

## SPSO decision report

**Case:** 201407179, Lothian NHS Board  
**Sector:** health  
**Subject:** clinical treatment / diagnosis  
**Outcome:** upheld, recommendations

### Summary

Ms C complained about the care and treatment she received when she attended St John's Hospital in 2000. In particular, Ms C maintained that she should not have been discharged following her consultation with a consultant cardiologist, due to a family history of sudden death from hypertrophic cardiomyopathy (HCM - a disease where the heart muscle thickens abnormally).

During our investigation, we took independent advice from a consultant cardiologist. We found that while it was not clear in 2000 whether or not Ms C had HCM, the results of tests carried out at that time were not quite normal. It was possible that the results could have been due to the early signs of HCM. The advice we received and accepted was that while no further investigation or treatment was appropriate at that time, Ms C should have been offered a two-year review. We found that Ms C should possibly have been given more information about her condition at that time. If Ms C had been followed up, it was possible that a definitive diagnosis of HCM might have been made sooner.

However, the advice we also received was that the lack of follow-up made no difference to Ms C's treatment. Ms C had an implantable cardioverter defibrillator (ICD - a device implanted in the body that can reestablish a normal heart rhythm) fitted in 2014. However, the advice we received was Ms C did not fulfil criteria for primary prevention ICD implantation either in 2000 or in 2014. The adviser noted that the decision to implant an ICD is always difficult and may be based on additional factors such as anxiety. However, we were concerned about the lack of communication between the clinical genetics team and cardiologists about whether an ICD had been recommended in 2014.

### Recommendations

We recommended that the board:

- apologise that follow-up investigation was not arranged in 2000;
- make relevant staff aware of the adviser's comments about the need for follow-up investigation in cases such as this, and provide details of the action taken as a result;
- make relevant staff aware of the adviser's comments about the adequacy of information given to a patient about their condition, and determine if there are any lessons to be learned from this case; and
- review the standard of communication between the clinical genetics team and cardiologists, and provide details of the action taken.