

R-007 Investigating morbidity and mortality outcomes in patients with Tetralogy of Fallot (TOF) WHSCT and UU

Cardiovascular disease (CVD) is the leading cause of death in Northern Ireland (NI). CVD registries have been shown to improve quality of care for patients, highlight guideline compliance and guide commissioning, exemplified by the Swede Heart Registry. Unfortunately, a dedicated cardiac registry does not exist in NI. Therefore the aim of this feasibility project is to retrospectively retrieve and characterize a unique Tetralogy of Fallot cohort from the Regional Data Warehouse (BSO) going back 20 years. To characterize these patients we will obtain patient demographics, any imaging, intervention, and therapy used over time and will record specific clinical outcomes such as ventricular tachycardia, right ventricular failure and death. Finally, we will assess data integrity, the potential pitfalls in ICD-9 and -10 coding, whether different datasets can be linked, and the timeframe to achieve such a project. Collaboration between Cardiologists and Northern Ireland Connected Health Innovation Centre will provide clinical knowledge, academic insight and analytical skills. Future potential to explore public data outside of the Honest Broker Service that is through the NI Connected Health Innovation Centre's relationship with other Health Providers, Public Bodies, Academic Knowledge networks and data held by Commercial Organisations in relation to medical devices, diagnostics, pharma and data analytics will be realised. The lessons learned from this pilot would facilitate further large scale data retrieval projects in more common cardiovascular disease cohorts such as heart failure, atrial fibrillation and ischaemic heart disease the leading cause of death in our society.