

**Reply to Forsyth et al, commenting on our paper ‘Survival following a diagnosis of heart failure in primary care’**

**Letter to the editor**

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Dear Sir

We welcome the interest in our paper 'Survival following a diagnosis of heart failure in primary care' and would like to address each of the points raised by Forsyth et al.<sup>1</sup>

Routinely collected data from primary care provide a unique information source to study patterns of disease. The Health Improvement Network (THIN) has been used to undertake many epidemiological studies, based on clinical codes from the electronic health record, which have been published in high-quality, international journals.<sup>2</sup> The reliability of clinical coding is an important consideration in conducting this type of research. As described in the methods section of the paper, we thoroughly searched the NHS Clinical Terminology Browser, in addition to the Quality and Outcomes Framework (QOF), and this was the source for the majority of the heart failure codes. The full coding list can be found in the Supplementary Material online.

The reference from Forsyth et al which supports the assertion that half of clinical codes are inaccurate or missing is a conference abstract of an audit of heart failure QOF registers in Scotland in 2014-5 which is not comparable to the comprehensive coding list, time period or geographical spread in our study.<sup>3</sup> Another study cited by Forsyth et al used a very broad coding strategy which included patients who were being investigated for heart failure including: 1J60.00 Suspected heart failure, 9N0k.00 Seen in heart failure clinic; 9N4w.00 Did not attend heart failure clinic; G58z.11 Weak heart.<sup>4</sup> In planning our study, we initially generated a thorough list of heart failure codes then, prior to data extraction, we derived a definitive, more restrictive list to ensure only patients with a diagnosis of heart failure were included.

We agree that making a distinction between heart failure with reduced ejection fraction (HFREF) and heart failure with preserved ejection fraction (HFPEF) is helpful and we did attempt to do this. Unfortunately, the codes in regular clinical use during the study period did not differentiate between HFREF and HFPEF, instead being a variant of heart failure e.g. 'Congestive Heart Failure', 'Congestive Cardiac Failure'. The codes which described the type of heart failure were rarely used so it was not possible for us to search on this basis. Echocardiogram codes, including those for left ventricular systolic dysfunction, were searched but these were present in less than a quarter of the cohort. This is probably due to the timing of the study which was between 1998 and 2012. The heart failure QOF indicator

was introduced in 2006 and before then there was no incentive to code echo findings separately.

The study that Forsyth et al report as 'in stark contrast' to our findings, was asking a different research question. Jhund et al reported mortality rates following an incident heart failure admission between 1986 and 2003.<sup>5</sup> The population requiring hospital treatment for acute heart failure is very different to the community cohort we report, and this study is also from an earlier time period.

The papers cited by Forsyth et al from a primary care setting are in support of our findings. Koudstaal et al reported a 5 year survival rate of 44% in 23,547 participants with a heart failure diagnosis recorded in primary care which, despite the coding differences, is similar to the finding in our study.<sup>4</sup> Hawkins et al used routinely collected primary care data and found no change in one year survival between 1999 and 2007.<sup>6</sup>

The reasons for the lack of improvement in survival rates in a primary care population are likely to be multiple and complex. We agree that more deaths from non-cardiovascular disease could be one explanation. Historically, investment in secondary care research and innovation has been higher than primary care and this may lead to a distorted view of progress which does not reach the wider general community population. We are undertaking further work to support and explain our findings. It is vital that we understand the epidemiology of heart failure in primary care to find areas where improvements might be possible to improve outlook for our patients.

Yours sincerely,

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On behalf of the authors

## **Declaration**

Ethical approval: The Health Improvement Network Scientific Review Committee (Ref No. 13-010).

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## References

- <sup>1</sup> Taylor CJ, Ryan R, Nichols L, Gale N, Hobbs FDR\*, Marshall T\*. Survival following a diagnosis of heart failure in primary care. *Fam Pract* 2017 pii: cmw145
- <sup>2</sup> Rait G, Walters K, Bottomley C, Petersen I, Iliffe S, Nazareth I. Survival of people with clinical diagnosis of dementia in primary care: cohort study. *BMJ* 2010;341:c3584
- <sup>3</sup> Forsyth P, Clackson T, O'Neil J, et al. Improving the validity of general practice heart failure registers in Scotland through collaborative clinical audit. *Eur J Heart Fail* May 2016;18:254
- <sup>4</sup> Koudstaal S, Pujades-Rodriguez M, Denaxas S *et al.* Prognostic burden of heart failure recorded in primary care, acute hospital admissions, or both: a population-linked electronic health record cohort study in 2.1 million people. *Eur J Heart Fail* 2016 doi: 10.1002/ejhf.709
- <sup>5</sup> Jhund PS, MacIntyre K, Simpson CR *et al.* Long-term trends in first hospitalization for heart failure and subsequent survival between 1986 and 2003: a population study of 5.1 million people. *Circulation* 2009;119(4):515-23
- <sup>6</sup> Hawkins NM, Scholes S, Bajekal M *et al.* Community care in England: reducing socioeconomic inequalities in heart failure. *Circulation* 2012;126(9):1050-7