Identification of clinically relevant cohorts of people with heart failure from electronic health data in Aotearoa: potential, pitfalls and a plan

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ABSTRACT

Heart failure (HF) is associated with high morbidity and mortality and contributes to substantial burden of disease, significant inequities and high healthcare cost globally as well as in Aotearoa. Management of chronic HF is driven by HF phenotype, defined by left ventricular ejection fraction (EF), as only those with reduced ejection fraction (HFrEF) have been shown to experience reduced mortality and morbidity with long-term pharmacotherapy. To ensure appropriate and equitable implementation of HF management we need to be able to identify clinically relevant cohorts of patients with HF, in particular, those with HFrEF. The ideal HF registry would incorporate and link HF diagnoses and phenotype from primary and secondary care with echocardiography and pharmacotherapy data. In this article we consider several options for identifying such cohorts from electronic health data in Aotearoa, as well as the potential and pitfalls of these options. Given the urgent need to identify people with HF according to EF phenotype, the options for identifying them from electronic health data, and the opportunities presented by health system reform, including a focus on digital solutions, we recommend the following four actions, with oversight from a national HF working group: 1) Establish a HF registry based on random and representative sampling of HF admissions; 2) investigate obtaining HF diagnosis and EF-phenotype from primary care-coded data; 3) amalgamate national echocardiography data; and 4) investigate options to enable the systematic collection of HF diagnosis and EF-phenotype from outpatient attendances. Future work will need to consider reliability and concordance of data across sources. The case for urgent action in Aotearoa is compounded by the stark inequities in the burden of HF, the likely contribution of health service factors to these inequities and the legislative requirement under the Pae Ora (Healthy Futures) Act 2022 that "*the health sector should be equitable, which includes ensuring Māori and other population groups – (i) have access to services in proportion to their health needs; and (ii) receive equitable levels of service; and (iii) achieve equitable health outcomes*".

Heart failure (HF) is a complex clinical syndrome caused by underlying abnormalities of cardiac structure and/or function that reduces the ability of the heart to fill with blood and/or eject adequate blood volume to meet the needs of the body.[1] Despite the availability of effective treatment, HF is associated with poor quality of life and high morbidity and mortality.[2] Globally, the number of people with heart failure almost doubled between 1990 and 2017 (from 33.5 to 64.3 million) with significant inequities by geography and socio-economic status.[3]

In Aotearoa, approximately 1.6% of adults were estimated to have HF in the 2020/2021 New Zealand Health Survey.[4] A recent trends analysis found that while the overall incidence of HF declined between 2006 and 2013, this reduction plateaued between 2013 and 2018 due to increasing rates of HF in younger age groups despite an ongoing decline in the elderly.[5] HF is one of the major causes of hospitalisation in this country, leading to 11,428 publicly funded hospital discharges with a mean stay of 12.9 days during the 2018/2019 financial year,[6] with overall costs to the New Zealand health system estimated at 1.5–2%[7] (approximately $360–$480 million dollars of Vote Health in 2022/2023[8]). All-cause mortality after first HF hospitalisation in New Zealand is high: 12.0%, 30.6% and 63.3% at 30 days, 1 year and 5 years, respectively.[9] Compared with non-Māori, Māori are twice as likely to die from HF (rate ratio (RR) 2.36, 95% CI 1.76–3.17), and four times as likely to be hospitalised for HF (RR 4.01, 95% CI 3.83–4.21).[10] Similarly, compared with the total New Zealand population, Pacific people are over twice as likely to be hospitalised for HF (standardised discharge ratio 2.62, 95% CI 2.44–2.81).[11]

Assessment of cardiac function, including measurement of left ventricular ejection fraction (LVEF), is an important step in the investigation of patients with HF and the most accessible modality to undertake this assessment is echocardiography.[1] LVEF measurement is of particular importance because it enables classification of HF into categories defined by the EF phenotype: HF with reduced LVEF (HFrEF), HF with mildly reduced LVEF (HFmrEF) and HF with preserved LVEF (HFpEF).[12,13] Data from the Framingham Heart Study indicates that the proportion of HF patients with HFrEF, HFmrEF and HFpEF was 31%, 13% and 56%, respectively, in 2005–2014, and 44%, 15% and 41%, respectively, in 1985–1994.[14] It is unclear to what extent the proportion of HF patients with each type and the change in proportion over time are likely to be relevant to HF patients in Aotearoa. While all patients with HF have higher mortality than people without HF, patients with HFpEF have a lower risk of death than those with HFrEF (adj HR 0.68 (95% CI 0.64 to 0.71) for 1 year mortality).[15]

Importantly, recommended management of chronic HF also varies by EF phenotype.[1] Disease modifying therapies for those patients with HFrEF now includes Class I evidence-based recommendations for multiple classes of pharmacotherapy, including angiotensin-converting enzyme (ACE) inhibitors/angiotensin receptor blockers (ARBs) or angiotensin receptor neprilysin inhibitors (ARNI; sacubitril/valsartan), β-blockers, mineralocorticoid receptor antagonists, SGLT-2 inhibitors and, where appropriate, HF device-based therapies including an implantable cardioverter defibrillator and/or cardiac resynchronization therapy. Such combined therapeutic approaches result in substantial improvements in morbidity and mortality for patients with HFrEF, but not for patients with HFpEF.[1,12] The current evidence-base is insufficient to make strong recommendations about specific therapies for HFmrEF.[12] In order to ensure such evidence-based interventions are being appropriately and equitably implemented, it is therefore essential to know not just whether or not patients have HF, but to define the HF EF phenotype.

A systematic review of evidence-based prescribing for patients with HFrEF found that the "treatment gap" (the proportion of patients who had an indication and no contraindication or limiting side effect but were not prescribed the recommended treatments) was up to 13.1% for ACE inhibitors/ARBS, 3.9% for β-blockers and 16.8% for mineralocorticoid receptor antagonists, and gaps were even greater when receipt of guideline-recommended target doses were considered and among the elderly, women and people with comorbidities.[16] Further, the review found that prescribing these drugs according to contemporary guidelines was associated with lower mortality risk.[16] Research from New Zealand indicates that among a cohort of patients presenting with acute coronary syndrome and who underwent coronary angiography in 2015, and who also had HFrEF, at one-year post discharge 76% and 85% were receiving ACE inhibitors/ARBS and β-blockers, respectively, and only 34% and 35% respectively were receiving >/=50% target doses of these medications.[17] While limited information is available regarding HFrEF treatment gaps for Māori and Pacific peoples, treatment gaps are more likely for Māori and Pacific people than for others living in Aotearoa given the evidence to date regarding CVD treatment gaps.[18] Improved systems are clearly needed to identify, monitor and close as well as to address inequities in treatment gaps.

Identifying clinically relevant cohorts of HF patients and examining the appropriateness of management is crucial from patient, health service and research perspectives. The ideal HF registry would incorporate and link HF diagnoses from primary and secondary care with echocardiography and pharmacotherapy data. However, disappointingly, a platform to readily identify patients of different HF phenotypes from routinely collected electronic health data in Aotearoa does not currently exist. This gap is due to several factors and multiple barriers, including data collection, quality, interoperability and funding. In this paper, we consider options available to identify such cohorts along with their potential benefits and disadvantages, including consideration of cost and accuracy, as summarised in Table 1.

Manual auditing

Manual auditing of individual patient records by clinicians against standard diagnostic criteria would generally be regarded as the "gold standard" for accurately identifying those with HF of different phenotypes. However, the major disadvantage of this approach is the substantial time required by staff whose capacity to undertake such tasks is generally very limited. Any manual process is also associated with error and inconsistency, with the level of inconsistency compounded by the number of people involved, especially when repeated over time and associated with changes in staff and systems (including documentation).

Hospitalisation coding

We can identify patients admitted with HF from national hospitalisation datasets reasonably reliably using the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM) coding system when both primary and secondary diagnoses are considered for relatively low cost.[20] ICD-10-AM has been implemented in New Zealand to classify diagnoses associated with hospitalisations since 1999. The major limitation of ICD-10 is that it only defines the clinical syndrome of HF and does not include definitions according to the EF phenotype.

ICD-11, which has been released for use from January 2022 by the World Health Organisation, provides distinct codes for HFrEF (BD11.2 Left ventricular failure with reduced ejection fraction) and HFpEF (BD11.0 Left ventricular failure with preserved ejection fraction) but there are no plans for New Zealand to move to ICD-11 within the next several years. Despite investigating the move for the last 3 years, Australia has also not decided when they might move from ICD-10 to ICD-11.

Reliable implementation of this revision is likely to require training and monitoring to ensure consistent and robust clinical documentation and coding practice. For example, despite the availability of imaging to clearly differentiate ischaemic and haemorrhagic stroke as well as distinct ICD-10 codes (I63 and I60/I61, respectively) quality improvement work focussed on improving clinical documentation as well as coding practice was required to minimise the inappropriate use of the code I64 (stroke not specified as haemorrhage or infarction).[19]

The other major limitation of a diagnostic coding-based approach to identifying HF in New Zealand is that currently the systematic coding of such diagnoses only occurs for admissions. HF can be diagnosed and managed in the community, through secondary care (in outpatient clinics) and/or primary care (in general practice). Diagnoses related to outpatient activity in secondary care are not routinely coded, and while Read and/or SNOMED-CT coding is in place in general practice this process may not be systematic or consistent; Read coding does not explicitly differentiate between phenotypes, information from echocardiology reports may be unavailable or incomplete and such data are not available at a national level.

Outpatient coding

This limitation in secondary care could be addressed by introducing a requirement to expand diagnostic coding in secondary care to include outpatient as well as inpatient activity. This could occur either through the same process currently used to code admissions (via clinical coders) or alternative processes such as clinician coding, as has been integrated into clinician outpatient workflow at Waitematā District Health Board (DHB).[19] While the former could leverage off existing infrastructure, there would be substantial ongoing costs. The latter involved establishment but limited ongoing costs.

Alternatively, natural language processing (NLP)-based strategies could be implemented to automatically generate diagnostic codes from clinical unstructured text (e.g., discharge summaries, specialist letters). While many off-the-shelf products are already available, an NLP-based strategy would require clinical validation to ensure satisfactory sensitivity and specificity, especially in the New Zealand healthcare setting. The latter point is important because the way HF is described and written about in clinical records in New Zealand, as well as exact medication names, may differ from the country in which the NLP algorithm was derived. As noted by a recent systematic review of current NLP processing methods and applications in cardiology, a major limitation of NLP-based approaches is the "inability to aggregate findings across studies due to vastly different NLP methods, evaluation and reporting".[21] Hence there would be a cost associated with establishing a New Zealand clinically validated NLP-based strategy, although most of these costs would be upfront. Further, any NLP approach will involve a balance of Precision and Recall (represented by the F score)[21]—the actual "feasibility" will be the shape of the Precision-Recall curve achievable at various levels of engineering effort. An algorithm will provide consistent performance if inputs are consistent, but reliability will be some balance of precision and recall where 80% performance on each could be deemed "good" by NLP standards. The systematic review noted above found that for studies that used NLP to identify and classify HF, F scores ranged from 74–94%.[21] A better understanding of such costs as well as feasibility and the Precision-Recall curve/F scores achievable of an NLP-based approach to determine EF-phenotype within Aotearoa will be obtained from an upcoming pilot of this approach, to be conducted by the Health Research Council-funded VAscular Risk Equity for All New Zealanders (VAREANZ) programme. The VAREANZ programme is also planning to work with primary care (via Primary Health Organisations) to obtain HF and EF-phenotype from coded (Read and SNOMED) primary care data.

Table 1: Options to identify heart failure phenotype.

Option		Advantages	Disadvantages
Manual audit		Gold standard (HF and EF phenotype) Any clinical setting	Clinical staff time/cost Potential for error/inconsistency Subset of patients only
Hospital coding		Reliable and consistent (HF phenotype) No/minimal additional cost All hospitalised patients	Unable to identify EF phenotype Need to be hospitalised
Outpatient coding (added to hospital coding)	Standard hospital coding process	Reliable and consistent (HF phenotype + potentially others) All outpatients	Administrative staff time/cost Not specific to HF
	Clinician coding	Gold standard (HF and EF phenotype + potentially others) All outpatients	Clinical staff time/cost Not specific to HF
	NLP-based coding	Potentially reliable and consistent (HF and EF phenotype + potentially others) All outpatients	Clinical staff time/cost Information technology costs Data scientist costs
Secondary care coding supplemented with echocardiography data		Potentially reliable and consistent (HF and EF phenotype + potentially others) All secondary care	Clinical staff time/cost Information technology costs Data scientist costs
Traditional clinical registry		Gold standard (HF and EF phenotype) Leverage off ANZACS-QI infrastructure	Clinical staff time/cost Lack of defined "home" to identify HF patients Need to be hospitalised
Registry based on random sampling of hospitalisation coding		Gold standard (HF and EF phenotype) Representative sample Leverage off ANZACS-QI infrastructure	Clinical staff time/cost Need to be hospitalised
Primary care coding		Includes people with HF managed in primary care Coding systems (Read and SNOMED) able to identify HF and EF phenotype	Not currently available at a national level Process may not be systematic or consistent Key information from secondary care may not be available Uncertain concordance with secondary care

Abbreviations: ANZACS-QI = All of New Zealand Acute Coronary Syndrome – Quality Improvement, EF = ejection fraction, HF = heart failure, NLP = natural language processing.

Secondary care coding supplemented with echocardiography data

One further possible option is to supplement hospitalisation (+/- outpatient) data (including diagnostic coding) on patients with HF with data from echocardiography databases to enable differentiation between patients with HFrEF and HFmrEF, and those with HFpEF. This approach was investigated for patients admitted with HF at the Waitematā and Counties Manukau DHBs in 2016 and 2018, respectively.[19] Both DHBs use the same echocardiography management, analysis and reporting system (Xcelera®). The clinician or sonographer undertaking the echocardiogram uses Xcelera® to report their findings of this investigation, including their clinical assessment of the patient's LVEF. Within Xcelera® this information is collected and stored both as specific measurements of LVEF, as well as the operator's summative assessment of LVEF, which can be captured using pre-specified text options from a drop-down menu, or free text.

The investigation found that while most echocardiograms had the summative assessment of LVEF documented using the drop-down menu (and therefore was easily extractable and analysable), a substantial proportion (in the order of 20%) were documented using free text. This proportion could potentially be reduced through staff training and quality improvement approaches to encourage greater use of drop-down menu options, and/or NLP approaches used to automatically code LVEF for residual free text. However, in an informal survey in 2018, there were at least seven different echocardiography reporting platforms in use nationally, including Xcelera®.[9] It is unclear whether extracting LVEF data would be as feasible for non-Xcelera® platforms, what processes would be needed to appropriately amalgamate data from different platforms, and whether all DHBs would have sufficient analytic capacity to extract the required data.

Traditional clinical registry

Patients with HF could be identified through clinical registries, such as the All of New Zealand Acute Coronary Syndrome – Quality Improvement (ANZACS-QI) registry. ANZACS-QI is a clinically led, web-based registry designed to enable consistent data capture of diagnostic and management information to support implementation of evidence-based guidelines for patients with acute coronary syndrome (ACS registry) and those receiving coronary angiography and percutaneous coronary intervention (CathPCI registry).[22] Patients are included in the registry by clinical or clerical staff on arrival at a coronary care unit or catheterisation laboratory, with clinical staff entering mandatory data throughout the admission.[22] Data capture and quality are optimised in ANZACS-QI through strong clinical leadership of this national initiative, training and monitoring, as well as separate funding by the Ministry of Health.[22]

A New Zealand HF registry to capture in-hospital HF patients was established more than 10 years ago under the auspices of the New Zealand branch of the Cardiac Society of Australia and New Zealand (CSANZ), and more recently this was transitioned to an acute decompensated HF registry available within the ANZACS-QI electronic platform. However, these HF registries have, to date, been unable to capture a representative or comprehensive cohort of patients. A key obstacle is that, in contrast to the ANZACS-QI ACS cohort, which can be comprehensively captured through catheterisation laboratories, there is a lack of a defined "home" for HF patients. Unlike ACS patients who are treated in cardiac catheterisation labs, HF patients are often managed alongside patients with a multitude of other conditions by general physicians and general medical services, including services for older people, as well as by cardiologists and cardiology services. Further, such registries do not generally capture hospital outpatient activity or HF management in the community, though the latter could be partially addressed through linkage to national data collections (e.g., pharmaceutical dispensing).

Registry based on random sampling of hospitalisation coding

The authors, as part of their work with the Ministry of Health-funded ANZACS-QI platform, are currently developing an approach that could address some of the limitations of a traditional HF registry related to resource and representativeness while leveraging the existing infrastructure of ANZACS-QI. In this approach, a random selection of HF admissions could be identified using national hospitalisation coding data, and participating hospitals retrospectively enter data manually for the sample of patients admitted to their hospital using the ANZACS-QI platform.[9] The registry will provide data on in-hospital HF process measures, such as LVEF assessment and medication use (including contraindications to use) for those with HFrEF to guide quality improvement initiatives. This approach

would have the advantage of identifying and reporting on a representative national sample of HF hospitalisations, regardless of the discharging service and patient comorbidity, and could be supplemented through linkage to national datasets to achieve an overview of HF management after discharge.

Primary care coding

HF can be diagnosed and managed in the community, as well as through secondary care. Read and/or SNOMED-CT coding is in place in general practice, and both are potentially able to differentiate between HF phenotypes. SNOMED is now the required standard clinical terminology for the New Zealand health and disability system (which will enhance interoperability across the health sector), provides many more clinically relevant concepts than Read coding (e.g., there is a specific SNOMED clinical term and code [703272007] for HFrEF), and its implementation is being accelerated across the whole health system in New Zealand, with a specific focus on upgrading from Read codes to SNOMED in primary care.[23] However, the coding process may not be systematic or consistent in primary care, as it is not specifically resourced as with secondary care. Information from secondary care including echocardiology reports (publicly or privately funded) may be unavailable or incomplete. There may be inconsistent understanding of diagnosis/phenotype between primary and secondary care where patients are engaged in both. For example, a New Zealand study found that the 39% of people with prior CVD hospitalisations were not recorded as having prior CVD when their CVD risk was first assessed in general practice.[24] This discordance between information contained in primary and secondary care increased over time, and was associated with lower dispensing of evidence-based medications and was more common among people aged under 55 years, women, and those of non-European ethnicities.[24]

Upcoming health system changes

The national health system reforms and Hira, the national health information platform, have been designed to enable better sharing of expertise (including digital and analytical) and data (including across regions and at the primary/secondary care interface) across the country. Hira will "draw together a person's latest health information as needed to create a single view; a virtual electronic health record rather than a single electronic health record".[25] Hira is a key enabler of the Ministry of Health's Digital Heath Strategic Framework[26] and Data and Information Strategy.[25] These health system changes offer exciting opportunities and show great promise but will take time to be fully implemented. At this stage, Hira won't be fully implemented until the end of 2026 and it is unclear exactly which data will be included as part of their scope. A key aspect of Hira is interoperability, so investment in optimising the accuracy, completeness and consistency in the recording of key clinically relevant data fields, such as the diagnosis of HF and HF type (HFrEF vs HFmrEF vs HFpEF) are crucial, particularly given the substantial mortality, morbidity and inequities in HF as well as the substantial health system costs associated with this treatable condition.

Next steps

Given the urgent need to identify people with heart failure according to EF phenotype, the options for identifying them from electronic health data, and the opportunities presented by health system reform, including a focus on digital solutions, we recommend the following four preliminary actions:

1. Establish a HF registry based on random and representative sampling of ICD-coded admissions, starting in hospitals with strong clinical leadership, and reporting on key clinical quality measures.
2. Investigate the feasibility of and processes to obtain HF and EF-phenotype from primary care-coded data.
3. Investigate the feasibility of and processes to amalgamate a subset of the most clinically important data for HF (including EF) from all echocardiography reporting platforms in use nationally.
4. Undertake pilot studies to investigate the feasibility and clinical validity of different approaches to enable systematic collection of HF diagnosis and phenotype for outpatient attendances for HF and determine which approach would be the most suitable for national implementation.

While these actions could be undertaken separately and by different groups, to ensure that the work will effectively and efficiently support high-quality healthcare and equitable outcomes for all patients and whānau with HF in a coor-

dinated and cohesive way, we recommend that it should have strong oversight by a national HF working group. As the working group would require the inclusion of clinicians and researchers with expertise in HF, equity, quality improvement and population health, it could be formed with membership from existing groups including Manawataki Fatu Fatu (a Māori and Pacific-led programme researching equity in heart health outcomes for Māori and Pasifika), CSANZ (particularly their HF working group), ANZACS-QI (in order to leverage off the ANZACS-QI electronic platform, central co-ordination and data quality improvement processes where appropriate and feasible), and VAREANZ (VAscular Risk Equity for All New Zealanders, a Māori and Pākehā co-led research programme assessing cardiovascular risk-management equity gaps nationally). Input should also be obtained from patients and whānau, Health NZ, the Māori Health Authority and the Ministry of Health. Future work will need to consider reliability and concordance of data across sources, as well as the most appropriate methods of data transfer.

The stark inequities in the burden of HF experienced by Māori and Pacific people and the likely contribution of health service factors to these inequities[26] add to the case for urgent action to enable the identification of clinically relevant cohorts of people with HF, as well as other major causes of morbidity, mortality and inequities in Aotearoa. Such action is legislatively mandated under the Pae Ora (Healthy Futures) Act 2022, the first principle of which is that "*the health sector should be equitable, which includes ensuring Māori and other population groups – (i) have access to services in proportion to their health needs; and (ii) receive equitable levels of service; and (iii) achieve equitable health outcomes*".[27]

COMPETING INTERESTS
Nil.

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