Developing Comprehensive Heart Failure Care in the ACT

1. Introduction and Background - Our Rationale for Change

1.1 Burden of Disease – Heart Failure

Heart failure (HF) is an increasingly prevalent clinical syndrome that limits length of life and profoundly impacts on function and quality of life. Epidemiological analysis demonstrates increasing incidence and improved survival rates of people living with HF. However, despite significant advances in HF management, clinical outcomes are poor and associated with escalating health care costs.¹ ii

Nationally in 2013-14, there were five main conditions; chronic obstructive pulmonary disease (COPD), diabetes complications, heart failure, cellulitis and kidney and urinary tract infections, that accounted for almost half (47%) of all potentially preventable hospitalisations and almost two-thirds (62%) of bed days for these admissions³. The presence of multiple chronic conditions in patients is also increasingly common with an estimated 50% of patients visiting GPs having two or more chronic conditions.iv

HF affects:
- over 300,000 Australians with another 30,000 new cases diagnosed each year. It accounts for 43,000 hospitalisations and 2200 deaths annually ²

We understand that:
- HF prognosis remains poorer than that for common cancers and there are significant variations in access to evidence based care for patients living with chronic HFvi
- HF is 1.7 times more prevalent and occurs at a younger age among Aboriginal and Torres Strait Islander peoples who are more likely to die from HF and the rate of potential preventable hospitalisation is three time higher than other Australiansvii
- the relative risk of developing heart disease is about 1.6 times greater for people with depression or depressive symptomsviii
- many individuals are not diagnosed in a timely manner and subsequent management is suboptimalix
- between 2006 and 2011 deaths from HF in Australia rose by 20%v
- hospital separations increased by 24% between 2002-03 and 2011-12xi
- HF was a primary diagnosis in 45,212 hospitalisations and contributory diagnosis in 94,599 hospitalisations across 2007-08xii
- the annual cost of HF in Australia is estimated at over $1b per year, with hospital care being the highest expenditure.xiii

HF is considered one of the most frequent potentially avoidable ED (re)presentations and hospital (re)admissions. Yet readmissions within 30 days of discharge can be as high as 20%-27%xiv and reported rates for readmissions within 3-12 months of initial discharge between 29% and 49.xv

Whilst the ACT ranked in the top five of all PHNs when examining age-standardised rates of potentially preventable hospitalisations (PPHs), over 813 chronic disease related occurrences per 100,000 population occurred across 2013-14 predominantly in older people (62.9% being over the age of 65 years). HF accounted for 521 PPHS (or 149 PPHs per 100,000 population) and constituted the second largest number of total PPH bed days (ie: 3958) in 2013-14, behind COPD.

Ref: brf_CHFC in ACT_Jan 2017
Table 1. ACT HF potentially preventable hospitalisations in 2013-14.\textsuperscript{xvi}

<table>
<thead>
<tr>
<th>PHN Name</th>
<th>Rank</th>
<th>PPH per 100,000 people (age-standardised)</th>
<th>Number of PPHs</th>
<th>Number of same day PPH</th>
<th>Total PPH bed days</th>
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<tr>
<td>ACT</td>
<td>2 of 31</td>
<td>149</td>
<td>521</td>
<td>41</td>
<td>3,958</td>
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<tr>
<td>Australia</td>
<td>195</td>
<td>53,168</td>
<td>4,235</td>
<td>360,769</td>
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</tbody>
</table>

HF accounted for some 4209 hospital separations and 33,774 bed days for those aged over 65 years, across the ten year period 2003-04 to 2012-13 with an average length of stay for this patient cohort of 8.0 days.\textsuperscript{xvii}

Figure 1: Hospital separations for selected chronic disease by age group, per cent, ACT 2012-13\textsuperscript{xviii}

Evidence suggests that interventions to reduce PPHs are more effective when they target specific conditions, rather than taking a large-scale policy approach.\textsuperscript{xix} This however needs to be balanced with the recognition that people with HF more often than not have multiple chronic conditions that need to be managed and that the treatment and management of one disease can often contribute to poorer outcomes for a co-existing disease.

An expert panel, assembled by the National Heart Foundation of Australia in 2013 asserts that “\textit{there is profound potential to improve HF-related outcomes at both individual and societal levels, through improved quality of care and system change}”.\textsuperscript{xx}

Goodlin et al (2009)\textsuperscript{xxi} suggests that “people with HF generally are symptomatic for some time before presenting for evaluation and receiving a diagnosis” and asserts the need for early identification and timely access to comprehensive HF management and palliation, advocating that “\textit{with initiation of appropriate medications, diet and fluid management and other interventions the burden of disease may diminish. .....Psychosocial or existing distress and strategies to manage and cope with HF should be provided concurrently with evidence-based disease-modifying interventions}”. Goodlin presents a comprehensive HF care model (set out below) that may provide a useful framework to consider primary care related HF condition management approaches.
Figure 1: Depiction of Comprehensive Heart Failure Care

Key:

Phase 1 – Initial symptoms of HD develop and treatment initiated
Phase 2 – Plateau of variable length reached with initial medical management or following mechanical support or heart transplant
Phase 3 – Functional status declines with variable slope, intermittent exacerbations of HF that respond to rescue efforts
Phase 4 – Stage D HF, with refractory symptoms and limited function
Phase 5 – End stage

Attached at Appendix A is an overview of this model of comprehensive chronic heart failure care.

This model provides an alternate approach to the stratification of chronic disease patients and the potential to segment patients and tailor service offerings according to clinical needs and physical functioning of a patient within each phase and is considered more suited to the appropriate management of multi-morbidity.

The model advocates early identification and diagnosis, effective and sustained clinical and medication regimes across the duration, and the provision of the bulk of services within the community setting encompassing specialist support to patients and GPs in the general practice setting and/or palliative care settings ie: “Even when a plateau of improved function is achieved, the patient and family will benefit from efforts that improve symptoms and assist the patient and family in coping with their HF and its impact on their lives”. Also included is accessible step up/down capability across the spectrum of care to address crisis situations or exacerbation of conditions, including access to specialist expertise to support the management of patients in primary care.

Goodlin et al confirm that in the US primary care clinicians provide the majority of HF care allied with expert HF and palliative care clinicians to provide comprehensive HF care encompassing cardiologists and HF specialists and other disciplines as appropriate.

Further, Goodlin et al report that palliative care services cater well for patients with cancer patients but not necessarily HF patients: heart failure differs from cancer in which curative treatments are discontinued as the patients reach the end stage. At the end of life the major focus for HF patients should be on palliation with an emphasis on supported decision making (eg: deactivation of defibrillators) and continuation of medications and treatments (ie: to the extent that blood pressure and function tolerate) and bereavement supports.

Ref: bc_CHF_Jan 2017
1.2 Models of Care in Australia and the ACT

HF disease management programs (DMPs) and models of care in Australia are predominantly cardiologist led, hospital based multidisciplinary clinics with some specialist cardiac nurse supports.

This is consistent with the ACT public health system model of care where services on the whole are specialist led with cardiac nursing support, rehabilitation and/or care co-ordination provided to highly complex patients.

This model of care, its effectiveness and sustainability are currently being questioned and alternative models that involve GPs with a special interest in HF liaising with and being upskilled by specialists within community based, multidisciplinary general practice setting are gaining prominence.

Scott and Jackson (2013) point out that in Australia in every 1000 encounters, general practitioners will manage seven patients with HF (0.7%). However, comparable UK data shows that half of all HF patients (50%) are diagnosed in the PHC setting and a third (33%) of all HF patients are managed predominately by GPs.

They also maintain that:

- on the basis of recent trials, patients referred to hospital based HF clinics derive no further benefit compared to GP based maintenance care after 12 months whilst another trial reduced this period to 3 months.
- a Cochrane review of some 25 trials concluded that at 12 months effective case management (ie: care coordination) reduced all-cause mortality by 34%, HF related readmissions by 54% and all-cause hospital admissions by 25%.
- multidisciplinary interventions reduced all cause and HF readmissions by 54% and 55% respectively.
- HF clinics showed non-significant reductions in all three outcomes.
- a Dutch trial suggested that the care of low risk patients with mild to moderate HF could be transferred to GPs with advanced HF skills within 4 weeks.
- early collaborative care involving cardiologists and GPs enables higher quality care and improved survival compared to cardiologist or GP care alone.
- three key elements required for effective HF management include trained specialist nurses, educated and activated consumers and carers, and accessible clinicians trained in HF and these can be delivered in PHC settings.
- PHC based HF management and the management of other comorbidities should be considered for the majority of HF patients akin to models of multidisciplinary ‘beacon’ general practice in partnership with visiting specialists.

1.3 Effective Chronic Disease Management (CDM) – General

From a system perspective we know that:

- ineffective management of chronic conditions leads to poor health outcomes and higher health care and system wide costs.
- CDM is complex and multi-faceted with many consumers requiring multiple, contingent and/or complementary services and sometimes conflicting treatments, spanning a complex and disconnected health system.
- those people with the highest levels of disadvantage, are likely to have the lowest levels of health literacy, are less able to self-manage and navigate the health care system and likely to have the highest levels of need.
current growth in demand for outpatient, specialist and hospital based services is unsustainable and in many cases unwarranted.

Similarly, we know that effective chronic disease prevention, detection and management systems (eg: the Wagner Extended Chronic Care Model\textsuperscript{xix}) are stronger if they are more comprehensive, integrated and coordinated, community focused, universal, affordable, person-centred and family oriented:\textsuperscript{xxvii}

- educated and empowered consumers/carers achieve better health outcomes, reduce demand on PHC and hospital services when the culture is supportive, education programs and supports are integrated into CDM systems/pathways and ongoing therapeutic relationships established with a single health care provider responsive to multiple patient needs and preferences
- shared care and care co-ordination are critical components of all best practice chronic care arrangements and advanced PHC
- general practice based initiatives (encompassing risk stratification and voluntary enrolment) have the potential to increase health outcomes, consumer experience of care and reduce health care costs associated with unnecessary use of ED, hospital and specialist services
- QiData initiatives strengthen general practice ability to identify those at risk of poor health outcomes and enhance quality and safety through appropriate call/recall (ie: CD screening, assessment, monitoring and management) capability
- a consistent approach to clinical care protocols and pathways for specific chronic diseases can make a real difference to health outcomes
- responsive step up/down capability spanning the spectrum of care encompassing PHC/community/sub-acute (re-ablement and rehabilitation)/acute and specialist services achieve better health outcomes
- digital technology, electronic health records and information sharing tools are key system enablers – enhancing service quality and safety, reducing duplication and waste
- person-centred and integrated care spans holistic health and social care needs of individuals.

2. Developing a comprehensive and systematic approach to HF care in the ACT

Whilst all the key elements of effective CDM systems are a prerequisite to effective HF management, multidisciplinary HF care is differentiated by the special needs of individuals who require specific HF evidence based treatment strategies to optimise health outcomes including symptom monitoring, a range of specific self-management strategies and titration of medications.\textsuperscript{xviii xxix}

\textit{A Consensus Statement for the development of “a systematic approach to chronic heart failure care” provides a framework to realign the health care system for the benefit of consumers and the system alike.}\textsuperscript{xl} A national expert reference group convened by the Health Foundation of Australia in 2013 sets out 19 recommendations for the development of comprehensive HF care. (See Appendix B).

On the whole, ACT’s health system, encompassing multiple funders and service providers, is well placed to progress the majority of recommendations set out in the HF Consensus Statement, i.e. a shared jurisdiction and population base, localised decision authority and potential funding mechanisms, strength of clinical leadership and cross sector partnership arrangements, and the convergence of priorities and improvement agendas, provides both opportunity and a platform for change.

Whilst many of the components and associated enablers set out in the Consensus Statement currently exist or are in development (albeit not necessarily within a coordinated framework), the fact
remains that a comprehensive and systematic approach to HF is not evident and an emphasis on hospital based care persists creating an unsustainable burden on specialist and acute services.

Our local challenge is not necessarily ‘what do we need more of?’ (although recognising there may be areas where investment to improve/save is required) but rather:

- What do we need to do differently to deliver comprehensive and systemic HF care in primary care settings?
- How do we harness, align and/or optimise what already exists?

And fundamentally:

- How do we maximise the benefit of the whole health system (ie: funders and providers alike) to achieve better outcomes, a better consumer experience, an optimised workforce and best value?

The emergence of Commonwealth (eg: Primary Health Care Advisory Group Final Report Better Outcomes for People with Chronic and Complex Health Conditions 2015) and Territory based health reform agendas (eg: current development of ACT Health’s Clinical Services Framework and the joint ACT Health/ACTPHN Clinical Council) now provides an opportunity to accelerate the development of a comprehensive and systematic approach to best practice prevention, management and palliation of HF founded on the Consensus Statement recommendations.

To address these issues CHN has secured ACT Health’s and Calvary Hospital’s commitment to collaboration and Commonwealth PHN Innovation Funds to drive clinician led whole-of-system and whole-of-person focused innovation across 2017-18. Utilising the Heart Foundation HF consensus model as a framework the objective if this innovation is to develop and implement a comprehensive and systematic approach to the management of HF that involves evidence-based, multi-disciplinary and patient-centred care.

Key components of our structured approach to this innovation include:

**Phase 1 - Planning and Preparation (by 31 March 2017)**
- Establishment of effective project governance and joint working relationships
- Introduction and development of a HF Clinical Leadership Forum
- Establishment of effective program management capability

**Phase 2 – Development (by 2 October 2017)**
- Co-design, development and pilot of a General Practice focused model of HF care
- Review of HF related palliative care approaches to inform both the model of HF care and the development of an ACT-wide model of palliative care
- Co-design and development of a HF specific outcomes framework and associated minimum data set (MDS)

**Phase 3 – Delivery (by 30 June 2018)**
- Development and implementation of a system-wide change and adoption strategy
- Development and delivery of a whole of system multi-disciplinary workforce development plan
- Development of a HF patient register (if considered appropriate)

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2 Consultancy services are currently being procured to directly inform the development of Phase 2 components.
Phase 4 – Evaluation (by 30 June 2018)

- A formative evaluation will be conducted across the duration of the project with the final report delivered at the end of the initiative.

3. Outcomes Sought

Long term outcomes sought from this innovation (ie: 3-5 years) include:

- improved consumer experience of whole-person focused HF care
- improved clinician experience of collaborative working
- reduced potentially preventable hospitalisations amongst “enrolled” HF patients
- enhanced end of life care for people with HF.

(Note: These will be measured over time through application of the jurisdiction-wide HF outcomes framework – see below).

Project specific outcomes and key deliverables include the establishment and adoption of a:

- multi-disciplinary HF clinical network and leadership forum
- person-focused, whole-of-system, standards driven and multi-disciplinary model of HF care
- jurisdiction-wide HF outcomes framework, register and minimum data set
- jurisdiction-wide HF specific protocols for palliative care spanning all settings
- a targeted and implemented change and adoption plan to drive whole-of-system reform
- whole-of-system multi-disciplinary workforce development plan.

The formative evaluation framework (to be developed) will confirm developmental and measures to support implementation. These may include for example:

- Enhanced clinical leadership capability within and across the local health system
- Enhanced inter-professional collaboration, networking and learning opportunities
- Developed clinically-led system change strategies
- Optimised GP and general practice capability
- Enhanced team based care in the general practice setting, service integration and continuity of care
- Effective step up and step down capability
- Enhanced performance monitoring, quality improvement and research capability.

(Note: Evaluation services are currently being procured).

4. Governance, Organisation, Resources and Relationships

System wide stewardship, leadership, capacity building and change management are critical components of this innovation. To ensure that the initiative is fully optimised:

- An ACT jurisdiction-wide multi-disciplinary clinical leadership forum will provide strategic oversight, leadership, guidance and drive to this initiative
- Specific action oriented working groups will established (as required) to drive specific areas of focus/improvement in line with the structured approach set out above.

Strategic partners and collaborative agencies and associated roles are set out over page.
### Table 2 Strategic Partners and Key Stakeholders

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<th>ACT PHN</th>
<th>ACT Health</th>
<th>Calvary</th>
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<td>Monitoring, review (PDSA) and formative evaluation</td>
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**Key:** ● Lead stakeholders with direct input; ○ Interested parties with indirect input.

Regular progress and performance reports will be provided to the joint ACT Health/CHN Coordinating Committee, the ACT Clinical Council, CHN’s Community Advisory Council and in line with corporate reporting requirements and an agreed performance and reporting framework. In addition briefings and regular communiques will be provided to broader stakeholders in line with an agreed Stakeholder Engagement Plan.
References

5. * AIHW data
17. * ACT Health Admitted Patient Care data, 2003-04 to 2012-13 (includes public and private hospital separations).
37. * Ibid.