Telehealth in the Home: Palliative and Aged Care in South Australia

PART 2 – Palliative Care

Report to the Department of Health

2014
# TABLE OF CONTENTS

1 INTRODUCTION AND OVERVIEW......................................................................................................................... 6

1.1 THE PALLIATIVE CARE (TELEHEALTH) RESEARCH TEAM .................................................................................. 6
1.2 STUDY DESIGN ..................................................................................................................................................... 7
1.3 RECRUITMENT ..................................................................................................................................................... 8
1.4 ETHICS ............................................................................................................................................................... 10
1.5 DATA COLLECTION ....................................................................................................................................... 10

2 DEMAND FOR HEALTH SERVICES ...................................................................................................................... 12

2.1 DEMAND FOR PALLIATIVE CARE SERVICES .................................................................................................. 12
2.2 OPPORTUNITIES AND CHALLENGES ............................................................................................................. 12
2.3 UPTAKE OF TELEHEALTH AND SELF-REPORTING ...................................................................................... 13

3 ACCESS TO HEALTH SERVICES ....................................................................................................................... 15

3.1 TELEHEALTH ACCESS FOR PATIENTS RECEIVING COMMUNITY PALLIATIVE CARE .................................... 15
3.2 PATIENT PERSPECTIVES ABOUT ACCESS TO HEALTH SERVICES ............................................................ 15
3.3 PALLIATIVE CARE AND THE DIGITAL TELEHEALTH NETWORK ................................................................... 16

4 IMPACT ON CLINICAL PRACTICE .................................................................................................................... 17

4.1 IMPACT OF TELEHEALTH ON PALLIATIVE CARE CLINICAL PRACTICE ......................................................... 17
4.2 GP AND PALLIATIVE CARE CLINICIAN EXPERIENCE OF GP CASE CONFERENCES ....................................... 18
4.3 PALLIATIVE CARE CLINICIAN EXPERIENCE OF TELEHEALTH INTERVENTIONS .................................................. 19
4.4 PALLIATIVE CARE CLINICIAN SURVEYS ABOUT ATTITUDES TO TELEHEALTH ........................................... 19
4.5 PALLIATIVE CARE FOCUS GROUP ABOUT ATTITUDES TOWARDS TELEHEALTH ........................................... 21

5 CLINICAL SERVICE EFFICIENCY .......................................................................................................................... 24

5.1 EFFICIENCY OF PALLIATIVE CARE SERVICES ............................................................................................... 24
5.2 CLINICAL NOTES ............................................................................................................................................... 24
5.3 WORKLOAD ACTIVITY ..................................................................................................................................... 26

6 EFFECTIVENESS OF TELEHEALTH CARE ......................................................................................................... 29

6.1 IDENTIFYING NEEDS ......................................................................................................................................... 29
6.2 BEYOND STANDARD ENTRIES ...................................................................................................................... 29
6.3 ENABLING GP CASE CONFERENCES ............................................................................................................. 30
6.4 QUALITY OF VIDEO AND AUDIO IN PALLIATIVE CARE VIDEO CONFERENCING .......................................... 31
6.5 PATIENT EXPERIENCE OF GP CASE CONFERENCES .................................................................................. 32
6.6 SELF-REPORTING OF FUNCTION .................................................................................................................. 38
6.7 SELF-REPORTING OF SYMPTOMS ................................................................................................................ 39
6.8 SELF-REPORTING OF QUALITY OF LIFE ....................................................................................................... 40
6.9 SELF-REPORTING OF CARER NEEDS ............................................................................................................ 41
6.10 CARER EXPERIENCE OF TELEHEALTH ........................................................................................................ 41
6.11 TELEMETRY ................................................................................................................................................... 43

7 EFFECTIVENESS OF TELEHEALTH TECHNOLOGY ............................................................................................. 44

7.1 EFFECTIVENESS OF TECHNOLOGY USED IN TELEHEALTH SERVICES: PALLIATIVE CARE VIEW ................. 44
7.2 PARTICIPANT TRAINING .................................................................................................................................. 44
7.3 NBN SERVICE DELIVERY ISSUES ................................................................................................................. 45
7.4 PARTICIPANT CONFIDENCE USING TECHNOLOGY ....................................................................................... 45
7.5 Unanticipated Issues: Technology Upgrades and Cyber-Threats ......................................................... 46
7.6 Video Conferencing Platforms .............................................................................................................. 46
7.7 Role of IT Support ................................................................................................................................. 46
7.8 System Usability Assessment .................................................................................................................. 47

8 Outcomes for Patients and Carers ........................................................................................................... 48
  8.1 Palliative Care Patient and Carer Outcomes .......................................................................................... 48

9 Outcomes for the Health Services ......................................................................................................... 51
  9.1 Outcomes for Palliative Care Services ............................................................................................... 51

10 Quality and Safety .................................................................................................................................. 52
  10.1 Iterative Improvements Through Formative Evaluation ....................................................................... 52
  10.2 Issues in Sustaining and Scaling Palliative Care Telehealth Model ...................................................... 53
  10.3 Project Learnings and Implications for the Future ............................................................................... 54

11 References .............................................................................................................................................. 56
TABLE OF FIGURES

Figure 1 - Overview of the model .......................................................................................... 7
Figure 2 - Overview of telehealth study processes ................................................................. 9
Figure 3 - Clinical algorithm for Palliative Care Telehealth Clinical Trial .............................. 17
Figure 4 - Be acceptable to patients .................................................................................... 19
Figure 5 - Provide quality community care........................................................................... 20
Figure 6 - Telehealth would increase clinical capacity ......................................................... 20
LIST OF TABLES

Table 1 - Data Collection Points for the Palliative Care Telehealth Study ......................... 11
Table 2 - Total number of entries made by tool ................................................................. 13
Table 3 - Distribution of reported scores (SAS) ................................................................. 14
Table 4 - Comparison of Telehealth to normal practice .................................................... 18
Table 5 - Experience of GP video case conference ........................................................... 18
Table 6 - Summary of Clinical Notes data ....................................................................... 25
Table 7 - Reported outcome of service contact by type of contact .................................... 25
Table 8 - Workload analysis ......................................................................................... 27
Table 9 - Mean staff costs per palliative community care visit ......................................... 28
Table 10 - “Other” symptoms recorded on SAS ............................................................... 30
Table 11 - GP case conferences .................................................................................... 31
Table 12 - Quality of audio, video and connectivity ........................................................ 31
Table 13 - Number of drop outs ..................................................................................... 32
Table 14 - Expected and actual SAS entries ................................................................... 40
Table 15 - System Usability Scores for Patients and Carers........................................... 47
1 Introduction and Overview

Palliative care relies heavily on community support for patients and their families at home. Despite the significant investment in inpatient palliative care facilities, the vast majority of palliative care continues to be provided in the home. Given the frailty of patients with a life-limiting illness and the challenges of caregiving, home-based care needs to explore ways of providing far better and more responsive real-time support. Telehealth is the perfect vehicle to improve this in-home support. Patient self-reporting processes with real-time feedback would enable early identification of changes and facilitate targeted clinical and service responses, potentially enhancing care and outcomes. Recent evidence also indicates that provider acceptance of telehealth within palliative care organisations plays a key role in its utilisation. As such, the benefits and burdens of telehealth, together with its acceptability to patients and their families and to health providers, is the subject of this important pilot work.

The processes involved in developing resources that are clinically meaningful and that interface with, or enhance, work practices are complex and multidimensional. Telehealth resources must satisfy the utility and usability criteria of clinicians and consumers of care, as well as meet the policy and system requirements of funders. This study evaluates the acceptability and feasibility of telehealth for patients, carers and clinicians. It also examines how to build a system that is clinically valuable and incorporates telehealth into community palliative care service delivery.

1.1 The Palliative Care (Telehealth) Research Team

The Palliative Care (Telehealth) Research Team (PCTRT) was established to guide the development of a telehealth model for use by the community team of a specialist palliative care service. Membership of the PCTRT included the Director of the Clinical Service, clinical staff (medicine, nursing, allied health), and researchers with expertise in clinical trial design, health services research, and evaluation. A project manager was appointed to support the project development. Input was sought and received during concept and module development from service providers, stakeholders, and patients and carers involved with the service. The palliative care project team had regular meetings with the Telehealth technical team, as well as with the external IT consultant and web provider. Meetings were also held with the clinicians providing direct care to enable input and feedback on the proposals and the development of the prototype.

The components of the palliative care telehealth model to support patient and carer in the home environment and to enhance clinical feedback are outlined in Figure 1. They include ongoing video-based conferences between service staff and the patient or carer, virtual case conferences with patient and carer, service staff and GP, self-report assessment tools for patient and carer, and remote activity monitoring.
1.2 Study design

The study design was a prospective cohort study of a telehealth-based intervention in palliative care patients. Participants received a combined telecare and telemonitoring package using an iPad tablet. The components of the package included:

- structured online video contacts between the patient and the Nurse Clinical Practice Consultant (CPC), and between the carer and the Nurse CPC and/or Caregiver Network Facilitator (CNF)
- patient self-assessment and online data entry using the following tools – Australia-modified Karnofsky Performance Status (AKPS), Assessment of Quality of Life (AQoL) and Symptom Assessment Scale (SAS)
- carer self-assessment and online reporting using Caregiver Assessment Questionnaire – Caregiver Network Service (CAQ-CNS) for the purposes of this study, and assessment of the patient’s function using the Australia-modified Karnofsky Performance Status (AKPS)
- health care utilisation monitoring via a self-report electronic diary
- planned responses if self-reported assessments met predefined thresholds including face-to-face videoconference, home visit and/or virtual case conference
- access to appraised and structured online information resources
- activity and weight monitoring using Fit Bit technology.
1.3 Recruitment

Forty-three community participants received active services from 6 June 2013 to 31 July 2014. Data collected prior to August 1 was undertaken as part of a quality improvement activity. Once ethics was received, two patients already participating as part of the quality improvement activity were formally consented to participate in the trial proper.

Of the 43 participants, 38 were patient-carer dyads and five had no carer. Seven participants lived alone, with two having visiting rather than resident carers. Two of the carers were siblings, three were daughters and the remaining 33 were partners or spouses. Seventeen of the patients were women (39.53%) and 26 (60.47%) were men. Only the carer was consented in one dyad as the patient’s level of cognition was insufficient for self-reporting of symptoms and function. The average age of patients was 71.6 years, with a range of 49 to 91 years. The most common diagnosis was lung cancer (32.6%) followed by other GIT cancer (11.6%), pancreas cancer (6.9%), skin cancer (6.9%), urological cancer (4.7%), bone cancer (4.7%), haematological cancer (4.7%), colo-rectal cancer (4.7%), prostate cancer (4.7%), gynaecological cancer (4.7%), other malignancy (4.7%), breast cancer (2.3%), non-malignancy (2.3%), cardiovascular disease (2.3%), and unknown cancer (2.3%).

Patients referred to Southern Adelaide Palliative Services (SAPS) that lived in identified areas related to “intended” NBN roll out areas and were receiving home-based care or attending outpatient clinics were invited to participate in the study. Participants needed to be 18 years or older. Those who demonstrated inability to manage the hardware or technology (unless living with a carer who could manage the technology), or who were non-English speaking without a suitable carer/proxy were excluded. Participants were able to withdraw from the research components of the study (i.e. AQoL, activity monitoring, health utilisation diary and computer use questionnaires) at any time without impact on their clinical care. They continued to have videoconferences and to enter clinical symptom data. Participants who were unable or not willing to continue using the iPad received standard care.

Potentially eligible participants were identified from the weekly Active Client List. They were approached by the SAPS clinical team, (usually the CNC or CNF) to consider participation in the study. Potential participants were then contacted by a member of the investigating team to discuss participation in the study. An appointment was made to outline the study and obtain consent. Given a lack of familiarity with technology in many cases, and potential burden given the stage of illness, a second appointment was typically made to demonstrate the technology uses and to enter the first set of data.

An overview of the study activity is outlined in Figure 2. Please note that this study included both clinical care components (AKPS, SAS, CAQ-CNS, online patient information, video reviews) and research specific components (AQoL, Fitbit® Aria™ scales, activPALs, Health Care utilisation diary).

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1 The requirement to live in an area identified for NBN rollout or in receipt of NBN services was removed part way through the project. Recipients were then able to receive services via 3G or ADSL.
Figure 2 - Overview of telehealth study processes

- Active client list
- Screening by SAPS clinicians
- Consent

Palliative Care Telehealth Trial

- Clinical care specific study components
- Staff technology assessments
- Research specific study components
- Telehealth attitudes & confidence questionnaires
- Training

- Patient self-report
- Carer self-report
- Video review
- Clinician interviews & focus groups

- Withdrawal/Death
- Bereavement Follow Up

- Fitbit data entry
- Health care utilisation diary
- Patient and Carer interviews

- Data Analysis
Participants were invited to complete surveys on familiarity with technology, confidence with technology and usability of the telehealth package. They were also invited to participate in interviews about their experience of telehealth.

Participants were offered the choice to only complete the clinical care components of the study if they felt the additional research components were burdensome.

1.4 Ethics

Ethics approval for the study was granted by the Southern Adelaide Clinical Human Research Ethics Committee on 2 August 2013. Five subsequent amendments were sought and all approved.

Amendment 1 (October 2013) requested minor modifications to the applications, computer/technology use questionnaires and the inclusion of patient and carer interviews.

Amendment 2 (January 2014) sought approval to modify participant information sheets to include access to other internet platforms such as 3G and ADSL, following approval from DOH to recruit outside NBN enabled areas. It also sought retrospective approval to include a survey of SAPS clinicians about attitudes towards telehealth and a prospective approval to repeat this survey. It also sought approval to conduct two focus groups with SAPS clinicians involved in the study, as well as clinicians who had participated only in the survey, to elicit more detailed attitudes towards telehealth in palliative care. This amendment also sought permission to extend use of the Fitbit to carers as well as patients to monitor how carer activity may change over time.

Amendment 3 (March 2014) sought approval to interview GPs about their experiences of video case conferences, and to trial activPALS as another form of activity monitoring with patients and carers.

Amendment 4 (May 2014) sought approval to conduct individual interviews with SAPS clinicians unable to attend focus groups about attitudes to telehealth. It also sought approval to survey the Statewide Palliative Care Clinical Network about attitudes to telehealth, and to offer telehealth supported clinical service until death for participants wishing to receive this.

Amendment 5 (June 2014) sought minor modifications to the survey of the Statewide Palliative Care Clinical network to enable it to provide electronic consent rather than completion of a hard-copy consent form.

1.5 Data collection

This report presents quantitative and qualitative data analyses. It deals with data from 43 community-based patients and 38 carers.

Data reported in this document was collected over a period of 11 months, from August 2013 to July 2014. Data collected during the project was used to inform direct clinical care and to support evaluation and research components of the project. The data points collected are outlined below in Table 1.
### Data Collection Points for the Palliative Care Telehealth Study

<table>
<thead>
<tr>
<th>PATIENT</th>
<th>CARER</th>
<th>STAFF</th>
</tr>
</thead>
<tbody>
<tr>
<td>iPad</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Report</td>
<td>Self-report</td>
<td>Clinical notes</td>
</tr>
<tr>
<td>• AKPS</td>
<td>• Carer tool (CAQ-CNS)</td>
<td>Case conference notes</td>
</tr>
<tr>
<td>• SAS</td>
<td>• Patient report</td>
<td>Technology quality Assessment</td>
</tr>
<tr>
<td>• AqoL</td>
<td>• AKPS</td>
<td></td>
</tr>
<tr>
<td>• Health utilisation diary</td>
<td>Information Access (Carer)</td>
<td></td>
</tr>
<tr>
<td>Information Access (Patient)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Video conference</td>
<td>Video conference</td>
<td>Video Conference</td>
</tr>
<tr>
<td>• SAPS Nurse</td>
<td>• Carer Facilitator</td>
<td>• Patient OR Carer</td>
</tr>
<tr>
<td>Video Case Conference</td>
<td>Video Case Conference</td>
<td>Video Case Conference</td>
</tr>
<tr>
<td>• GP, SAPS, Carer</td>
<td>• GP, SAPS, Patient Bereavement Care</td>
<td>• Patient, Carer, GP Bereavement Care</td>
</tr>
<tr>
<td>Fitbit</td>
<td>Fitbit</td>
<td></td>
</tr>
<tr>
<td>Fitbit and Aria® Scales</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Technology Assessment**

<table>
<thead>
<tr>
<th>Technology familiarity</th>
<th>Technology familiarity</th>
<th>Telehealth attitudes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Modified computer self-efficacy scale (mCSES)</td>
<td>modified Computer Self Efficacy Scale (mCSES)</td>
<td>Focus group</td>
</tr>
<tr>
<td>System useability scale ( SUS)</td>
<td>System Useability Scale ( SUS)</td>
<td>Interviews</td>
</tr>
<tr>
<td>Patient/carer interviews</td>
<td>Patient/carer interviews</td>
<td>Clinical notes (technology quality; clinical value)</td>
</tr>
</tbody>
</table>

**Workload Analysis**

<table>
<thead>
<tr>
<th>Caseload summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient interaction (Time estimates)</td>
</tr>
</tbody>
</table>

**Table 1 - Data Collection Points for the Palliative Care Telehealth Study**

In addition to the data collected from the 43 patients living in the community, data is provided separately on three residents with palliative care needs living in a residential aged-care facility. They received telehealth services via the Digital Technology Network (DTN) managed by SA Health. The telehealth grant agreement initially required an NBN or equivalent connection to meet recruitment requirements. Given the issues with delayed rollout of the NBN in South Australia, alternate connections equivalent to NBN were sought. This included the use of the DTN. Data on the three DTN patients is reported in section 3.3.
2 Demand for Health Services

2.1 Demand for palliative care services

South Australia’s Health Care Plan 2007-2016 has already highlighted an increasing demand for palliative care services in the coming years. At present, the Southern Adelaide Palliative Service (SAPS) receives approximately 1,400 referrals a year and serves a total population of about 350,000 people. There are been 400 and 450 people on their active client list at any time. Most of these will be cared for at home for a significant proportion of the time before death, even if they do not die at home. With an ageing population, projected increases in cancer diagnoses and a greater burden of disease relating to progressive chronic disease, more patients will have palliative care needs.

The SA Palliative Care Plan (2009-2016) indicated that by 2012, between 30-40% of those people referred to a palliative care service should be supported to die at home. This would suggest that between 420 and 560 people of the yearly referrals should be supported to die at home each year. As those with palliative care needs increase, this will also increase demand within the community. However, enabling care and death at home is hampered by a lack of ongoing monitoring of vulnerable and frail patients. Without appropriate support, there may be consequent demand for hospital admissions.

2.2 Opportunities and challenges

Traditional palliative care services are typically based on late referrals to the service predicating a need for home assessments, as patients who request a death at home are often too unwell to attend an ambulatory setting. Over the past decade, a shift to more timely referrals has meant that palliative care is often involved earlier in disease trajectory, particularly in supporting management of difficult and complex symptoms. Further demand for palliative care services is possible given the impact of chronic disease progression as patients move from stable management of serious conditions to advancing impacts of the underlying disease activity where death may be a consequence. The introduction of a telehealth service offers a great opportunity to monitor and support community patients at home via videoconferencing and remote monitoring. Proactively monitoring symptoms, rather than responding to crises, potentially enables teams to deliver care in a more efficient manner that will have flow on effects to other inpatient and community health services. However, the ability to meet demand via telehealth may be slowed by interoperability issues and a lack of continuous reliability.

Change of clinician practice is another potential barrier. Early adoption of technology is natural for some in the workforce while for others it poses significant stress. Reluctance to change practice to a telehealth option for monitoring of patients is due, in part, to fear of missing something that would otherwise be picked up from a physical home assessment.

Telehealth offers an efficient way to provide needs-based care. Real-time monitoring and knowledge of what is happening on a continuing basis for the community based clients is something that has not previously been available to Southern Adelaide Palliative Services. The current model results in limited contact between visits; the telehealth intervention captures escalating clinical need that otherwise remains hidden until a crisis arises. Given
policy direction and consumer desires to remain at home, telehealth is not merely a nicety but a necessity.

2.3 Uptake of telehealth and self-reporting

The potential contribution of telehealth with respect to demand for palliative care service provision can be seen in the alerts. Alerts are generated when moderately-to-severely distressing symptoms are reported, there is a fall in function to a predetermined trigger level, or an unplanned health care utilisation. For palliative care patients, changes in symptoms are not uncommon, and relatively high scores can also be expected at some points or with some co-morbidities. For example, breathlessness scores may increase and may remain high as a patient’s disease progresses. This will result in ongoing alerts. Alerts function to notify of a change and to remind the clinician to continue to monitor breathlessness even if the symptom cannot be fully corrected.

Alerts provide some indication of the unmet health care needs of patients which may not be recognised by standard health care processes (i.e. intermittent phone calls, visits, clinics etc). Table 2 outlines the number of times data was entered for each of the tools.

<table>
<thead>
<tr>
<th>Tool</th>
<th>Total number of entries made by tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alert</td>
<td>Total</td>
</tr>
<tr>
<td>AKPS (function)</td>
<td>1,058</td>
</tr>
<tr>
<td>SAS (symptoms)</td>
<td>3,009</td>
</tr>
<tr>
<td>HCU (health-care utilisation)</td>
<td>434</td>
</tr>
<tr>
<td>AQOL-4D (Quality of Life)</td>
<td>957</td>
</tr>
<tr>
<td>CAQ-CNS (Carer self-assessment)</td>
<td>263</td>
</tr>
</tbody>
</table>

Table 2 - Total number of entries made by tool

There were 611 AKPS entries less than or equal to 70. A data entry of ≤ 70 would have triggered an alert. Importantly it is worth noting in some of these instances, if an alert had not been available, emergency hospitalisation may have resulted.

This data suggests that the telehealth system may be a mechanism that can support more efficient monitoring of community-based patients and assist in managing the projected increased demand.

It is worth noting that alerts resulted from data entered by patients with ages ranging from 49 to 90 years. This shows that even older patients are capable of managing the remote reporting system.

Table 3 shows the number recorded symptom scores for each symptom across the trial. A score of ≥ 5 generated an alert that was sent to the community nurse. There were 4,386 alerts that were generated because the score entered for one of the SAS symptoms was ≥ 5. Pain and fatigue were the most commonly reported symptoms.
### Distribution of reported scores (SAS)
(Where 0 = Absent or no distress and 10 = Worst possible distress)

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty Sleeping</td>
<td>986</td>
<td>520</td>
<td>340</td>
<td>558</td>
<td>125</td>
<td>137</td>
<td>106</td>
<td>112</td>
<td>74</td>
<td>37</td>
<td>15</td>
</tr>
<tr>
<td>Appetite Problems</td>
<td>1304</td>
<td>366</td>
<td>282</td>
<td>205</td>
<td>306</td>
<td>183</td>
<td>130</td>
<td>120</td>
<td>70</td>
<td>38</td>
<td>9</td>
</tr>
<tr>
<td>Nausea</td>
<td>1610</td>
<td>324</td>
<td>337</td>
<td>367</td>
<td>119</td>
<td>92</td>
<td>69</td>
<td>47</td>
<td>30</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Bowel Problems</td>
<td>1257</td>
<td>405</td>
<td>360</td>
<td>174</td>
<td>183</td>
<td>274</td>
<td>127</td>
<td>109</td>
<td>81</td>
<td>14</td>
<td>26</td>
</tr>
<tr>
<td>Breathing Problems</td>
<td>691</td>
<td>298</td>
<td>433</td>
<td>781</td>
<td>327</td>
<td>176</td>
<td>62</td>
<td>66</td>
<td>40</td>
<td>5</td>
<td>191</td>
</tr>
<tr>
<td>Fatigue</td>
<td>91</td>
<td>365</td>
<td>540</td>
<td>474</td>
<td>335</td>
<td>328</td>
<td>245</td>
<td>214</td>
<td>185</td>
<td>33</td>
<td>200</td>
</tr>
<tr>
<td>Pain</td>
<td>640</td>
<td>607</td>
<td>437</td>
<td>312</td>
<td>291</td>
<td>242</td>
<td>200</td>
<td>186</td>
<td>61</td>
<td>27</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>6579</td>
<td>2825</td>
<td>2729</td>
<td>2871</td>
<td>1686</td>
<td>1432</td>
<td>939</td>
<td>854</td>
<td>541</td>
<td>164</td>
<td>456</td>
</tr>
</tbody>
</table>

**NB:** These counts are higher than the reports of the SAS totals as one participant telehealth alert may identify several symptoms (pain, fatigue, shortness of breath).

**Table 3 - Distribution of reported scores (SAS)**

This data shows that patients can provide relevant clinical data to help guide health professionals in a clinical response.
3 Access to Health Services

3.1 Telehealth access for patients receiving community palliative care

Telehealth has the potential to reduce burden on patients in the community by providing an enhanced level of access and engagement with palliative care. It enables a level of monitoring previously only accessible to inpatients, and as such provides opportunity for proactive needs based care in the community.

Tables 2 and 3 in the preceding section provide information on how the telehealth model facilitates access to the palliative care service. Indeed, remote monitoring provides a new mode of information provision to the service by patients and carers. Carers have a new means of reporting needs via self-monitoring and videoconferencing. The number of alerts demonstrates a new form of access with 4,386 alerts having been received by SAPS.

In addition, there have been 101 video conferences - 24 with the patient, 34 with the carer and 43 with the patient and carer. It is also worth noting that there have been seven video case conferences between patients, carers, community nurses and GPs, providing a new means of clinical care. Both these activities are new types of service access providing a new form of clinical care. Potentially, they offer an avenue to increase and enhance service access.

3.2 Patient perspectives about access to health services

Qualitative analysis of the interviews conducted with patients and carers involved in the telehealth trial provides information on how recipients of care believe that telehealth affects access to service. Data analysis of interview content demonstrates that telehealth has enabled access for targeted needs-based care that is highly valued by both patients and carers.

Access to palliative care services has been particularly enhanced by telehealth for those patients whose disease burden prevents them from travelling, enabling ongoing management at home.

PC006

It is like having palliative care here in the home…Yeah, I mean, the thing is if we wanted to leave a note as well for Patrick, we can leave that under the two at the bottom where it says other…I was getting mega headaches, I can just put on there.

Video reviews have the added benefit over telephone for those with hearing deficits, as they allow participants to lip read. However, some older participants reported they prefer face-to-face or a phone call, as this is what they are familiar with.

Carers also had the opportunity to record physical, emotional and spiritual needs that may impact on their capacity to care for their loved one.

Interviewer

So you pushed a 10. Were you surprised that she replied? Or responded?

PC026C

Yeah, I was. I didn’t think she would get back so quick (laughing). It was quick! But it was good.
### 3.3 Palliative care and the Digital Telehealth Network

Three videoconferences were performed via DTN for residents and their families in residential aged care with a palliative care physician. The major focus of these interactions was advance care planning, focusing on goals of care, levels of intensification and site of care.

**Patient 1** had metastatic melanoma and advanced dementia. Discussion with her daughter - her Enduring Power of Guardianship (EPOG) - clarified the goals and site-of-care, as well as the expected prognosis. Advice was given about symptom management and anticipatory prescribing of end of life.

**Patient 2** had advanced dementia. Discussion with her son clarified goals and site-of-care, and limitations of care to be provided (e.g. no enteral feeding). This consultation was also a chance to clarify some misperceptions of palliative care after a previous bad experience of end-of-life care.

**Patient 3** had advanced dementia with neuropathic pain following a below-knee amputation. Discussion explored advance-care planning, symptomatic management for neuropathic pain, and strategies for managing dementia related behaviours.

Again, these three videoconferences provided access to a new form of service. They facilitated engagement between a palliative care service and a community member with palliative care needs and their family and health providers. All three videoconferences went smoothly with no technical issues.
4 Impact on Clinical Practice

The introduction of telehealth palliative care intervention has brought a myriad of changes and had a subsequent impact on delivery of clinical care. While telehealth cannot replace all face to face meetings, it enhances screening of clinical need by enabling clinicians to visually assess patients and carers from their office and to proactively identify change through alerts. This section deals with the impacts on, and experiences of, health professionals. Patient and carer impacts and experiences are reported in Sections 7 and 8.

4.1 Impact of telehealth on palliative care clinical practice

Implementation of telehealth has required the development of a clinical algorithm that describes the treatment protocol. This algorithm underpins the generation of alerts based on reported symptom scores by patients and carers. The clinical algorithm was established in consultation with the treating clinicians and is detailed below.

![Figure 3 - Clinical algorithm for Palliative Care Telehealth Clinical Trial](image)

The nurses made 121 ratings on conducting clinical assessments using telehealth compared with a phone call. Nurses commonly indicated that telehealth was better (48.7%), followed by similar (22.3%), much better (16.5%), worse (9.1%) and much worse (3.3%). One hundred and eleven ratings were made comparing telehealth to face-to-face. Telehealth was primarily rated as similar (63.1%), followed by better (27.0%), worse (6.3%), much worse (2.7%) and much better (0.01%).

Please refer to Table 4 for more detail.
Telehealth can also enable video case conferences to be held with GPs from their surgery, to the patient and carer at home, and the palliative care nurse and palliative care consultant at their office. Previous research has shown that case conferences can increase the likelihood of continuing care and death at home. However, palliative care case conferences in South Australia have remained very low. Telehealth-enabled case conferences offers a mechanism to increase the number of conferences and ensure that participants are aligned.

Seven video case conferences have been held during the study. In each, a carer, patient, GP, and clinical nurse consultant were present. In one case conference a palliative care consultant was also present. The last case conference was multidisciplinary in nature with clinicians spread across three sites: the GP in their surgery, the social worker and palliative care nurse at the hospice, and RDNS and home care at the patient’s house with the patient, his wife and daughter. Video case conferences were all initiated by an AKPS trigger identifying the need for intervention and all took place with the patient in their own home. The conferences ranged between 13 and 40 minutes. In terms of quality and experience, the SAPS nurse categorised all conferences as either better or much better compared with a phone call and similar to face-to-face meetings in all but one instance (Table 5). Patient experience of GP case conferences is discussed in Section 6.4.

<table>
<thead>
<tr>
<th>Case conference</th>
<th>Quality compared with phone call</th>
<th>Quality compared to face-to-face</th>
<th>Overall experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Much better</td>
<td>Similar</td>
<td>Very good</td>
</tr>
<tr>
<td>2</td>
<td>Much better</td>
<td>Similar</td>
<td>Good</td>
</tr>
<tr>
<td>3</td>
<td>Better</td>
<td>Similar</td>
<td>Good</td>
</tr>
<tr>
<td>4</td>
<td>Much better</td>
<td>Similar</td>
<td>Good</td>
</tr>
<tr>
<td>5</td>
<td>Much better</td>
<td>Similar</td>
<td>Very good</td>
</tr>
<tr>
<td>6</td>
<td>Better</td>
<td>Similar</td>
<td>Good</td>
</tr>
<tr>
<td>7</td>
<td>Better</td>
<td>Worse</td>
<td>Good</td>
</tr>
</tbody>
</table>

Table 5 - Experience of GP video case conference
These views of the telehealth for regular videoconferences, and for virtual case conferences, suggest that clinicians see video-based communication as acceptable in terms of quality for clinical care.

### 4.3 Palliative care clinician experience of telehealth interventions

Four palliative care nurses have been involved in the implementation of a palliative care telehealth intervention. They entered responses about their experience of telehealth each time they write clinical notes about video reviews or phone calls.

Nurses identified instances in which telehealth made a difference to clinical practice. Nurses indicated that technology had been very effective in enabling the patient or carer to be reassured (57.3%), quicker problem management (23.2%), identification of problems that may not have been recognised (20.5%), ability to resolve issues that would have previously required a home visit (16.8%), and ability to share information with other health professionals (7.6%).

### 4.4 Palliative care clinician surveys about attitudes to telehealth

Prior to commencement of a telehealth service, 38 staff in SAPS were surveyed about their views and perceptions on how the addition of telehealth might impact service delivery to patients and carers, when compared to current practice. Staff perspectives included items relating to telehealth acceptability to patients and carers, facilitating more contact, and the impact on monitoring patients’ symptoms and functions.

Using a Likert scale from 1 (Strongly Disagree) to 7 (Strongly Agree), staff had an average score of 4.5 in terms of telehealth acceptability to patients. As seen in Figure 4, most staff at least partially agreed or strongly agreed that telehealth would be acceptable to patients. No staff completely disagreed that telehealth would be acceptable to patients.

![Figure 4 - Be acceptable to patients](image-url)

**Figure 4 - Be acceptable to patients**

[Likert scale, (Strongly Disagree (1) to Strongly Agree (7))]
Staff had an average score of 5 in relation to whether telehealth would support the provision of quality community care. Similar to patient acceptability, many staff agreed or strongly agreed that telehealth would enable them to provide quality community care. No staff strongly disagreed that telehealth would provide quality community care. (Figure 5)

![Figure 5 - Provide quality community care](image)

**Figure 5 - Provide quality community care**

[Likert scale, (Strongly Disagree (1) to Strongly Agree (7)]

Staff also had relatively positive views about the contribution of telehealth to clinical capacity. Staff had an average score of 4.5 in relation to perceptions about increasing their clinical capacity. (See Figure 6) Staff typically had moderate levels of agreement for this statement, and only one staff member strongly disagreed that telehealth would help to increase clinical capacity.

![Figure 6 - Telehealth would increase clinical capacity](image)

**Figure 6 - Telehealth would increase clinical capacity**

[Likert scale, Strongly Disagree (1) to Strongly Agree (7)]
4.5 Palliative care focus group about attitudes towards telehealth

A component of the project evaluation was to investigate clinicians’ and key stakeholders’ perspectives and experiences of the Telehealth Palliative Care Intervention (TPCI) to inform implementation of the intervention in ‘everyday’ clinical service provision. The aim of this section of the report is to present the qualitative findings from focus groups and interviews with key stakeholders. The objectives of the focus groups and semi-structured interviews were to:

- explore key stakeholder perspectives and experiences of telehealth;
- explore clinicians’ direct experiences of using telehealth;
- explore clinicians’ and other key stakeholders’ perspectives of the benefits and challenges for patients, families and clinicians of using telehealth applications; and
- explore the enablers and barriers for utilisation of telehealth in a palliative care setting including how telehealth applications can be integrated into current service provision and be used and improved upon in the future.

Focus groups and interviews were conducted in May and June 2014. There were three groups of participants: SAPS clinicians directly involved in the telehealth project (FG1) (n=4); SAPS clinicians not directly involved in the TPCI (FG2) (n=4), and other key stakeholders i.e. the service director and a key medical clinician who were investigators on the project as well a holding key positions in the clinical service.

Five key themes emerged from the data:

- **Theme 1 - Redefining models of care**: This theme highlights how the TPCI appeared to interrupt ‘business as usual’, challenging current service provision and care models. The subthemes - working smarter and working safer - highlight how staff consider telehealth as one possible solution to address what they consider as increasing clinical demand, decreasing resources, and issues of efficiency.

  
  "The thing that I realised it would do is actually force us to examine what we are doing a lot harder because as we wrote our protocol or process documents around what sort of care we would deliver, it forced us to reflect on our current practice and it means we probably need to do some work around articulating what normal practice is and the bare minimum standard should be" (Staff specialist, palliative care and project investigator)

  "And it does provide you an avenue to work smarter and be better about time management, particularly because our service provides staff, I don’t know, 45, 50km from where we are based. That is a lot of driving time when you consider you have to come back as well" (Participant, FG1)

- **Theme 2 - Clinical benefits of telehealth**: This theme relates to the impacts of the TCPI on clinical care and encompasses the sub themes: Making connections; the visual medium; expressing empathy through ‘seeing’; clinical assessment and the
visual; real-time clinical data, and empowering patients and families.

And we also pick it up on them when they say; on the phone they say: ‘Oh I am doing pretty well’, ‘Well you actually look blue; you don’t look well. What is the vomit bucket sitting on the bed next to your for?’ Whereas you wouldn’t know that over a phone call (Participant, FG1)

- **Theme 3 - Person-centred symptom management:** The value of context and clinical judgement: This theme articulates the role of the TCPI monitoring tools and their relationship with clinicians’ knowledge of particular patients.

  “I would have 30 people (patients) that, you know, tap that knowledge (of patients) in my brain. No, Mary is fine, even though it (SAS score) says 4/10, that is fine, leave it alone” (Participant FG1).

- **Theme 4 - The troubles with telehealth:** This theme conveys the effects on staff when TCPI technologies do not function as planned, along with the effects on relationships when TCPI is introduced. It encompasses the subthemes technological and teething troubles, and material and affective disconnections:

  I think the technological issues are a headache. From where we have been, but also going forward. And that you can get things all set up and working but tomorrow they are not working and that is a real problem and you, it’s not a ‘set and forget’. You can’t get the technology working and expect that it stays working. So I think that is a huge issue and certainly when the machines are playing up and they can’t get through. Like all of a sudden it is easier just to go back to the normal ways of doing it. (Staff specialist, palliative care and project investigator).

  “That is exactly the words I was going to say, a trust relationship. Rapport. Which you don’t always get straight up on an iPad (Participant, FG1)

- **Theme 5 - Unintended consequences:** This theme describes unanticipated effects of implementing the TCPI and includes the subthemes: Carer burden; the absence of a ‘disease’-free day; bringing decline into consciousness; alert burden.

  “I was just inundated with all these bits of paper every day; all these alerts. I didn’t know any of the patients and every day they (alerts) were coming at me. I was ready to throw! I was just ignoring them in the end” (Participant, FG1)

The staff highlighted a number of implementation recommendations for the TCPI to be successfully integrated into everyday clinical practice and service provision. They suggested:

- Redefine and refine the care model and service provision in relation to the TCPI.
• The TPCI would augment and complement current service provision rather than provide an alternative for home visits.
• Further refinement of the TPCI is required including, but not limited to the interface; monitoring tools and apps; and patient and family resources.
• IT support and infrastructure in situ.
• Implementation plan includes involvement of staff in clinical redesign as well as support and education of staff in the TCPI.
• Consideration is given to relationship and integration with other healthcare software and hardware.
5 Clinical Service Efficiency

5.1 Efficiency of palliative care services

Telehealth implementation will require business process changes. Hence an understanding of the implications for the service and the health system is critical. A series of studies were undertaken to assess the implications for clinical service efficiency. They include the capacity of the telehealth tools to predict current or expected clinical need. Data on the entry of scores for the clinical tools has been reported in Tables 2 and 3. This demonstrated that clinicians can be alerted to changes in patient condition through remote self-monitoring.

5.2 Clinical Notes

Following completion of a telehealth activity (e.g. video review or phone call in response to an alert), nursing staff wrote up clinical notes pertaining to this service. They also provided some detail on the characteristics of the service. This data provides information on the contribution performance of telehealth in terms of identification of clinical need, occasions of service and whether they were scheduled or unscheduled, and where/how the service was provided (phone, video call or face-to-face).

In total, there were 180 recorded contacts made with patients, carers or both. The primary mode of contact was video-conferencing (56.7%), followed by phone call (29.4%), then face-to-face (13.9%). Contact was most often made with both carers and patients (44.9%), followed by carer only (35.9%) and patient only (19.1%). Scheduled contact (67.3%) was more common than unscheduled contact (32.7%). Unscheduled reasons for contact were primarily a SAS trigger (25.5%), followed by message from patient (20.0%) or AKPS trigger (21.8%) and CAQ- CNS trigger (18.2%) or non-completion for 2 days (14.6%).

This indicates that clinical responses are being made to data being entered by the patient. The data shows that 57 unscheduled contacts were made. Key findings are summarised in Table 6.
### Summary of Clinical Notes data

<table>
<thead>
<tr>
<th></th>
<th>Phone call</th>
<th>Video conferencing</th>
<th>Face-to-face</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contact made with</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>8</td>
<td>24</td>
<td>2</td>
</tr>
<tr>
<td>Carer</td>
<td>29</td>
<td>34</td>
<td>1</td>
</tr>
<tr>
<td>Both</td>
<td>16</td>
<td>43</td>
<td>23</td>
</tr>
<tr>
<td>Location of clinician</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient’s own home</td>
<td>4</td>
<td>9</td>
<td>25</td>
</tr>
<tr>
<td>Daw House office</td>
<td>27</td>
<td>66</td>
<td>-</td>
</tr>
<tr>
<td>Clinic</td>
<td>20</td>
<td>22</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>People present</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SAPS Nurse 1</td>
<td>27</td>
<td>63</td>
<td>24</td>
</tr>
<tr>
<td>SAPS Nurse 2</td>
<td>26</td>
<td>32</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Contact reason</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scheduled</td>
<td>22</td>
<td>80</td>
<td>14</td>
</tr>
<tr>
<td>Unscheduled</td>
<td>32</td>
<td>17</td>
<td>9</td>
</tr>
<tr>
<td>Unscheduled reasons</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Message from patient</td>
<td>7</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>AKPS trigger</td>
<td>4</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>SAS trigger</td>
<td>3</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>CAQ-CNS trigger</td>
<td>9</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Non-completion for 2 days</td>
<td>7</td>
<td>1</td>
<td>-</td>
</tr>
</tbody>
</table>

**Table 6 - Summary of Clinical Notes data**

One hundred-and-one notes on the outcome of a service contact (scheduled or unscheduled) were recorded. A change in medication was a common noted outcome. It is worth noting that the data indicates that four admission recommendations were made following a video call. Details can be found in Table 7.

### Reported outcome of service contact by type of contact

<table>
<thead>
<tr>
<th></th>
<th>Phonecall</th>
<th>Videocall</th>
<th>Face to face</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication change</td>
<td>10</td>
<td>15</td>
<td>11</td>
</tr>
<tr>
<td>Admission recommendations</td>
<td>1</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>No change</td>
<td>12</td>
<td>33</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>27</td>
<td>61</td>
<td>23</td>
</tr>
</tbody>
</table>

**Table 7 - Reported outcome of service contact by type of contact**
While telehealth has the potential to reduce the need for face-to-face clinical assessment, it does not eliminate it. The telehealth service can however help to identify need prospectively, monitor emerging symptoms and responses to treatment more consistently, and target clinical resources to need more effectively.

### 5.3 Workload activity

Data are reported for 22 palliative community care visits between 2nd and 15th September 2013 in Area 4 (pre-telehealth) and 32 visits between 17th and 30th March 2014 (post-telehealth). The two groups were similar with respect to diagnosis.

However, the reason for visit, and proportion of joint visits, differs between both groups with proportionally more reviews conducted post-telehealth compared with pre-telehealth (59.4% versus 40.1% respectively) and fewer joint visits (6.3% versus 27.3% respectively). All of the pre- and post-telehealth palliative community care visits involved an advanced nurse, whereas few involved a medical practitioner (27.3% pre- versus 6.3% post-telehealth respectively) (Table 8). The proportion of palliative community care visits requiring travel reduced by 31.8% following implementation of the telehealth-based intervention (81.8% pre- and 50.0% post-telehealth).
<table>
<thead>
<tr>
<th>Variable</th>
<th>Pre-telehealth N=22</th>
<th>Post-telehealth N=32</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travel undertaken, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>18 (81.8)</td>
<td>16 (50.0)</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
<td>12 (37.5)</td>
</tr>
<tr>
<td>Not Reported</td>
<td>4 (18.2)</td>
<td>5 (12.5)</td>
</tr>
<tr>
<td>Travel time, minutes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>38 (n=18)</td>
<td>42 (n=13)</td>
</tr>
<tr>
<td>Median</td>
<td>38</td>
<td>40</td>
</tr>
<tr>
<td>Min-max</td>
<td>15-105</td>
<td>20-80</td>
</tr>
<tr>
<td>Clinician Location, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td>2 (9.1)</td>
<td>13 (40.6)</td>
</tr>
<tr>
<td>Clinic</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Home</td>
<td>18 (81.8)</td>
<td>14 (43.8)</td>
</tr>
<tr>
<td>Nursing home</td>
<td>0</td>
<td>1 (3.1)</td>
</tr>
<tr>
<td>Not reported</td>
<td>2 (9.1)</td>
<td>4 (12.5)</td>
</tr>
<tr>
<td>Reason for visit, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New</td>
<td>10 (45.5)</td>
<td>5 (15.6)</td>
</tr>
<tr>
<td>Review</td>
<td>9 (40.1)</td>
<td>19 (59.4)</td>
</tr>
<tr>
<td>Linked to an inpatient episode</td>
<td>0</td>
<td>2 (6.3)</td>
</tr>
<tr>
<td>Not reported</td>
<td>3 (13.6)</td>
<td>6 (18.8)</td>
</tr>
<tr>
<td>Diagnosis, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>19 (86.4)</td>
<td>27 (84.4)</td>
</tr>
<tr>
<td>Non-cancer</td>
<td>2 (9.1)</td>
<td>5 (15.6)</td>
</tr>
<tr>
<td>Not reported</td>
<td>1 (4.5)</td>
<td>0</td>
</tr>
<tr>
<td>Joint visit, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6 (27.3)</td>
<td>2 (6.3)</td>
</tr>
<tr>
<td>No</td>
<td>16 (72.7)</td>
<td>30 (93.8)</td>
</tr>
<tr>
<td>Staff attendance, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Senior medical practitioner</td>
<td>4 (18.2)</td>
<td>2 (6.3)</td>
</tr>
<tr>
<td>Junior medical practitioner</td>
<td>2 (9.1)</td>
<td>0</td>
</tr>
<tr>
<td>Advanced nurse</td>
<td>22 (100)</td>
<td>32 (100)</td>
</tr>
</tbody>
</table>

Table 8 – Workload analysis
The mean pre-intervention staff costs per palliative community care visit, including travel time is $171 (95% CI $136, $210; see Table 9). Following implementation of the telehealth-based intervention, the mean staff costs per visit, including travel time reduces to $66 (95% CI $44, $90). This mainly reflects lower observed senior and junior practitioner attendance, and reduced advanced nursing patient care and travel time. Overall, pre-intervention unadjusted staff costs are estimated to be $105 (95% CI $62, $150) greater per palliative community care visit than post-telehealth staff costs (Table 9). This is mainly attributable to the $64 additional pre-intervention advance nursing costs.

<table>
<thead>
<tr>
<th>Staff role</th>
<th>Mean costs per visit (95% CI)</th>
<th>Pre-telehealth</th>
<th>Post-telehealth</th>
<th>Increment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senior medical practitioner</td>
<td>$30 ($0, $65)</td>
<td>$5 ($0, $16)</td>
<td>$25 (-$5, $61)</td>
<td></td>
</tr>
<tr>
<td>Junior medical practitioner</td>
<td>$16 ($0, $40)</td>
<td>$0</td>
<td>$16 ($0, $40)</td>
<td></td>
</tr>
<tr>
<td>Advanced nurse</td>
<td>$125 ($112, $138)</td>
<td>$61 ($42, $81)</td>
<td>$64 ($39, $87)</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>$171 ($136, $210)</strong></td>
<td><strong>$66 ($44, $90)</strong></td>
<td><strong>$105 ($62, $150)</strong></td>
<td></td>
</tr>
</tbody>
</table>

Table 9 - Mean staff costs per palliative community care visit

The exploratory findings of this ‘Telehealth in the home’ substudy suggest the introduction of the telehealth-based intervention reduces overall staff time per palliative community care visit, mainly due to a reduction in advanced nursing time. The data suggest this reduction could be due to reduced travel time and patient contact time. Approximately $105 mean cost savings per visit were associated with the reduction in staff resource use with 95% CI ranging from $62 to $150, a statistically significant and important difference. The results are consistent with systematic review evidence that suggests telehealth-based interventions reduce staff resource use (Rojas S and Gagnon MP 2008, Davalos M, French M et al. 2009, Peeters J, Mistiaen P et al. 2011, Oliver, Demiris et al. 2012). There is a lack of consensus whether telehealth-based interventions are cost-effective compared with other models of care possibly due to variations in the definition and configuration of telehealth-based interventions, and the context of care in published studies (Mistry 2012). Furthermore, the methodological reporting and quality of studies in this research area is often poor (Rojas S and Gagnon MP 2008, Davalos M, French M et al. 2009, Peeters J, Mistiaen P et al. 2011, Mistry 2012).

The costing analysis focuses on staff costs only. A comprehensive costing analysis including the costs of the telehealth-based intervention, patient and informal carer costs and health care utilisation costs is needed to more robustly assess the net cost implications of the telehealth-based intervention.
6 Effectiveness of Telehealth Care

The development of the telehealth model for community-based palliative care provides a great opportunity to improve care for this vulnerable population. The SAPS Service Director reported that “this model provides us with a mechanism for providing needs-based care in their house.”

This section highlights elements of a telehealth service that provide additional benefits, as well as patient and carer perspectives on the effectiveness of telehealth.

6.1 Identifying needs

As noted earlier in this report, this trial has demonstrated that community-based patients and carers are willing and able to provide data about their condition using tablets (Table 2). It has shown types of clinical responses to patient data entry (Table 7). The automatically generated alerts have therefore proactively identified need which was previously unreported to health clinicians.

Patients and carers noted that self-reporting enhances the accuracy of their communication with nursing and medical staff. The routine of daily completion acts as a memory aid, enabling them to report more accurately on changes in symptoms. This was true for both patients and carers.

One participant noted in interview that self-reporting symptoms helps him be more accurate and honest with himself, his wife and clinicians.

PC006 And I just feel the doctors are getting the information over a couple of weeks where we may only see them once a month and you try to remember how you felt over the month and that... They can say “Well Mark, you turned around and answered on that you had pain, pain, pain, now you are telling me you didn’t.” It jogs my memory and it gives a truer effect.

6.2 Beyond standard entries

Not only were patients able to enter predetermined symptoms as specified by the Symptom Assessment Scale, but they were able to use free text to enter other symptoms or concerns not identified by the SAS. There were 127 entries by patients or carers into “other” SAS symptoms detailed in Table 10. Participants provided context around reported pain such as sore legs, noses, toes and fingers, overall body pain and stomach pain. They also reported other issues not captured in the screening scores for seven symptoms. Patients noted they had swelling symptoms involving legs and feet. Itchy skin and nail infections were also common reports. Five entries involved mood problems, and these were mostly related to depression and distress. Less common entries related to dry mouth, insomnia, urinary problems and headache.
“Other” symptoms recorded on SAS

<table>
<thead>
<tr>
<th>Symptom/Complaint</th>
<th>Number of “Other”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>90</td>
</tr>
<tr>
<td>Nails (sore/infected)</td>
<td>21</td>
</tr>
<tr>
<td>Itchy skin</td>
<td>18</td>
</tr>
<tr>
<td>DVT</td>
<td>11</td>
</tr>
<tr>
<td>Mood</td>
<td>8</td>
</tr>
<tr>
<td>Coughing</td>
<td>8</td>
</tr>
<tr>
<td>Oedema</td>
<td>6</td>
</tr>
<tr>
<td>Balance/Fall</td>
<td>6</td>
</tr>
<tr>
<td>Vomiting</td>
<td>4</td>
</tr>
<tr>
<td>Bowel/urinary</td>
<td>4</td>
</tr>
<tr>
<td>Trouble breathing</td>
<td>2</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>2</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>1</td>
</tr>
<tr>
<td>Insomnia</td>
<td>1</td>
</tr>
<tr>
<td>Nosebleed</td>
<td>1</td>
</tr>
<tr>
<td>Ulcer</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 10 - “Other” symptoms recorded on SAS

This indicates that patients are taking the opportunity to provide details on symptoms identified as troublesome, or to highlight specific symptoms or concerns not captured by the SAS major items.

6.3 Enabling GP case conferences

Telehealth has provided a functionality to enable case conferencing. Case conferences with the general practitioner are valuable interactions to discuss the current status of, and future plan for, patients. Recent literature suggests that a case conference may reduce hospital presentations and improve functional maintenance (Abernethy et al, 2013). Participation in case conferences in palliative care has been problematic. Patient and carer involvement is valuable, but creates substantial logistics in facilitating real-time involvement of the multiple parties.

Seven video case conferences were conducted over the course of the study in response to a pre-determined decline in function. All seven case conferences were initiated in response to an AKPS trigger. All but one took place with the patient in their own home, the latter was held whilst the patient was in Daw House. The case conferences ranged between 13 and 40 minutes.

Characteristics of the case conferences are outlined in Table 11. In terms of quality and experience, the SAPS nurse categorised all conferences as being either better or much better than a phone call, and similar in all cases but one (worse) than face-to-face.
6.4 Quality of video and audio in palliative care video conferencing

The palliative care telehealth intervention comprised two types video conferencing. The first scheduled review was a short (~ 10 minute) conversation with patients via the iPad in order to review their medical status. The second type of review was in response to an alert triggered by an increase in symptoms, drop in function or identified carer need.

Nurses made a clinical decision in consultation with the patient and carer at the time of the alert regarding appropriateness of phone call only or video review. Characteristics of the videoconferencing, including quality of video, audio, and drop-outs, are included in Tables 12 and 13. Generally the quality of audio and video was good.

<table>
<thead>
<tr>
<th>GP case conference</th>
<th>Location</th>
<th>Contact Type</th>
<th>Initiated By</th>
<th>Duration (mins)</th>
<th>Video Quality (1 – 5)</th>
<th>Audio Quality (1 – 5)</th>
<th>Ability to Connect (1 – 5)</th>
<th>Ease of Use for Clinicians (1-5)</th>
<th>Number of Dropouts</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Patient Home</td>
<td>Vidyo</td>
<td>AKPS Trigger</td>
<td>13</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>Patient Home</td>
<td>Vidyo</td>
<td>AKPS Trigger</td>
<td>17</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>Patient Home</td>
<td>Vidyo</td>
<td>AKPS Trigger</td>
<td>35</td>
<td>4</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>Patient Home</td>
<td>Vidyo</td>
<td>AKPS Trigger</td>
<td>40</td>
<td>4</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>5</td>
<td>Inpatient</td>
<td>Vidyo</td>
<td>AKPS Trigger</td>
<td>20</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>6</td>
<td>Patient Home</td>
<td>Vidyo</td>
<td>Other SAPS staff</td>
<td>20</td>
<td>5</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>7</td>
<td>Patient Home</td>
<td>Vidyo</td>
<td>Other SAPS staff</td>
<td>40</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 11 - GP case conferences

The number of drop-outs suggests that, in general, drop-outs were not a problem; but there were instances of problems in connecting, and of freezing during video calls.

<table>
<thead>
<tr>
<th>Quality of Audio, Video and connectivity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Quality of audio (N = 45)</td>
</tr>
<tr>
<td>1 Poor</td>
</tr>
<tr>
<td>Quality of video (N = 42)</td>
</tr>
<tr>
<td>1 Poor</td>
</tr>
<tr>
<td>Ability to connect (N = 47)</td>
</tr>
<tr>
<td>1 Poor</td>
</tr>
</tbody>
</table>

Table 12 - Quality of audio, video and connectivity
<table>
<thead>
<tr>
<th>Number of drop outs</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>28</td>
</tr>
<tr>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
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<tr>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Many</td>
<td>2</td>
</tr>
<tr>
<td>Froze x2</td>
<td>1</td>
</tr>
<tr>
<td>Froze x 3</td>
<td>1</td>
</tr>
<tr>
<td>Unable to connect</td>
<td>3</td>
</tr>
<tr>
<td>Unable to connect...kept timing out</td>
<td>2</td>
</tr>
<tr>
<td>Client requested a phone call</td>
<td>1</td>
</tr>
<tr>
<td>Unable to use Vidyo – phone call</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 13 - Number of drop outs

6.5 Patient experience of GP case conferences

The value and clinical utility of case conferences has been highlighted in participant interviews. Seven case conferences were conducted with GPs, and one of these case conferences involved a multidisciplinary team. All participants were satisfied that the case conference had achieved what they and the clinicians needed. A number of key factors have been identified.

- Coordinating care
- Connecting clinicians
- Opportunities and challenges of video
- Alleviating burden

**Coordinating care**
Participants experienced video case conferences as a way to keep their GP informed about their care needs. The case conference was found to be an opportunity for patients and carers to ask their GP questions in the presence of palliative care clinicians, and have these addressed in an expedient manner, e.g. revision of medications and arrangement for scripts. Participants also placed high value on being heard by the GP and the palliative care clinician over the course of the case conference. Case conferences were seen as a way to keep their GP (and in one case, the multidisciplinary team) informed and educated about their care needs. All participants were highly appreciative of their GPs participation in a case conference and several suggested this should become a more routine practice.

Interviewer: Are you talking about communications between you?

PC010: Communications

Interviewer: Between you and the GP and (nurses name).

PC010: Yeah, and, because actually they were asking each other questions too.
**Connecting clinicians**
Participants placed high value on the collaboration between palliative care and their GP. They noted palliative care clinicians often led the discussion, and appreciated being an integral part of that conversation. Participants also derived great satisfaction from observing the clinicians interacting about their care. They believed the GP in particular benefited from the visual contact with palliative care clinicians, maybe ‘meeting’ for the first time. This communication was seen to enhance their care and helped to clarify roles and actions required in the patient’s present and future care. Participants also felt that when palliative care and the GP meet via video, the risk of information about patient care being misconstrued was reduced.

*Interviewer* Are you saying, Frank, that by having them both, the nurse and the GP together on the iPad meant that they were both hearing exactly the same thing from you?

*PC003* Yeah, Yeah, there are no misconstrues.

**Opportunities and challenges of video**
A video case conference was experienced by participants as mirroring a face-to-face interaction, and better than a phone call.

*PC011* You could see a face, you can talk to a face better than you can a voice on a telephone... that was much better. I mean you could ask the same questions but being able to see the face and the response of the face to the questions was good I thought... Because you have got the opportunity to ask questions and you don’t have to wait a week or two for her to come and visit. I am not sure how we are going to get on to her.

It not only enhanced communication for team members, it enabled clinical assessment of disease progression and bodily changes.

*PC010* I can show him what is wrong with me. I can show them the nodes, like I did today.

*Interviewer* On your neck?

*PC010* These have gotten bigger again, you know.

*Interviewer* Yeah.

*PC010* You know you can see it. Ah. I do feel you get more personalised service. Oh you have the feeling of getting more personalised attention when it is face-to-face.

*Interviewer* On the screen?

*PC010* On the screen. You know what I mean.
Several participants identified sound and vision issues that occurred during their GP case conferences that required some adjustments. One patient had problems hearing the conference due to his deafness, and this meant that additional time was required in order for him to hear and respond to what was being said. In most cases, the audio-visual problems were corrected by positioning of the iPad. Some participants stated that they would not have been able to manage joining the conference without assistance from IT or palliative care. One patient felt that the large number of people involved (multidisciplinary case conference) had been challenging in terms of hearing what was said and who had said it.

**Alleviating burden**
As disease progresses, travel to and from appointments becomes increasingly difficult. Several participants highlighted the fact that attending a case conference from their own home alleviated the burden of travel which had significant physical, symptom and emotional benefits.

PC006C And you don’t have to travel.

PC006 Oh yes. The travelling’s an absolute nightmare.

Interviewer How important is it for you to not travel?

PC006 Very, very. It saves me three to four days of agony.

Interviewer So the agony comes after you have travelled.

PC006 Yeah.

Interviewer Okay.

PC006 All the bumps and sways and

PC006C And the energy.

PC006 I get, even in the motorised wheelchair, they get you, by the time I get back in my bed it feels like I have run three marathons. And I don’t eat nothing, I don’t drink anything. All I want to do is sleep.

Alleviating burden also took the form of reducing pressure on the GP. Participants were concerned about wasting the GP’s valuable time, and noted the importance of having IT support for the GP at the time of case conference to ensure it ran smoothly.

### 6.5 Palliative care patient and carer capacity to participate in telehealth
Interviews with patients and their carers revealed actual and potential values that telehealth could have in this setting. Twenty-seven face-to-face interviews were conducted with 19 patients and 18 carers between December 2013 and July 2014. Interviews took between 14 and 53 minutes to complete, and were conducted either in the patient or carer’s home or in hospital. Participants described their experiences of the Telehealth project and the associated research activities. A small sub-group (n=7) were also interviewed about their experiences of an online video case conference with the palliative care staff and their GP.
This is reported in Section 6.4. Patient ages ranged from 49 to 90, years with a mean age of 71 years. Seven patients were male and 12 were female. All but two had cancer. Four carers were males and 14 were female and the majority, (n=17) were the patient’s spouse or partner. Two patients did not have a carer and two carers were interviewed alone as their spouse had passed away.

Interviews were semi-structured, audio-recorded and transcribed. The transcripts were loaded into QSR NVivo which was used to manage the data. A pragmatic approach informed data analysis which involved immersion in the data, coding and creation of categories (Green et al, 2007; Patton, 2002; Miles and Huberman, 1994). This report limits itself to findings based on the categories and does not include an interpretation of findings against theory. It addresses issues of acceptability and feasibility of telehealth for palliative care patients and their carers.

Patient and carer experience of using an iPad to self-report symptoms, function and video connection with clinicians was individually experienced. These experiences were mediated by a range of factors such as patient and carer attitude toward and previous experience with technology, patient physical health status, carer perceived burden and the ease of internet connectivity. Categories are outlined below.

- Technology familiarity, timing and training.
- Being connected: technological and personal connections.
- Self-reporting: logistics and interpersonal factors.
- Benefits and potential improvements.

**Technology familiarity, timing and training**

Although most patients and carers had some experience using computers or mobile phones, few had used an iPad. Participants who had previous experience with an iPad were more confident using the technology for their health needs. A number of participants with limited experience of technology were less confident. However, for many participants, confidence and ability to physically use the iPad and to self-report symptoms and function improved over time with practice and training.

**Interviewer** Can you tell me a bit about what it has been like to use an iPad for your healthcare?

**PC002** I found it interesting, very interesting, and I find it very simple… have no problem whatsoever with it… it is a novelty to me and I have never had one of these before.

**Interviewer** So, you said a novelty, you have not had an iPad before?

**PC002** No, no, or a computer.

**PC002C** Well, he hasn’t touched the computer, we have had a computer, I have had a computer ever since 1998. Bob has never touched it,
never looked at it, never been interested in it whatsoever. Gets this little iPad and ‘woo, this is lovely’.

PC030 I already know how to touch and not to poke.

Interviewer For some people that is a challenge.

PC030 “Yeah, you just touch gently and when I first started using an iPad I was poking the screen and it wouldn’t work and I was really getting frustrated. And that took me about two or three days to overcome.”

Those who continued to find data entry and video difficult described feeling overwhelmed by their changing health needs or not understanding technology. A small number of participants’ health remained stable over their time on the project and reported entry of health data repetitive. They chose to continue participation, however, as they saw it contributing to the care of others in the future.

**Being connected: technological and personal connections**

Patient and carer experiences of getting the iPad to connect to the internet in order to self-report their care needs was variable. It was often determined by factors outside their control such as their geographical location and strength of signal available. Those participants who had ongoing issues with connectivity (drop-outs, visual clarity, sound) were more likely to opt for phone calls or home visits instead of video reviews. Others described being less inclined to complete self-reporting due to the intermittent nature of connection. Participants with limited experience described drop-outs and intermittent connection as frustrating and wondered if they had done something wrong or broken the iPad. Conversely, those with more exposure to technology described how they used a range of strategies to reconnect. These included seeking assistance from the project team/clinicians, trying again at a different time or moving rooms to find the strongest signal.

PC035 “I have found it (iPad) to be very nice, I like it a lot but it frustrates the heck out of me that sometimes you just can’t get online with it….And it doesn’t seem to fix itself in a short time. Like you have to come back out later or something like that. So, whereas at other times, it goes on like that. And that is good. If you can do that every time and I don’t understand why, that is all so frustrating…Sometimes that works and sometimes it doesn’t. There is no certainty of when it is going to do what it, which would be very frustrating for, you know some people would find that incredibly frustrated and just say ‘Oh, stupid thing’, throw it away and not do it.

Interviewer “You feel frustrated but you don’t give up because you know…”

PC035 “Yes because I know that (connection) is the problem but it would be lovely to know what the problem is so you can see if you can go and fix it.”

Some participants experienced video calls as more personal than phone calls, and several described them like being in the same room or face-to-face. They valued the two-way nature
of visual communication, particularly the ability to observe body language and bodily changes.

Interviewer  How was it when you compare it to a phone call?

PC003  “Oh far better. Far better because I say when you are talking into a phone you are talking to a machine. It is like when you get an answering machine, leave a message and that. But you are talking eye-to-eye then you understand one person what the other can feel.”

This two-way communication was experienced as reassuring and more honest in that the nurse had to give them their full attention that might not be there during a phone conversation.

**Self-reporting: logistics and interpersonal factors**

As noted in *Technology familiarity, timing and training*, participants found it physically easy to use the iPad. A number of patients described how they incorporated self-reporting into their daily routine to ensure they remembered to do it. They also wanted to provide a consistent picture of their status over time. It became more challenging to complete self-report tools when patients experienced an escalation of symptoms. However, carers were able to act as proxy for patients when they felt unable to complete the self-rating tools. This worked well for some dyads but not others. Patients and carers described tension that arose when they and their spouse/partner disagreed about how to score symptoms or function. A number of participants perceived the symptom assessment scale as inflexible, and when filled in daily it did not allow them to contextualise or describe their symptoms accurately. Conversely, others noted it helped them be more accurate with the reporting of their symptoms.

PC006  *I mean I don’t always underestimate how I feel but sometimes I do.*

Interviewer  Yeah.

PC006  *She has said it when the doctors have been sitting here and somebody said, oh well you said its Pain 5 but you told me after that before it was 7. Why don’t you, she said you always make it better than it is. Maybe I do, I don’t know.*

PC006C  *And if I am there I am his little conscience (laughing) sitting on his shoulder*

Although there was a function that enabled patients to describe issues outside the numerical scores, not all made use of this function. While the scope and nature of support available via telehealth was made explicit at consent and training, not all participants remembered this. Some expressed frustration when they did not experience the responsiveness they were expecting. This speaks to the importance of clear regular communication about the scope of any clinical intervention and ensuring participants understand this scope.

**Benefits and potential improvements**

Key benefits of telehealth as identified by participants included the regular monitoring of fluctuations in their health status and well-being via self-report and video. There was a strong sense of reassurance that telehealth enabled a direct connection to the palliative care
service. The safety net of contact provided via telehealth was strong for patients who lived alone. Other patient-identified benefits included reduced need for travel for both patients and the palliative care staff. This minimised exacerbation of symptoms such as pain and fatigue experienced during travel to see a health clinician. Some expressed satisfaction at the opportunity to participate in a research program that may benefit others. Participants that lived the furthest away from the hospice noted potential telehealth benefits for people in rural and remote areas.

Participants’ suggested possible improvements to the telehealth included the capacity to view changes in their self-reported scores of symptoms over time (e.g. in the form of a graph). However, other participants noted this would highlight their deterioration and did not want this information. Others stated they would like to have immediate contact particularly if there was a decline in the patient’s condition or a new problem had been identified.

PC017  It would be nice to have contact straight away, pretty well, when the numbers go up. Just to see what we can go and do, sort of thing. I don’t press the numbers for no reason. It’s not there for fun.

Interviewer  If you were to have some more (contact) with (nurse), what sort of things would you like to cover?”

PC017  I don’t know. Just when the numbers come up we just want a response that is all. That is all we ask for. Not much. Just a phone call to see what is going on.

Capacity to have more flexibility in recording symptoms such as increased ability to write extra comments and provide context for the numerical symptom scores were also suggested.

Using electronic self-report to remotely monitor patients is dependent upon patients entering data. Given the importance of function on quality of life, carer burden and prognosis, activity monitoring may provide data on significant changes in health for patients which may also trigger review and intervention. Details are provided below on the key clinical indicators.

6.6 Self-reporting of function

The Australia-modified Karnofsky Performance Status (AKPS) is a validated variant of the Karnofsky Performance Status (Abernethy, A et al. 2005). The Australian version has criteria that can be applied in either the inpatient or community setting, which is more appropriate to the population seen in palliative care. This objective measure has high inter-rater reliability and is sensitive to changes in function over time. A score of 0 to 100 (in increments of 10) is assigned to participants based on their ability to undertake a range of daily tasks. The score gives an indication of the participant condition (in terms of physical ability) and can assist in prognostication.

Patients and carers were instructed to complete the AKPS on a weekly basis. If a patient was unable to physically enter data, carers, clinicians or others were able to on behalf of the patient. A proxy was not to interpret the patient’s function, instead ask the patient to rate their own level of function and physically enter the numbers on their behalf. If acting as
proxy, the carer noted this on the iPad at time of entry. Carers were also instructed to score their rating of the patient’s level of function in a second version of the AKPS in the carers’ applications. This enabled carers to provide an alternative perspective if the patient was overestimating their level of function.

On average, patients entered data 1.25 times per week, corresponding to data entry 25% of the time more than expected. On average, carers entered data 0.60 times per week corresponding to data entry 40% of the time less than expected. Approximately 40% of patients met or exceeded expected requirements for AKPS submission. This data suggests that patients and carers do enter data but that their pattern of entering data varies from that originally perceived to be ‘ideal’.

When patients submitted the AKPS, the average score was 69.7, and when carers submitted the AKPS on behalf of the patient, the average score was 66.2.

### 6.7 Self-reporting of symptoms

The number and severity of problems in combination with stage of illness and functional status are the best predictors of service need. The Symptom Assessment Scale (SAS) (Aoun et al. 2011) has seven predefined symptoms – sleep, appetite, nausea, bowels, breathing, fatigue and pain. There are also two open fields for user-defined symptoms. Each symptom is scored on a 0-10 numerical rating scale. If the patient reports any new symptom score ≥ 5 an automated email alert will be forwarded to the SAPS nurse. Patients were instructed to complete the SAS daily. If a patient was unable to physically enter data, carers, clinicians or others were able to enter data on behalf of the patient. A proxy was not to assess the patient’s symptoms, instead ask the patient to rate their symptoms and physically enter the numbers on their behalf. If acting as proxy, the carer noted this on the iPad.

A one-off hand analysis of actual data entry against requested data entry was completed for data collected up to 30 April 2014. This analysis was designed to show whether patients could manage to enter often enough and in a sufficiently useful pattern to be valuable.

Patients entered their own data into the symptom scale (SAS) 88.4% of the time, while carers completed the SAS the remaining 11.6% of the time. The SAS was expected to be competed daily. Patients, on average, entered data 0.73 times daily or 27% of the time less than expected. Two patients entered the data more frequently than daily. (Table 14).

Symptom assessment is an important element of the telehealth trial. While completion of data entry is less than that seen as ideal, the level of data entry is high at over 70% of that requested. It is also worth remembering that all entered data was more than captured in usual care, so even limited data entries were providing information about the patient. Remote self-monitoring provides a significant amount of data about individual patients given that current assessments are intermittent and dependent on clinician visits to the home.
## Table 14 - Expected and actual SAS entries

<table>
<thead>
<tr>
<th>Patient</th>
<th>Expected entries</th>
<th>Actual entries</th>
<th>Weekly average</th>
</tr>
</thead>
<tbody>
<tr>
<td>PC001</td>
<td>171</td>
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<tr>
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<td>319</td>
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*PC014. No entries by patient as only carer was consented in this dyad. Patient unable to participate due to impaired cognition.

### 6.8 Self-reporting of quality of life

The AQoL-4D is a standardised measure of health status developed by the Centre for Health Program Evaluation, Australia, in order to provide a simple, generic measure of health for clinical and economic appraisal. The AQoL asks patients to rate four domains that have three items each – independent living, relationships, mental health and senses. It takes between one-two minutes to complete. Participants were instructed to complete the AQOL-
4D weekly. As with the SAS and AKPS, if the patient was unable to complete the AQoL, a carer or other could act as proxy and manually enter data on their behalf.

In total, 957 AQoL 4D entries were made. The average number of entries per patient was 27.9 and the median was 5.5. These were nearly always made by the patient (96.1%) and rarely by the carer (3.9%).

The AQoL data will be further analysed through correlations with SAS data to determine its clinical utility and to assess its value as a global indicator of changing circumstance for the patient. We will compare the scores for this population with previously published Australian population norms (Hawthorne et al, 2007).

6.9 Self-reporting of carer needs

The CAQ-CNS is an online version of the carer needs SAPS screening tool. It has been renamed the Caregiver Assessment Questionnaire – Caregiver Network Service (CAQ-CNS) for the purposes of this study. The CAQ-CNS assesses the physical, emotional and spiritual aspects of caring. Each response is scored on a 0-10 numerical rating scale. It is normally administered in an interview context. Carers were invited to complete this at baseline and weekly thereafter. There was also the option to complete it only as needed to reduce unnecessary burden if their needs did not change.

In total, there were 263 full entries. Thirty-five of 38 carers completed the tool at least once (92.10%) with a range of entries from 1 to 63. A score above 7 on any item was classified as an alert, and this occurred 283 times in total.

In total, there were 64 recorded contacts made with carers alone. The primary mode of contact was video-conferencing (53.12%), followed by phone call (45.31%), then face-to-face (1.56%).

6.10 Carer experience of telehealth

Eighteen carers participated in interviews about their experiences of using telehealth as a means to support their family member’s needs and also their own care needs. Categories were:

- This is about them, not me.
- Dealing with what I have to do.
- Carers as proxy.
- I know someone’s there.

This is about them, not me

A number of carers perceived their needs as secondary to those of the patient. Although carers described how they had difficulties attending to their own needs, they talked about putting these needs “on the backburner” (PC001). They perceived the patient as having greater needs.

PC013C What is the purpose of how I feel? I thought the aim was to keep her on track… Well, I think as far as I am concerned I think it is unnecessary
Interviewer For you?
PC013C Yeah, for me to put forward my feelings or welfare. I think we are very interested in how (patient) goes.

Dealing with what I have to do
The role of caring for someone at the end-of-life is a demanding one. Carers talked about being incredibly busy, and while willing to support the patient in self-monitoring, they would rather get on with the other tasks they had to do. One carer even asked her husband to complete her carer needs tool on her behalf.

Interviewer Is it just that you are busy that you get Ian to fill it in for you?
PC011C Yes.
Interviewer Or is it because you are not keen about the iPad?
PC011C Oh most probably not keen about the iPad but more because I am busy...I can be doing something else if I tell him what to put there.

For some carers with limited technology experience, learning how to do this was perceived as an additional burden and they chose not to enter data.

Carers as proxy
Carers were invited to act as proxy for patients if they were feeling too unwell to complete self-report tools. Carers described the importance of reporting accurately on the patient’s behalf. Several reported how acting as proxy prompted discussion about symptoms. In some instances this improved understanding of how the patient was feeling although this proved to be a source of tension for other couples.

PC030C Well the benefits are that when Joanna is sick I can fill out the survey for her if she is not well enough to fill it out herself.
PC03 He was saying what shall I put down, what do you think you should be? What, something else, six or something didn’t you?
PC030C No, should you be seven and you said, no, four.
Interviewer So you had some differences in how you would have scored the symptoms?
PC030C: Well, I didn’t know how Joanna felt. So it was good to have some feedback from her.

Not all carers were comfortable to act as proxy. One husband chose not to act as proxy because he believed his wife’s health needs were her business alone. They were private about their own health issues and did not discuss them with each other. When his wife’s health deteriorated, she asked the RDNS to act as proxy for her.

I know someone’s there
Although a number carers did not see the role of telehealth as actively supporting them,
another group welcomed support that was offered. Substantial carer support for one carer led to uptake on the telehealth online-bereavement support program.

PC016C  Where (nurse’s name), she is straight onto me and says, you know
PC016   I think you need to see a doctor. She is so concerned about me. Which I really appreciate.

In summary, analysis of carer experience of telehealth highlights a range of responses. It has the potential to enhance communication between carers and care providers, as well as between carers and patients. Several considered it not relevant for their needs and emphasised that the care of patients should be priority.

6.11 Telemetry

Functional decline over time is an important prognostic indicator for palliative care. The Fitbit Zip™ offers an opportunity to remotely monitor the level of activity of the patient. This can be matched with a proactive response from the palliative care team to assertively follow up and adjust management plans. This device is small, light and unobtrusive, and is designed to fit on the belt or undergarment. The battery life is three to four months, and thus requires little maintenance from the patient. The Fitbit Zip enables passive and continuous tracking of patient activity. The device automatically syncs patient activity information to the iPad. Patients were also provided with Fitbit Aria™ scales, which measure weight and bioelectrical impedance, and communicate results wirelessly to the iPad. Patients were asked to weigh themselves weekly.

Twenty-six of 28 eligible patients wore Fitbit Zip at least once during their time in the program. The minimum use was 6.78% of the time and the maximum use was 97.67% of the time. On average, patients wore their Fitbit Zip 54.1% of the time. It should also be noted that it is difficult to determine on days with zero steps counted whether patients were wearing the Fitbit Zip and taking no steps, small slow steps or not wearing the Fitbit Zip at all.
7 Effectiveness of Telehealth Technology

Implementing a telehealth care system is heavily reliant on the suitability of the underpinning technology. This study specifically sought to utilise common technology platforms that reflected current community patterns of use, and to determine acceptability to the user. However, the project was adversely affected by series of unexpected issues including uncertainty about the progression of NBN rollout.

7.1 Effectiveness of technology used in telehealth services: Palliative care view

The original agreement specified that services needed to be delivered via NBN. Given delays and interruptions to the NBN rollout in SA, the capacity to meet specified recruitment targets was at risk. A series of options in terms of other locations which may have been able to have NBN connections (eg Prospect) were investigated. This led to multiple revisions and alternatives for other proposed NBN sites which did not and could not eventuate. The DTN, an equivalent delivery platform managed by SA Health for country services, was also investigated. There was a pilot investigation with three patients using this technology. However, this solution did not have a direct capacity to outreach to the community, instead addressing palliative care needs in the residential aged care setting. Each option required investigation and planning and distracted from the capacity to deliver clinical service via telehealth.

There were also a series of technology challenges for integration. In essence, the system required a web-based solution and was not able to directly interface with the hospital data system. In addition, SA Health began introducing a new patient data system in the same period (ePAS). These added to the complexity of the environment for the project.

Among the other technical issues confronting the project was the need for individualised solutions for patients and families, given variability in signal strength across the geographical regions, drop-outs in the video conferencing system, lack of technical knowledge and skills among the clinical population, need for supports for older participants, and specific ICT issues. There was also the need to review platform options to support the various activities of the project. There were delays in initial setup due to a lack of agreement about the preferred video conferencing system.

7.2 Participant training

Training was an important aspect of technology management for participants. Nearly all participants found the iPads and applications easy to use. Those unfamiliar with iPads and/or computers required encouragement to use them. However, most were pleasantly surprised at how easy the iPad was to use. Some solutions needed to be found to support specific users. These included the use of stylus for data entry and adjustable iPad stands as people became bedbound.

Participant training commenced at consent, followed by a second face-to-face training session where participants entered their first set of data. Some participants requested a follow up phone call to make sure they were entering data correctly. All participants were provided with an instruction manual tailored to the iPad and applications they were using. A checklist for “What to do when”, and for video reviews was included in this manual.
The project was originally designed to test the impact of the NBN on the delivery of telehealth services. As the ability to recruit within a static NBN became unsustainable, the capacity to utilise other technologies enabled recruitment to meet the required numbers. A range of internet connections were used. Initially participants in non-NBN areas were provided with an iPad with an inbuilt 3G/4G internet connection. However, as a number of participants experienced drop-outs, routers and 4G USB modems or dongles were introduced. Individualised solutions needed to be found for some participants to ensure connectivity. Details on connection issues can be found in Table 11.

Some technology items proved too difficult for some participants to use. Fitbit Aria scales, Fitbit Zips and Vidyo required frequent liaising, set-up and sometime multiple visits to the person’s home. Clinical and research staff needed to be able to troubleshoot and support clients.

7.3 NBN service delivery issues

There were also some failures in service delivery. Six palliative care participants have had NBN connections, although one of these requested to use a 4G wifi dongle as their NBN connection was arranged for and used by their son. They had also experienced a power failure whilst on NBN, which resulted in loss of all ability to use internet and phone and hence they were very reluctant to use NBN. NBN was requested by the telehealth project for a seventh participant, however, he rang independently to see if he could get a faster connection (previous connection time offered was a month). He has since had multiple appointments cancelled or unannounced visits by NBN Co and Telstra. When offered yet another connection time a further month down the track, he requested something faster and stated he was dying. This expedited the request by 2 weeks and he was ultimately connected to the NBN. This participant had multiple drop-outs using video conferencing and also for self-reporting of symptoms using 3G. He and his wife chose not to use the video conferencing system until they had an NBN connection. While his GP was willing to participate in a case conference, it was not possible until NBN connection were completed and tested. He did not have a case conference with his GP and has since died. This speaks to the importance of timely internet connections for palliative care patients receiving telehealth.

7.4 Participant confidence using technology

Patients, carers and clinicians have had a range of experiences with technology from enhancing care to complicating care unnecessarily. Video conferencing platforms such as FaceTime and Vidyo were familiar to some, but not the majority of participants. Those more familiar with computers were more comfortable with these types of clinical review. Several participants found that a teleconference was preferable to a phone call.

PC 003  

The iPad was better than a phone call… because you have more personal contact…Well, I can watch their lips. And I do a fair bit of lip reading…and it comes through clearer whereas the phone goes off and the volume is up and down.”
It was more, in inverted commas ‘intimate’...um the way it was but I could see him very well.

However, some older participants with limited experience and confidence using technology found video reviews less helpful than face-to-face or phone calls.

Well, I just like to talk face-to-face, you know sort of, like we are now as opposed to doing it through a machine. I don't like leaving messages on the phone, I don't like any of this modern technology. I am old fashioned but at 80 years of age, what is expected. I am not technically minded, never have been. I can't even record on the television, record a program, I leave that to Lorna.

7.5 Unanticipated issues: Technology upgrades and cyber-threats

Technology upgrades and cyber threats outside the control of the project also influenced the project. For example, a transient security threat for technology platforms, the Heartbleed bug had a significant, albeit brief, impact on this project. Heartbleed is a weakness in the encryption security of programs such as email, internet sites and for specific programs such as Fitbit. It has the potential to allow hackers to access data from a range of sites and services. As a security measure, Fitbit forced a reset on all passwords on their products. This required a manual reset of all Fitbit passwords on the tablets. Each participant was contacted and a time made for IT to visit to reset their passwords. Unfortunately this coincided with a scheduled roll out of upgrades to the apps. This created a further burden for participants and highlighted the need for ongoing IT support.

7.6 Video conferencing platforms

There were extensive discussions about the most appropriate platform to support the video conferencing needs of the project. FaceTime was initially used. While it worked well and was simple for clients (single touch to open), it only allowed for one-to-one conferencing and couldn’t support a multiparty conference. Various options were examined. The need for simplicity for an unwell, predominantly ageing population with limited confidence and experience of using technology was stressed. We could not expect users to be able to reboot machines to solve integration problems. IT testing of various options led to the final selection of Vidyo as the preferred videoconferencing platform.

There were 13 occasions recorded on clinical notes where a drop-out occurred at least once. (Table 13). Furthermore, there were five recorded occasions were no connection was made at all. In these circumstances, video conferencing was replaced with another form of contact (e.g., phone call). These numbers may not accurately record the number of drop-outs. During the transition between an interim Vidyo program and the final system set up enabled through Flinders University, participants experienced numerous drop-outs. A number of dropouts appear to be related to geographical locations (e.g., Port Willunga, Hallet Cove).

7.7 Role of IT support

IT has been critical to the progress of the project. Local IT support in installing applications, sorting out integration, managing remote passwords etc meant that, in general, a very simple
and reliable interface for users could be provided. While the ideal would have been to have a device agnostic system and a Bring Your Own device (BYOD) option to determine the clinical utility independent of device and platform, this was not seen as a practical option for this initial study. Ongoing technical support as well as initial technical input in design and development was critical to the delivery of the service.

7.8 System usability assessment

Patients and carers completed the System Useability Scale (Brooke 1996), which was administered no earlier than four weeks from commencement of receipt of a telehealth service. It was frequently administered at time of interview to minimise burden on participants. Interview times ranged from four to ~12 weeks to accommodate hospital admissions, health status and personal circumstances.

Data has been analysed from those who had completed the survey up to 30 April 2014. Patients (n=15) and carers (n=14) responded to the 10-item System Usability Scale (Brooke 1996) on a 5-point Likert scale (1='Strongly Disagree, to 5='Strongly Agree'). Responses were converted to range of possible values from zero to 100. Items related to patients and carers experiences of the system in regard to confidence, complexity, ease of use, integrated function and inconsistency. The average score for patients (M=64.33) was slightly lower than carers' scores (M=67.83). Previous research has found the average score from more than 500 studies across a range of applications is 68 (Sauro 2011) (Table 15).

<table>
<thead>
<tr>
<th>System Usability Scores for Patients and Carers</th>
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<tbody>
<tr>
<td>Mean</td>
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<tr>
<td>-------</td>
</tr>
<tr>
<td>Patient (n=15)</td>
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<td>Carer (n=14)</td>
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Table 15 - System Usability Scores for Patients and Carers

This suggests that older and vulnerable populations are not dissimilar from the general population and could utilise technology as part of their care arrangements.
8 Outcomes for Patients and Carers

8.1 Palliative care patient and carer outcomes

There are a number of key benefits for patients through the use of telehealth to support clinical care in the community. These include the capacity to have symptom scores reviewed by nurses and to have more proactive engagement in continuing care through scheduled video conferences.

Several data activities provide further details. Earlier tables have highlighted the additional data available to clinicians on patients in the community that has not previously been available. These include number of self-report of symptoms by patients and alerts as to symptom severity. Additional video based patient and carer meeting also have demonstrated patient and carer benefits. Some of these benefits can also be seen through adjustments to clinical care as found in clinical notes.

Case conferences with the patient and carer, GP and specialist palliative care, enabled though Vidyo, highlight an additional form of care enhancement. An example of this is described in 5.1 Effectiveness of Telehealth Care.

Patient and carer interviews have also illuminated patient and carer outcomes and benefits. Alerts have enabled proactive care and circumvented crises, including the prevention of unplanned admissions. A case study highlights the benefit of a self-reported symptom alert trigger.

Case Study 1
In this case study, the palliative care clinical practice consultant nurse conducted an unplanned video review of a patient in her home in response to a SAS trigger. This review enabled the nurse to assess the patient from his office, and subsequently arrange an appointment for the patient at the palliative care outpatient service the following day. The patient attended this outpatient service where she was assessed as requiring home oxygen. This was arranged and patient was able to return home. The Clinical Notes for PC013 record the clinical decision making, completed by the clinician on their iPad. A PDF is emailed to the nurse.

Until the introduction of the Enterprise Patient Administration System (EPAS), an electronic medical record in South Australia, the clinical note was emailed directly to the nurse who would print it out and insert in the clinical history. (Since the introduction of EPAS, these notes are scanned and entered electronically.)
In this instance the patient’s husband, Malcolm, also described the video conference interaction with the nurse over the iPad and outcome of this interaction during an interview about he and his wife’s experience of telehealth. (Please note the name is a pseudonym.)

PC013C And we discussed it over that [iPad] and then he [Nurse Clinical Practice Consultant] decided, because I worried about it, that we should go into the Repat. And we saw the doctor and she tested her...
for oxygen and immediately that afternoon we had oxygen on the floor 
so that was good.

Finally, the potential for enhancing carer support and engagement in the bereavement 
period has been explored. To date there has been very little interest from carers to the offer 
for support via telehealth following the death of the patient. Many carers view the iPad as 
equipment that needs to be returned as soon as the patient dies. Despite encouraging 
carers to hold onto the iPad just in case they change their mind, most have insisted on its 
collection. Currently one carer has agreed to bereavement support and the determining 
factor appears to be related to the strength of the relationship that has developed between 
the carer and the Caregiver Network Facilitator. The bereavement intervention still remains 
largely untested.
9 Outcomes for the Health Services

9.1 Outcomes for palliative care services

There are a number of possible benefits for palliative care services associated with telehealth in the community. Telehealth provides the opportunity to gain information about patients that has not previously been available. It can enhance screening of clinical need by enabling clinicians to visually assess patients and carers from their office and to proactively identify change through alerts. Self-report and alerts can help to manage workload and prioritise responses. Earlier tables have highlighted the additional data available to clinicians on patients in the community that has not previously been available. These include number of self-report of symptoms by patients and alerts as to symptom severity. Additional video-based patient and carer meetings also have demonstrated patient and carer benefits. Some of these benefits can also be seen through adjustments to clinical care as found in clinical notes.

The example of the clinical review in palliative care outpatients following an alert triggered by an increased SAS score in Case Study 1 demonstrates the potential to reduce hospital admissions and ED presentations. In this case the palliative care nurse was able to coordinate specialist review as an outpatient which resulted in medical management enabling the patient to remain at home. One unexpected outcome from a GP case conference was increased communication from one GP to the community palliative care nurse, averting an inappropriate palliative care referral and subsequent saving of man hours required to triage such a referral.

There are a range of potential benefits for health services that can result from the telehealth palliative care model. Rapid identification of change in patient circumstances can also prompt proactive action as shown in Case Study 1.

There is also the possibility that telehealth can enable reallocation of staff time released through lessened travel time. An analysis of community clinician workload data pre- and post-intervention demonstrated a reduction in travel time.

Staff also identified a range of possible outcomes for the health services resulting from the adoption of telehealth approaches and these were reported in Section 5.
10 Quality and Safety

The Australian Charter of Healthcare Rights describes the rights of patients and other people using the Australian health system. These rights are essential to make sure that, wherever and whenever care is provided, it is of high quality and is safe. These rights relate to access, safety, respect, communication, participation, privacy and comment. The effect of telehealth on these rights has also needed to be considered.

A number of strategies have been used in designing and developing this module to enhance quality and safety for those involved with telehealth service delivery. These include

- The framework for development was based on a model developed following an analysis of processes used in telehealth (Tieman et al, 2014)
- Clinical algorithms were developed to make accessible responses to clinical indicators captured through self-reporting. They were developed in consultation with clinicians who were to deliver the telehealth intervention. Please refer to Figure 6 for a summary of the clinical algorithms. A bereavement protocol was developed in conjunction the bereavement services officer and the Caregiver Network Facilitator.
- Use of alerts to monitor changes in the patient’s symptom burden and /or to highlight carer needs and concerns.
- If participants did not enter data for 2 days, an email alert was forwarded to the Southern Adelaide Palliative Service nurse on the 3rd day.
- Published evidence on telehealth activities was reviewed. Appropriate guidelines were examined.
- Weekly meetings of the PC(T)RT were held across the course of the project. This enabled review of both technical and clinical issues associated with the project. Project staff also met separately with nursing staff to identify any considerations about the project. These processes provided a mechanism to identify and/or monitor issues and to rapidly respond to any safety and/or quality issue

10.1 Iterative Improvements through formative evaluation

The importance of formative evaluation and user testing in ensuring that the telehealth resources were fit for purpose and relevant to user is discussed in more detail below.

Participant feedback during the course of the study and also via interviews revealed that irrespective of verbal, written and practical instruction about the scope of the project, some participants perceived the iPad as their primary means of communicating with palliative care via a Contact Nurse application. The Contact Nurse was designed to send an email to the nurse asking them to make contact with the patient. The patient information materials and training during the consent process highlighted that the nurse was able to respond only within normal clinical practice hours, Monday-Friday, 8-5, and between clinical appointments. However, trialing of the iPad system with two patient-carer dyads as a quality improvement activity showed that patients and carers continued to see the Contact Nurse as an emergency call
number. This led to a modification for the system to read “Need help now?” with a pop up that provided instruction to contact either GP, the palliative care 24-hour contact number or 000 if an ambulance was required. This information is duplicated on a fridge magnet routinely provided by Southern Adelaide Palliative Services and also in the instruction manual. This information could also be relayed routinely as part of the fortnightly video review. Repetition is important as people are only able to take in finite amounts of information when learning new skills (e.g. use of iPad). It is also compounded by fluctuating mental status and age-related cognitive changes.

10.2 Issues in sustaining and scaling palliative care telehealth model

There are a number of issues that need to be addressed when considering scalability and sustainability of the palliative care telehealth model. The initial focus needs to be on palliative care patients at the end of the project. Participants will continue to be provided with telehealth service till death. The research components of the study will be stripped out of the system and patients and carers will be able to continue receiving video conferences with Southern Adelaide Palliative Services staff and entering data for SAS and AKPS. Carers will continue to have teleconferences with the caregiver network facilitator and will be able to continue undertaking needs assessment with the carer tool. Where possible, video case conferences will continue to be undertaken, subject to funding and connection issues for GPs.

There is tentative acceptance that telehealth can offer benefits to the service. There is an ongoing series of discussions within the clinical service and the Health Department about opportunities and next steps. Key factors that will influence this decision include the perceived benefit for patients and carers, commitment and leadership from the clinical service, the availability of IT support, ability and capacity of clinical staff to introduce and support patients and carers in using the simplified resources, and departmental support for continuation of this form of service. A secondary issue for the service with respect to continuation of a telehealth service will be whether to retain this service only in the southern region of its catchment area or to extend it to all clients across the service. Expansion of telehealth within the service would require significant support for change management as it would be a re-engineering of current practices. This direction could also signal the need for telehealth applications that could be used on any platform to enable patients and carers to “bring their own device”.

Longer-term sustainability within the service could necessitate the Department of Health taking ownership of the telehealth applications and maintaining them on its IT infrastructure for community use. At present there is no direct avenue to enable community-based patients to self-enter data to the SA Health IT systems. All these sustainability options would require ongoing discussions with the SA Department of Health. There have been preliminary discussions about IT support and support for videoconferencing between Southern Adelaide Palliative Services and its partner rural palliative care services.

To scale the telehealth model for use by other palliative care services not only with South Australia but across Australia would require resolution of several issues. These include support for a web-based platform to provide access, reforming of the key apps to enable device agnostic
use, negotiation about terms and conditions of use, contribution to ongoing costs, and articulation and management of security, privacy and clinical care responsibilities. The clinical algorithms underpinning the model would also need to be discussed against current practice in other services. The possibility of expanding the telehealth service for use within primary care has also been discussed. In essence, further use would require development of a model of business and operation. It is worth noting that there has been interest from several palliative care services in other states about the telehealth model and its possible use and testing other sites. One possible option is to seek research funding to undertake further assessment of the clinical effects compared to standard care and to determine applicability in particular settings (eg rural Australia) or with particular client groups (eg lung cancer or motor neuron disease).

Sustainability also needs to address the issue of clinical currency. Telehealth systems need to be sufficiently flexible to incorporate new evidence as it emerges. Just as clinical guidelines are time bounded, telehealth applications and systems need to be reviewed regularly for their ongoing relevance and currency. This speaks to the need for ongoing clinical oversight in the development of models of telehealth that are sustainable. Long term sustainability of any telehealth service needs to be built on a value proposition for clinicians, that is, that telehealth improves patient outcomes.

With respect to technological considerations in addressing sustainability, it is important to recognise the difference between applications and systems of care. The palliative care telehealth model reflected a system of care that is built on symptom and performance monitoring with alerts as to change and communication with the patient and with the carer. It also recognised the need for engagement with primary care through case conferencing. All the elements are important and are built on a model of care that is known to be effective from research evidence and embedded clinical algorithms.

A lack of interoperability between systems will also influence sustainability and scalability. The ability to engage with multiple devices is essential to support scalability. Solutions (technical and political) are needed that enable clinical information entered by patients and carers to be made accessible within health records held by health services without intermediary steps. Similarly, systems, such as video conferencing, to support communication need to be selected for their capacity to be immediately used by a range of parties including GPs, family members who are not resident with the patient, and other service providers such as community nursing or pharmacists. Waiting for connectivity to be provided which could take weeks or months will not work with this population whose health could decline rapidly or whose symptom burden could increase suddenly. The operational system also needs to be user friendly and stable. For those who are approaching the end of life, technology needs to be supportive not challenging!

### 10.3 Project learnings and implications for the future
This project has provided many telehealth learnings. There is significant value in undertaking preliminary usability testing to ensure the devices and systems are suitable for intended users and work in the ways envisaged.

To date, the key learnings are:

- Clinical relevance in design, testing, implementation and review is important.
- Usability testing and/or quality assurance are important steps in development.
- Patients and carers are able to enter data.
- Age has not been a barrier to being able to be taught and supported to use technology.
- Data entered by patients and carers in the community can support clinical decision making and clinical management.
- Technology problems are inevitable. Unanticipated technology problems such as platform upgrades or cyber threats can create delivery issues.
- Telehealth resources need to be simple and intuitive in their use.
- Telehealth is seen as valuable and with much to offer to the participants.
- Telehealth is reliant on effective multidisciplinary and multiprofessional skills and hence on effective working relationships between teams.
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