

21 July 2023

## **Patient treatment options for inherited cardiac conditions**

**As a patient with an inherited cardiac condition (hypertrophic cardiomyopathy) I would like to establish what centres within the ICS would I be under the care of? I.e., what hospitals have a dedicated inherited cardiac conditions team?**

See Below answers first 2 queries together

**If they do not have a dedicated team or would not treat the condition where would patients be referred to?**

The Northern Ireland Inherited Cardiac Conditions Service is the regional service for ICCs in NI and is based within the Belfast Trust, specifically in the Belfast City Hospital. It is recognised as an official regional referral service by the UK Association for Inherited Cardiac Conditions (AICC) and listed as such on their directory of services within the UK. Not all patients with an ICC require long term care under the NI ICC service but if genetic testing or management advice is required patients will be seen and then may be discharged to their local cardiology service with advice on long term follow up and management. The Belfast service (the Hub) also has a dedicated “spoke” within the Western Trust where dedicated ICC clinics are run within Altnagelvin, Omagh and the South West Acute Hospitals. Patients who have been seen at the Belfast Service and a management plan put in place can then have long term follow up closer to home in these hospitals.

**Specifically, would a local hospital manage drug treatment up until the stage of surgery (septal ablation or surgical myectomy)? If surgery is not offered where would the patient be referred to?**

Management of patients with hypertrophic cardiomyopathy is usually drug based. Approximately one third of patients may have outflow tract obstruction associated with their cardiomyopathy and the majority of these will be managed medically. This is usually led or at least guided by the Belfast service but shared care with local services also exists. If patients fail medical management, invasive options such as pacemaker implantation, alcohol septal ablation and surgery are considered. The Belfast service would offer pacemaker implantation (can be implanted in any Trust in NI that offers pacemakers). For consideration of specialist invasive options, the patients’ detailed information is forwarded to the Bart’s Heart Centre in London. The Belfast team then present the patient’s case to the Bart’s MDT to discuss best management options. If surgery or alcohol ablation indicated, an Extra Contractual Referral is made for funding, and the patient sent to Bart’s for these treatments. Follow up post intervention is then done in Belfast, but once patient stable, can be offered by local cardiology team.