Networking an Integrated Palliative Care Information System Across the Care Continuum

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Abstract

Community based Health Services have traditionally used electronic health information management systems (EHIMSs) that are different to, and have not interfaced with, inpatient EHIMSs. For an Australian regional Palliative Care Service that provided care to patients in a variety of facilities and community locations the lack of an EHIMS that traversed the continuum of care represented a barrier to efficient service delivery. Utilising a pre-existing inpatient EHIMS (Cerner Powerchart) a local solution was developed and implemented that addressed a number of key service requirements. These were that clinical documentation would be accessible to staff regardless of location and be accessible 24/7; that patient movements in and out of key facilities could be tracked in real time; that the Palliative Care record would be visible to other health care providers such as the Emergency Department and Primary Care practitioners; and that service reporting functionality would be automated. This networked integrated information system (NIIS) has successfully supported and enhanced the delivery of Palliative Care across the continuum of care.

Keywords: Medical records systems, computerized; palliative care

1. Introduction

Electronic Health Records and Information Management Systems are an increasingly common feature in the health care landscape as their potential benefits are seen to be integral to modern health service delivery [1]. The variety of products seeking to meet health care provider needs is both large in number and diverse in scope. Core functions such as health information and data, result and order management, decision support and electronic communication [2] are increasingly standard as providers seek to meet clinician and health organisation need. All such systems are built on specific assumptions about the relationship between the patient and the clinician and / or service, with the most common temporal relationship being based on an admission to a facility. In general, primary care or community services utilise one set of systems while the inpatient environment utilises another, even when they belong to the same health care entity. For health care services that traverse multiple locations, and that have a patient relationship that may include multiple admissions to multiple facilities and that extends over months rather than days, existing electronic health information management systems (EHIMS) have difficulty in accommodating such complexity, and the working examples are few [3-4]. Within the discipline of Palliative Care itself EHIMS are location dependent, with strong community based systems evolving [5-6] but with little evidence of seamless access in inpatient settings. Despite this present reality, the need for broadly integrated and shared electronic record systems that more accurately reflect the health care provision environment has been identified and underpins future directions in EHIMS [7-8].

1.1 Background

Located north of Sydney, NSW the Central Coast Palliative Care Service

(CCPCS) provides specialist palliative care for a population of over 300,000. The Service works within an integrated model of care that provides points of contact in multiple inpatient and community care settings. Patients accepting referral to the Service have an ongoing association with it that may cover days to many months. Until 2004 the CCPCS had only paper based documentation systems, with limited computer based information management (primarily list creation). Strategic planning resulted in the recognition of the need to move to an EHIMS that would strongly parallel the multi site nature of the CCPCS and support the provision of a fully integrated palliative care service across the health service area regardless of site of care. Several key Service questions were identified as needing to be addressed by any such system. How could a specialist health service that has points of contact with its patients in both inpatient and community care settings document its interactions so that information was equally accessible regardless of location? How could such information be made available to staff who may require access 24 hours a day, seven days a week? How could admissions to, and discharges from, inpatient locations be tracked in real time, especially those registered patients admitted under other health teams? How could essential information be made available to relevant staff from other health care areas (such as General Practitioners or the Emergency Department) so as to better inform their care decisions? And finally, how could this be achieved on the limited budget options available to a small specialist health service?

2. Methods

A first step was the employment of a clinical informatics project manager to oversight the diagnostic, planning and implementation phases. The staff of the CCPCS constituted a customer focus group and were consulted on information needs and design of documentation templates. This facilitated a strong participatory process of engagement that is known to generate improved

commitment [9]. A project team of CCPCS and Information Technology staff met regularly to guide the project.

A scoping document identified current workflow, issues with inadequate clinical information flow, and anticipated changes to workflow, electronic data collection and reporting. An analysis of the existing Area Health Service Patient Administration System (PAS) and results reporting system (Cerner Powerchart) identified existing and potential information management opportunities. This was critical as the available funding was insufficient to purchase a new EHIMS, nor was it desirable to add further systems to the existing mix of inpatient and community programs.

This initial assessment and planning process resulted in the formation of an innovative solution to the identified needs. Existing and potential functionality in the Cerner product could be harnessed to create the required clinical documentation and EHR processes, while the establishment of an external access portal would address the required access parameters. To facilitate this solution a series of partnerships with external providers Cerner, Hewlett & Packard and Citrix were established as the project progressed.

Existing clinical documentation was reviewed and electronic equivalents created. This included a registration care plan, progress notes and consultation letter. New electronic clinical documentation opportunities were recognised and actioned. These included a new electronically stored, advance care directive/plan, and a multidisciplinary review. Reports that informed and measured service delivery and key performance indicators were developed and integrated into the new system. The resulting EHIMS was named the Central Coast Palliative Care Networked Integrated Information System (NIIS)

The project consisted of a series of planned milestones. Infrastructure to support the accessing and utilisation of the NIIS was procured. This included laptop computers for community located Palliative Care clinicians and CDMA modems to allow remote access 24/7. The electronic versions of exist-

ing clinical documentation were trialled and reviewed by CCPCS staff, with modifications incorporated into the evolving product. New workflow processes were identified, trialled and adjusted. New electronic documents were created, trialled and incorporated into the product. Remote access protocols were developed, trialled and established. Staff education sessions were planned and implemented to develop skills in using both new hardware and the NIIS. Access was established for Emergency Department staff and Community Nursing staff so that Palliative Care status and current management plans could be rapidly identified. The NIIS was then launched to all stakeholders and was showcased to senior Health Service management and other Area Health Services.

3. Results

3.1 Detailed Description of the Elements of the NIIS

Registration of Palliative Care Patients

NIIS incorporates a fully functional service specific registration database which interfaces with the local Health Service Patient Administration System (HOSPAS) allowing real time registration of patients to the Palliative Care Service. This has been achieved through the use of Cerner Millennium PowerChart. The Millennium Database has a live link from the HOSPAS system where all patient data is captured. Patient demographical data is then available to the Millennium PowerChart System. The registration of Palliative Care patients was achieved by the use of a Cerner tool called "*PM Launch*". This tool enables the clerk to register community palliative care patients using an ERM (Enterprise Registration Management) *Admit/Modify Conversation*. Upon patient discharge from the service a *Discharge Conversation* is launched.

The Admit/Modify Conversation incorporates patient search functional-

ity showing patient demographic data ie MRN, Name, Address etc. The Conversation creates the *Community Encounter* type and a *Medical Service* of palliative care. The Admit/Modify Conversation allows the entering of referral and registration dates along with the capture of statistical information such as reason for referral, referral source etc.

The Discharge Conversation uses the same functionality as the Admit/Modify Conversation, however, this conversation captures discharge related data such as discharge date, reason for discharge, discharge location etc.

Encounter definition. A *Community Palliative Care Encounter* starts at referral to the Palliative Care Service and ends at discharge. During the community Palliative Care encounter there may be a number of in-hospital encounters. The creation of this enduring encounter was an innovation in terms of the local existing use of Cerner Powerchart. All palliative care clinical documentation and statistical reports are linked to the community palliative care encounter regardless of the patient's location.

Patient Tracking System

The Palliative Care clinicians rely heavily on the ability to track patient movement between the community and inpatient setting. As such an enormous amount of work went into ensuring that all registered palliative care patient admissions were available in real time to the clinicians.

Referral List. Using Cerner *List Maintenance* functionality, the Referral list was created from data entered into the *ERM Admit/Modify Conversation*. This "*location list*" shows patients that are currently at referral phase (ie a pre-admit phase), who have not yet been registered with the service. Once patients are registered they automatically drop of the referral list. The referral list assists with the workflow requirements of the team, including the tracking of first patient contact within 48 hours of referral.

Registration List (Master List). This list shows all current registered palliative care patients. Again this list runs off the *ERM Admit/Modify Conversation*. Once a patient is discharged from the service they will automatically drop off this list. To assist with patient tracking, a "*provider lifetime relationship*" is created in the *Admit/Modify Conversation* for each registered palliative care patient. The Registration List or Master List is created in list maintenance using *a "lifetime relationship list"* and proxy to all of the palliative care clinicians.

Inpatient List. A Clinical Service specific inpatient list regardless of whom the patient was admitted under allowing more comprehensive follow up in the inpatient setting and therefore improved continuity of care and discharge processes. This list monitors registered patients site of care informing staff of admissions from community to inpatient facilities and vice versa allowing targeting of resources and automatic flow of information between these areas removing barriers to an efficient continuum of care.

The Inpatient List is a copy of the Master List. The inpatient list uses a "*custom list*" with a filter of *inpatient*. This list shows detail such as attending physician, inpatient location and ALOS. The limitation of this list is that "*custom lists*" do not automatically update themselves as patients move in and out of inpatient care settings. A copy of the master list must be made each day to ensure that this functionality is efficiently maintained.

Palliative Care Specialist List. This list uses "*provider list*" functionality. The list automatically updates as patients who have a current *attending physician relationship* with the Palliative Care Specialist move in and out of the inpatient care setting. This list allows the Palliative Care Specialist to see in real time his/her current patients, inpatient location and length of stay.

Community Palliative Care Nurse Specific Lists. Viewable patient lists were created to mirror current Area Nursing Sector patient groups, to allow practitioner monitoring of allocated patients and therefore better targeting of service clinical resources in a timely fashion. This list is a copy

of the master list. The sector list uses a "*custom list*". The Palliative Care Liaison Nurses manually add and remove patients from this list.

Networked Interdisciplinary Electronic Patient Record

A networked interdisciplinary electronic patient record which provides accurate clinical information via secure user specific access to authorised health professionals including the patient's GP by either the Area Health IT network or Internet in a timely fashion improving continuity of care and more efficient interdisciplinary networking. The e-record can be viewed or updated in both community and inpatient setting. It is available 24/7 via the Central Coast Health IT network, internet and remote access.

Registration/Care Plan. An updateable electronic care plan which when completed triggers the registration of the patient. The Registration/Care Plan and is stored in the e-record and faxed automatically to the patients GP and other relevant health professionals. The Registration/Care Plan is entered by the Palliative Care Liaison Nurse upon registration of the patient to the Palliative Care Service. Cerner PowerChart Clinical Documentation functionality was used to create the input screen (PowerForm). The PowerForm facilitates the entry of data for both statistical analysis and information for the Registration/Care Plan that is faxed to the General Practitioner. Controls on the input screen include alpha response, date formates, provider directory and rich text (free text).

Some examples of the PowerForm input screens are as follows:

Referral screen (Figure 1). A series of radio buttons, date fields, look up tables and free text fields allow quick entry of core referral details.

Diagnosis screen (Figure 2). Diagnosis is a free text control. It has been found that it is easier for the clinicians to enter the information into a free text control, however Cerner Clinical Documentation is capable of allowing a searchable list of ICD10 description values for diagnosis.

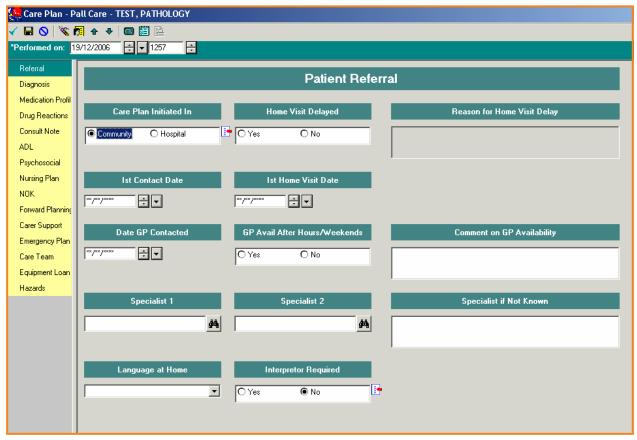**Medication screen (Figure 3).** Medi-

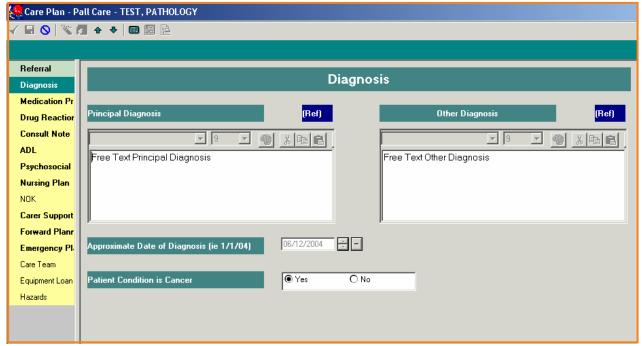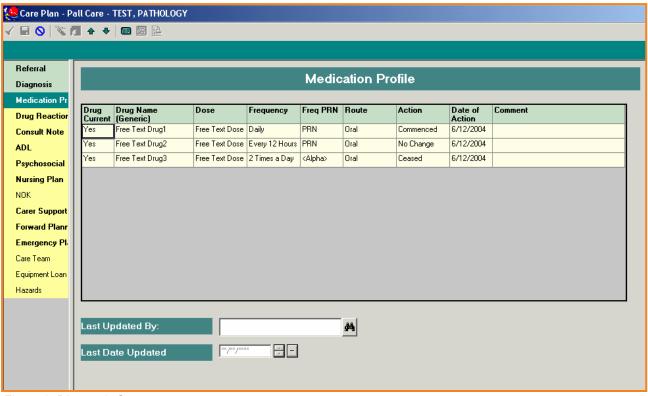Figure 1. Referral Screen.

Figure 2. Diagnosis Screen

Figure 3. Diagnosis Screen

cation Profile uses a table. Drug name and dose are currently free text. Frequency, Route and Action are alpha responses. Data items on the screen had input from Clinicians and Pharmacy. Hospital Pharmacists at Central Coast hospitals currently use Millennium PowerChart to create a Medication Profile. If Pharmacy has completed an inpatient medication profile, it is then available to the palliative care liaison nurses and doctors to update post discharge.

Drug reactions and allergies screen (Figure 4). Free text fields in table format allows entry of known drug reactions and allergies.

Initial Consult Note screen (Figure 5). A smart template has been put behind this rich text control to bring up pre-determined prompts for the clinicians to complete required information in the PowerForm.

ADL & ECOG Scale screen (Figure 6). Combination of multi-select tick boxes and single select radio buttons used to highlight current performance capability. The alpha responses contained in the controls have been fully customised to suit the palliative care solution.

Psychosocial and Nursing Plan.

Rich text controls that allow formatting ie bold, underline, font size and justification.

Psychosocial Notes and Nursing Plan screens. Both of these screens are free text fields with no template or other structure.

Next of Kin screen (Figure 7). This screen consists of a free text table, with the "Active" field determining if the data line is extracted to the Care Plan.

Forward Planning screen (Figure 8) . A series of radio buttons and free text fields allows the documentation of information related to end of life planning, and minimises unnecessary repetition of sensitive information.

Carer Support screen (Figure 9). Effective home based end of life care is enhanced through the identification and coordination of key community services and supports. Radio buttons and free text fields capture this information.

Emergency/ After Hours Plan screen (Figure 10). Information collected on this screen assists weekend and after hours services in their care decision making.

Care Team, Equipment Loan & Hazards screens. Free text fields and tables similar to those in earlier screens

are used in these to record information as required

Registration Care Plan Clinical Note. A *smart template* using rich text formatting has been developed to extract *DTA* data entered into the *PowerForm*. This *smart template* is opened in the Clinical Note tab in PowerChart. Once the clinical note is complete the Palliative Care Liaison Nurse must sign, verifying with their username and password. On signing a number of processes are triggered. *Cerner Charting* is initiated and the Registration Care plan is put into an automatic fax distribution to the General Practitioner. The fax distribution looks to see if any Registration/Care Plans have been completed within a certain time frame. The RRD (*Remote Report Distribution*) faxes to the General Practitioner assigned in the *ERM Admit/Modify Conversation*. The Palliative Care Administration Officer is automatically advised of the registration and moves the patient from the Referral list to the Master List.

The Registration/Care Plan is available to community and inpatient clinicians in the electronic medical record (*Flowsheet*) along with other clinical documentation, pathology results, ra-
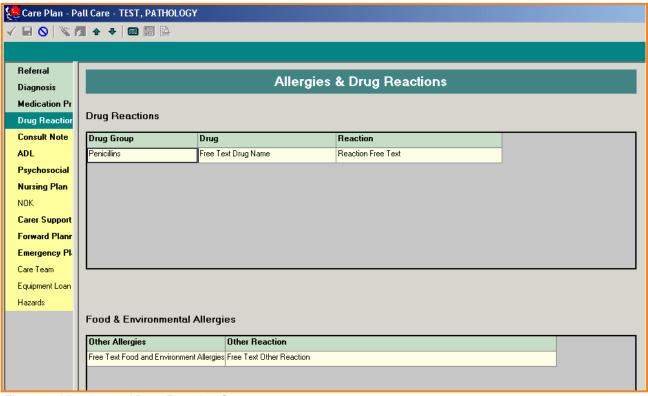
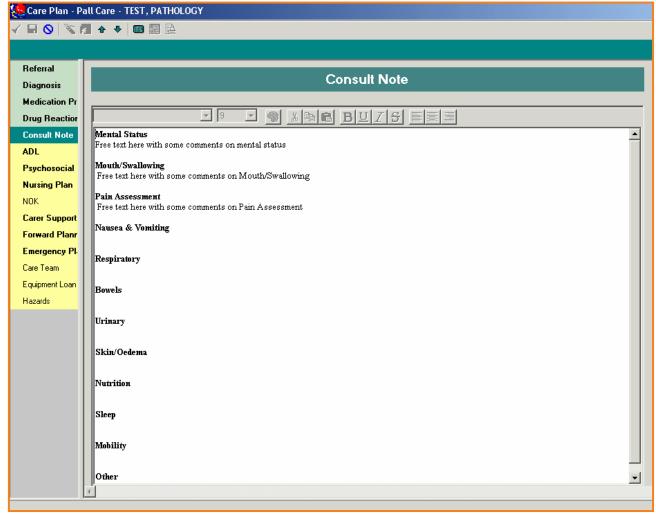*Figure 4. Allergies and Drug Reaction Screen*

Figure 5. Initial Consult Screen

diology etc.

The electronic Advance Care Directive (ACD). There is variation in the way that health professionals approached situations where the possible use of life-sustaining treatment was being considered. There were concerns that such treatments are being used in terminally ill patients resulting in over-zealous treatment or, less frequently, under-treatment. Advance care planning and the use of advance care directives are processes by which an individual's care preferences can be determined and documented. The opportunity to incorporate information about care preferences within the NIIS represented a significant advance in communication across care settings. Ensuring that this documentation was available in real time for patients presenting at the Emergency Department allows the use of life-sustaining treatments in ways that are more consistent with the individual's choice and priorities at the end of life. Changes in policy nomenclature after the implementation of the NIIS now direct that the term Advance Care Plan (ACP) is the correct terminology for the type of document captured in the Palliative Care record [10].

Advantages of the electronic ACP. *Security*: permissions were set in Millennium PowerChart to enable only Palliative Care physicians to complete the ACP clinical note. The clinical note will only be shown to other uses of Millennium PowerChart once it has been verified by the Physician.

Visibility: Millennium PowerChart displays an Advance Care Directives tab (nomenclature to soon change to ACP). This tab is visible to all users of Millennium PowerChart. The "Not for Intubation or Cardio-Pulmonary Resuscitation" clinical note is displayed under this tab.

Respect: when the patient presents in the emergency department, the clinician opens the electronic patient record on Millennium PowerChart. The attached Advance Care Plan is visible and can be addressed. The visibility of this document reduces the risk of unnecessary distress that may be brought about by re-discussing end of life care preferences.

Progress Notes, both Inpatient and Community. Palliative Care nursing and medical staff in both community and inpatient settings are completing notes on patient progress. This information is extremely important for the inpatient/community continuum of care. The progress note is signed/verified by the user and is then available in the electronic medical record where it can be accessed in real time by other clinicians caring for the patient. The inpatient and community progress notes use *clinical note* functionality in Millennium PowerChart.

Consult Letters. Consulting Palliative Care physicians have the ability to create a consult letter which is saved against the patient file. The consult letter is signed/verified by the consulting physician and stored in the electronic medical record. The consult letter uses *clinical note* functionality with a rich text *smart template* in Millennium PowerChart.

Pathology, Xray, CT, Nuclear Medicine results reporting. Millennium PowerChart uses HL7 real time interfaces from Pathology and Radiology systems. All Palliative Care documentation appears in the patient's flowsheet (Figure 11) with all other clinical information.
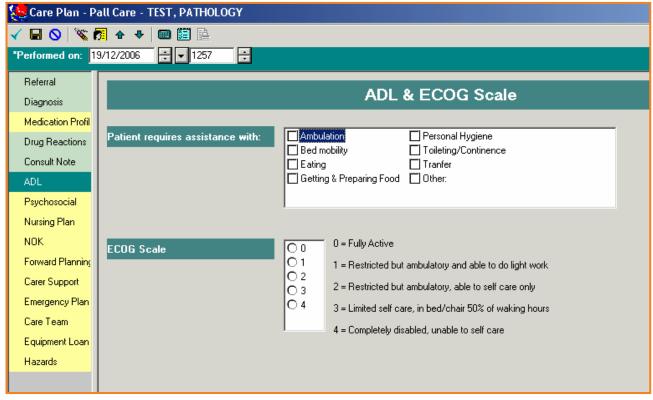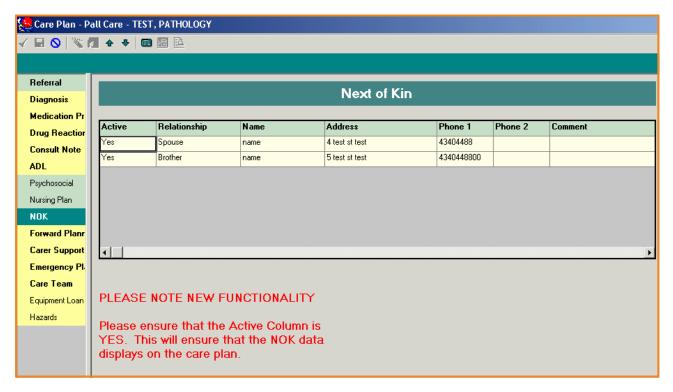

Figure 6. ADL and ECOG Screen
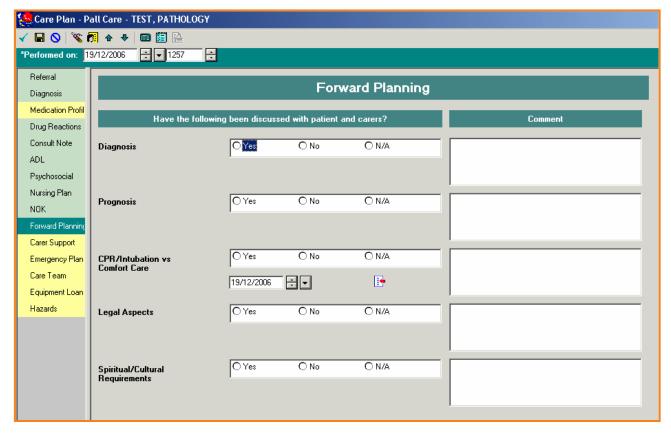
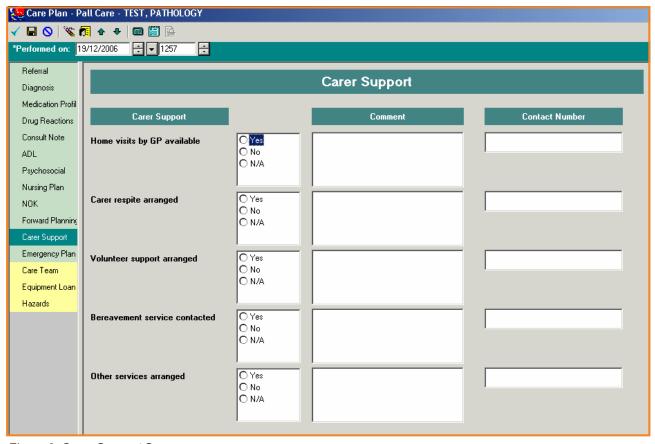Figure 7. Next of Kin Screen

Figure 8. Forward Planning

Figure 9. Carer Support Screen

Palliative Care Electronic Discharge Referral. The electronic discharge referral uses a combination of *PowerForm*, *Problem List* and a *Clinical Note* functionality to complete. Once the Discharge Referral is signed/verified by the clinician it is stored in the electronic medical record and available to other clinicians caring for the patient.

Service Reports. Service reporting information is drawn from the either the ERM Admit/Discharge Conversations, the input screens for the care plan, multidisciplinary review and the clinical notes. Five Service reports were integrated into the NIIS (Table 1).

Remote Access. Clinicians in the field required the ability to remotely access PowerChart from the patient's home or residential aged care facility. This functionality has streamlined and improved the efficiency of the data entry requirements of the Palliative Care Service. Remote access from patient's homes allows a higher level of informed clinical decision making without the need to for the health professional to have to "Return to base" to obtain information or complete documentation.

Remote access capability provides a clinical service in both community and inpatient settings. It facilitates a 24/7 service delivery profile and allows

for a multidisciplinary approach to care. Palliative Care Liaison Nurses and on-call medical staff use the Telstra 1X CDMA Cellular Network.

1X network is a data network based on CDMA Mobile Phone Technology. 1X allows connection to the Internet at speeds up to 144kb/s which is twice the normal dial up access speed.

Remote Access Solution Design. The core of this design is based upon the seamless connection to services at Central Coast from effectively any location that has Internet access. Although the solution is fundamentally aimed at the Palliative Care clinical staff, it can be extended to other areas

Report	Description
Patient Data Report	Demographic data, activity data
Inpatient Report	Total number of inpatients who have been registered with service
Referral Report	Source (GP/Specialist) and location
Discharge Report	Discharges from service, numbers and type Deaths location of discharge hospital/community Average length of registration
Service Delivery Report	Careplans completed, Multidisciplinary reviews undertaken

Table 1. Service Reports Generated from NIIS

of remote access. Citrix is the locally preferred method of deployment for the Cerner Millennium application. This solution is not limited to Cerner PowerChart. It has the ability to act as a portal into almost any application that is used within the Area Health Service such as email, Intranet, Web Browsing and file shares.

3.2 Outcomes from the NIIS

The immediate result of the project was that Palliative Care clinical information became seamless in terms of where data was created and accessed. Inpatient pathology and medical imaging results, Palliative Care progress notes and discharge plans are available to community based Palliative Care clinicians and key Primary Care providers. Management plans and progress notes created in the community are available to inpatient Palliative Care clinicians and other key clinical areas (eg Emergency). Clinical information is now accessible in real time 24/7, providing better support for clinical decision making. The establishment of remote access has allowed clinical documentation to be completed in any

location, reducing community travel time "back to base".

A further notable outcome was real time tracking of admissions to and discharges from Area Health facilities of registered Palliative Care patients. This has facilitated faster inpatient follow-up, earlier discharge planning, and faster community follow up following discharge. Patients of the Palliative Care Service have key information documented once and visible to all relevant care providers, reducing intrusive repeat questioning and optimising their safety [11]. The creation of a mechanism for electronic advanced care directives, visible to inpatient and community located clinicians, has the capacity to reduce unwanted medical interventions.

4. Discussion

The NIIS project demonstrated that trans-regional health services that provided services across the care continuum could benefit from a suitable EHIMS. The keys to the project's success were the realisation of unused capacity and function within an exist-

ing inpatient EHIMS, the creation of a remote access strategy, and the time taken to map existing service workflow and consult with the clinicians who would be using the newly created systems and processes. Several cycles consisting of "Draft version / Demonstration / User Feedback / Revision" resulted in high levels of end user ownership of the project, and an outcome that was perceived to be a "best fit" with Service needs with maximum clinician "buy-in"[12]. The mix of fixed fields and free text fields in the created documents reflected the clinicians natural narrative style in their clinical report writing [13].

Despite these successes the NIIS is not without its frustrations. Similar to other EHIMS implementation experiences there was an initial negative shift in the ratio of clinical / non-clinical time [14]. Although this improved over time the community clinicians experienced a sense of imperative in documenting clinical encounters in real time or same day, as a patient may be admitted to a facility during the night, and their commitment to continuity of care compelled them to increase time spent in completing clinical notes [15]. Community lev-
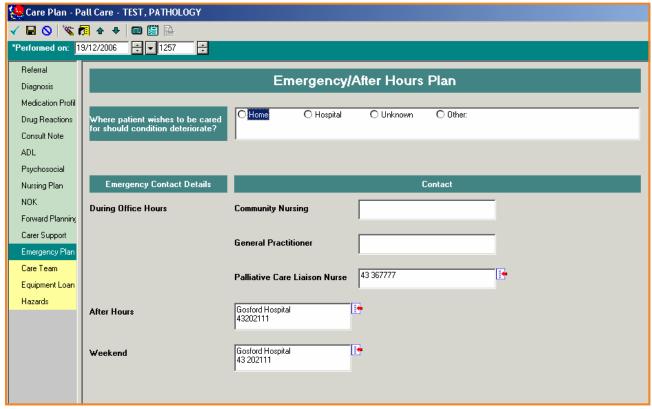

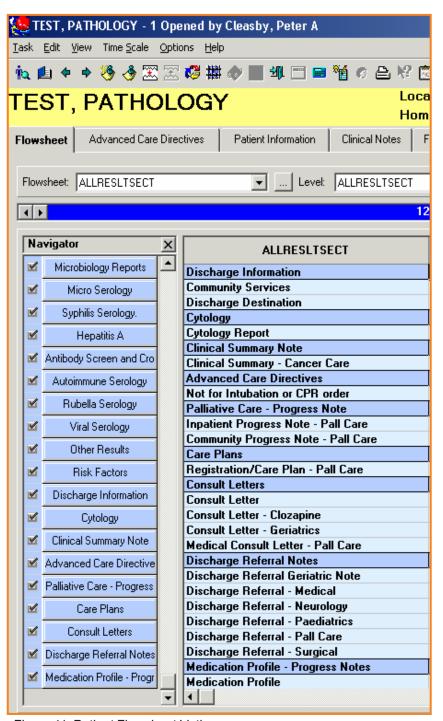Figure 10. Emergency/ After Hours Screen

Figure 11. Patient Flowsheet Listing

els of electronic documentation were greater than inpatient levels. Although not examined, the reason would appear to be that the electronic record became the sole document in the community palliative care setting, while electronic documentation existed alongside paper records in the inpatient environment.

The remote access solution, operating with hardware utilising the then best available wireless speed, has

proved less than optimal, especially when coupled with negotiating the necessary security protocols and firewalls. Further, the planned closure of the Australian CDMA network will necessitate a change in remote access method [16]. The more recent availability of faster wireless options may provide a means of addressing this issue. Also the desire to extend access to Primary Care Physicians (General Practitioners) was unable to be realised for a

range of technical and procedural issues. A current pilot project is underway that is attempting to progress these matters.

5. Conclusion

The Central Coast Palliative Care Service Networked Integrated Information System represents a successful adaptation and enhancement of existing software systems and processes to achieve an electronic health information management solution that supports clinical documentation, service planning and decision making. It provides access for multiple providers across multiple care settings around the clock, reflecting the clinical reality of a modern integrated Regional Palliative Care Service. The processes and systems developed have application for other health services that have multi site points of clinical contact with their patients.

Acknowledgements

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