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11 December 2019

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Rachel Galloway
HM Assistant Coroner
HM Coroner's Office
Manchester City Area
Exchange floor
The Royal Exchange
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Manchester M2 7EF



Our ref EH-302753

Dear Ms Galloway,

I write in response to your letter of 5 November 2019, regarding the death of Mr Stuart Clarke.

We have considered the circumstances surrounding Mr Clarke's death, and the concern raised in your report, that there are no national guidelines for referral from primary care to secondary care and/or from secondary care to tertiary care for patients with known valve disease

Based on the clinical detail provided, it's not clear how severe Mr Clarke's symptoms were or if any other symptoms were present. However, it appears likely that the NICE guideline on chronic heart failure in adults (NG106) is relevant.

This guideline contains the following recommendations regarding the speed of specialist assessment

1 2 3 Because very high levels of NT-proBNP carry a poor prognosis, refer people with suspected heart failure and an NT-proBNP level above 2,000 ng/litre (236 pmol/litre) urgently, to have specialist assessment and transthoracic echocardiography within 2 weeks. [2018]

1 2 4 Refer people with suspected heart failure and an NT-proBNP level between 400 and 2,000 ng/litre (47 to 236 pmol/litre) to have specialist assessment and transthoracic echocardiography within 6 weeks. **[2018]** 

Where chronic heart failure is thought to be due to heart valve disease, we make this recommendation, but we do not specify a referral time since this would depend on the severity of the symptoms

1.2 15 Refer people with heart failure caused by valve disease for specialist assessment and advice regarding follow-up [2003]

Ultimately, we consider the degree of urgency would be a matter for clinical judgement and will depend on the individual clinical scenario. It is important that services are organised in such a way to respond appropriately to clinical scenarios to allow progression through the pathway in an appropriate and timely way. The organisation of such services would be the responsibility of the Trust, with oversight from the specialist commissioner (NHS England).

NICE is at the early stages of developing a clinical guideline on heart valve disease presenting in adults: investigation and management. One of the issues to be covered by this guideline are the indications for patient referral from primary care to a specialist. The draft guidance is expected to go out for consultation with stakeholders in November 2020, and we expect to publish our final guideline to the NHS on 20 May 2021.

Details of the concerns you have raised have been highlighted to the guideline developers, so they can consider indicating which factors merit more and less urgent referral, where the evidence is available

This guideline will also be considering the indications for TAVI, and its clinical effectiveness and cost effectiveness. However, we are unlikely to cover issues relating to the patient pathway from secondary to tertiary care, as TAVI is commissioned by NHS England (as outlined within their publication titled 'Clinical Commissioning Policy Transcatheter Aortic Valve Implantation (TAVI) For Aortic Stenosis'

Yours sincerely,

Sır Andrew Dillon Chief Executive