

## **Multidisciplinary care at Radboudumc, an evaluation of the overall health status in Marfan patients**

Radboudumc is an expert centre for Marfan and aortic related diseases. There are approximately 400 Marfan patients at Radboudumc for which care is organized based on the specific needs of every patient. Intake of new patients and monitoring of existing patients takes place for adults as well as children and is organized in multidisciplinary meetings.

A tool is used (NCSI) to find out what the specific needs of each patient is and how this changes over time. The tool aims to help the patient determine his or her own integral health status which contains more than just the status of physiological disorder.

The NCSI consists of 3 different applications and depicts in trafficlights the status of 4 main health domains and addresses 16 subdomains. The patient determines the the scores and recognition of the outcomes is therefore high. Furthermore, personally relevant treatment goals can be determined based on the specific outcomes.

It is noted that Marfan patients show higher experienced issues in health status when compared to the population of congenital heart diseases which are monitored in the same outpatient clinic. There is limited deviations in scores between Marfan men and women. The differences in outcomes compared to the population with congenital heart disease are largest in the young age-groups (<25 and 26-40). Further research into this should provide further clarification on this.

An NCSI format specifically for Marfan patients is developed and now used. A widespread use of NCSI (or NCSI-like methods) to monitor the overall health status of patients would surely enhance health management of Marfan patients.