social outcomes. Part of these efficiencies aim to cover the costs of delivering the service and make payments to investors commensurate with the outcomes achieved.

Under this model of care, Silver Chain is the *sole provider* of the community palliative care service for the WSLHD. This is distinct from other LHD's usual model of community palliative care where multiple providers may be contracted to support the LHD provide community palliative care services to a patient (eg LHD community services, other community wrap around palliative care services such as Last Days of Life packages¹ (PEACH²)).

The CPC service delivers enhanced community-based palliative care 24/7 in the home providing clinical care, practical support for daily activities, support for families and carers and bereavement support. The service has been designed for (but is not confined to) people in their last three months of life and supports clients to die in the place of their choice. A client is admitted to the CPC service, with Silver Chain providing overall management and responsibility for the client's total care needs for a single fee.

Services are delivered by multidisciplinary teams led by *specialist palliative care consultants* consisting of:

- registered nurses;
- social workers;
- assistants in nursing;
- a spiritual support worker;
- medical staff;
- volunteer coordinator; and
- volunteers.

Bereavement care is provided to families and carers of the deceased client for up to six months following their death, according to need.

People requiring end of life care residing in the WSLHD catchment area are referred to Silver Chain from LHDs, GPs, and other community and aged care providers to the service.

1.2.1 CPC Service Principles

The CPC service operates under the following core principles to provide palliative care services for persons and their families/carers. The service model is underpinned by the World Health Organisation principles of palliative care³ and guided by the

¹ Last days of life packages provide community-based services in conjunction with LHD palliative care to support a person to die in their home environment. Provided by organisations such as Hammond Care and Silver Chain, the services supplement the existing range of locally available services and boost the overall capacity of local palliative care services. Services include: specialist home nursing and support and in other areas services include personal care, domestic assistance and service coordination.

² South Western Sydney LHD is the contract holder for the PEACH program. PEACH supplements existing community palliative care nursing services provided in a LHD. Silver Chain is contracted to provide personal care services during business hours and in-home evening palliative care registered nurse support and overnight telephone/videoconference client/carer support.

³ World Health Organization & Worldwide Palliative Care Alliance, Global Atlas of Palliative Care at the End of Life, WHO & WPCA, 2014.

Palliative Care Australia National Standards⁴ and the National Palliative Care Strategy.⁵

Table 1: CPC Service Principles

Principle	Description
Care at home	Enables those with an advanced life limiting illness to receive care in their own home , if they desire and where clinically appropriate.
Symptom control	Provides ongoing monitoring, assessment and management of burdensome symptoms .
Individualised care	Provides person centred services based on the individual needs and goals of the client, their caregivers and family.
Holistic care	Ensures a holistic, multidimensional approach that integrates the physical, psychosocial, and spiritual aspects of care.
Coordinated care	Ensures care is coordinated to improve quality of life and minimise the burden on the client, their caregiver/s and family.
Carer support	Ensures the carer is provided with information, support and education to maximise their own wellbeing and their ability to care for the client.
Bereavement support	Ensures the client, their caregiver/s and family have access to bereavement care , information and support services.
Community capacity	Develops community capacity to respond to the needs of people who have an advanced life limiting illness, their caregiver/s and family through effective collaboration and partnerships.
Equitable access	Ensures equitable access to palliative care that is available for all people based on clinical need.
Responsive service	Ensures a responsive service that offers timely assessment and delivery of services.
Evidence based	Ensures practices are informed by evidence .
Quality and effectiveness	Demonstrates quality and effectiveness of services.

1.2.2 Service Partners and Roles

The four key service partners involved in the management and delivery of the CPC service are shown in Table 2. All service partners were members of the original JDP and now operate as members of the JWG for the SII and the service.

⁴ PCA, Standards for Providing Quality Palliative Care for all Australians, PCA, Canberra, 2005.

⁵ National Palliative Care Strategy 2010, Commonwealth of Australia, Canberra, 2010.

Table 2: CPC service partners

Service Partners	Role
Silver Chain Group	Service provider of the CPC service Investor in the CPC service
Western Sydney Local Health District	Provision of referrals and information to the CPC service Provision of in-patient services and clinics as required by CPC clients
Ministry of Health	Responsible for issuing standing charge and outcomes payments to Silver Chain Contract management and data analysis reporting
NSW Office of Social Impact Investment	Oversight and guidance for the CPC service SII
All partners	Member of the Joint Working Group

1.3 Scope of Service Delivery

The CPC service commenced on 1 July 2017. It will be operational for seven years and aims to provide service to 8,432 persons (annual cohort 1,236)⁶. Palliative care services are delivered to eligible persons in their homes from the Silver Chain base located in Western Sydney.

Eligible persons for the CPC service must be diagnosed with an advanced, progressive, life-limiting condition which includes but is not limited to diseases such as cancer, chronic obstructive pulmonary disease and congestive heart failure; degenerative conditions such as Huntington's disease and dementia; and people with trauma-related injuries. Eligible persons must reside in the WSLHD catchment area.

1.4 Evaluation Overview

The evaluation program commenced in 2017 and will conclude in 2025. The evaluation is focused on the implementation and outcomes of the CPC service. The evaluation is not intended to provide assessment of overall Silver Chain's structure and function.

The evaluation will not assess the outcomes of the control group, other than how they compare to the outcomes of the intervention group (annual cohort).

The findings of the evaluation will support the JWG and other service partners to identify and incorporate key learnings throughout the service's delivery, and to support informed decision making for the CPC service's future (including its potential for scalability, as well as the development of other health based social impact investments in the future).

The evaluation is assessing the implementation, effectiveness and cost-effectiveness of the CPC service in achieving its outcomes, with the following key areas for investigation:

Implementation

⁶ The IA stated the Year 1 Cohort is 926 clients to support initial service ramp up period with remaining Years 2–7 annual cohort of 1,236 clients

- Consider and advise on implementation of the program, including the referral pathway and referrals, WSLHD support and participation, appropriateness of the service model and client participation.

Outcomes

- Examine the outcomes for clients, their families, their carers and the community; and
- Analyse variation in the achievement of different outcomes for different client groups and the factors that influenced this.

Cost-Effectiveness

- Understand the cost effectiveness of the service delivery model from the perspective of the NSW Government and the patient at a minimum;
- Determine whether the proxy measures (NWAU reduction, reduction in hospitalisations (bed days)) used for payment in the social impact investment arrangement are an appropriate indicator of the social benefits the arrangement is intended to achieve and whether there are more appropriate indicators, including other non-financial social benefits;

Unintended Consequences

- Identify any unintended consequences or perverse incentives arising from the Community Based Palliative Care Service or the social impact investment arrangement.

Innovation

- Advise on innovations and amendments to the program design and any effects of the amendments on the outcomes achieved.

1.5 Method

The evaluation is a mixed method, theory-based design drawing on secondary program monitoring data and primary data collected from: Silver Chain staff and operations, WSLHD staff, Ministry of Health staff, CPC clients and CPC referrers. The focus and scope of the data collection and analysis for the outcomes, process and cost effectiveness are detailed in Appendix 1.

Paxon obtained ethics approval from WSLHD Human Research Ethics Committee in February 2019 to conduct this evaluation (HREC Ref: 18/WMEAD/512).

1.6 Evaluation Reporting Stages

The overall timeframe for the evaluation of the CPC service is seven years with four key reporting stages during this time:

- Evaluation Framework (completed);
- **Implementation Report – outlining a review of the implementation process and the outcomes of the first year of the project – 2019 (this report);**
- Interim Report – provided at the halfway point of the project – February 2022; and
- Final Report – February 2025.

Each report will address process, outcomes and cost-effectiveness components, though the emphasis will shift. This report focuses on the implementation and outcomes for the first year of the service, while subsequent reports will have an increasing emphasis on outcomes and a more detailed analysis of costs.

1.7 Implementation Report

In Part A, we have presented an overview of the CPC service in the context of SII program and the community palliative principles that have informed the development of the CPC service in Western Sydney. This Implementation Report now focuses on the evaluation questions covering the implementation and first year of service.

In Part B, the evaluation considers the implementation process including the joint working phase process to establish the CPC service. Parts C and D review the service delivery and outcome results for the first year of operations.

The data sources for the process evaluation are:

- Aggregate service monitoring data covering the period 1 July 2017 to 31 June 2018 (Annual Report 2017/18);
- Independent Certifier's report for the CPC service – social impact investment (BDO report) – 2017/18;
- CPC service Patient Outcomes in Palliative Care (PCOC) aggregated service data for January 2018 – June 2018, compared against national benchmarks;
- CPC service referral data;
- Interviews with key stakeholders (Silver Chain, WSLHD, Ministry of Health, OSII, clinicians) n= 20;
- Survey data (Client/carer surveys n=56 and Health professional survey n=7);
- SII financial and service projection data provided by OSII; and
- Administrative and CPC service data provided by Silver Chain.

1.8 Data limitations

Stakeholder Interviews and Analysis - Stakeholder interviews have aimed to capture experiences and highlight views about the achievements and issues. Descriptions of the views are provided qualitatively rather than indicating the number of people who may share a particular view. As a result, issues highlighted through interviews may not be fully representative of the overall stakeholder satisfaction or otherwise of the service. Clients/carers were invited to participate in a face to face interview with over 60 invitations supplied, with no client/carers electing to take the opportunity.

Survey Analysis – The response rates to the FAMCARE and external stakeholder survey were both <15%, potentially leading to survey bias. Results and analysis in this report should be read in light of the fact that they are potentially not representative of the overall carer and clinician views and experiences.

Data Analysis - Raw quantitative data for the CPC service clients has not been analysed for this report. Paxon accessed aggregated quantitative data included in the Annual Report 2017/18. The decision was made to only use the aggregated data as it provided sufficient details to assess the evaluation questions related to the CPC service at this stage of the evaluation.

Service Costs – Service costs of similar palliative care services and in-patient services delivered by WSLHD to CPC service clients were not available for this report and therefore have not been analysed. Paxon utilised the NWAU price to determine the cost of usual care of similar services for comparison metrics when undertaking the cost-effective analysis.

Non admitted activity was not captured in the NWAU comparison figures for the counterfactual control group, and as a result, there are limitations in the comparison of full health service usage and cost across all LHDs for palliative patients.

PCOC Data – Palliative Care Outcomes Collaboration data has been utilised to review the clinical outcomes of clients admitted to the CPC service and benchmarked to other community-based palliative care services. In this report, data for the period January 2018 – June 2018 has been reviewed. PCOC data submission does not occur within the first six months of the service commencement and as a result data was not available for July 2017 – December 2017. In subsequent evaluation reports full year service data will be presented. This dataset is distinct from the required Minimum Data Set (MDS) data submitted by Silver Chain for the service to WSLHD.

PART B

CPC SERVICE IMPLEMENTATION



2 CPC Service Implementation

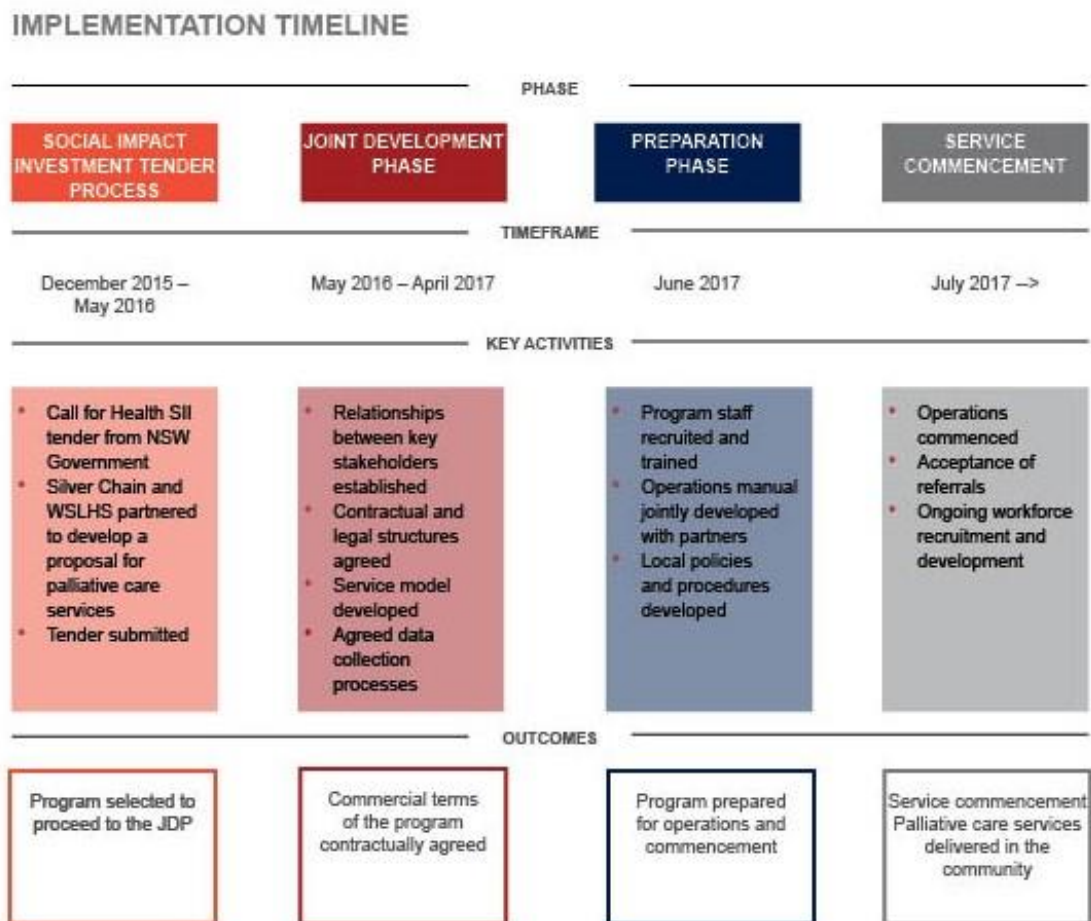
The first evaluation report has a focus on the implementation of the CPC service, specifically considering:

- The service was implemented within the agreed timeframes;
- Strong governance management, monitoring and reporting mechanisms are in place to support the service delivery; and
- The service has been responsive to implementation and project learnings and innovative practices as they emerge

Innovative practices relating to the implementation and service learnings will be discussed in a later section.

2.1 Implementation Timeline

Figure 1: Implementation Timeline



2.2 Implementation Achievements and Challenges

Joint Development Phase (JDP) was successfully completed

The JDP was completed over a period of 11 months from May 2016 to April 2017 by a small working group consisting of Silver Chain, WSLHD, NSW Health and OSII representatives. Stakeholders reported that this period was resource intensive and required the team members to work together to navigate complex decisions. Importantly, stakeholders identified the strong commitment and leadership demonstrated by WSLHD and Silver Chain CEOs to progress the proposal (and provide suitable compromise when required) was a key factor in the success of this phase.

Stakeholders noted that the CPC service was the first health based SII project and the concept and processes to negotiate SII were new to all parties. It was identified that the knowledge gained during the JDP process, especially by the LHD and NSW Health regarding establishment of health based SII's will benefit future similar health projects.

All stakeholders who participated in the JDP identified that a common shared understanding of the requirements and SII outcomes evolved during the 14-month negotiation period, and it was commented on the maturity of the joint development group to set and achieve the outcomes.

It was identified that negotiation between all parties benefited from:

- Having strong commitment and support through NSW Health and OSII to progress the initiative;
- Having the key decision-makers for each organisation as part of the joint development group and a willingness to compromise and deal with key risk areas as they were identified;
- Having a consistent representation from all parties. As there was a stable representation, a strong sense of purpose and trust between all parties was able to be established and was identified a critical issue to progress the SII;
- Having a shared and strong desire to improve palliative care services for the local community and recognition of the limitations in existing services available in Western Sydney;
- Having representation from key clinicians on the joint development group, with the knowledge of the current services and client requirements in Western Sydney; and
- Having agreement on a single measurable variable (such as an NWAU) for the contract payments and reporting.⁷ The NWAU was initially selected as was a recognise concept and measurement by all parties, and other external government agencies (eg NSW Treasury) and having a single measurement concept promoted a shared understanding of the intended (and measurable) outcomes for the service. *(Note: long term appropriateness of the NWAU measure will be considered as part of the evaluation program).*

A robust JWG governance structure is in place for oversight and monitoring of the CPC service

Following from the joint development group, the JWG was established consisting of representatives from Silver Chain, WSLHD, NSW Health and OSII to provide governance and oversee the delivery and evaluation of the CPC service.

The JWG meet on a quarterly basis, often communicating more frequently as required on specific matters (eg: staffing, outcome measurement, data reviews, medical governance requirements). Stakeholders reported that the governance structure was working well and reflects the ongoing commitment to the successful delivery of the CPC service and the overall program by all parties.

A positive aspect identified by stakeholders was the ability for the JWG to work together to address complex and critical issues to the service delivery. For example, improvements in safety and quality reporting between WSLHD and Silver Chain have been undertaken with the integration of CPC service team members on the WSLHD Safety and Quality Committee reporting on CPC service clients.

⁷ In the first year of the CPC service, Bed Days variable was also used as a measurement for evaluation.

Minimum data set reporting on a monthly basis has been implemented, with quarterly and annual reports analysed and reviewed through the JWG.

The short preparation phase leading to implementation was highly resource intensive

At the conclusion of the JDP, the IA was signed on the 21 April 2017 and enabled the commencement of the preparation phase for implementation. The formal and public announcement of the CPC service approval, along with other palliative care initiatives across NSW was made by the Minister for Health on 13 June 2017.

As a result of the deferred announcement, the preparation phase for the service impacted on the timely commencement of the recruitment drive and delayed the service promotion and detailed operational discussions with wider WSLHD clinicians and operations. Until that time, there was limited WSLHD and local clinician transition discussions and public information able to be released.

This timeframe proved a challenge for the parties and the JWG, with all members recounting a high volume of work required to prepare the service for commencement on 1 July 2017.

Table 3: Key dates for the implementation/preparation phase

Implementation Dates	Description
21 April 2017	Implementation Agreement signed Project remains in SII confidential negotiation phase
21 April – 13 June 2017	Internal Silver Chain service commencement planning and processes implemented Internal WSLHD service transition planning and processes commenced Limited formal/public announcements possible during this time
13 June 2017	Minister for Health formally announces the funding for the new CPC service ⁸ Wider WSLHD clinicians, agencies and public informed of service transition for palliative care services.
13 June – 1 July 2017	Silver Chain/WSLHD commences formal clinical and public consultations and stakeholder engagement Recruitment strategies for CPC service medical and clinical roles implemented by Silver Chain
1 July 2017	Commencement of CPC service WSLHD community palliative care services transition to new provider for new referrals New community palliative care referrals accepted for the CPC service.

While the service was the first to be provided by Silver Chain in the Western Sydney area, the organisation had significant expertise and resources in place to support the establishment of the new CPC service. As the provider, Silver Chain is a well-

⁸ Brad Hazzard Minister for Health, NSW Government (13 June 2017). NSW Budget: record \$100m palliative care funding. Press Release. Available: https://www.health.nsw.gov.au/news/Pages/20170613_01.aspx

established health and community care provider in other jurisdictions. As a result, the new Western Sydney service was able to access and utilise the wider group's approach, policies, procedures, clinical and implementation resources, and infrastructure.

To support the preparation phase, Silver Chain's initial planned implementation staffing and resources were required to be supplemented during this period with clinical, administration and project management staff seconded from the organisation's WA and SA community and palliative care services.

There was acknowledgement that the providers existing and sophisticated community services, clinical governance frameworks, HR/administration processes and data report management back end systems provided significant advantage in supporting the short preparation and implementation phase and ongoing service delivery.

An internal implementation review by Silver Chain identified that a three-month time period for the preparation period (publicly announced) would have been beneficial to support public and clinician engagement. Specifically, the internal review found that as a result of short time frames between contract signing, formal/public announcements and go live, there was:

- Unnecessary pressure on staff to implement the new services;
- As a result, processes were not as developed as they could have been impacting on the perceived negative response by some clinician stakeholders; and
- Short implementation timing required a two-stage solution to access a suitable base facility in the region.

The recommendation from this internal implementation review was that:

- Wherever possible, seek to negotiate with a funder to allow service commencement up to three months post contract signing, particularly for palliative care related services; and
- Silver Chain/funders to recognise that palliative care start-ups are more complex and time consuming than other community-based services.

Similarly, for WSLHD, there was a requirement to implement significant change management processes to support human resource (and reassignment of staff from the existing home care service to other positions), staff transition and changes to clinical service delivery (including clinical protocols, referral processes and staff education) requirements.

WSLHD stakeholders identified that additional resources to support the initial consultation, role and service transition would have benefited the overall transition process from LHD services to the new CPC service.

While overall the CPC service was able to commence accepting referrals on 1 July 2017, a longer preparation timeframe would have been beneficial to the service and stakeholders.

Challenges in recruiting workforce for the CPC service in the implementation phase

New service establishment and recruitment of specialist palliative care nurses by Silver Chain was identified as challenging within the commencement timeframe. It was identified that an extended implementation timeframe would have supported a targeted recruitment strategy for specialist palliative care clinicians.

The anticipated early recruitment of staff from existing WSLHD palliative programs to the new CPC service did not occur as anticipated. Feedback from WSLHD and Silver Chain identified the recruitment barriers of:

- The inability to transfer WSLHD staff entitlements to the new employer.
Consultation with JWG members indicated that this was not considered in initial

discussions and should be considered for any SII health project developed moving forward; and

- The change of working conditions for community nurses (eg: Silver Chain community staff are required to participate in afterhours rosters which is not a requirement for WSLHD community nursing staff).

During the implementation period, a secondment strategy was jointly developed by Silver Chain and WSLHD to support clinical staffing requirements. Three staff took advantage of the secondment opportunity during the first year which was less than anticipated by the strategy. Additional clinical staff were seconded from other Silver Chain services and regions to ensure clinical and medical coverage during the first year.

To support the commencement of the service, a specialist palliative care consultant from WSLHD was seconded to the Silver Chain service to provide onsite clinical governance and leadership. Preliminary feedback has been positive on the impact that the role is having in providing confidence in the service for local clinicians. Had the medical specialist not agreed to be seconded from WSLHD, specialist palliative consultant recruitment may have been problematic during the first year.

Confidential SII negotiation process impacted the implementation of the CPC service and wider clinician/stakeholder relationships

Development of the SII for the CPC service included a confidential negotiation period with government to and the proposed service provider. This period included the joint development and contract negotiation phases.

Stakeholders recognised that the introduction of a new palliative care service model into a region requires significant consultation between service agencies, consumers, and health professionals to address the region's requirements. All stakeholders identified that the requirement for a confidential SII negotiations reduced the opportunity and ability of all parties (NSW Health, WSLHD, Silver Chain) to consult more widely on the service's development.

As a result, a broad range of local palliative care physicians and clinicians were unable to be consulted as the service model was developed. While a WSLHD clinician representative was part of the service's JDG, they were unable to seek wider feedback from their colleagues due to the required confidential process.

There was approximately three weeks from the formal and public announcement of the new CPC service, to the required commencement and transfer of clients/staff (where possible) to the service. A small number of WSLHD palliative and community care staff during the evaluation consultation reflected from this period that they felt '*blind-sided*' by the announcement that the LHD palliative care service was being transferred to an alternative provider. Their key concerns were related to the impact that the service change would have on their clients and the change to their valued work teams and structure in the timeframe.

Consultation identified that this negatively impacted on the initial acceptance and understanding of the new service by WSLHD and local palliative/community care clinicians. Further, it was expressed during consultations by a small number of WSLHD clinicians that there continues to be a concern in the ability of community based palliative care services to provide care for more complex palliative care patients in the community, often requiring hospital based services in the interim.

The 2018 NSW Health review of social impact investments (O'Connell Advisory report) into resourcing for SIIs identified the importance of consulting widely during the SII formation and execution. Specifically, the review found that building key

relationships through partnering and working with SII commissioners (agencies), service providers and the targeted cohort of patients was key to a successful SII.⁹

For the CPC service, extensive consultation with affected employees in WSLHD palliative and community care services impacted by the change in service was not able to be undertaken during the confidential SII negotiation period. Wider consultation commenced in mid-June 2017 following the formal announcement of the new service to commence on 1 July 2017. During this process, WSLHD ensured that existing positions were held to support consultation and redeployment in WSLHD for continuing employees.

Typical lead up processes (2-3 months) for advertising new services, recruitment of staff, and key stakeholder communication to support the new service were not able to be fully implemented until mid-June 2017 following the formal announcement, for a 1 July 2017 commencement.

This work was largely completed within the small group of WSLHD and Silver Chain members under the confidential SII negotiation process. Members of this team identified that the required confidential nature of the process, negatively impact on the opportunity to explore and undertake wider consultation with clinicians and community members to contextualise the CPC service model of care to the WLSHD region.

Consideration for future health SII's would be to ensure that sufficient service implementation timeframes are factored into new projects to support change management, recruitment and public education processes.

⁹ O'Connell Advisory (2018). Social impact investment initiatives: resources. NSW Ministry of Health.

PART C
CPC SERVICE REVIEW
2017/18



3 CPC Service Review

This section reviews the CPC service outputs and achievements of short-term outcomes for the first year of service (2017/18). The short-term outcomes identified for the CPC service include:

- Referrals and coordinated discharge planning process in place;
- Comprehensive care planning and optimal symptom management;
- CPC service satisfaction from clients and carers (listening to client's wishes and choice of place of care supported); and
- Strong stakeholder relationships are established.

This section also considers some of the barriers and challenges identified during the first year of CPC service, and the innovations/changes to the model of care for the service.

3.1 CPC Referral, Admission and Discharge

3.1.1 Referral Outputs and Sources

Eligible persons referred to the CPC service did not reach, but are tracking towards agreed predicted referrals

The Annual Report identified that 852 referrals were made to the CPC service in Year 1 (Table 4). Of the 852 referrals received:

- 840 referrals were deemed eligible persons. 12 referrals were found to be non-eligible as they either lived out of area, died before transition to care or did not agree to the service;
- 70% (589 persons) of the deemed eligible persons referred to the service were provided by WSLHD; and
- The remaining 30% (251 persons) of eligible persons were referred from other sources including GPs, private hospitals, self-referrals, and community care services.

Table 4: Referrals and Eligible Person Referrals 2017/18

	All Referrals			Eligible Persons Referred		
	WSLHD	Other	Total	WSLHD	Other	Total
Year 1	601	251	852	589	251	840
	71%	29%		70%	30%	

Source: NSW Health Annual Report, 1 July 2017 to 30 June 2018, Silver Chain Community Palliative Care Service

The annual cohort numbers (intervention group target) and the WSLHD agreed minimum referrals are set in the Implementation Agreement (IA) (Table 5).

Table 5: Annual Cohort and Agreed Minimum Referrals

Description	Annual Cohort ¹⁰	Agreed Minimum Referrals ¹¹ by WSLHD	WSLHD Referrals Proportion of Annual Cohort	Other Referrals Proportion of Annual Cohort
Annual Cohort 1	926	720	78%	22%
Annual Cohort 2, 3, 4, 5, 6 and 7	1,236	720	58%	42%

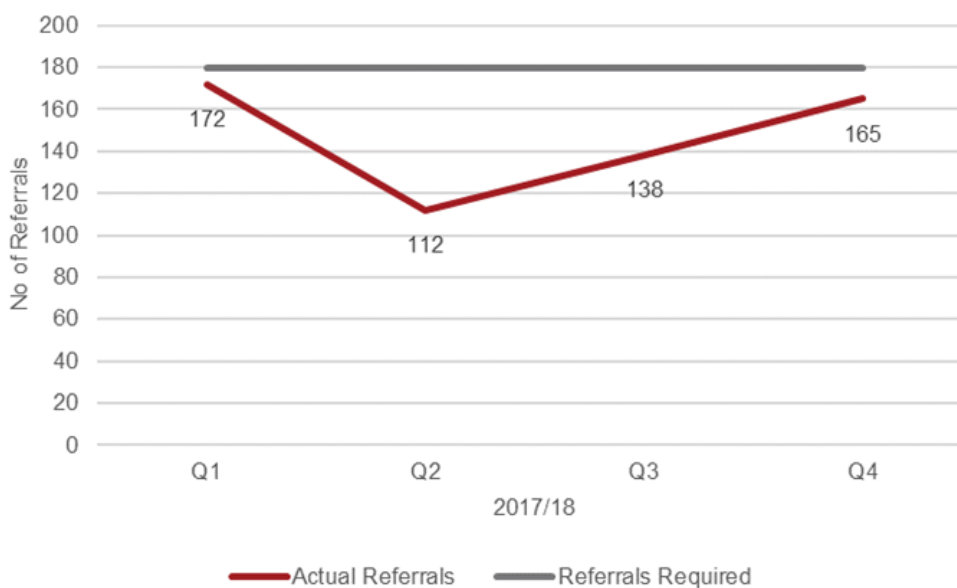
Year 1 annual cohort of 926 (interventional group clients) increases to 1,236 for Years 2-7. The lesser number for Year 1 recognised the operational implementation and ramping of the CPC service in its first year of operations. The WSLHD agreed minimum referrals was set at 720 per annum. The overall WSLHD referral proportion reduces from 78% to 58% in Year 2, recognising that Silver Chain will target and accept referrals from other sources including allied health professionals.

The 589 eligible persons referred from WSLHD in Year 1 to the service fell short of the agreed minimum referrals by 131 for Year 1 (18.1%).

The 251 eligible persons referred from Other Sources in Year 1 to the service achieved above the proportion to the annual cohort (27%).

Initial WSLHD referrals peaked at 174 for Q1 and then dropping in subsequent quarters to Q2(112), Q3(138) and Q4(165). In order to achieve the minimum referral requirement, 180 referrals were required to be provided by WSLHD per quarter in Year 1. (Figure 2)

Figure 2: Quarterly CPC Referrals received from WSLHD for 2017/18



Anecdotally, the initial referral volume from WSLHD to the CPC service on commencement was considerably higher than anticipated with limited ramping of referrals in Q1 to account for the establishment of the service.

¹⁰ S13.2 of the Implementation Agreement

¹¹ S13.3 of the Implementation Agreement

As a result, in Q2 there was an intentional reduction of referrals from WSLHD to support the CPC service provider as they continued to ramp up services and a full complement of clinical staff.

Referral management was a key discussion item in the JWG quarterly meetings as part of the ongoing monitoring of the service for this period. As a consequence of the intentional reduction in referrals in Q2, WSLHD and the CPC service provider implemented a weekly monitoring of referrals to track and manage referral volumes received from WSLHD clinicians.

Consultation identified that while the first year referral target of 926 (as compared to Years 2-7 of 1,236) acknowledged the ramping requirement for the first year of operations, a more targeted strategy to support an initial ramping of referrals between WSLHD and CPC service provider over the Q1 and Q2 would have benefited the overall implementation of the CPC service.

The intentional reduction in referrals in Q2 accounts for the lesser number of referrals received as compared to Q1 and is associated with the overall lower levels of referrals received from WSLHD over the first year of the CPC service.

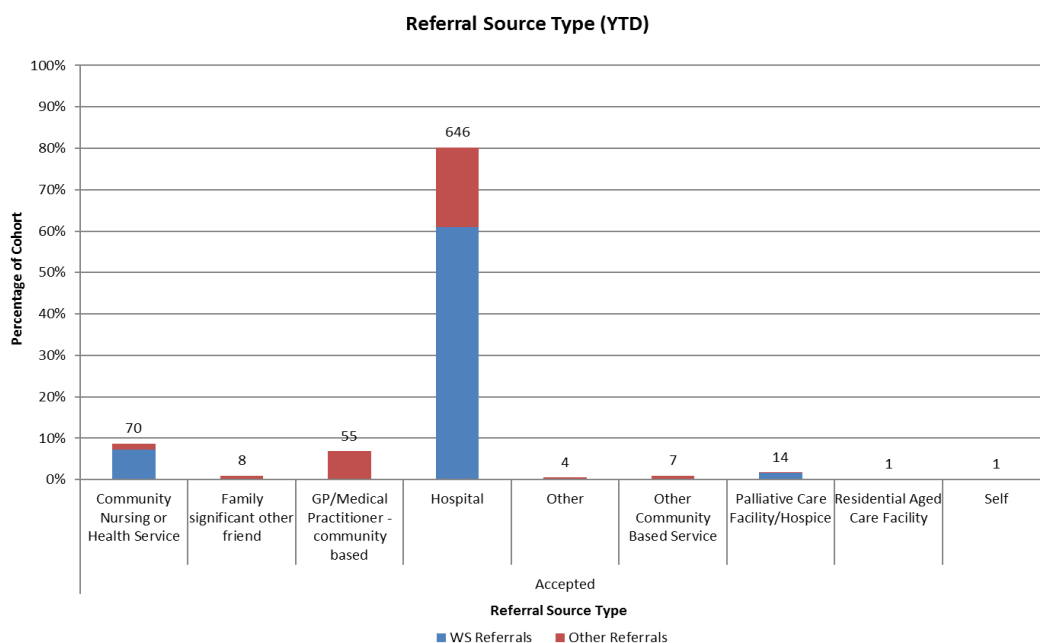
CPC service has received referrals from a range of sources

Eligible people may be referred from a range of sources, including, but not limited to:

- WSLHD doctor (or other LHD if the person resides in the service boundaries) or their authorised representative;
- General Practitioner (GPs);
- Nurse Practitioner;
- Community based Palliative Care agency or service;
- Residential aged care facility (RACF) or specialist disability accommodation service; or
- Self/ carer/ family/ friends.

For 2017/18, 80% of the referrals accepted in the service were referred from a hospital (61% WSLHD, 19% other sources outside of WSLHD). Other referral sources for the first year included doctors, GPs and community nurses. From Year 2, allied health professionals will be able to refer to the service, and the expansion of the referral sources will be reviewed in subsequent evaluation reports.

Figure 3: Referrals by source



Source: NSW Health Annual Report, 1 July 2017 to 30 June 2018, Silver Chain Community Palliative Care Service

This data is consistent with the outcomes reported in the PCOC report which identified that 78% (379 referrals) of the referrals received by the service during the 6-month period (Q3 and Q4) were from public hospitals.

Table 6: PCOC Report – CPC service referrals by source – January – June 2018

Referral Source	Number of Referrals
Public Hospital	379
Private Hospital	20
GP	39
Community based service	31
Self/carer/family/friends	2
Other	15
Total Referrals Jan-June 2018	486

Source: PCOC Patient Outcomes in Palliative Care, January – June 2018, Silver Chain – Western Sydney LHD (September 2018).

Accepted CPC service referrals were below the Year 1 annual cohort target

Of the 840 eligible referrals, 806 referrals (96%) were accepted by the CPC service (Table 7). Accepted clients at 806 was lower than the predicted Year 1 cohort of 926 intervention group members.

Table 7: Eligible referrals accepted by CPC service 2017/18

	Eligible Persons Referred (IG Members)			Referrals Accepted (%age of IG)			Referrals Declined (%age of IG)		
	WSLHD	Other	Total	WSLHD	Other	Total	WSLHD	Other	Total
Year 1	589	251	840	565	241	806	24	10	34
%	70%	30%		67%	29%	96%	3%	1%	4%

Source: NSW Health Annual Report, 1 July 2017 to 30 June 2018, Silver Chain Community Palliative Care Service

There was a high acceptance rate of eligible referrals to the CPC service, which indicates that the eligibility requirements for the service matched the capacity and suitability of the clients for admission to the service. Consultation identified referrals declined were primarily as a result of a client or their family/carer choosing not to participate in the service.

The overall low admissions to the CPC service reflect primarily that there was a shortfall of WSLHD referrals in the first year of 131 and that the minimum 720 referrals were not achieved.

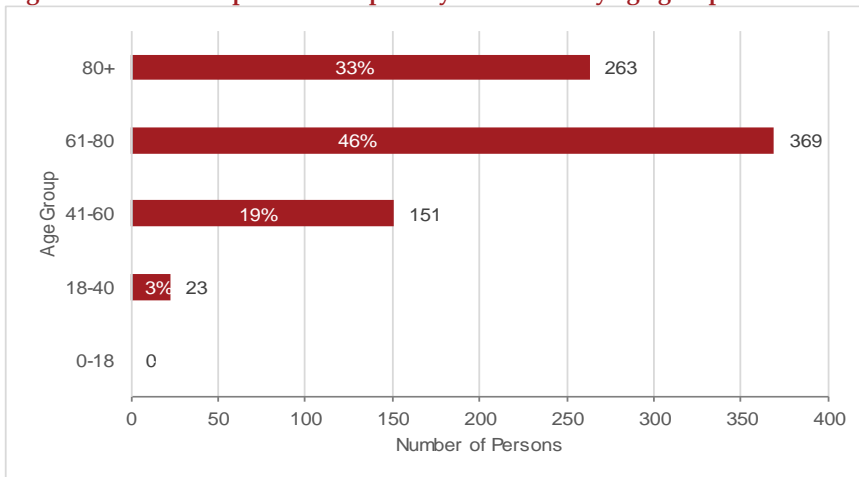
Referrals and acceptance rates from other sources (GPs, other private hospitals, hospice) achieved above the estimated proportion (22%) for Cohort 1. This will increase substantially for Cohort 2 requiring referrals from sources other than WSLHD to be at 42% of all referrals received.

3.1.2 Characteristics of Referred Eligible Patients

Mainly older people accessed the CPC service

Ages of the 806 eligible persons who were admitted to the CPC service in 2017/18 ranged between 18 and 80+. 78% (632 people) of the persons were over the age of 60 (), with 33% (263 people) of the cohort aged 80+. (Figure 4).

Figure 4: Number of persons accepted by the service by age group



Source: NSW Health Annual Report, 1 July 2017 to 30 June 2018, Silver Chain Community Palliative Care Service

More males than females received CPC services

Of the eligible persons who were admitted to the CPC service in 2017/18, 55% (443 people) were male and 45% (363 people) were female.

Figure 5: Number of persons accepted to the CPC service by gender



Source: NSW Health Annual Report, 1 July 2017 to 30 June 2018, Silver Chain Community Palliative Care Service

Majority of people admitted to the CPC service had a cancer related diagnosis

A review of the referrals accepted by the CPC service for 2017/18 by the primary diagnosis type found:

- 68.98% of accepted referrals were for cancer-related primary diagnosis;
- 23% of the accept referrals were for non-cancer related diagnosis; and
- 8% of the accepted referrals were for an unknown primary diagnosis.

Table 8: Service referrals accepted by primary diagnosis

	Primary Diagnosis	Accepted (YTD)		Declined (YTD)	
		Number	%	Number	%
Cancer					
101	Bone and soft tissue	3	0.37%	0	0
102	Breast	52	6.45%	0	-
103	CNS	24	2.98%	0	-
104	Colorectal	56	6.95%	3	8.82%
105	Other GIT	58	7.20%	2	5.88%
106	Haematological	29	3.60%	2	5.88%
108	Lung	75	9.31%	1	2.94%
109	Pancreas	41	5.09%	2	5.88%
110	Prostate	29	3.60%	1	2.94%
111	Other urological	19	2.36%	0	-
112	Gynaecological	30	3.72%	0	-
113	Skin	25	3.10%	1	2.94%
114	Unknown Primary	97	12.03%	3	8.82%
180	Other primary malignancy	18	2.23%	1	2.94%
	Total Cancer	556	68.98%	16	47.06%
Non-Cancer					
201	Cardiovascular disease	5	0.62%	0	-
203	End stage kidney disease	5	0.62%	1	2.94%
204	Stroke	5	0.62%	0	-
205	Motor Neurone Disease	10	1.24%	0	-
207	Other dementia	9	1.12%	0	-
209	Respiratory failure	19	2.36%	0	-
210	End stage liver disease	5	0.62%	0	-
280	Other non-malignancy	130	16.13%	4	11.76%
	Total Non-Cancer	188	23.33%	5	14.71%
Not Reported					
	Total Unknown	62	7.69%	13	38.24%

Source: NSW Health Annual Report, 1 July 2017 to 30 June 2018, Silver Chain Community Palliative Care Service

The cancer to non-cancer diagnosis admission rates to the CPC service is comparable to other NSW/ACT palliative care services (including hospital/hospice and community services).¹²

Table 9: Principle reason for palliative care admission diagnosis – comparison for CPC service, NSW/ACT and national services (PCOC)

Diagnosis	CPC Service (2017/18) (a)	NSW/ACT palliative services (b)	National palliative services (b)
Cancer	68.9%	79.2%	74.5%
Non-cancer	23.3%	20.1%	24.1%
Not stated	7.7%	0.7%	0.4%

Source (a): NSW Health Annual Report, 1 July 2017 to 30 June 2018, Silver Chain Community Palliative Care Service

Source (b): PCOC Patient Outcomes in Palliative Care, January – June 2018, NSW and ACT (September 2018)

Initial CPC service modelling was completed on a client mix of 80% cancer and 20% non-cancer diagnosis to access the service. It was acknowledged at the time of service planning and development that this was likely to shift closer to 50% cancer and 50% non-cancer over the life of the service.

In future evaluations, the percentage ratio of cancer to non-cancer diagnosis admission to the service will be reviewed, along with changes in length of stay in the CPC service to determine if a review of Agreed Minimum Referrals will be required to account for any changes to the diagnosis admission ratios.

International studies have found that although the benefits of providing palliative care to non-cancer patients have been increasingly recognised, compared to cancer patients, the use of palliative services among patients with non-cancer diseases is extremely low and the timing of referrals is typically late.^{13 14} Limitations in the knowledge regarding the needs of end stage non cancer patients and their families has been identified as a key barrier associated with low use and late referral to palliative care.¹⁴

A focus on education and increasing awareness of access for non-cancer patients to the CPC program to referring clinicians would support reducing barriers associated with low use and late referrals. Specifically, this could include the CPC service (in partnership with WSLHD) identifying condition specific health professionals (non-cancer) with the aim to:

- develop stronger relationships and education on services available from the CPC service; and
- establish clinical pathways for condition specific (non-cancer) that include the use of palliative care services.

¹² PCOC (2018). Patient outcomes in palliative care. NSW and ACT January – June 2018. Available: www.ahsri.uow.edu.au/pcoc/reports

¹³ Chen M (2019). Inequity of palliative care for non-cancer patients. *Journal of Nursing Research* 27(2). 1-2.

¹⁴ Zheng L et al (2013). How good is primary care at identifying patients who need palliative care? A mixed method study. *European Journal of Palliative Care*, 20(5). P216-222

3.1.3 CPC Service Client Discharges

Service discharges are predominantly due to client's death

Of the 605 client discharges between 1 July 2017 and 30 June 2018, 81% (490 clients) were due to the client's death (Table 10). Of the remaining 19%, the main reasons for discharge included: client moved to another institutional setting¹⁵, residential aged care, or out of area, or client terminated the service.

Table 10: Reasons for discharge from service

Reason for Discharge	Number	%
1. Client no longer needs assistance – improved status	8	1.30%
2. Client no longer needs or has declined assistance from agency	2	0.30%
3. Clients need have not changed but agency cannot or will not provide services	1	0.20%
4. Client moved to residential aged care	14	2.30%
5. Client moved to other institutional setting	42	6.90%
6. Client moved to other community-based service	8	1.30%
7. Client moved out of area	12	2.00%
8. Client terminated service	15	2.50%
9. Client died	490	81.00%
10. Other reason	9	1.50%
99. Not stated/inadequately described	4	0.70%
Total	605	

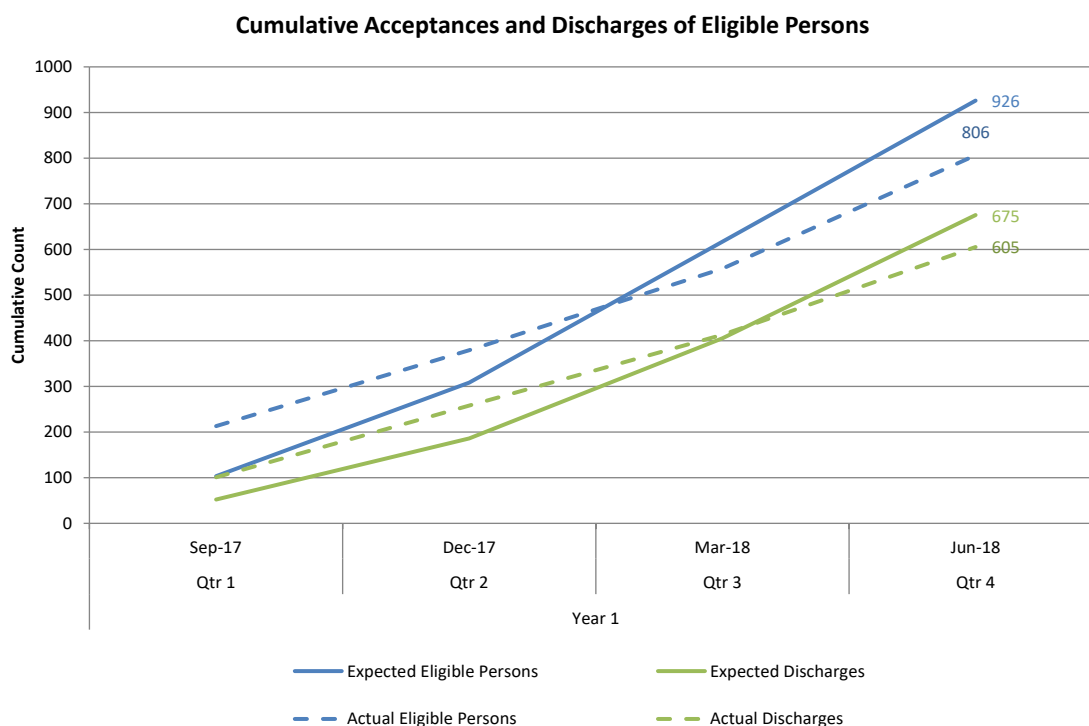
Source: NSW Health Annual Report, 1 July 2017 to 30 June 2018, Silver Chain Community Palliative Care Service

CPC client discharges were consistent with expectations

Of the eligible people admitted to the CPC service in 2017/18, 75% (605 discharges) were discharged within the year in line with expectations (73% were expected to be discharged from the service in Year 1).

¹⁵ This includes the following destinations outcomes of extended care/rehabilitation facility, hospital (planned/unplanned), or palliative care facility/hospice.

Figure 6: Cumulative acceptances and discharges of eligible persons from the service



Source: NSW Health Annual Report, 1 July 2017 to 30 June 2018, Silver Chain Community Palliative Care Service

Majority of the clients died within three months of being accepted into the service

The CPC service’s focus is to provide palliative care support to people within their last three months of life. For 2017/18, the majority of clients (88%) were admitted and died within three months (Table 11). The average length of stay exceeded 6 months only for 12 clients (2.4%).

Table 11: Number of persons who died in the CPC service by average length of stay

Length of Stay	Persons	Cumulative Persons	%age	Cumulative %age
<= 1 week	66	66	13.5%	13.5%
> 1week and <= 1 month	177	243	36.1%	49.6%
> 1 month and <= 2 months	142	385	29.0%	78.6%
> 2 months and <= 3 months	46	431	9.4%	88.0%
> 3 months and <= 6 months	47	478	9.6%	97.6%
> 6 months	12	490	2.4%	100.0%
Total	490			

Source: NSW Health Annual Report, 1 July 2017 to 30 June 2018, Silver Chain Community Palliative Care Service

PCOC service data for January – June 2018, identified that the average length of episode for clients was 32.9 days (mean 20.0 days). This was comparable with other community palliative services in NSW/ACT at 38.8 days (mean 25.0 days) and national services at 38.6 days (mean 29 days) (Table 12) in the same time period.

Table 12: Length of episodes (in days) summary – comparison of CPC service, NSW/ACT and National - January – June 2018

Length of Episode	Community Palliative Care Services		
	CPC service(a)	NSW/ACT 2018 (b)	National - All Services (a/b)
Average length of episode (days)	32.9	38.8	38.6
Median length of episode (days)	20.0	25.0	26.0

Source (a): PCOC Patient Outcomes in Palliative Care, January – June 2018, Silver Chain – Western Sydney LHD (September 2018).

Source (b): PCOC Patient Outcomes in Palliative Care, January – June 2018, NSW and ACT (September 2018)

Comparable with international studies on palliative care services, admissions between 30-40 days are significantly shorter than the overall three-month period outlined for the CPC service. While there is a multifactorial nature for the shorter admission lengths, studies have identified that increasing age of the client on admission is associated with shorter duration of palliative care.¹⁶ Additionally, studies have found that early referrals to community palliative care services are a key determinant of home death amounts and length of stay for patients with advanced disease.¹⁷

3.1.4 Referral and Admission Process - Short Term Outcome

Referral processes are targeting the eligible cohort

The referral process is a key enabler to the success of the CPC service. For the first year, 852 referrals were received with 840 deemed as eligible referrals and commensurate with the CPC service criteria. Of the 12 referrals deemed not eligible for the service, the person either lived out of area, died before transition to care or did not agree to the service.

For the first year there was a high level of referral acceptance rate demonstrating that appropriate and eligible referrals were provided to the service. Stakeholders identified that one of the key supports assisting this process has been the commencement of the CPC hospital liaison nurse attending LHD MDT meetings supporting pre-eligibility screening of patients and reducing non-acceptance of referrals.

Referrals to the CPC service were considerably higher than expected in the first three months of operations as part of the initial commencement of the service. Referrals decreased in Q2, and then rose back to estimated quarterly levels by Q4.

Agreed referral processes are developing well

Overall, the agreed referral processes developed during the JDP are working well between partners. A summary of the referral process as outlined in the Operations

¹⁶ Bennett M et al (2016). What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study of community and hospital palliative care provision in a large UK city. *BMJ Open* 6(12). Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5168608/#_ffn_sectitle

¹⁷ Fukui S et al (2011). Late referrals to home palliative care service affecting death at home in advanced cancer patients in Japan; a nationwide survey. *Annals of Oncology*. 22(9). Available: <https://academic.oup.com/annonc/article/22/9/2113/211632>

Manual is set out under Appendix 4 and a summary of the key agreed referral processes and the progression against the practises is provided in Table 13.

WSLHD clinicians identified initial issues in accessing interstate phone connections for WSLHD sites for fax distribution of referrals to the Silver Chain Contact Centre and this was addressed early in the service's commencement by WSLHD ICT to enable access.

Additionally, WSLHD spent considerable time in refining the standard electronic referral form and process (including data transfer from the eMR) to streamline the referral process for WSLHD hospital-based clinicians. Consultation identified that the initial internal WSLHD process required multiple steps to populate the electronic referral form, and that as a result of the refinement, improvements have been acknowledged in time taken to complete a referral.

The ability for each organisation to support information sharing was impacted by ICT/patient confidentiality policy/procedures for third parties to access organisational information (including eMRs) and client electronic databases. Work is progressing for the ability for Silver Chain staff to access the WSLHD eMRs and for WSLHD staff to access Silver Chain client systems. The solutions are currently in progress with each organisation's ICT services.

In the interim, WSLHD staff seconded to CPC service have retained WSLHD IT access to the eMRs and are able to access and provide this information source. A long-term solution is currently being negotiated between parties.

WSLHD clinicians raised initial concerns regarding the ability to contact local CPC service medical/clinicians without the requirement to go via the Silver Chain Contact Centre. While the preference was to use the Contact Centre in order to monitor and record contact points, local numbers have now been made available to WSLHD clinicians for direct access to clinical and medical personnel based in Western Sydney. Consultation with stakeholder has identified that this interim solution has assisted in addressing this concern raised.

In order to address initial concerns about the sending and receipt of referrals, and the numbers of referrals provided to the CPC service, WSLHD and Silver Chain have implemented a weekly monitoring process for CPC referrals to assist in managing the performance requirements (referrals numbers as outlined in the IA) to support ongoing management of this process.

Referral numbers were lower than projected in 2017/18

In considering the potential reasons for the lower than projected referral results, the following has been identified during the evaluation.

There is recognition that for Q2 WSLHD intentionally reduced the number of referrals sent to the CPC service provider to support the initial implementation of the service. This resulted in an overall lower number of referrals for the full year. The developing staffing capacity and recruitment in the early stages of the service establishment impacted on the ability of the CPC service provider to accept and maintain large numbers of referrals as experienced in Q1 over the duration of Q2.

Consultation identified that the community palliative care HealthPathways (online clinical and referral information portal used by clinicians at the point of care)¹⁸ had not

¹⁸ HealthPathways provide clinicians locally agreed information to make the right decisions together with patients, at the point of care. The pathways are designed primarily for general practice teams, but are also

been established and contextualised for the Western Sydney region in 2017/18 as an alternative and important source of information and clinical referral pathway for hospital -based and community clinicians.¹⁹ Availability of specific palliative HealthPathways may have supported additional referrals from community, public and private hospitals sources. These alternative referral sources will be critical in the following year(s) of the service as referrals from other than WSLHD are projected to account for approximately 42% of total referrals. In the 2017/18, referrals from other sources accounted for 29% of the total referrals.

available to specialists, allied health professionals, and other health professionals in the Western Sydney area.

¹⁹ HealthPathways are managed through the Western Sydney Primary Health Network provider WentWest.

Table 13: Referral processes and progress 2017/18

Process	Referral Process Description	Progress Against Agreed Referral Processes
Pre-Referral Process	Silver Chain will participate in a pre-Referral discussion about the individual with the Referrer	Silver Chain hospital liaison nurse participates in WSLHD multi-disciplinary team (MDT) meetings as part of the pre-referral identification process.
Referral Process	<p>All Referrers, other than self-Referrals and Referrals from carers, family and friends, will use the Referral Form to outline the specific needs of the individual at the time of Referral.</p> <p>All referrals (other than self-referrals) are faxed to the Silver Chain Contact Centre.</p> <p>Urgent referrals are made by phoning the Silver Chain Contact Centre.</p> <p>Referrals can be sent 24 hours, 7 days a week.</p>	<p>Referrals from WSLHD are received directly from the eMR/referral and electronically faxed to the Silver Chain Contact Centre (WA based).</p> <p>Other source referrals use the Silver Chain Palliative Care referral form (NSW) available on CPC service website. Referrals are directed to the Silver Chain Contact Centre.</p> <p>Silver Chain has the capability of reviewing referrals (via fax and phone) 24 hours, 7 days a week.</p> <p>WSLHD clinicians identified initial issues in accessing interstate phone connections for fax distribution and this was addressed by WSLHD ICT following service commencement.</p> <p>Silver Chain is addressing issue raised for auto confirmation upon receipt of electronic faxes. Solution is in progress and will provide confirmation that referral has been received (time stamped).</p> <p>WSLHD have streamlined the internal referral form improving integration with eMR.</p>
Referral Consideration	Silver Chain will accept or decline Referrals within 24 hours of receipt.	The Reviewers were unable to ascertain if referral considerations were met within 24 hours of receipt. However, there has been no evidence based on clinician or stakeholder interviews in to suggest delays in referral considerations by the provider were impacting on the service.
Transfer of Care	WSLHD will provide all relevant patient information to Silver Chain in a secure manner	<p>Information sharing between WSLHD and CPC service has been impacted by policy/procedures for third parties to access organisational information (including eMRs) and client electronic databases.</p> <p>Work is progressing for the ability for Silver Chain staff to access the WSLHD eMRs and for WSLHD staff to access Silver Chain client systems. Solution is currently in progress with each organisation's ICT services.</p> <p>WSLHD staff seconded to CPC service have retained WSLHD IT access to eMRs and are able to access and provide this information source in the interim.</p>

Process	Referral Process Description	Progress Against Agreed Referral Processes
		<p>A long-term solution is currently being negotiated between parties.</p> <p>WSLHD clinicians raised initial concerns regarding the ability to contact local CPC service medical/clinicians without the requirement to go via the Silver Chain Contact Centre. While the preference was to use the Contact Centre in order to monitor and record contact points, local numbers have now been made available to WSLHD clinicians for direct access to the service.</p>
<p>Referrals back to the LHD</p>	<p>Silver Chain will liaise with the Hospital Treating Team and Non-Emergency Patient Transport Ambulance to arrange admission and patient transport respectively.</p>	<p>CPC service experienced some initial issues with clients returning to hospital via ambulance services resulting in unplanned or avoidable emergency admissions for clients.</p> <p>Silver Chain took subsequent action including: client education for emergency issues, ambulance plans and liaison with ambulance services to identify clients and protocols to reduce these events.</p> <p>Silver Chain hospital liaison nurse participates supports in-patient clients, liaison with clinicians and return to the community service.</p> <p>Referrals back to LHD and client unplanned ED/hospital admissions are monitored in the JWG Quarterly meetings.</p>
<p>Management of Referral Volumes</p>	<p>At the time of referral, if the Services' volumes exceed 250 clients, Silver Chain will undertake an assessment of current volumes of Referrals, lengths of stay and developing Referral trends to determine whether or not a new Client may be Accepted.</p>	<p>Referral volumes reviewed during quarterly JWG meetings.</p> <p>WSLHD and Silver Chain have implemented a weekly monitoring process for CPC referrals. Referrals and client admissions from WSLHD are recorded by contract managers. Information is tracked and reviewed weekly.</p>

3.2 Delivering Client Centred Care

The following section reviews the CPC service’s delivery of client centred care services. In the absence of SII specific benchmarks for these items, the intent is to demonstrate the performance of the CPC service compared to similar community palliative care services in NSW/ACT and nationally. PCOC comparative data has been used for January – June 2018 (Q3 and Q4 of the first year).

Timely commencement of care for accepted referrals

PCOC benchmark data for timely commencement of accepted referrals to the CPC service demonstrates that the provider commenced clients ready for care within two days of being ready) for 100% of the clients (January – June 2018). Compared to the benchmark and NSW/ACT services, the CPC service achieved a higher rate of commencements for service.

Table 14: Timely Commencement of Palliative Care - comparison of CPC service and NSW/ACT community setting to national benchmark (January – June 2018)

	National Benchmark (a/b)	CPC service (a) ²⁰	NSW/ACT community setting(b)
Care commencing with two days of the person being ready	90%	100%	92.6%

Source (a): PCOC Patient Outcomes in Palliative Care, January – June 2018, Silver Chain – Western Sydney LHD (September 2018).

Source (b): PCOC Patient Outcomes in Palliative Care, January – June 2018, NSW and ACT (September 2018)

Patient symptoms and problems are being addressed and managed

The PCOC measures five symptom and problem areas:

- Pain - clinician reported severity
- Pain - patient reported distress
- Fatigue - patient reported distress
- Breathing problems - patient reported distress
- Family / carer problems - clinician reported severity

A positive client outcome is achieved if the client, or family/carer, has an absent to mild symptom/problem at the end of a palliative care phase.

The results (Table 15) from the PCOC for the CPC service suggests that the anticipatory care outcomes are marginally under the national benchmark whilst the responsive care outcomes are being met above national benchmarks.

²⁰ The PCOC Report was not prepared for the period Jul-Dec 2017 noting that the results for the first 6 months of the service were not considered significant by the collaborative recognising that it is a learning period.

Table 15: PCOC Report Outcomes – symptoms and problems in the absent to mild range at phase end (January – June 2018)

	National Benchmark	CPC Service (a) <small>Error! Bookmark not defined.</small>	NSW/ACT community setting (b)	National community setting (b)
Anticipatory Care¹				
Pain (clinician reported)		87.9%	85.6%	85.7%
Pain (patient reported)		88.9%	83.4%	84.6%
Fatigue (patient reported)	90%	87.0%	82.5%	79.8%
Breathing problems (patient reported)		96.0%	92.2%	93%
Family/Carer problems (clinician reported)		83.0%	84.2%	83.6%
Responsive Care²				
Pain (clinician reported)		68.2%	51.7%	57.1%
Pain (patient reported)		75.0%	41.7%	52.0%
Fatigue (patient reported)	60%	82.6%	30.4%	35.9%
Breathing problems (patient reported)		63.1%	30.4%	38.4%
Family/Carer problems (clinician reported)		63.7%	42.5%	49.4%

- 1) The anticipatory care outcome measures and benchmarks relate to patients who have absent or mild symptom / problem at the start of a phase of palliative care. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild symptom / problem.
- 2) The responsive care outcome measure and benchmarks relate to patients, or family/carer, who have a moderate or severe symptom / problem at the start of their phase of palliative care. Achieving an absent / mild symptom or problem outcome at phase end has been identified as more clinically challenging, so to meet this benchmark, 60% of these phases must end with the patient experiencing absent or mild symptom / problem.

Source (a): PCOC Patient Outcomes in Palliative Care, January – June 2018, Silver Chain – Western Sydney LHD (September 2018).

Source (b): PCOC Patient Outcomes in Palliative Care, January – June 2018, NSW and ACT (September 2018)

Responsiveness to Managing Patient Needs (Unstable Phase)

Effective symptom management is key, and often the most challenging component of providing palliative care services.^{21 22 23} It requires comprehensive and holistic

²¹ McCusker M et al (2013). Palliative Care for Adults [Internet]. 5th ed. Institute for Clinical Systems. Updated 2013. 82p. Available: https://www.icsi.org/_asset/k056ab/PalliativeCare.pdf

²² Lorenz KA et al (2008). Evidence for improving palliative care at the end of life: a systematic review. *Annals of internal medicine*. 148(2):147-59. Available: <https://www.ncbi.nlm.nih.gov/pubmed/18195339>

²³ Green E et al (2010). Cancer-related pain management: a report of evidence-based recommendations to guide practice. *Clinical Journal of Pain* Jun];26(6):449-62. Available: <https://www.ncbi.nlm.nih.gov/pubmed/20551720>

assessment with frequent evaluation, timely response and appropriate intervention. Effective symptom control not only reduces patient distress and suffering, but facilitates functioning and mobility and, subsequently, improves quality of life.

For clients receiving palliative care services, movement to an unstable phase, this alerts the clinical staff that there is a requirement for urgent changes to the plan of care or that an emergency intervention is required.²⁴ An unstable phase is triggered if:

- a client experiences a new, unanticipated problem;
- a client experiences a rapid increase in the severity of an existing problem; and/or
- a client’s family/carers experience a sudden change in circumstances that adversely impacts the client’s care.

The client will move from the unstable phase in one of two ways:

- a new plan of care has been put in place, has been reviewed and does not require any additional changes. This does not necessarily mean that the symptom/crisis has been fully resolved. However, the clinical team will have a clear diagnosis and a plan for the client’s care. In this situation, the client will move to either the stable or deteriorating phase; or
- The client is likely to die within a matter of days and in this situation, the client will be moved into the terminal phase.

The PCOC benchmarks the time that a client spends in the unstable phase for respective services against the national benchmark. To meet this benchmark, at least 90% of unstable phases must last for three days or less.

Table 16: Patients Unstable for Three Days or Less – comparison of CPC service and NSW/ACT community setting to national benchmark (January – June 2018)

	National benchmark (a/b)	CPC service(a)	NSW/ACT community setting(b)
Patients Unstable for Three Days or Less ¹	90%	83.9%	77.5%

Source (a): PCOC Patient Outcomes in Palliative Care, January – June 2018, Silver Chain – Western Sydney LHD (September 2018).

Source (b): PCOC Patient Outcomes in Palliative Care, January – June 2018, NSW and ACT (September 2018)

The national PCOC benchmark of 90% is set across both hospital/hospice and community services.

The responsiveness of the CPC service in managing patient needs was below the national benchmark of 90% indicating some delays in either changing a client’s plan of care or providing emergency intervention as required. When compared to other NSW/ACT community palliative care services only (excluding hospital/hospice services), the CPC service responsiveness to managing the client’s needs in the unstable phase was above comparable rates of 77.5%, noting that average community service did not achieve the benchmarks.

²⁴ Allingham S, Mossamet N, Burns S, Foskett L and Clapham S (2018) Patient Outcomes in Palliative Care in Australia: National report for July – December 2017. Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, University of Wollongong

A review of PCOC data from 2015 – 2018 identifies the community services have typically trended below the set benchmarks for this performance indicator.²⁵

Reasons for the differences in symptom outcomes between hospital and home are multifactorial.²⁶ When physical symptoms exceed the intensity of care that can be delivered in the community, people are frequently admitted to hospital for symptom management.²⁶

3.2.1 Casemix adjusted outcomes

The PCOC compares eight casemix adjusted scores used to evaluate the change in symptoms for similar palliative care clients. Clients in the same phase who started with the same level of symptom have their change in symptom compared to the reference period (January to June 2018).

The Casemix adjusted scores are calculated relative to a baseline reference period. A Casemix adjusted score:

- greater than 0 means that on average the outcomes of patients' in the CPC service **were better than for similar clients** in the reference period
- less than 0 means that on average, the outcomes of patients' in the CPC service were **worse than for similar clients** in the reference period
- equal to 0 means that on average, the outcomes of patients' in the CPC service were **about the same as similar clients** in the reference period

The data suggests that for all four clinician reported problems (pain, other symptoms, family/carer problems and psychological/spiritual problems) the average outcomes of clients' in the CPC service were slightly lower than those experienced for similar clients in the reference period.

Conversely for client reported symptom distress (pain, nausea, breathing problems and bowel problems), the PCOC results showed that the average outcomes of client's in the CPC service were better than for similar patients in NSW/ACT community settings, and National community settings in the reference period.

²⁵ PCOC Patient Outcomes in Palliative Care, January – June 2018, Silver Chain – Western Sydney LHD (September 2018).

²⁶ Eagar K et al ((2018). Palliative care is effective: but hospital symptom outcomes superior BMJ Supportive & Palliative Care Published Online First: 31 August 2018.

Table 17: PCOC Report Outcomes – Casemix adjusted outcomes January – June 2018

Outcome Measure	National Benchmark	CPC service (a)	NSW/ACT community setting(b)	National community setting(b)
Clinician Reported Problems				
Pain		-0.07	-0.09	-0.04
Other Symptoms	0.0	-0.01	-0.05	0.00
Family/Carer Problems		-0.05	-0.02	0.01
Psychological/spiritual problems		-0.08	0.00	0.02
Patient Reported Symptom Distress				
Pain		0.24	-0.26	-0.11
Nausea	0.0	0.07	-0.19	-0.07
Breathing Problems		0.26	-0.10	0.02
Bowel Problems		0.17	-0.11	0.05

Source (a): PCOC Patient Outcomes in Palliative Care, January – June 2018, Silver Chain – Western Sydney LHD (September 2018).

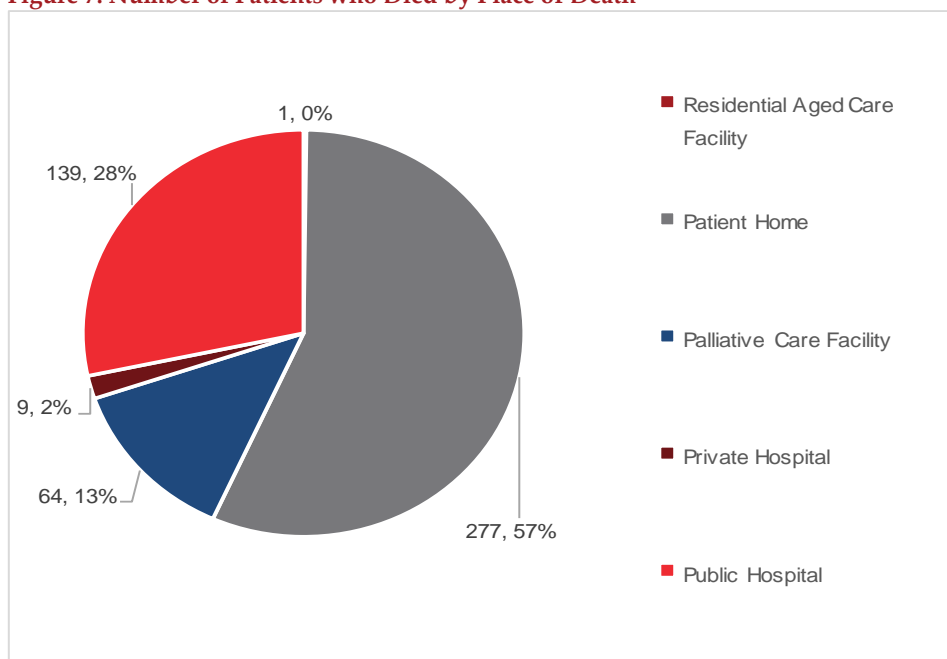
Source (b): PCOC Patient Outcomes in Palliative Care, January – June 2018, NSW and ACT (September 2018)

3.2.2 Targeting client goals of care

70% of CPC service clients died in place other than a tertiary hospital

For the first year of the CCP service, 70% of clients died in their place of choice other than a hospital (home, residential aged care, palliative care facility), with 57% of clients able to die in their home environment supported by family/carers and the CPC service clinical team. (Figure 7)

Figure 7: Number of Patients who Died by Place of Death



Source: NSW Health Annual Report, 1 July 2017 to 30 June 2018, Silver Chain Community Palliative Care Service

Comparison of place of death for CPC service clients with other palliative care services (inpatient and community) identifies that the majority of people receiving palliative care in Australia will die in a hospital/hospice. However, it is recognised that the CPC service provides alternative care options for admitted clients (Table 18).

Table 18: Place of death summary – comparison of CPC service, NSW/ACT and National palliative care services (2017/18 and 2018)

Place of death	Palliative Care Services		
	SC Western Sydney (a)	NSW/ACT 2018 (b)	National - All Services (b/c)
Private residence	57%	14.1%	20.7%
Residential aged care facility	2%	2.5%	6.9%
Hospital/hospice	41%	83.2%	71.9%
Not stated/inadequately described	0.0%	0.2%	0.5%

Source(a): NSW Health Annual Report, 1 July 2017 to 30 June 2018, Silver Chain Community Palliative Care Service

Source (b): PCOC Patient Outcomes in Palliative Care, January – June 2018, NSW and ACT (September 2018)

Source (c): PCOC Patient Outcomes in Palliative Care, January – June 2018, Silver Chain – Western Sydney LHD (September 2018).

To have choice and control over where death occurs is considered central to a good death.^{27 28} In recognition of this, most end-of-life care strategies promote the need to support people to die in their place of choice.²⁹ Surveys consistently show that between 60% and 70% of Australians would prefer to die at home if they had the choice.³⁰

However, research also suggests that where caregivers commit to providing care and to address the client’s preference to be at home, they subsequently become aware of the complexities involved.³¹ Preferences for dying changed from home to hospital/hospice due to uncontrolled pain and other symptoms as part of the trajectory of the disease process, acute events (e.g. falls, injuries), treatment of reversible conditions for comfort and to maximize length of life, imminent death, caregivers burden/inability to safely care at home, and “naivety” on what to expect, amongst other reasons.³¹

This highlights that while intent of any CPC service is to provide the opportunity for clients to die in the place of choice at home, there will continue to be the use of tertiary hospitals as a place of death resulting from change of mind or circumstances.

²⁷ Smith, R. (2000) A good death. *BMJ* 320:129.

²⁸ Ellershaw J., Dewar S, Murphy D (2010). Achieving a good death for all. *BMJ*;341:c4861.

²⁹ Department of Health (2008). End of Life Care Strategy – Promoting high quality care of all adults at the end of life.

³⁰ Swerissen H, Duckett SJ (2015). What can we do to help Australians die the way they want to? *Medical Journal of Australia* 202 (1): 10-11.

³¹ Gomes B et al (2013). Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care*. 12(2).

It is noted that the CPC service does not have specific targets for place of death, recognising that a client/carer's preference may change during the course the palliative care episode.

3.3 Client/ Carer Satisfaction with CPC Service

Carers identify having a positive and satisfactory experience with the CPC service

The FAMCARE-2 survey was used to measure client/carer satisfaction with the CPC service (Appendix 2). The 17 question Likert survey was developed for use in palliative care settings and measures satisfaction for different areas of care such as management of physical symptoms, provision of information, family support and client psychological care.

Surveys were distributed by mail to 611 clients/carers who were admitted in the service during 1 July 2017 to 30 June 2018. Considering returned uncompleted surveys, the final sample group was 554 clients/carers. Given the nature of the CPC service and the timeframe from the client's admission to the survey distribution, respondents were primarily family/carer members. Fifty-six (56) questionnaires were completed and returned for analysis with a survey return percentage of 10.4%.

Analysis of the client/carer survey results acknowledges the low survey return numbers and that this may lead to both selection and non-response bias for the results. Demographic characteristics of respondents are likely to differ significantly from the demographics of the overall patient population. Therefore, the low response rate for the carer/client surveys requires that caution be used in interpreting the survey response data.³²

The 17 questions were rated from Very Satisfied (1) to Very Dissatisfied (5). The 17 questions were then further grouped into 4 sub scales that refer to:

- Management of the physical symptoms and comfort
- Provision of information
- Family support
- Patient psychological care

For analysis, the lower the sub scale mean (between 1 – 5), the more the clients were satisfied with items related to the sub scale area.

Overall, despite the small survey returns, respondents identified as having positive and satisfactory experiences across all the domains of care. Specifically:

- All survey questions were rated S (satisfied) or VS (very satisfied) by >85% of participants;
- The three items with the highest frequencies of positive responses were:
 - *Information given about the side effects of treatment, 100%*
 - *The doctor's attention to the patient's symptoms, 98%*
 - *The way in which the patient's condition and likely progress have been explained by the palliative care team, 96%*
- The items with the lowest frequencies of positive responses were:
 - *Practical assistance provided by the palliative care team, 88%*
 - *The palliative care team's response to changes in the patient's care needs, 90%*
 - *Emotional support provided to the patient by the palliative care team, 90%*

³² Compton J et al (2019). Evidence of selection bias and non-response bias in patient satisfaction surveys. Orthopaedic Journal 39(1): 195-201. Available: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6604521/>

- Average subscale scores ranged from 1.40 (respect for patient dignity) to 2.33 (patient comfort), identifying a consistency between these areas of the service delivery (Table 19).

All question responses provided as being Satisfied or Very Satisfied by >80% of participants. Dissatisfied or Very Dissatisfied responses for each question did not exceed 15%(Table 19).

Table 19: Mean responses for FAMCARE-2 subscales using mean score for pooled responses for any N/A or blank response (n=56)

Item	Subscale	Mean	SD	%VS	%S
Management of physical symptoms and comfort					
1	The patient's comfort	1.60	0.88	68.18%	29.55%
6	Speed with which symptoms are treated	1.60	0.93	66.67%	27.08%
7	Palliative care team's attention to the patient's description of symptoms	1.51	0.81	64.15%	32.08%
8	The way in which the patient's physical needs for comfort are met	1.54	0.91	77.55%	18.37%
12	The doctor's attention to the patient's symptoms	1.43	0.72	74.47%	23.40%
	SUBSCALE AVERAGE	1.53	1.90	70.26%	26.00%
Provision of information					
2	The way in which to patient's condition and likely progress have been explained by the palliative care team	1.53	0.78	59.26%	37.04%
3	Information given about the side effects of treatment	1.65	0.70	56.82%	45.45%
5	Meetings with the palliative care team to discuss the patient's condition and plan of care	1.51	0.85	70.59%	25.49%
14	Information given about how to manage the patient's symptoms (eg pain, constipation)	1.55	0.83	71.43%	24.49%
	SUBSCALE AVERAGE	1.56	1.59	64.63%	32.95%
Family support					
9	Availability of the palliative care team to the family	1.60	1.00	67.31%	25.00%
10	Emotional support provided to family members by the palliative care team	1.61	1.01	72.92%	20.83%
	The practical assistance provided by the palliative care team (eg bathing, home care, respite)	1.85	1.14	61.76%	26.47%
	The way the family is included in treatment and care decisions	1.62	0.89	58.33%	35.42%
	SUBSCALE AVERAGE	1.66	2.03	65.48%	26.78%

Item	Subscale	Mean	SD	%VS	%S
Patient psychological care					
4	The way in which the palliative care team respects the patient’s dignity	1.40	0.82	78.85%	17.31%
15	How effectively the palliative care team managed the patient’s symptoms	1.67	1.00	68.75%	22.92%
16	The palliative care team’s response to changes in the patient’s care needs.	1.66	1.15	66.67%	23.53%
17	Emotional support provided to the patient by the palliative care team.	1.67	1.05	64.71%	25.49%
SUBSCALE AVERAGE		1.60	2.03	69.80%	22.28%

Thematic analysis was undertaken on the survey responses. The data set consisted of 45 completed comment responses from the data of 56 FAMCARE-2 questionnaires. These comments were analysed thematically by becoming familiar with the data, generating initial themes, reviewing (with multiple reviewers) to cross code the themes, defining and reporting the themes. The analysis was interpretive and inductive which reflected the open-ended structure of comments section. The following key themes were identified:

- Good, professional and accessible care;
- Caring and compassionate service;
- Preference for the patient to die at home honoured;
- Consistency of clinical and care staff;
- Afterhours access and communication;
- Palliative care skills for clinical and care staff; and
- Patient information/education.

Good, Professional and Accessible Care

When service users were invited to complete the comments section, the qualitative analysis indicated an overall high level of satisfaction with the palliative care service. Survey respondents characterized the care as being professional, responsive, efficient, helpful and available within the context of respectfulness.

The care given to my husband was above and beyond anything I would have expected. Survey Respondent 2017/18 Cohort

Caring and Compassionate Service

Service users recognised that a caring and compassionate service was a key aspect of the healthcare provided by Silver Chain Community Palliative Care staff. Survey respondents characterised the care as being compassionate and respectful for the patients and families with support provided across the full spectrum of illness, dying, death and bereavement.

The Silver Chain team were very supportive and comforting to the family. Help and advice was always available. Survey Respondent 2017/18 Cohort

Preference for the Patient to Die at Home Honored

Survey respondents expressed gratitude for choice to be able to die at home as a result of the availability of help and support offered by the CPC service.

I cannot express my family's gratitude to the silver chain team. Their support allowed us to care for mum in her own home in the final stages of pancreatic cancer. The team were wonderful to Mum, but also to us as a family. Survey Respondent 2017/18 Cohort

While the majority of families/carers accessing the service were overwhelming positive to the service, a number of comments highlight areas for improvement during the first year of service.

Consistency of Clinical and Care Staff

Two responses raised concerns around the ability of the new community palliative care service to provide a continuity of care through consistent clinical and care staff.

There wasn't a consistent nurse. So every time we basically had to start over again. Survey Respondent 2017/18 Cohort

If the team consisted of the above names every week I would have written very satisfied. Patients need to be seen by the same nurses each week. They form a bond with these nurses. Survey Respondent 2017/18 Cohort

Access after hours

Three responses highlighted concerns around accessibility of Silver Chain staff after hours and via the Perth call centre.

The only areas for improvement was access to staff after hours. My mother passed away at home at 8:30pm and I had trouble getting through to a staff member which was quite stressful. Survey Respondent 2017/18 Cohort

Palliative care skills for clinical and care staff

Four responses highlighted concerns with visiting clinical and care staff palliative care skills to provide care to their family member. Survey respondents noted that some staff appeared to have limitations in some nursing skills and wanted additional support for the family member for items such as wound dressing changes, assistance with movement, toileting and washing. One survey respondent also commented on their perception of insufficient bereavement support post their family member's death.

Some didn't even know what to do. Like changing patient obs or changing a dressing. They come in and leave within minutes of arriving. Survey Respondent 2017/18 Cohort

One respondent identified their concerns with limited medical in-home visits provided through the community palliative care program.

The doctor visited my husband only once in the 4 months that he was a client- when he came out of [name withheld] Palliative care visit; Bathing, home care, respite not provided at all; AINS could not attend at times suitable for client. Also, this service could not be provided daily; contact with Silver Chain done via Perth- very inconvenient for in NSW; feel too few staff available to cover large area. Survey Respondent 2017/18 Cohort

Patient information/education

One response highlighted the opportunity to improve patient information that was provided in home and education for the family/carer.

However, patient/carer information and mostly that which was in the folder was not a few things:- written to an appropriate health literacy eg stool chart too hard to use, medication chart unusable and technical; -the folder included an assessment sheet that would be used if the patient died at home. This should not be accessible to patients. The whole folder needs an overhaul based on co-design with patients/carers. Survey Respondent 2017/18 Cohort

3.4 Clinician, Community and Key Stakeholder Relationship Development

Professional Satisfaction with CPC Service – Survey Responses

Paxon developed an external stakeholder survey to measure satisfaction with the service. The tool used a Likert Scale response to 13 questions that sought to measure overall service satisfaction, communication, professional and medical governance, and quality of care for clients and carers/families. In addition to the questions, a comment box inviting comments on any aspect of palliative care provided was included in the survey, with responses reviewed on themes.

Surveys were distributed to 123 clinicians who had provided two or more referrals to the CPC service during 1 July 2017 to 30 June 2018. Twenty-three surveys were returned *not at the address* and were removed from the clinician cohort resulting in a final distribution number of 100 surveys.

Seven (7) surveys were returned (3 medical practitioners and 4 registered nurses) with a survey response rate of 7%. This is a very low response rate for the survey and should be taken into account when interpreting the results.

Analysis of the external stakeholder survey results acknowledges the low survey return numbers and that this may lead to both selection and non-response bias for the results. Demographic characteristics of respondents are likely to differ significantly from the demographics of the overall stakeholder population. Therefore, the low response rate for the external stakeholders surveys requires that caution be used in interpreting the survey response data.³³

Overall, despite the small survey response, 7 survey participants identified as having an unsatisfactory experience with the CPC service.

- All survey questions were rated D (dissatisfied) or VD (very dissatisfied) by >50% of participants;
- The four items with the highest positive responses were:
 - *Your level of involvement once the Community Palliative Care Service is in place, 50%*
 - *Availability of the palliative care teams to your queries and/or concerns, 50%*
 - *Timeliness of being informed of the status of your referrals, 33%*
 - *The quality of patient's care in which psychological and emotional needs are met, 33%*
- Five items shared the lowest frequencies of positive responses:
 - *Community Palliative Care Service during the last 18 months, 16.7%*

³³ Compton J et al (2019). Evidence of selection bias and non-response bias in patient satisfaction surveys. Orthopaedic Journal 39(1). Available: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6604521/>

- Shared medical governance for patient care, 16.7%
- The palliative service coordination overall, 16.7%
- The quality of the patients' care in which physical needs for comfort (pain management) are met, 16.7%
- The palliative care team's response to changes in patients' care needs, 16.7%
- Average subscale scores ranged from 3.00 (Q5, level of involvement) to 4.14 (Q13, response to change in needs)

Review of the 7 returned surveys (6 completed comment responses) were analysed thematically by becoming familiar with the data, generating initial themes, reviewing (with multiple reviewers) to cross code the themes, defining and reporting the themes. The analysis was interpretive and inductive which reflected the open-ended structure of comments section. The following key themes were identified:

- Continuity of care;
- Communication;
- Hospitalisation of clients; and
- End of life clinical skills.

Continuity of Care

Three external stakeholders expressed concern at a lack of continuity of care- specifically that clients and their families do not see the same nurse.

Continuity of nursing care- trust is built over time. These families will not trust a revolving door of different nurses each visit. All pts prior to SCG knew who their nurse was- now feedback from families is that they have no idea who looks after them and have to start afresh each visit.
Survey Respondent 2017/18

Communication

Three external stakeholders were dissatisfied with the communication from the CPC service provider.

"Difficult to receive a call back when following up on a referral or concern of the family. Most of the time my phone call or follow up is not returned at all. I have to call a manager to gain information, which she is really busy herself." Survey Respondent 2017/18

Hospitalisation of Clients

Three external stakeholders identified concerns that CPC service clients were hospitalised or referred to the ED while admitted to the service too frequently.

"No continuity of care, no consultation or choice given to pts/carers on what service they would prefer, no adequate follow up, the default is always ED if no beds in a PCU" Survey Respondent 2017/18

Limited end of life skills

Two external stakeholders considered that the CPC service clinical staff did not have the skills and capacity to manage the end of life process, and therefore were not able to provide adequate support or explanations to families around the end of life process and requirements to clients.

"have staff that recognise dying, both medical and nursing; have staff that have knowledge and ability to walk patients and relatives through EOL/the dying process" Survey Respondent 2017/18

Overall, survey respondents identified that they were dissatisfied with the CPC service provided during 2017/18.

It is acknowledged that a low response rate in a patient satisfaction survey may lead to both selection and non-response bias. Demographic characteristics of respondents are likely to differ significantly from the demographics of the overall patient population.

Therefore, the low response rate for the carer and external stakeholder surveys requires that caution be used in interpreting the survey response data.³⁴

³⁴ Compton J et al (2019). Evidence of selection bias and non-response bias in patient satisfaction surveys. Orthopaedic Journal 39(1). Available: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6604521/>

Table 20: Mean and frequencies for External Stakeholder Survey items (n=7)

Questions		No	Mean	Standard Deviation	% Satisfied		% Unsatisfied	
Item Range: 1 Very Satisfied to 5 Very Unsatisfied					VS - 1	S - 2	DS - 4	VDS - 5
Q1	Community Palliative Care Service during the last 18 months	7.00	3.43	0.90	-	28.57%	71.43%	-
Q2	Ease of referral process for patients	7.00	3.57	1.05	-	28.57%	57.14%	14.29%
Q3	Timeliness of being informed of the status of your referrals	7.00	3.43	1.05	-	33.33%	50.00%	16.67%
Q4	Communication with the Community Palliative Care Service teams	7.00	4.00	1.07	-	16.67%	33.33%	50.00%
Q5	Your level of involvement once the Community Palliative Care Service is in place	6.00	3.00	1.00	-	50.00%	50.00%	-
Q6	Availability of the palliative care teams to your queries and/or concerns	7.00	3.14	0.99	-	50.00%	25.00%	25.00%
Q7	Shared medical governance for patient care	7.00	4.14	1.12	-	16.67%	16.67%	66.67%
Q8	Your professional role in the treatment and care decisions for patients	7.00	3.71	1.16	-	28.57%	42.86%	28.57%
Q9	The palliative care service coordination overall	7.00	3.86	0.99	-	16.67%	50.00%	33.33%
Q10	The quality of the patients' care in which physical needs for comfort (pain management) are met.	7.00	4.00	1.07	-	16.67%	33.33%	50.00%
Q11	The quality of patients' care in which psychological and emotional needs are met?	7.00	3.57	1.18	-	33.33%	33.33%	33.33%
Q12	Emotional support provided to patients' and family members by the palliative care team.	7.00	3.57	1.40	14.29%	14.29%	42.86%	28.57%
Q13	The palliative care team's response to changes in patients' care needs.	7.00	4.14	1.12	-	16.67%	16.67%	66.67%

3.4.1 Relationship Establishment – Short Term Outcomes

Clinician stakeholder relationships in development

Clinician stakeholders report mixed levels of satisfaction with the CPC service. While survey feedback from clinicians (WSLHD/non WSLHD clinicians) identified general dissatisfaction for the CPC service, face to face consultations held with 7 clinicians had a mixed response.

Feedback from some WSLHD stakeholders/clinicians noted their concerns regarding service delivery for clients with high complex palliative care needs. Specifically, it was identified that if a client's clinical symptoms required a highly responsive service, they had concerns that the community-based service would be able to provide this to the same level and responsiveness as the hospital-based service. This may indicate that not all palliative care clients eligible to be referred to the CPC service in WSLHD would be suitable for a home-based service and would require tertiary level palliative care option.

Importantly, it was recognised during the consultation process that where the client's palliative care needs were relatively stable, the CPC service was very suitable to their requirements. It was also identified during the consultations that the CPC service provided an expansion and improvement of previously available community based palliative care services in the WSLHD area.

Clinician stakeholders also noted their concerns from client/carer feedback received of multiple care givers and nurses attending the client in the home, and the impact on continuity of service for the client. This issue was also raised in the client/carer survey by some respondents.

Additionally, there was some concerns raised about the clinician's ability to directly access the CPC service providers in Western Sydney, noting that placed calls and referrals are managed by Silver Chain through their 24/7 national call centre. Consultation with the CPC service provider identified that alternative contact processes have been put in place during the first year of operations to support referring clinicians to have direct contact with local Silver Chain medical and clinical teams and that this had eased this concern from clinicians. This innovation to the CPC service was a direct response to clinician raised concerns regarding access direct access to Western Sydney based staff.

To support the service, a palliative care medical specialist from WSLHD was seconded for the first year to lead the medical component of the service. WSLHD clinicians identified this role as being critical to supporting the relationship development across both services.

On a wider level, there was some concerns reported by stakeholders about using the SII model for the delivery of *public health services* and the limited engagement with WSLHD clinicians during the original development process. WSLHD reported that in response, regular monthly presentations to clinicians by the LHD had been put in place during the first year to provide education and information on the palliative care services, linkage with the CPC service and the use of the SII model.

It cannot be underestimated the negative impact of the limited consultation process and the subsequent short preparation phase undertaken to develop and implement the CPC service during 2015-2017, and the resulted change to the palliative care service provision in the LHD.

All WSLHD clinicians and management interviewed raised this issue during consultations held 18 months post commencement of the CPC service highlighting their concerns on the transition and change management processes implemented. Specifically, the requirement to have a targeted and longer focus and resources (eg, HR resources, time for transition process, education) for managing the transition.

The feedback about the CPC service identifies the need for all parties to provide more education to the sector about the service, as well as opportunities to increase the sector's trust using a SII model to deliver health services.

Strong JWG relationships in place

Overall, members of the JWG, WSLHD and Silver Chain reported positive and strong established working JWG relationships in the first year. Senior leaders within the organisations were seen as responsive and proactive in supporting the establishment of the CPC service.

There is clear evidence that Silver Chain and WSLHD are working collaboratively to identify and refer clients to the service and to address issues as they arise. As previously outlined, the establishment of the referral pathways (and addressing issues/concerns) has been successful (albeit actual referrals numbers were under the minimal referral requirement) and there is a high level of engagement between the parties.

The JWG meeting on a quarterly basis, and governance frameworks have been established.

Ongoing staffing recruitment and capacity development impacted on first year service delivery outcomes remains a challenge

The ability to attract experienced community based palliative care clinical staff remains an ongoing risk for the CPC service. It is recognised that NSW has one of the lowest population ratio of palliative care nurses when compared with other jurisdictions (10.9 per 100,000 population)³⁵ further impacting recruitment of specialist staff to the service.

The short preparation phase impacted on the initial recruitment strategies that would have enabled the service to be staffed at a high capacity in the early stages of the implementation. Further, one of the original recruitment strategies to source clinical staff from the WSLHD community service program that the CPC service was replacing did not eventuate as the majority of WSLHD palliative care staff did not transfer to the new organisation.

Silver Chain's ability to second clinical staff internally to support the service was a key factor that enabled the commencement of the service in July 2017 with appropriate clinical and medical resources.

Despite the challenges faced in recruitment of clinical staff to the service, there is a high engagement of staff to the program and active professional development programs in place.

Community and local health sector understanding of the CPC service

While the majority of client referrals will continue to be sourced through WSLHD, there is an opportunity to expand on the community referral base of GPs, aged care facilities, and other health care providers. As the CPC service matures, the evaluation will consider these referral pathways to determine suitability and volume.

Consultations with stakeholders identified several additional external factors that may have impacted (both negatively and positively) on the initial acceptance of the new CPC service within the health sector including:

³⁵ Palliative Care Australia (2018). Background Report to the Palliative Care Service Development Guidelines. Available: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Background-to-Service-Delivery-2018_web.pdf

- Concerns from the community regarding privatisation of services across the NSW health sector;
- The introduction of a new community service provider in the region;
- The perception that there was a lack of stakeholder and community engagement for the development of the new palliative care service model (including medical/clinical professions, advocacy groups, unions);
- The community and service providers' perception that announced NSW Government funding of approximately \$100m for expansion of palliative care services was targeted to one region and one service provider;
- The limited community understanding of SII services and opportunities, which remains still a relatively new concept for funding health services; and
- The perception that transfer of CPC services to a private provider had the impact of reducing palliative care in-patient services provided by WSLHD.

Consultations identified that within the first year of service, Silver Chain had placed a strong focus on WSLHD clinician relationship development, recognising that the majority of referrals will primarily be provided from the hospital(s) in the first year. Feedback identified that targeted GP and wider community education strategy would be implemented in the second year of the service. A targeted approach to sector awareness and education of the capacity of the CPC service, especially in relation to GP education and support, should be further explored.

3.5 Innovation and model adaption

CPC service model required adaption

The original CPC medical model (based on a similar service provided by Silver Chain in WA) proved not to be viable in the new program in the implementation phase. There was early recognition through the JWG that the initial medical governance structure required additional medical staffing and resources. Specifically, there was a recognition that:

- The targeted region's GPs did not have a common understanding of CPC service and community palliative care programs;
- There was recognition that palliative care and community based palliative care was evolving in the NSW environment and at the time of commencement, there was not the same acceptance of this type of service by a third party in the community as there is in other jurisdictions³⁶; and
- The establishment of trust between WSLHD palliative care physicians, local GPs and the service provider had not been fully established and required significant stakeholder management on behalf of all parties.

As a result, the service model was adapted with the introduction of a shared care model of medical governance for WSLHD clinicians and additional medical FTE created and filled.

The shared care model of governance was introduced to enable the referring WSLHD clinician to share joint medical governance for a client's care during their admission to the CPC service. The focus was to support communication and coordination of the client's care and to support a rapid needs response with hospital-based services as required. Shared care was used for a small number (less than 10) of admitted CPC service clients at the referring clinicians request during the first year. The majority of

³⁶ NSW Health (2019). End of life and palliative care framework 2019-2024. NSW Government. Available: <https://www.health.nsw.gov.au/palliativecare/Publications/eol-pc-framework.pdf>

client's admitted to the CPC service had medical governance transferred from the referring clinicians to CPC clinicians.

To support the initial commencement of the service, a specialist palliative care consultant from WSLHD was seconded to the Silver Chain service to provide onsite clinical governance and leadership. Preliminary feedback has been positive on the impact that the role is having in providing confidence in the service. Had the medical specialist not agreed to be seconded from WSLHD, specialist palliative consultant recruitment may have been problematic.

Innovation causes discomfort

The innovative aspects of CPC service, the first SII in health with outcome-based payments and use of a third party to deliver full service community palliative care meant that all the parties involved were required to adapt aspects of their normal business practices and referral patterns.

As previously identified in the implementation section, the confidential process in which the CPC service was initially developed resulted in an opaque process and understanding to those who weren't closely involved in the JDP. Involvement in unknown, untested and potentially complex approaches naturally resulted in a sense of risk and discomfort amongst individuals, clinicians and organisations involved as the service was established.

For example, where the WSLHD community services team had provided care and management to a long-term palliative care client, as the client moved to the end of life phase (within three months of death), they would be referred to the CPC service. Continuity of care was raised by WSLHD clinicians (same team members) as potentially impacting on the client's and carer's palliative process.

Implementation issues and challenges in the early implementation stage largely reflect what we know from the implementation literature. Notably, that large scale practice change will impact differently on different staff and in different parts of organisations. Challenges associated with service integration and confidence in the service are being addressed as part of the innovation and adoption of the service by the JWG and individual member organisations. For example,

- WSLHD has established SII education sessions to inform staff of the CPC service and outcomes;
- In response to clinician concerns of medical resources in the CPC service, Silver Chain expanded the medical resources for the service; and
- WSLHD/Silver Chain expanded participation in WSLHD quality and assurance forums to support delivery of care for the service.

4 Measuring Service Outcomes

4.1 Service Outcome Measurement

The Service Outcome Measurement Framework developed for the CPC service identified the following primary outcome domains:

- The primary outcome domain - acute service utilisation outcomes in both the Intervention and the Control Groups in the last three months of life. Indicators include
 - admissions
 - presentations to ED
 - bed days
 - NWAU

The domains noted above are addressed under this section.

Small reduction in NWAUs for Year 1 intervention group is not statistically significant

The primary outcome measure for the service provided under the IA is the absolute difference in the number of NWAUs (and, in the first year, Bed Days) in each annual cohort of the intervention group, compared with the relevant annual cohort of the control group (referred to as the Avoided NWAUs).

The Year 1 Annual Report indicates that clients in the intervention group experienced a small, but not statistically significant reduction in NWAUs compared to the control group. Based on the results contained in the Independent Certifier³⁷ report **50.95 NWAUs** were avoided by the intervention group compared to the control group (Table 21).

Table 21: NWAUs for the Intervention Group and the Control Group (Counterfactual) Year 1

	Counterfactual NWAUs (N=582) Total Mean (SEM)	Recorded NWAUs (N=582) Total Mean (SEM)	Average Avoided NWAUs (N=582) Mean diff (95% CI)	Deemed Avoided NWAUs* (N=131) Total (95% CI)	Avoided NWAUs** (N=582) Total (95% CI)
Year 1	2943.97 5.06 (0.406)	2878.22 4.95 (0.209)	0.113 (-0.776 to 1.002)	14.80 (-101.67 to 131.27)	50.95 (-350.04 to 451.93)

Whilst the avoided NWAUs showed a small positive difference between the two cohort groups, the bed days used by the intervention group were higher relative to the control group (Table 22). The results show that intervention group used 1,712.2 more bed days (95% CI: -2871.1-553.3) in the three months before death, compared to the control group.

A review of the ED presentations and hospitalisation trends to identify any trends impacting the utilisation of bed days identifies the following usage patterns:

- The average number of ED presentations, hospital admissions and Bed Days are lower for Intervention Group members with cancer in the three months before death, compared to Control Group members with cancer for Year 1.

³⁷ Independent Certifier’s Report for the Community Based Palliative Care, Social Impact Investment, December 2018

- Conversely, acute service utilisation was higher for the non-cancer Intervention Group members in the measurement period (i.e. last three months of life), compared to the non-cancer Control Group.

Table 22: Bed Days experienced by the Intervention Group and the Control Group (Counterfactual) in Year 1

	Counterfactual Total Bed Days (N=582) Total Mean	Recorded Total Bed Days (N=582) Total Mean	Average Avoided Bed Days (N=582) Mean diff. (95% CI)	Avoided Bed Days^ (N=582) Total (95% CI)
Year 1	9076.3 15.6	10788.5 18.5	-2.94 (-4.93 to -0.95)	-1712.2 (-2871.1 to -553.3)

It was identified that the service experienced some initial issues with unplanned and/or avoidable emergency admissions (and hospitalisations) for their clients at the commencement. As a result, a number of initiatives and innovations were developed to reduce these events through:

- Informing NSW Ambulance about processes and protocols for the service’s clients;
- Working with clients to develop Ambulance Palliative Care Plans (intended to assist ambulance callouts where Silver Chain had not been informed or notified); and
- Working with Carers to contact Silver Chain before calling an ambulance for non-emergency care.

The outcomes of these initiatives will be reviewed in future evaluations. However, it is anticipated that with these initiatives in place, the ED admissions could be expected to be reduced in the intervention group compared to the control group.

Table 23: Overview of Admissions and ED Presentations for the Intervention Group and the Control Group in Year 1

Diagnosis	Count of Persons	ED Presentations Total Mean	Same day Hospitalisation Total Mean	Overnight Hospitalisation Total Mean	Bed Days Total Mean
Intervention Group					
Total	582	808.0 1.4	94.3 0.2	1096.4 1.9	10788.5 18.5
Cancer	256	340.8 1.3	44.9 0.2	484.5 1.9	4592.0 17.9
Non-Cancer	326	467.2 1.4	49.4 0.2	612.5 1.9	6204.3 19.0
Control Group					
Total	582	819.0 1.4	135.7 0.2	978.6 1.7	9076.3 15.6
Cancer	245	383.7 1.6	53.6 0.2	539.9 2.2	5016.4 20.5
Non-Cancer	337	435.3 1.3	82.2 0.2	438.1 1.3	4052.2 12.0

Source: NSW Health Annual Report, 1 July 2017 to 30 June 2018, Silver Chain Community Palliative Care Service

4.2 CPC Service 2017/18 High Level Service Funding and Costs

CPC Service SII Funding Structure

The CPC service SII is funded as an outcomes-based contract underpinned by a standing charge and outcomes-based payment between the NSW Government and Silver Chain.

For the CPC service, the standing charge amount per cohort (Table 24) was calculated to cover approximately [REDACTED] of the operational costs for the service (with the remaining [REDACTED] to be covered based on the performance of the service). For the first year only, the standing charge included recurrent and capital components to support implementation of the service. The inclusion of a standing charge in the SII funding structure was used for management of financial risk for the investor (Silver Chain).³⁸

Table 24: Standing Charge (Quarterly Instalments and Annual Payment) Cohorts 1-7 compared to Expected Service Delivery Costs

Cohort	1	2	3	4	5	6	7
Quarterly Payment	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]
Annual Payment	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]
Expected Operational Costs	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]

Funding for independent certification and evaluation of the CPC service is provided directly to the CPC service provider and separate to the standing charge.

The outcome-based payment is based on the savings to the health system generated as a result of clients being admitted to the CPC service. These savings are determined by reduction in the intervention group’s use of public hospital/health services compared to a public hospital/health service usage of the counterfactual control group.

Specifically, the outcome payment is scaled based on the avoided NWAUs for each cohort. The level of these payments reflects the SII benefits generated by the CPC service (Table 25). For 2017/18, the avoided NWAUs of **50.95** resulted in the outcome-based payment to the CPC service provider at the minimal level (Level 1 - [REDACTED]).

Table 25: Outcome Payment net of Standing Charge (2017/18 – Cohort 1)

Cohorts	Payment Level							
	Level 1	Level 2	Level 3	Level 4	Lever 4	Level 5	Level 5	Level 6
Avoided NWAUs	0-1086	1087-1176	1177-1283	1284-1411	1412-1552	1553-1693	1694-1835	1836+
Cohort 1	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]

Under the lowest performance scenario, the outcome payment of [REDACTED] equates to [REDACTED] of expected operational costs (Table 24). As such, under this performance

³⁸ With many international SII bond models, all financial risk is transferred to investors. However, this is not the case with SIIs in NSW. Recognising the early stages of the social impact investment market, the NSW Government has provided a ‘standing charge’ as a way to help manage financial risks for investors. OSII (2015). *Principles for social impact investment proposals to the NSW Government*. Sydney: NSW.

scenario, the contract would fund [REDACTED] of expected service delivery cost (being [REDACTED] via upfront standing charge and [REDACTED] via the outcome payment).

Funding for the 2017/18 CPC service of [REDACTED] therefore consisted of:

- Standing Charge – [REDACTED] - the standing charge consisted of a recurrent and capital payments;
- Outcome Payment – [REDACTED] based on the minimal avoided NWAUs achieved sliding scale (Level 1); and
- Independent certification and evaluation payments were paid direct to the CPC provider of [REDACTED].

CPC Service Costs – 2017/18

Table 26 outlines the high-level operational costs to deliver the CPC service in 2017/18. Implementation and recurrent costs totalled [REDACTED] of which [REDACTED] supported the implementation of the service, with recurrent service expenditure at [REDACTED]. Comparison of funding to expenditure in Year 1 of the CPC service identified a net loss to the CPC service provider of [REDACTED] (Table 27).

Table 26: CPC Service Direct and Indirect Costs for 2017/18 – Project and Recurrent

Cost Category	Project Costs	Recurrent Costs	Total Costs
Direct Expenditure			
Direct Staff	[REDACTED]	[REDACTED]	[REDACTED]
Direct Travel	[REDACTED]	[REDACTED]	[REDACTED]
Direct Consumables	[REDACTED]	[REDACTED]	[REDACTED]
Direct Cost of Goods Sold	[REDACTED]	[REDACTED]	[REDACTED]
Total Direct Expenditure	[REDACTED]	[REDACTED]	[REDACTED]
Indirect Expenditure			
Management/administration	[REDACTED]	[REDACTED]	[REDACTED]
Accommodation	[REDACTED]	[REDACTED]	[REDACTED]
Other Operating costs	[REDACTED]	[REDACTED]	[REDACTED]
Capital costs	[REDACTED]	[REDACTED]	[REDACTED]
Group support	[REDACTED]	[REDACTED]	[REDACTED]
Total Indirect Expenditure	[REDACTED]	[REDACTED]	[REDACTED]
Total Expenditure	[REDACTED]	[REDACTED]	[REDACTED]

Table 27: CPC Service Comparison Expenditure to Funding – 2017/18 (\$'000)

Funding/Category	Recurrent Costs
Standing Charge - recurrent	[REDACTED]
Standing Charge - capital	[REDACTED]
Total Standing Charge	[REDACTED]
Outcome Payment	[REDACTED]
Certification and Evaluation	[REDACTED]
Total Funding	[REDACTED]
CPC Service Costs (Silver Chain)	[REDACTED]
Variance to Funding	[REDACTED]

Under the SII agreement, operational costs were only intended to be covered up to █████ for the CPC service provider at the lowest performance level. However, lower than expected operational costs affected that ratio, with the CPC service provider receiving funding to cover █████ of operational costs in 2017/18.

Table 28: Government payment relative to CPC service operational costs - 2017/18

Cost Category	Expected	Actual	Variance
CPC Service operational costs	█████	█████	█████
Government standing charge	█████	█████	
Outcome payment	█████	█████	
Total government payment	█████	█████	
Government payment relative to CPC service operational cost	███	███	███

4.3 Cost Effectiveness Evaluation of CPC Service

Methodology

An economic evaluation of the SII project using cost effectiveness evaluation considered whether people in last three months of their life admitted to the CPC service have less overall utilisation of the public health system than the counterfactual control group of comparable people who are not using that service. Essentially, the cost effectiveness evaluation assesses the cost to government of the CPC service compared to usual care for similar patients accessing health services.

Usual care costs to government for this analysis has been informed by the counterfactual control group’s activity NWAU usage for 2017/18.

$$Usual\ Care\ Government\ Funding = Counterfactual\ NWAUs * State\ Price$$

The cost to government for the CPC service comprises costs through the contractual mechanisms of a CPC Standing Charge and Outcome Payment. Additional activity costs for the CPC service clients (intervention group) admitted to hospital while enrolled in the CPC service have also been included in the overall CPC service cost to government. Intervention group hospitalisation costs have been determined by NWAUs used multiplied by the NSW State Price³⁹. The CPC service cost to government uses the following formula:

$$CPC\ Service\ Costs = Standing\ Charge + Outcome\ Payment + Intervention\ Group\ Hospitalisation\ (NWAUs * NSW\ State\ Price)$$

As the government is required to fund hospitalisation activity for CPC clients (additional NWAUs) the true cost to government for the project includes costs for admitted hospital activity in addition to the contractual payments under the CPC service SII agreement.

³⁹ For 2017/18 to NSW Health State Price for National Weighted Activity Unit (NWAU17) was \$4,691.

Limitations to Cost Effectiveness Analysis - Unaccounted Costs to Government

Measuring the cost effectiveness of the CPC service requires a comparison of the estimated CPC service cost to the cost of delivering usual care to the counterfactual control group.

The Independent Certifier’s report identified that there were 2,943.97 counterfactual NWAUs for the control group in 2017/18. Based number of NWAUs and the 2017/18 NSW State Price, the estimated cost of delivering usual care to this group was \$13.8 million in 2017/18.

Table 29: Estimated Cost of NWAUS for the Counterfactual Control Group (\$000) (Actual and Forecast)

Cost Category	17/18	18/19	19/20	20/21	21/22	22/23	23/24
NWAU Cost for the Control Group	\$13,810	\$18,897	\$19,371	\$19,855	\$20,352	\$20,860	\$21,383

NSW LHDs have a variety of funding sources and programs for delivering additional wrap around palliative care to the usual care in their regions. There is not one standard service model across all NSW LHDs and the additional in-home palliative care support services provided depend on the resources and availability of community providers in the region. Examples include end of life packages and PEACH packages.

Analysis undertaken by the Productivity Commission to inform their Inquiry Report into Australia’s human services identified that the average cost of providing community-based palliative care by non-for-profit providers ranged between \$6,000 to \$10,000⁴⁰ (average \$8,000) per person. This provided an average of between 40 and 100 hours of care, delivered over a period of weeks up to several months. An average amount was not able to be determined for NSW services.

Consequently, to ensure a direct cost comparison of the palliative care services (usual care) delivered to the counterfactual control group and the CPC service intervention group, the comparison calculation would need to factor other palliative care service costs not captured within the NWAUs.

Therefore, the counterfactual control group NWAU comparison may not be representative of the full amount of costs to deliver usual palliative care to these patients.

In the absence of provision of funding data for additional palliative care services provided to patients (counterfactual control group) for each LHD, there are limitations to the following results and a clear cost comparison is unable to be determined. This information was sought but unable to be provided during this evaluation period.

It is noted that the CPC service model is different to the end of life packages provided in other LHDs in that the CPC service provides a full complement of community-based palliative care, assumes medical governance, and provides after death bereavement services.

The next evaluation will be strengthened, and a more direct cost comparison would be achieved if an average community package cost can be developed for the NSW LHDs,

⁴⁰ Productivity Commission, Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Inquiry Report (Page 145).

including an understanding of the percentage of the counterfactual control group who access this service.

Cost-Effectiveness Analysis

Cost effectiveness analysis has estimated that the CPC service delivery cost to Government for 2017/18 was [REDACTED] (Table 30). For 2017/18 this included:

- Standing Charge CPC service - [REDACTED]
- Outcome payment based on sliding scale for success of the CPC service NWAU avoidance - [REDACTED]
- CPC client hospital admissions (2017/18 NWAUs – 2,878.22) - \$13,502,000.

Table 30: Estimated CPC Service Costs (\$000) – Actual 2017/18

Cost Category	2017/18
Cost of Usual Care Delivery (NWAU - Counterfactual Control Group)	
NWAU activity costs	\$13,810
Additional palliative care service activity (LHD)	N/A
Cost of CPC service delivery	
Standing charge	[REDACTED]
Outcome payment	[REDACTED]
CPC client hospital admission (NWAUs) costs	\$13,502
Total cost	[REDACTED]
Net benefit (cost) to Government	[REDACTED]

The estimated service delivery costs (actual and forecast) have been derived using the assumptions outlined in Table 31 using the methodology outlined below:

- forecasting the operating costs under the CPC service over a seven-year period based on the assumptions and growth from Year 1 of the service;
- estimating the 2017/18 hospitalisation cost of the intervention group by applying the NSW State Price to NWAUs and then developing forecasts based on the assumptions detailed in Table 33.

Table 31: Estimated CPC Service Costs (\$000) – Actual 2017/18, Forecast from 2018/19

Cost Category	17/18	18/19	19/20	20/21	21/22	22/23	23/24
Cost of Usual Care Delivery (NWAU - Counterfactual Control Group)							
NWAU activity costs	\$13,810	\$18,897	\$19,371	\$19,855	\$20,352	\$20,860	\$21,383
Cost of CPC service delivery							
Standing charge	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]
Outcome payment	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]
CPC Client Hospital Admission (NWAUs) costs	\$13,502	\$18,475	\$18,938	\$19,412	\$19,897	\$20,395	\$20,906
Total cost	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]
Net benefit (cost) to Government	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]

A reduction in the hospital activity (NWAUs) by clients admitted to the CPC service was a proposed SII benefit in the design and commencement of the service. In 2017/18, the anticipated avoidance of NWAUs for the intervention group was minimal, that is, intervention group members utilised hospital services at a similar rate to the counterfactual control group.

As a result, there was a *net cost to the Government* of ██████████ in 2017/18 for the CPC service based on 66 avoided NWAUs.

For comparison, to deliver a net benefit to the government in 2017/18, the CPC service would have been required to deliver 2,008 avoided NWAUs for the intervention group.

Based on 2018/19 forecasts (Table 31), the CPC service will be required to have 1,863 avoided NWAUs for the intervention group to deliver a net benefit to the government.

Comparison of costs per admission identifies a higher cost per admission for the CPC service (██████████) compared to usual care (██████████) counterfactual group activity. This accounts for hospital admissions (additional NWAUs) by the intervention group during 2017/18.

As per the net benefit to government results, forecasting for cost per admission is based on the current achievement of avoided NWAUs, and this will be further reviewed in subsequent evaluation reports to explore cost drivers in more detail.

Table 32: Cost per Admission (AUD per admission)

Cost Category	17/18	18/19	19/20	20/21	21/22	22/23	23/24
Admissions	806	1076	1076	1076	1076	1076	1076
NWAU equivalent	2,944	3,930	3,930	3,930	3,930	3,930	3,930
Usual care delivery cost per admission	██████████	██████████	██████████	██████████	██████████	██████████	██████████
CPC service delivery cost per admission	██████████	██████████	██████████	██████████	██████████	██████████	██████████

Modelling Assumptions

The following table shows the assumptions used in the cost-effectiveness modelling.

Table 33: Cost effectiveness evaluation modelling assumptions

Assumption	Input
Escalation rate	2.50% p.a.
Forecasting period	7 years
Weighted fixed costs	41.16%
17/18 State Price	\$4,691
17/18 admissions	806 clients
Maximum admissions	1,076 admissions
Counterfactual control group NWAUs (2017/18)	2,943.97
Intervention group recorded NWAUs (2017/18)	2,878.22
Intervention group avoided NWAUs (2017/18)	50.95
Intervention group deemed avoided NWAUs (2017/18)	15.50

PART D – SUMMARY



5 Conclusions and Recommendations

5.1 Conclusions

The CPC service has been established and operating in the WSLHD area

The CPC service is based on an existing service model with strong evidence for its effectiveness, within an evidence-based service framework. From the evidence available, the initial stages of establishment of CPC service have been positive and within the timeframes required. The service has been well resourced and fully operational as per the first-year requirements in IA.

Key service requirements including the referral process, service delivery, governance and working relationships between JWG members, data collection and review are working as intended.

This evaluation report considered the first year of operations, and as with any new service, implementation issues arose. With the CPC service, these have largely been around staffing and recruitment, service and data information sharing and integration, and the ramping of service provider capacity to support the service requirements.

Change management processes and limited timeframe to support the introduction of the new service have impacted on the smooth transition of palliative care services from WSLHD to the CPC service. Based on stakeholder consultation, there are some small areas of dissatisfaction voiced by clinicians arising from this process, requiring a continuing strategy of consultation and support from the CPC service provider to enhance communication.

Limited impact on hospital admissions avoided in first year

In the first year of the CPC service, there has been limited impact on hospital admissions avoided for clients admitted to the service. A small, but not statistically significant reduction in NWAU when compared to the control group was achieved in 2017/18. When reviewing avoided hospital bed days, compared to the control group, CPC service clients had a greater number of hospital bed days in the three months before death.

It was identified that the CPC service experienced some initial issues with unplanned and/or avoidable emergency admissions (and hospitalisations) for their clients on commencement of the service and as the service capacity was being developed. As a result, a number of initiatives were put in place to address emergency/unplanned admissions for the client cohort. As the CPC service matures and the outcomes of these initiatives impact the service, future evaluation will review the ongoing trend of hospital service usage and comparative NWAU impacts.

5.2 Recommendations

On the basis of the preliminary findings, we recommend the following actions for the CPC service:

1. Silver Chain and WSLHD to continue to work on relationship building at the local WSLHD clinician level through education and information sessions on the CPC service's capacity and outcomes.
2. Silver Chain to consider strategies to improve communication and information sharing between WSLHD clinicians and the CPC service clinicians to ensure that client palliative care needs (including complex care requirements) are met in a timely and responsive manner.

3. Silver Chain and WSLHD continue to support education and awareness amongst local community clinicians/community care providers of the SII model for delivering palliative care services to the community.

5.3 Considerations for the next evaluation report

The next evaluation report will be provided in February 2022 at the halfway mark of the program. This will cover four years of service and data review for comparisons of service delivery, outcome measurements and innovations undertaken.

The next interim evaluation report will focus on outcome areas:

- Client and carer satisfaction with the CPC service;
- Patterns of hospital utilisation and impact on the primary outcome domain NWAU measurements;
- Service usage and trends identified;
- Proportion of cancer related and non-cancer related clients access to the CPC service; and
- Innovations and learnings implemented over the first year of service and their impact on subsequent service delivery years.

Based on the issues highlighted in this report, the next evaluation report will also consider:

- Impact of innovations put in place by Silver Chain to reduce ED attendance and use of hospital-based services while client is admitted in the CPC service;
- CPC service staffing capacity and ongoing recruitment requirements;
- CPC service medical governance model in practice and use of the shared care model and outcomes;
- Provision of care to high complex palliative care clients; and
- Local community awareness of the CPC service and referral patterns from non WSLDH pathways.

List of Acronyms

Acronyms	Description
CPC	Community palliative care
eMR	Electronic medical record
GP	General Practitioner
HLN	Hospital Liaison Nurse
IA	Implementation Agreement
JDP	Joint Development Phase
JWG	Joint Working Group
LHD	Local Health District
MDT	Multi-disciplinary team
MoH	NSW Ministry of Health
NWAU	National Weighted Activity Unit
OSII	Office of Social Impact Investment
SII	Social Impact Investment
WSLHD	Western Sydney Local Health District

APPENDICES



Appendix 1: Evaluation Method

The evaluation adopts a mixed-method approach with process, outcomes and funding components.

The evaluation method provides both summative and formative review using mixed methods to obtain qualitative (text and observations) and quantitative (numerical and financial) information.

The evaluation process will provide an integrated evaluation and will use both cross sectional and longitudinal (repeated measures) data collection over the project period.

The evaluation will focus on quantitative analysis, with the use of a smaller number of qualitative interviews/case studies with a sample of clients/carers, key staff from Silver Chain, WSLHD and MoH (as identified) to explore in more depth issues highlighted by the quantitative outcomes.

The evaluation design takes account of the emergent nature of the community palliative care service and makes provisions to estimate the counterfactual (what would have happened in the absence of the community palliative care service) through the use of the comparator patient control group.

The use of the comparator patient control group evaluates the Primary Outcome Domain query for *“Patterns of hospital utilisation move towards more planned and less crisis driven, costs reflect better management in the community, hospital deaths decrease.”*

Process and Outcome Evaluation

The purpose of the process and outcome evaluation was to document the implementation and first year of operations as a basis for understanding outcomes and to identify issues that may lead to improvements in outcomes or efficiency.

Secondary sources

We used de-identified secondary data from WSLHD and Silver Chain to review service delivery, client characteristics, NWAU usage and comparison with the control group. These include:

- Aggregate service monitoring data covering the period 1 July 2017 to 31 June 2018 (Annual Report 2017/18);
- Independent Certifier’s report for the CPC service – social impact investment (BDO report) – 2017/18;
- CPC service Patient Outcomes in Palliative Care (PCOC) aggregated service data for January 2018 – June 2018, compared against national benchmarks; and
- CPC service referral data.

Primary Sources

Primary data was collected from stakeholder interviews (face to face and telephone interviews) and surveys.

Stakeholder interviews were undertaken in August 2017 and March 2019. Interviews (n=20) were conducted with clinicians, and representatives from Silver Chain, WSLHD, OSII, and NSW Ministry of Health). Interviews were used to gather structured information on the JDP process, implementation and first year of operations. Specifically, interviews covered:

- Context and service system factors impacting on joint development phase, implementation and ongoing service operation;
- Working relationships with SII members (including JWG and JDP);
- Referral processes;
- Clinical and service delivery of the program, and integration with health services;
- Opportunities for improvements and changes.

Interview notes were taken and thematically analysed. Themes covered the CPC service structure and governance, system interactions, service delivery practice, and overarching enablers, barriers and timeframes.

Client/carer satisfaction surveys were distributed to 611 palliative care patients/families who were admitted in the service during 1 July 2017 to 30 June 2018 with a total of 56 returned. Given the nature of the service and the timeframe from the patient's admission to the palliative care service, the majority of respondents were from family/carer members.

Clinician satisfaction surveys were distributed to 100 people who had provided a referral to the service during 1 July 2017 to 30 June 2018 with a total of 7 returned.

Survey comments were analysed thematically by becoming familiar with the data, generating initial themes, reviewing (with multiple reviewers) to cross code the themes, defining and reporting the themes. The analysis was interpretive and inductive which reflected the open-ended structure of comments section.

Cost Effectiveness Evaluation

The cost effectiveness evaluation was designed to assess the variance between CPC service delivery and the typical Government delivery. The following approach was used:

- forecasting the operating costs under the CPC service over a seven-year period based on the assumptions and growth from Year 1 of the program;
- forecasting costs to Government by applying the State Price to forecast NWAUs based on the counterfactual and avoided NWAUs reported; and
- assessing the Cost to Government by applying the Payment Schedules based on the appropriate cohort of avoided NWAUs and the additional NWAUs recorded.

Net cost to government forecasted is based on the current achievement of avoided NWAUs, and this will be further reviewed in subsequent evaluation reports to explore cost drivers in more detail.

Appendix 2: Client Satisfaction Survey

FAMCARE-2 Overview

Paxon utilised the FAMCARE-2 survey tool to measure client/carer satisfaction with the service, with the tool having been validated and utilised in similar evaluations of palliative care services internationally. The original FAMCARE tool was developed for use on inpatient units, measuring different areas of care such as availability of care, physical patient care, psychosocial care and information giving. The FAMCARE-2 version was modified for use in services delivered by palliative care teams rather than a doctor or a nurse, and items refer to symptom management rather than pain management alone. The FAMCARE-2 is shorter and more concise than the original FAMCARE version and refers to a team approach to palliative care, rather than focusing on doctors (primarily) and nurses.

FAMCARE-2 makes reference to more symptoms than pain alone and offers more response options. The FAMCARE was specifically developed for care of patients with advanced cancer, while the FAMCARE-2 was extended for use in palliative care settings, making it suitable for use for the Silver Chain palliative care evaluation.

The tool uses a Likert Scale response to 17 questions. Clients/family members were asked to respond to the questions using the following:

- Very Satisfied (1)
- Satisfied (2)
- Undecided (3)
- Dissatisfied (4)
- Very Dissatisfied (5)
- Not Applicable (6)

Analysis has utilised the mean and standard deviation for the responses, and this will be compared to future cohorts being evaluated for the service.

The 17 questions have then been further grouped into 4 sub scales that refer to:

- Management of the physical symptoms and comfort
- Provision of information
- Family support
- Patient psychological care

For analysis, the lower the sub scale mean (between 1 – 5), the more the clients were satisfied with items related to the sub scale area.

In addition to the questions, a comment box inviting comments on any aspect of palliative care received was included in the survey, with responses reviewed on themes.

Survey Responses and Results

Surveys were distributed to 611 palliative care patients/families who were admitted in the service during 1 July 2017 to 30 June 2018. Given the nature of the service and the timeframe from the patient’s admission to the palliative care service, the majority of respondents were from family/carer members.

Table 34: Silver Chain Client Survey Sample

Cohort 2017/18	
Clients Admitted	611
Surveys Returned/No address	57
Survey Sample Group	554
Surveys Completed	56
Surveys Returned Percentage	10.4%

56 surveys were completed and returned for analysis.

The survey commenced with a series of demographic questions:

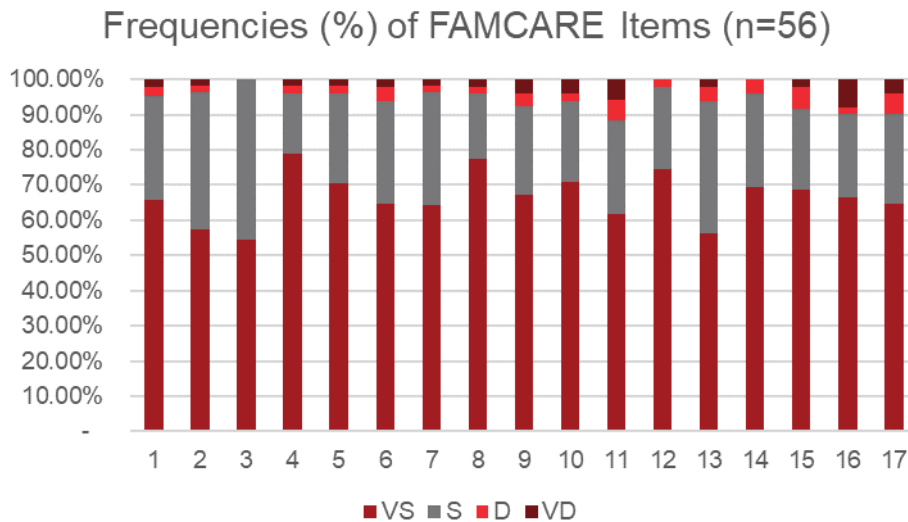
- Do you identify as Aboriginal or Torres Strait Islander?
- Do you identify with a particular ethnic original or cultural background? If yes, please specify

No respondents identified as Aboriginal or Torres Strait Islander. Six respondents did not answer the question on ethnic/cultural background. Sixteen respondents identified as from an ethnic and cultural background.

Overall survey participants identified as having positive and satisfactory experiences across all the domains of care. All question responses provided as being Satisfied or Very Satisfied by >80% of participants. Dissatisfied or Very Dissatisfied replies for each question did not exceed 15% of respondents (Table 35) (Figure 8).

Average subscale scores ranged from 1.40 (respect for patient dignity) to 2.33 (patient’s comfort), identifying a consistency between these areas of the service delivery (Table 36).

Figure 8: Frequencies (percentage) of FAMCARE2 items



Thematic Analysis

The data set consisted of 45 completed comment responses from the data of 56 FAMCARE-2 questionnaires. These comments were analysed thematically by becoming familiar with the data, generating initial themes, reviewing (with multiple reviewers) to cross code the themes, defining and reporting the themes. The analysis was interpretive and inductive which reflected the open-ended structure of comments section.

The following key themes were identified:

- Good, professional and accessible care;
- Caring and compassionate service;
- Preference for the patient to die at home honoured;
- Consistency of clinical and care staff;
- Afterhours access and communication;
- Palliative care skills for clinical and care staff; and
- Patient information/education.

Good, Professional and Accessible Care

When service users were invited to complete the comments section, the qualitative analysis indicated an overall high level of satisfaction with the palliative care service. Survey respondents characterized the care as being professional, responsive, efficient, helpful and available within the context of respectfulness.

Upon my wife's passing in Sept 2017 I emailed both the Federal and State Health Ministers conveying my thanks and appreciation. Survey Respondent 2017/18 Cohort

The care given to my husband was above and beyond anything I would have expected. Survey Respondent 2017/18 Cohort

Caring and Compassionate Service

Service users recognised that a caring and compassionate service was a key aspect of the healthcare provided by Silver Chain Community Palliative Care staff. Survey respondents characterised the care as being compassionate and respectful for the patients and families with support provided across the full spectrum of illness, dying, death and bereavement.

Extremely comforting during a trying time for the family. Survey Respondent 2017/18 Cohort

The Silver chain team were very supportive and comforting to the family. Help and advice was always available. Survey Respondent 2017/18 Cohort

Preference for the Patient to Die at Home Honored

Survey respondents expressed gratitude for choice to be able to die at home as a result of the availability of help and support offered by the Silver Chain Community Palliative Care service.

Silver Chain played a very important part in our families (sic) life and gave dad a comfortable way (ie being in his own home with loved ones) in his last days. Survey Respondent 2017/18 Cohort

I cannot express my family's gratitude to the silver chain team. Their support allowed us to care for mum in her own home in the final stages of pancreatic cancer. The team were wonderful to Mum, but also to us as a family. Survey Respondent 2017/18 Cohort

While the majority of families/carers accessing the service were overwhelmingly positive to the service, a number of comments highlight areas for improvement during the first year of service.

Consistency of Clinical and Care Staff

Two responses raised concerns around the ability of the new community palliative care service to provide a continuity of care through consistent clinical and care staff.

There wasn't a consistent nurse. So every time we basically had to start over again. Survey Respondent 2017/18 Cohort

If the team consisted of the above names every week I would have written very satisfied. Patients need to be seen by the same nurses each week. They form a bond with these nurses. Survey Respondent 2017/18 Cohort

Access after hours

Three responses highlighted concerns around accessibility of Silver Chain staff after hours and via the Perth call centre.

When I called after hours to speak with an on-call nurse due to my husband having difficulty breathing, the call back could be 20-30 minutes and one becomes very anxious waiting for a call back. Survey Respondent 2017/18 Cohort

The only areas for improvement was access to staff after hours. My mother passed away at home at 8:30pm and I had trouble getting through to a staff member which was quite stressful. Survey Respondent 2017/18 Cohort

Palliative care skills for clinical and care staff

Four responses highlighted concerns with visiting clinical and care staff palliative care skills to provide care to their family member. Survey respondents noted that some staff appeared to have limitations in some nursing skills and wanted additional support for the family member for items such as wound dressing changes, assistance with movement, toileting and washing. One survey respondent also commented on their perception of insufficient bereavement support post their family member's death.

Some didn't even know what to do. Like changing patient obs or changing a dressing. They come in and leave within minutes of arriving. Survey Respondent 2017/18 Cohort

One respondent identified their concerns with limited medical in-home visits provided through the community palliative care program.

The doctor visited my husband only once in the 4 months that he was a client- when he came out of [name withheld] Palliative care visit; Bathing, home care, respite not provided at all; AINS could not attend at times suitable for client. Also, this service could not be provided daily; contact with Silver Chain done via Perth- very inconvenient for in NSW; feel too few staff available to cover large area. Survey Respondent 2017/18 Cohort

Patient information/education

One response highlighted the opportunity to improve patient information that was provided in home and education for the family/carer.

However, patient/carer information and mostly that which was in the folder was not a few things:- written to an appropriate health literacy eg stool chart too hard to use, medication chart unusable and technical; -the folder included an assessment sheet that would be used if the patient died at home. This should not be accessible to patients. The whole folder needs an overhaul based on co-design with patients/carers. Survey Respondent 2017/18 Cohort

Summary

Overall, survey respondents identified that they were very satisfied/satisfied with the Silver Chain Community Palliative Care services provided during 2017/18. When service users were invited to complete the service evaluation and provide commentary on aspects of care provided, the qualitative analysis indicated overall satisfaction with the palliative care service.

Service users structured their responses around their experiences of how care was delivered. This process of care delivery focused on the emotional experience of care and incorporated aspects associated with tenor of care such as support provided, dignity, compassion and acceptance. The comment analysis highlights the importance of the emotional experience of care to patients and their family/carers, providing insight into specific examples of where and how this care occurs.

Importantly, it needs to be recognised that this service was in the commencement year in 2017/18, noting that there are opportunities to provide for improvement in the areas of: Clinical and care staffing consistency and skills levels, afterhours access; and patient information as Silver Chain matures the program in the Western Sydney areas.

Table 35: Mean and frequencies for FAMCARE-2 items (n=56)

Questions		No	Mean	Standard Deviation	% Satisfied		% Unsatisfied	
Item Range: 1 Very Satisfied to 5 Very Unsatisfied					VS - 1	S - 2	DS - 4	VDS - 5
Q1	The patient's comfort	48	2.33	1.64	65.91%	29.55%	2.27%	2.27%
Q2	The way in which the patient's condition and likely progress have been explained by the palliative care team.	55	1.65	0.97	57.41%	38.89%	1.85%	1.85%
Q3	Information given about the side effects of treatment.	52	1.81	0.98	54.55%	45.45%	-	-
Q4	The way in which the palliative care team respects the patients' dignity.	55	1.40	0.84	78.85%	17.31%	1.92%	1.92%
Q5	Meetings with the palliative care team to discuss the patient's condition and plan of care.	55	1.51	0.87	70.59%	25.49%	1.96%	1.96%
Q6	Speed with which symptoms are treated.	52	1.73	1.13	64.58%	29.17%	4.17%	2.08%
Q7	Palliative care teams' attention to the patient's description of symptoms.	55	1.51	0.82	64.15%	32.08%	1.89%	1.89%
Q8	The way in which the patient's physical needs for comfort are met.	56	1.54	0.91	77.55%	18.37%	2.04%	2.04%
Q9	Availability of the palliative care teams to the family.	55	1.71	1.15	67.31%	25.00%	3.85%	3.85%
Q10	Emotional support provided to family members by the palliative care team.	54	1.74	1.17	70.83%	22.92%	2.08%	4.17%
Q11	The practical assistance provided by the palliative care team (eg bathing, home care, respite).	39	2.00	1.41	61.76%	26.47%	5.88%	5.88%
Q12	The doctor's attention to the patient's symptoms.	51	1.55	1.00	74.47%	23.40%	2.13%	-
Q13	The way the family is included in treatment and care decisions.	50	1.88	1.26	56.25%	37.50%	4.17%	2.08%
Q14	Information given about how to manage the patient's symptoms (eg pain, constipations)	55	1.67	1.01	69.39%	26.53%	4.08%	-
Q15	How effectively the palliative care team manages the patient's symptoms.	54	1.89	1.27	68.75%	22.92%	6.25%	2.08%
Q16	The palliative care team's response to changes in the patient's care needs.	53	1.77	1.30	66.67%	23.53%	1.96%	7.84%
Q17	Emotional support provided to the patient by the palliative care team.	54	1.78	1.21	64.71%	25.49%	5.88%	3.92%

Table 36: Mean responses for FAMCARE-2 subscales using mean score for pooled responses for any N/A or blank response (n=56)

Item	Subscale	Mean	SD	%VS	%S
Management of physical symptoms and comfort					
1	The patient's comfort	2.33	1.64	65.91%	29.55%
6	Speed with which symptoms are treated	1.73	1.13	64.58%	29.17%
7	Palliative care team's attention to the patient's description of symptoms	1.51	0.82	64.15%	32.08%
8	The way in which the patient's physical needs for comfort are met	1.54	0.91	77.55%	18.37%
12	The doctor's attention to the patient's symptoms	1.55	1.00	74.47%	23.40%
	SUBSCALE AVERAGE	1.72	2.54	69.43%	26.42%
Provision of information					
2	The way in which to patient's condition and likely progress have been explained by the palliative care team	1.65	0.97	57.41%	38.89%
3	Information given about the side effects of treatment	1.81	0.98	54.55%	45.45%
5	Meetings with the palliative care team to discuss the patient's condition and plan of care	1.51	0.87	70.59%	25.49%
14	Information given about how to manage the patient's symptoms (eg pain, constipation)	1.67	1.01	69.39%	26.53%
	SUBSCALE AVERAGE	1.66	1.92	63.10%	33.93%
Family support					
9	Availability of the palliative care team to the family	1.71	1.15	67.31%	25.00%
10	Emotional support provided to family members by the palliative care team	1.74	1.17	70.83%	22.92%
	The practical assistance provided by the palliative care team (eg bathing, home care, respite)	2.00	1.41	61.76%	26.47%
	The way the family is included in treatment and care decisions	1.88	1.26	56.25%	37.50%
	SUBSCALE AVERAGE	1.82	2.50	64.39%	27.88%
Patient psychological care					
4	The way in which the palliative care team respects the patient's dignity	1.40	0.84	78.85%	17.31%
15	How effectively the palliative care team managed the patient's symptoms	1.89	1.27	68.75%	22.92%
16	The palliative care team's response to changes in the patient's care needs.	1.77	1.30	66.67%	23.53%
17	Emotional support provided to the patient by the palliative care team.	1.78	1.21	64.71%	25.49%
	SUBSCALE AVERAGE	1.71	2.33	69.80%	22.28%

Appendix 3: External Stakeholders Satisfaction Survey

External Stakeholder Survey Overview

Paxon developed an external stakeholder survey to measure satisfaction with the service. The tool uses a Likert Scale response to 13 questions. External stakeholders were asked to respond to the questions using the following:

- Very Satisfied (1)
- Satisfied (2)
- Undecided (3)
- Dissatisfied (4)
- Very Dissatisfied (5)
- Not Applicable (6)

Analysis has utilised the mean and standard deviation for the responses, and this will be compared to future cohorts being evaluated for the service. The 13 questions have then been further grouped into 3 sub scales that refer to:

- Service Satisfaction and Communication;
- Professional and Medical Governance; and
- Quality of Care for Clients and Carers/Families.

For analysis, the lower the sub scale mean (between 1 – 5), the more the clients were satisfied with items related to the sub scale area.

In addition to the questions, a comment box inviting comments on any aspect of palliative care provided was included in the survey, with responses reviewed on themes.

Survey Responses and Results

Surveys were distributed to 100 clinicians who had provided two or more referrals to the CPC service during 1 July 2017 to 30 June 2018. Seven (7) surveys were return (3 medical practitioners and 4 registered nurses). The low response rate to the service should be taken into account when reviewing the survey outcomes and responses.

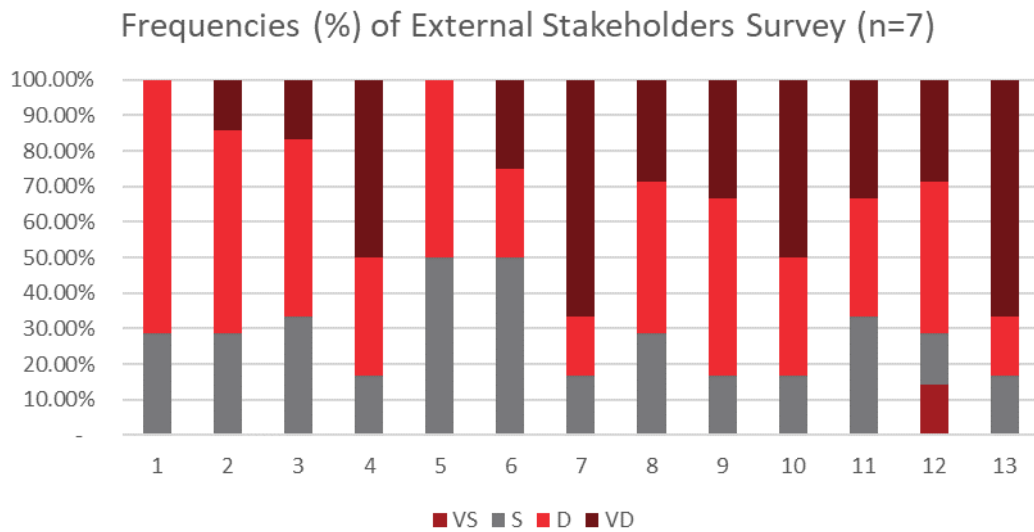
Table 37: Silver Chain External Stakeholder Survey Sample

	Cohort 1
Clients Admitted	123
Surveys Returned/No address	23
Survey Sample Group	100
Surveys Completed	7
Surveys Returned Percentage	7%

Overall survey participants identified as having negative and unsatisfactory experiences across all domains. All question responses provided as being Dissatisfied or Very Dissatisfied by >50% of participants. Dissatisfied or Very Dissatisfied replies for each question did not exceed 50% of respondents (Table 38) (Figure 9).

Average subscale scores ranged from 3.00 (your level of involvement once the community palliative care service is in place) to 4.14 (the palliative care team’s response to changes in clients’ care needs), identifying a consistency between these areas of the service delivery (Table 39).

Figure 9: Frequencies (percentage) of External Stakeholder Survey items



Thematic Analysis

The data set consisted of 6 completed comment responses for the External Stakeholders questionnaire. These comments were analysed thematically by becoming familiar with the data, generating initial themes, reviewing (with multiple reviewers) to cross code the themes, defining and reporting the themes. The analysis was interpretive and inductive which reflected the open-ended structure of comments section.

The following key themes were identified:

- Continuity of care;
- Communication;
- Hospitalisation of clients; and
- End of life clinical skills.

Continuity of Care

Three external stakeholders expressed concern at a lack of continuity of care- specifically that clients and their families do not see the same nurse.

Continuity of nursing care- trust is built over time. These families will not trust a revolving door of different nurses each visit. All pts prior to SCG knew who their nurse was- now feedback from families is that they have no idea who looks after them and have to start afresh each visit. Survey Respondent 2017/18

Communication

Three external stakeholders were dissatisfied with the communication from the CPC service provider.

“Difficult to receive a call back when following up on a referral or concern of the family. Most of the time my phone call or follow up is not returned at all. I have to call a manager to gain information, which she is really busy herself.” Survey Respondent 2017/18

“Lack of consultation/communication when the model changes.” Survey Respondent 2017/18

“Improve communication times between call a follow up call by teams - Team members of call centres please be mindful when calling or speaking to a health professional that we are not ‘lay’ people” Survey Respondent 2017/18

Hospitalisation of Clients

Three external stakeholders identified concerns that CPC service clients were hospitalised or referred to the ED while admitted to the service too frequently.

“Give staff enough time in the home to do thorough assessment of client, not go in and look and say this is too hard and ring a PCU for a bed” Survey Respondent 2017/18

“No continuity of care, no consultation or choice given to pts/carers on what service they would prefer, no adequate follow up, the default is always ED if no beds in a PCU” Survey Respondent 2017/18

Limited end of life skills

Two external stakeholders considered that the CPC service clinical staff did not have the skills and capacity to manage the end of life process, and therefore were not able to provide adequate support or explanations to families around the end of life process and requirements to clients.

“have staff that recognise dying, both medical and nursing; have staff that have knowledge and ability to walk patients and relatives through EOL/the dying process” Survey Respondent 2017/18

“The skills of the staff appear to be lacking good EOL assessment skills and communication skills to the pt’s family. Families are not provided good information or education on keeping the pt at home at the EOL” Survey Respondent 2017/18

Summary

Overall, survey respondents identified that they were very dissatisfied/dissatisfied with the CPC service provided during 2017/18. When external stakeholders were invited to complete the service evaluation and provide commentary on aspects of care provided, the qualitative analysis indicated overall dissatisfaction with the palliative care service. This reflects with the consultation and interviews undertaken with clinicians for the evaluation.

The comment analysis highlights the importance of developing and maintaining relationships with clinicals and the wider care multi-disciplinary care team.

Importantly, it needs to be recognised that this service was in the commencement year in 2017/18, noting that there are opportunities to provide for improvement in the areas of: staffing consistency, communication with medical staff, reducing client hospitalisation and end of life care knowledge and skills as the CPC service matures the program in the Western Sydney area.

Table 38: Mean and frequencies for External Stakeholder Survey items (n=7)

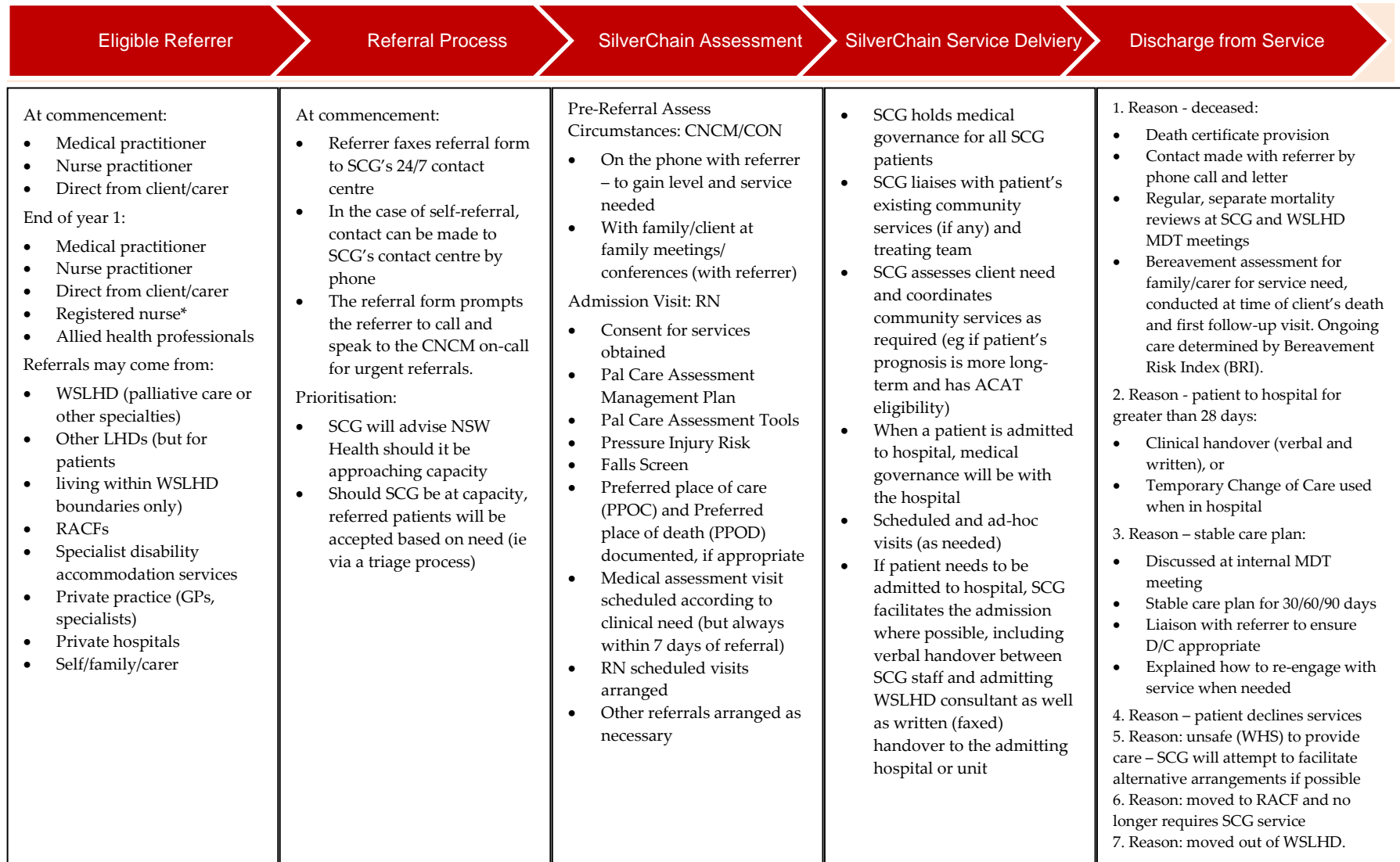
Questions		No	Mean	Standard Deviation	% Satisfied		% Unsatisfied	
Item Range: 1 Very Satisfied to 5 Very Unsatisfied					VS - 1	S - 2	DS - 4	VDS - 5
Q1	Community Palliative Care Service during the last 18 months	7.00	3.43	0.90	-	28.57%	71.43%	-
Q2	Ease of referral process for patients	7.00	3.57	1.05	-	28.57%	57.14%	14.29%
Q3	Timeliness of being informed of the status of your referrals	7.00	3.43	1.05	-	33.33%	50.00%	16.67%
Q4	Communication with the Community Palliative Care Service teams	7.00	4.00	1.07	-	16.67%	33.33%	50.00%
Q5	Your level of involvement once the Community Palliative Care Service is in place	6.00	3.00	1.00	-	50.00%	50.00%	-
Q6	Availability of the palliative care teams to your queries and/or concerns	7.00	3.14	0.99	-	50.00%	25.00%	25.00%
Q7	Shared medical governance for patient care	7.00	4.14	1.12	-	16.67%	16.67%	66.67%
Q8	Your professional role in the treatment and care decisions for patients	7.00	3.71	1.16	-	28.57%	42.86%	28.57%
Q9	The palliative care service coordination overall	7.00	3.86	0.99	-	16.67%	50.00%	33.33%
Q10	The quality of the patients' care in which physical needs for comfort (pain management) are met.	7.00	4.00	1.07	-	16.67%	33.33%	50.00%
Q11	The quality of patients' care in which psychological and emotional needs are met?	7.00	3.57	1.18	-	33.33%	33.33%	33.33%
Q12	Emotional support provided to patients' and family members by the palliative care team.	7.00	3.57	1.40	14.29%	14.29%	42.86%	28.57%
Q13	The palliative care team's response to changes in patients' care needs.	7.00	4.14	1.12	-	16.67%	16.67%	66.67%

Table 39: Mean responses for External Stakeholder Survey subscales using mean score for pooled responses for any N/A or blank response (n=7)

Item	Subscale	Mean	SD	%VS	%S
Service satisfaction and communication					
1	Community Palliative Care Service during the last 18 months	3.43	0.90	-	28.57%
2	Ease of referral process for clients	3.57	1.05	-	28.57%
3	Timeliness of being informed of the status of your referrals	3.43	1.05	-	33.33%
4	Communication with the Community Palliative Care Service teams	4.00	1.07	-	16.67%
6	Availability of the palliative care teams to your queries and/or concerns	3.14	0.99	-	50.00%
	SUBSCALE AVERAGE	3.51	2.27	-	31.43%
Professional and medical governance					
5	Your level of involvement once the Community Palliative Care Service is in place	3.00	1.00	-	50.00%
7	Shared medical governance for client care	4.14	1.12	-	16.67%
8	Your professional role in the treatment and care decisions for clients	3.71	1.16	-	28.57%
9	The palliative care service coordination overall	3.86	0.99	-	16.67%
	SUBSCALE AVERAGE	3.70	2.14	-	22.38%
Quality of care for clients and carers/Families					
10	The quality of the clients' care in which physical needs for comfort (pain management) are met.	4.00	1.07	-	16.67%
11	The quality of clients' care in which psychological and emotional needs are met?	3.57	1.18	-	33.33%
12	Emotional support provided to clients' and family members by the palliative care team.	3.57	1.40	14.29%	14.29%
13	The palliative care team's response to changes in clients' care needs.	4.14	1.12	-	16.67%
	SUBSCALE AVERAGE	3.82	2.40	2.86%	16.19%

Appendix 4: Referral Pathways

Source: Appendix B, Operations Manual





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