

## **Title**

Are there patients missing from community heart failure registers? An audit of clinical practice.

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## **Abstract**

**Background:** General practitioners in the UK are financially incentivized, via the Quality Outcomes Framework, to maintain a record of all patients at their practice with HF and manage them appropriately. The prevalence of heart failure (HF) recorded in primary care registers (0.7-1.0%) is less than reported in epidemiological studies (3-5%). Using an audit of clinical practice, we set out to investigate if there are patients “missing” from primary care HF registers and what the underlying mechanisms might be.

**Design:** Audit of clinical practice at a UK General Practice (N=9390).

**Methods:** Audit software (ENHANCE-HF®) identified patients who may have HF via a series of hierarchical searches of electronic records. HF was then confirmed or excluded based on the electronic records by a HF specialist nurse and patients added to the register. Outcome data for patients *without* HF was collected after 2 years.

**Results:** HF prevalence was 0.63% at baseline and 1.12% after the audit. Inaccurate coding accounted for the majority of missing patients. Amongst patients *without* HF who were taking a loop diuretic, the rate of incident HF was 13% and the rate of death *or* hospitalization with HF was 25% respectively during 2 year follow up.

**Conclusion:** There are many patients missing from community HF registers which may detriment patient outcome and practice income. Patients *without* HF who take loop diuretics are at high risk of HF related events.

## **Keywords**

Chronic Heart Failure, Diuretics, General Practice, Pharmacological Manage



## Main text

### Introduction

Heart failure with reduced ejection fraction (HeFREF) affects 3.5-7.0% in patients aged 65-75,<sup>1,2</sup> and up to 11% of those >80.<sup>3,4</sup> Heart failure with normal ejection fraction (HeFNEF) accounts for at least half of heart failure diagnoses.<sup>5,6</sup> The current overall prevalence of HeFNEF and HeFREF is estimated to be 4.9% and 3.3% respectively.<sup>7</sup> Prevalence is expected to rise with an ageing population.<sup>8-10</sup>

There are multiple interventions proven to prolong life in patients with HeFREF.<sup>11</sup> Consequently, general practitioners (GPs) in the United Kingdom are financially incentivized by the Quality Outcomes Framework (QOF) to maintain a register of patients with heart failure and to manage them appropriately.<sup>12</sup>

The prevalence of heart failure, measured by the proportion of patients within a practice population on a heart failure register, is much lower than expected from epidemiological reports; approximately 0.7-1.0%.<sup>13</sup> The reasons for this are unknown; one possible explanation is for the discrepancy is that the clinical features of heart failure are non-specific and common which may lead to misdiagnosis.<sup>4,14</sup> Incomplete or incorrect electronic coding may also play a role.

To investigate, we performed an audit of clinical practice at a single GP surgery in the UK using an electronic audit tool and a dedicated heart failure specialist nurse (HFSN). Our primary aim was to discover why patients may be missing from community heart failure

registers and not a cost-benefit analysis of the process of identifying patients and increasing the numbers of patients on the register.

## **Methods**

### *The practice*

Montague Medical Practice in Goole, East Yorkshire has 5 GP partners serving a patient population of around 9300 (table 1).<sup>15</sup> The practice uses SystemOne electronic records software. A piece of audit software, ENHANCE-HF® [Oberoi Consulting, Derby, UK], was installed at the practice and a dedicated HFSN (ACG) was placed on site to help manage any patients identified as having heart failure. The project ran as an audit of the practice's activity from April to December 2015, further data collection was undertaken in April 2017.

### *ENHANCE-HF®*

The software performed a series of searches on the electronic database (table 2). Patients with heart failure or who may have heart failure were identified by QOF Read codes, old Clinical Terms Version 3 (CTV3) Read codes or Clinical Terms Version 29 (CTV29) Read codes in their electronic record.

The searches identified patients who were either on the current heart failure register or recorded as having left ventricular systolic dysfunction (LVSD), as well as patients with other Read codes relating to heart failure or left ventricular failure (LVF). It also identified patients without Read codes relating to heart failure but with features suggesting the diagnosis:

those with a high serum natriuretic peptide, those taking angiotensin converting enzyme inhibitors (ACEI), angiotensin receptor blockers (ARB), beta-blockers (BB), mineralocorticoid receptor antagonists (MRA), loop diuretics or sinus node blockers.<sup>16</sup>

### *Follow-up*

2 years after completion of the initial project, follow up data was collected for patients who were part of the audit. "Heart failure" was confirmed if there was evidence in the electronic records of either:

- an echocardiogram showing mild-moderate LVSD or worse in conjunction with symptoms of breathlessness or ankle swelling
- a letter from a cardiology specialist confirming the diagnosis
- a hospital discharge summary with heart failure as either a primary or secondary diagnosis.

### *Audit Cycle*

#### Step one

The software searches found all patients on the heart failure and LVSD registers. Electronic records of these patients were then reviewed by the HFSN to confirm the diagnosis. Patients on the LVSD register but not the heart failure register were added if the diagnosis was

confirmed. Finally, the software identified patients who had outdated Read codes relating to LVSD. Patients' records were reviewed and the patient added to the appropriate registers if the diagnosis was confirmed.

### Step two

Using a hierarchical series of steps, the software then identified patients who were not on the heart failure or LVSD registers but who fell into one of the following (mutually exclusive) groups:

- raised serum natriuretic peptides (NPs) on record
  - Brain natriuretic peptide (BNP) >100pg/mL
  - N-terminal peptide of prohormone of brain natriuretic peptide (NT-pro-BNP) >400 pg/mL
- taking digoxin *in combination with* ACEi/ARB
- taking an MRA *or* ivabradine,
- assigned Read codes relating to LVF or heart failure.
- taking a combination of beta-blocker, ACEi and loop diuretic.

The HFSN reviewed the case notes of all patients identified. Those with signs, symptoms or results (cardiomegaly on chest x-ray, raised NPs) consistent with heart failure were referred for echocardiography. Patients with high serum NPs taken >3 months ago were referred for repeat blood tests. Patients with high serum NPs and atrial fibrillation (with no other sign, symptom or result suggestive of heart failure) were not included.



Finally, patients not on the register who had results or correspondence that confirmed heart failure (such as reduced left ventricular ejection fraction on echocardiogram or a letter confirming diagnosis from a cardiologist) were added to the register.

### Step three

The final step involved identification of patients who were not on the heart failure or LVSD register but who fell into one of the following groups:

- Patients taking loop diuretic
- Patients taking loop diuretic *and* ACEi or ARB
- Patients taking loop diuretic *and* BB

Again, those with results or correspondence *confirming* HF in the electronic record were added to the HF register. Those with signs, symptoms or results *suggestive* of HF were referred for further investigation and added to the register if the diagnosis was confirmed.

### **Results**

A total of 276 patients was identified by the searches (total practice n=9390; 2.9%) at baseline: 59 of these were on the heart failure register giving a prevalence of 0.63% for the practice.

## Step 1

There were 14 patients on the LVSD register and 2 patients with old LVSD Read codes who were not on the HF register. 1 patient was on the heart failure register in error and was removed. After corrections, the number of patients on the heart failure register increased to 74 (prevalence 0.79%).

## Step 2

Step 2 identified 106 patients with possible heart failure based on drug use. 53 patients had raised NPs. 48 patients were taking a combination of ACEi/ARB, BB, MRA, loop diuretics, digoxin or ivabradine. 5 patients who were not on the register had Read codes relating to LVF or heart failure in their records (but *not* the LVSD Read code) (figure 1).

Of the 106 patients:

- 17 had a diagnosis of heart failure on the electronic records and were added to the register.
- 62 did not have findings suggestive of heart failure in their records;
- 23 patients were referred for further investigation:
  - heart failure was confirmed in 7 patients,
  - heart failure excluded in 9 patients
  - 7 patients did not have investigations completed
- 3 patients died before being assessed
- 1 patient had had Read codes for LVF assigned in error.

Step 2 thus identified an additional 24 patients with heart failure, bringing the total on the register now to 98 (prevalence 1.04%).

### Step 3

Step 3 identified a further 95 patients who were taking a loop diuretic. 37 patients were taking loop diuretics alone, 48 patients were taking loop diuretic and ACEi/ARB and 10 patients were taking loop diuretic and BB (figure 1).

Of the 95 patients:

- 75 patients did not have signs, symptoms or results suggestive of heart failure in their records
- 4 patients had a diagnosis of heart failure on the electronic records and were added to the register.
- 16 patients were referred for further investigation:
  - heart failure confirmed in 2 patients;
  - heart failure excluded in 8 patients; and
  - 6 patients did not have investigations completed.

Step 3 thus identified an additional 6 patients with heart failure bringing the total on the register now to 104 (prevalence 1.12%).

### *Loop diuretics*

Steps 2 and 3 identified 109 patients who were not on the heart failure or LVSD register at baseline but were taking loop diuretics either alone or in combination with other medications. Of these 109 (14 from step 2 and 95 from step 3), 15 were added to the heart failure register at the end of the project.

Of the remaining 94 patients who were not diagnosed with heart failure by the initial audit (table 3):

- 22% of patients had complained of oedema at consultations during the audit period.
- 15% had complained of breathlessness at consultations during the audit period.
- 20% had a record of a condition that may be associated with peripheral oedema such as hypothyroidism
- 36% were taking a calcium channel blocker

The rate of incident heart failure at 2 years was 13%, all-cause mortality was 23%, giving a rate of heart failure hospitalization or death of 25%.

## **Discussion**

Our results are consistent with comparisons between epidemiological reports and QoF data: a significant number of patients with heart failure is missing from a representative primary care register. Using a staged process, mostly using an automated system, a total of 45 patients was added to the heart failure register.

Absent or incomplete Read codes accounted for the majority of missing patients in the practice (n=36); possibly a consequence of the ever-changing ways in which patients can be coded for various symptoms or conditions on electronic records.

Accurate coding allows GPs to identify patients at increased risk of adverse outcome. Strict adherence to guidelines, such as up-titration of medications to maximum tolerated doses, improves outcome in patients with heart failure.<sup>17-19</sup> Absent or incomplete coding may mean that some patients with heart failure are missed and their care may suffer as a result.

Patients who take loop diuretics without a diagnosis of heart failure are at significant risk of adverse outcome related to heart failure. Loop diuretics are first line treatment for venous congestion in heart failure,<sup>20</sup> but peripheral oedema is not always cardiogenic.

Consequently, diuretic use is common and not isolated to patients with HF.<sup>21-23</sup> Treatment with diuretic agents, such as chlorthalidone, reduce the incidence of heart failure in those at risk.<sup>24</sup> However, diuretics may mask the signs and symptoms of heart failure with which patients present, thus reducing the recorded incidence without treating the underlying disease, and delaying diagnosis which may lead to poorer outcomes as a consequence.<sup>25</sup>

The prevalence of heart failure at the end of the project is still less than expected from epidemiological reports. In our audit, the majority of patients taking loop diuretics without a diagnosis of heart failure did not qualify for further investigation as there was no record of signs or symptoms of the diagnosis. However, if loop diuretics are masking the features that would prompt further investigation, the prevalence of heart failure among those taking loop diuretics may be much higher.

The National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care in Greater Manchester ran similar projects between 2008 and 2013 with the Greater Manchester Heart Failure Investigation Tool (GM-HFIT).<sup>26</sup> This also found heart failure prevalence to be much lower than expected at baseline and used the GM-HFIT audit

tool to identify patients with possible heart failure and increase prevalence (table 4).<sup>26</sup> Our audit found a higher prevalence of heart failure using ENHANCE-HF<sup>®</sup> audit software (1.12%).

It may be argued that our results, combined with the GM-HFIT results, suggest the actual prevalence of heart failure is *lower* than epidemiological studies predict. Indeed, some studies have suggested the rate of over-diagnosis of heart failure may be as high as 17-18% in general practice.<sup>27</sup> However, we only found only 1 patient recorded incorrectly on the HF register. Furthermore, heart failure may be undiagnosed in a large proportion of elderly patients with clinical signs of the disease.<sup>2,4,14,28,29</sup> We think that it is more likely that heart failure is under-recognised in the community (as we have demonstrated) rather than the prevalence over-estimated by epidemiological studies.

### *Clinical implications*

Audit tools, such as ENHANCE-HF<sup>®</sup>, can identify patients who may be missing from heart failure registers and increase patients numbers on registers. Patients who take loop diuretics without a diagnosis of heart failure are at high risk of adverse outcome. The need for loop diuretics in such patients should be reviewed and appropriate investigations arranged should there be the suspicion of heart failure.

### *Strengths and limitations*

Our project demonstrates that incorrect electronic coding is the main reason why patients may be missing from primary care heart failure registers and that patients who take a loop

diuretic without a diagnosis of heart failure are at high risk of heart failure events; it is plausible that loop diuretics may disguise symptoms of heart failure thus delaying diagnosis and treatment. We have also demonstrated a simple method for assessing a practice population for patients who may be missing from the heart failure register. Identifying such patients may increase practice income via the QOF framework and may improve patient outcome; most of the gain came from automated computer searches of existing practice registers. However, our work was never intended to provide a cost-benefit analysis of the process.

However, our work was never intended to provide a cost-benefit analysis of the process nor may it be generalizable to all practices. Furthermore, the benefits of being on a heart failure register are merely implied by current evidence: access to specialist services in the community may improve outcomes,<sup>30</sup> but there is limited evidence that maintaining a heart failure register per se improves outcomes or guideline adherence.

The cut-offs for natriuretic peptides we used were based on National Institute for Clinical Excellence guidelines. European Society of Cardiology heart failure guidelines use far lower cut-offs (>125 pg/mL for NTproBNP; >35 pg/mL for BNP) which would surely increase the number of patients identified in further audits.<sup>11</sup> Finally, we were unable to comment on the proportion of patients with HeFNEF as such information was not included on the heart failure register or hospital correspondence.

## **Conclusions**

Heart failure registers identify patients with complex care needs, management plans and poor outcomes. Epidemiological studies suggest there are many patients with heart failure missing from primary care registers, this may be primarily due to absent or inaccurate electronic coding rather than under-diagnosis. The widespread use of loop diuretics in patients without heart failure may mask the disease, delay diagnosis and negatively impact outcome as a result; such patients seem to be at high risk of heart failure events.

## **Author Contributions**

JG, ACG and ALC contributed to the conception and design and JJC contributed to the design of the study. Data was collected by JJC, JG and ACG, data was analysed by JJC and the manuscript was drafted by JJC and ALC.

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## **Conflicting interests**

The authors declare that there is no conflict of interest.



**Figure title and caption**

Figure 1

Title: Patients added to the heart failure register

Legend: Schematic of the ENHANCE-HF<sup>®</sup> audit process and the number of patients identified at each step.

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