Summary of Decide-TAD results

We are carrying out research to help people with Thoracic Aortic Disease (TAD) and their families. TAD is a silent disease until it results in a tear in the wall of the aorta that can cause death. Stopping this tear is a research priority for NHS England. Thoracic Aortic Disease is commonly caused by genetic mutations which can mean families of those who have this disease might be at risk of the disease as well. Screening of the family members using scans and genetic tests may lead to early detection and treatment and therefore save lives. We are looking at whether providing Thoracic Aortic Disease patients and their relatives with a decision support tool (a type of information booklet in electronic or paper form) can help people decide about having scans and genetic testing.

What did we do?
In the first part of the research, the study team worked with people with the disease, and their relatives and support groups, to produce a first version of the decision support tool to help people understand the condition and consider their options. We also produced training materials for clinical staff to help them support patients making decisions about screening. We recruited patients with Thoracic Aortic Disease and their relatives in two hospitals in England. We also recruited relatives who had lost a family member to the disease. People were given the decision support tool to read through and discuss with family members. Then they took part in an interview to talk about the decision support tool and provide feedback and suggest changes and improvements. We also interviewed clinical staff who looked at the decision tool and training materials to help clinical staff use the decisions support tool with patients. We asked them to tell us how they would use the training materials in their discussions with patients and asked them to make suggestions for improvements.

What did we find out?
Patients and their relatives gave us feedback about the layout and contents of the decision support tool. This led to changes in page layouts and print colours. Diagrams were improved to make them clearer and more detailed. Some sections were re-drafted following feedback. People were very positive about the decision support tool and said they valued the quality and depth of information provided. Many described internet searches to try and find out information about the condition. This search was often not helpful. They described how the decision support tool meant that this internet searching was no longer needed. Clinical staff who reviewed both the decision support tool and staff training materials felt they would be very useful in supporting conversations around decisions about scans and genetic testing.

How are we using the results?
Following feedback from patients, relatives and clinical staff, the decision support tool and staff training materials were improved and further versions produced. These will be used for the next stage of the study where we test if patients and clinicians can use the decision support tool in their care. were also improved and suggestions incorporated into a further version.

Where can you learn more about this study?
You can learn more about this study on the following website page: https://le.ac.uk/lctu/trials