



Annual Report 2015

Care for Heart Children
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Abbreviations

AI = aortic valve leakage
ALCAPA = anomalous left coronary artery from the pulmonary artery
AS = aortic valve stenosis
ASD = atrial septal defect
AVSD = atrioventricular septal defect
BDG = bidirectional Glenn procedure
BT shunt = Blalock-Taussig shunt
CoA = Coarctation of the Aorta
DORV = double outlet right ventricle
ECMO = extra corporeal membrane oxygenator
HLHS = hypoplastic left heart syndrome
MS = mitral stenosis
PAPVD = partial anomalous pulmonary venous drainage
PDA = patent ductus arteriosus
RVOTO = right ventricular outflow tract obstruction
RV-PA conduit = right ventricle-to-pulmonary artery conduit
SAS = subvalvular aortic stenosis
SVAS = supra-ventricular aortic stenosis
TA = tricuspid atresia
TAPVD = total anomalous pulmonary venous drainage
TCPC = total cavopulmonary connection
TGA = transposition of the great arteries
TOF = Tetralogy of Fallot
UVH = univentricular heart
VSD = ventricular septal defect

Presentation of units

For pediatric cardiological patients, the most usual diseases are congenital structural heart defects, arrhythmia and myocardium-related diseases such as myocarditis and cardiomyopathies. Heart surgery, catheterizations and heart transplantations for children and youth are centralized nationally to the Children's Hospital (Helsinki).

Ward K4 is a pediatric cardiac ward with 14 beds, six of which are intended for intensive monitoring. Patients are admitted to the ward for cardiac catheterizations and heart surgeries. Additionally, patients are admitted to the ward for medical examinations and establishment of medication. One to two pediatric cardiologists work on the ward as well as a pediatric resident, 30 nurses and one ward secretary. Heart surgeons act as consultants on the ward.

At the operating unit one operating room is allocated for open heart surgery and equipped with mobile angiography device for hybrid procedures (surgery requiring perioperative angiography). The pediatric cardiac surgical team consists of four cardiac surgeons, ten cardiac anesthesiologists, four perfusion nurses, and several nurses trained for pediatric cardiac surgical care. This team (with pediatric surgeons) also performs all pediatric organ transplantations in Finland.

The Intensive Care Unit K9 is a heavy mixed pediatric intensive care unit with 12 beds. The majority of patients have undergone cardiac surgeries or require intensive care for congenital cardiac disease. Cardiac patients account for two thirds of the unit's Therapeutic Intervention Score (TISS).

In the catheterization laboratory, diagnostic hemodynamic and angiographic examinations are performed as well as interventional catheterizations, electrophysiological examinations, arrhythmia ablation treatments and endocardial pacemaker installations. Transesophageal echocardiographic and electrophysiologic examinations are also performed under anesthesia. In the catheterization laboratory at a time there are always two pediatric cardiologists as well as two catheterization registered nurses, an anesthesiologist and anesthetic nurse.

Pediatric cardiac outpatient care is carried out in the Cardiac Outpatient Unit (three receptions, five days a week), in Children's Hospital Pediatric Outpatient Clinic (one reception, three days a week) and in Jorvi Hospital Pediatric Outpatient Clinic (one reception, three days a week). A fetal cardiac outpatient clinic is at the Cardiac Outpatient Unit twice a week. Cardiology consultations for the wards and other subspecialty outpatient clinics are conducted daily, and a cardiology consultant also works in the heart operating room as well as in K9 and in neonatal intensive care unit K7. Six pediatric cardiologists work at the outpatient clinics and perform the consultations and eight registered nurses work at the Cardiac Outpatient Unit.

Training to nursing and medical students is provided to a considerable extent in the unit, and active scientific research is also performed.

Ward K4

K4	2011	2012	2013	2014	2015
In-patient periods (n)	1143	1028	1025	1046	1062
In-patient days (n)	4927	4616	5040	4688	4786
Average hospital stay (days)	4,27	4,46	4,9	4,44	4,46
Average net occupancy rate (%)	68	66	72	64	69

Table 1. Total number of Cardiac ward K4's treatment periods, treatment days, hospital stay and net occupancy rate during 2011 - 2015.

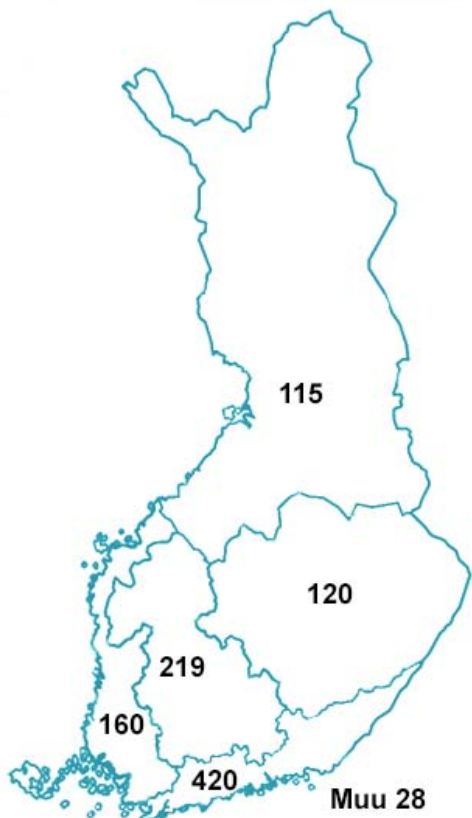


Figure 1. Distribution of patients treated on Cardiac ward K4 by university hospital districts in 2015

Heart surgery

Pediatric cardiac and transplantation surgery in Finland is centralized at the Children's Hospital in Helsinki. In addition, approximately 5 to 10 heart operations are performed on Estonian patients at the Children's Hospital annually. The annual level of approximately 300 operations became established already 25 years ago. In the following 10 years, the current wide spectrum of procedures and good results were achieved through general and local development. The percentage of newborn patients (approx. 25%) and repeat surgeries (approx. 30%) have also remained constant. The proportion of closed heart surgeries has decreased during the time period from approx. 35% to nearly 20% corresponding the general development within the specialty. The operative mortality rate (< 30 days after surgery) was 0.3% last year, and the hospital mortality rate (after surgery, during the same treatment period) was 1.3%.

Our aim is to correct any heart defects as early as possible and as completely as possible to achieve the usual age-appropriate heart status while also taking the child's health status into consideration. Currently, the average age of operated patients is 2.4 years. The proportion of children under the age of one year is approximately 55%. The proportion of repeat surgeries is expected to stay constant because some defects need to be repaired in several stages either due to the child's growth or the nature of the defect. The long-term prognosis of pediatric patients undergoing heart surgery in Finland is good (Figure 6).

The following figures depict the key numbers of our operations from the beginning of pediatric cardiac surgery in 1953 all the way to the end of 2015.

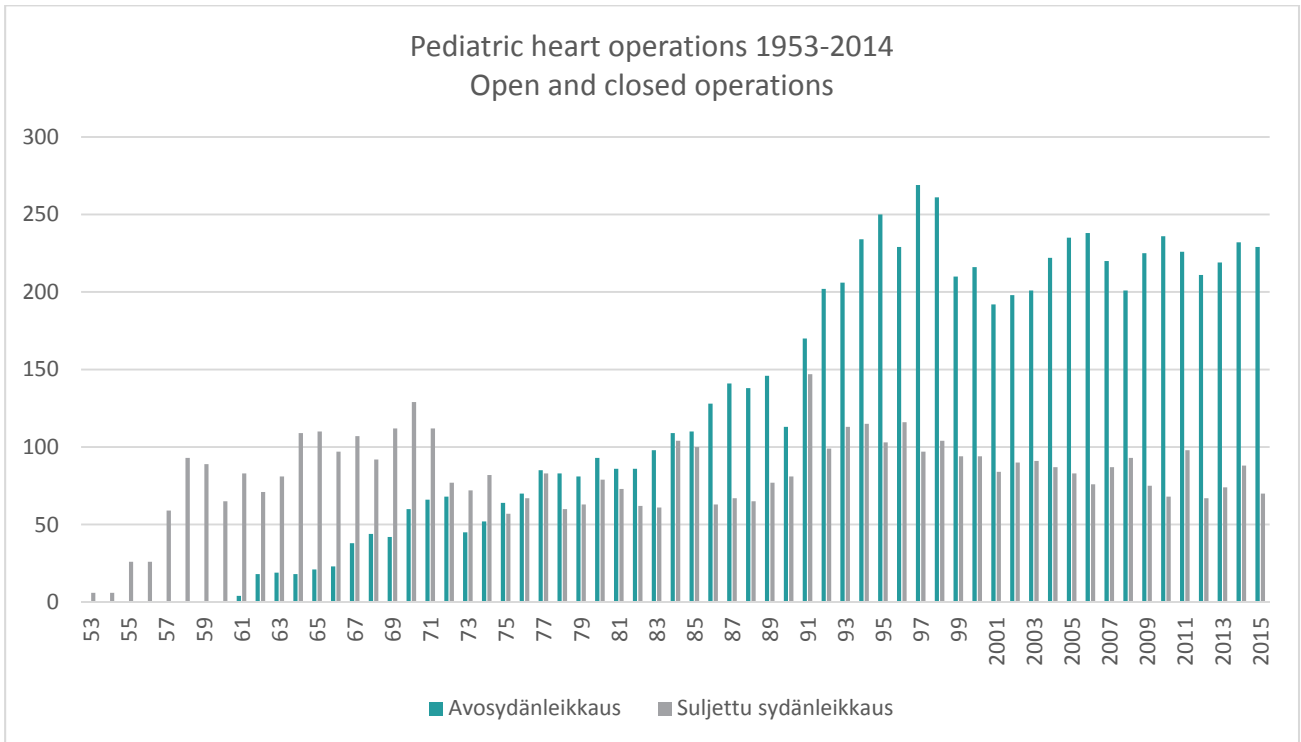


Figure 2. Open (green) and closed (grey) heart surgeries at the Children’s Hospital annually during 1953–2015.

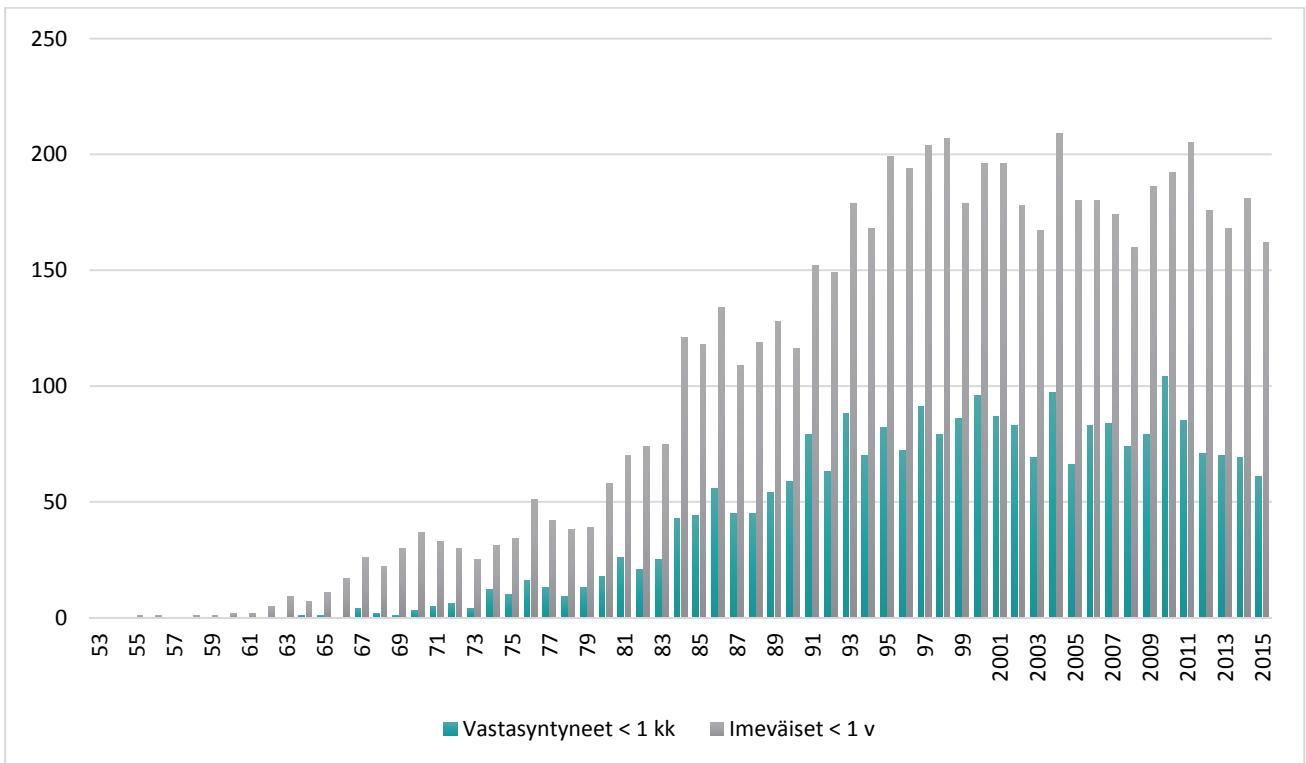


Figure 3. Annual numbers of neonates (< 1 month, green) and infants (< 1 year, grey) undergoing heart surgery.

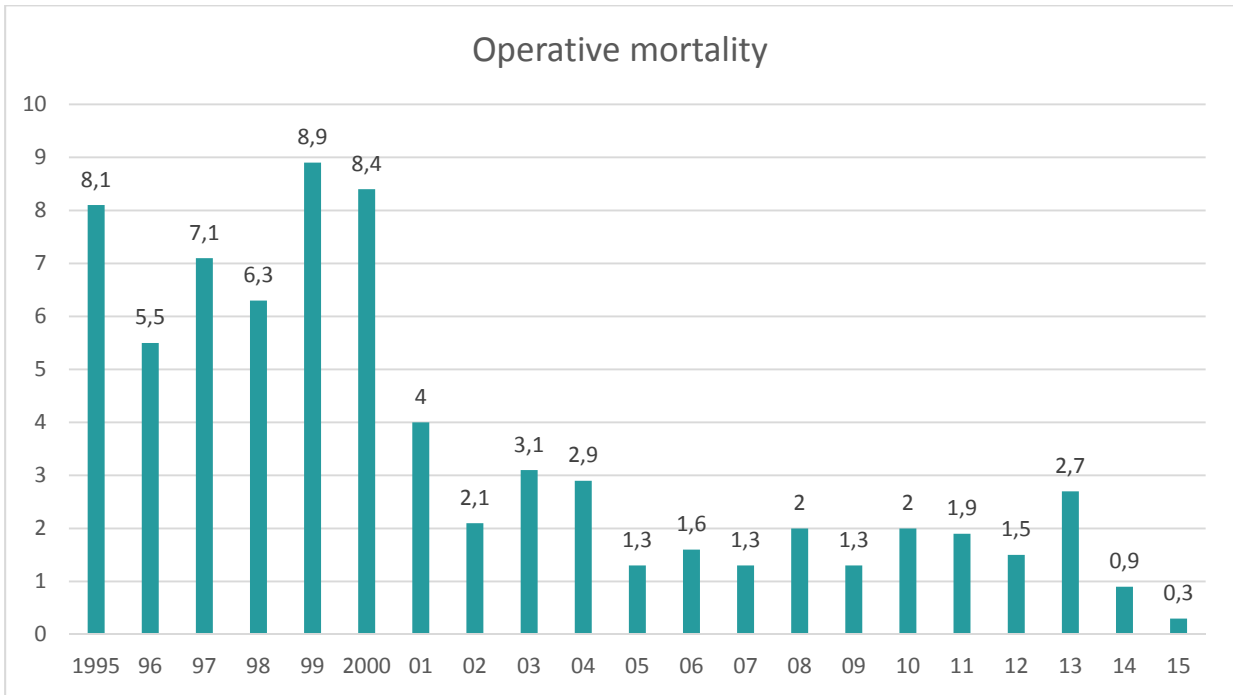


Figure 4. Operative mortality (%) during 1995–2015, all patients.

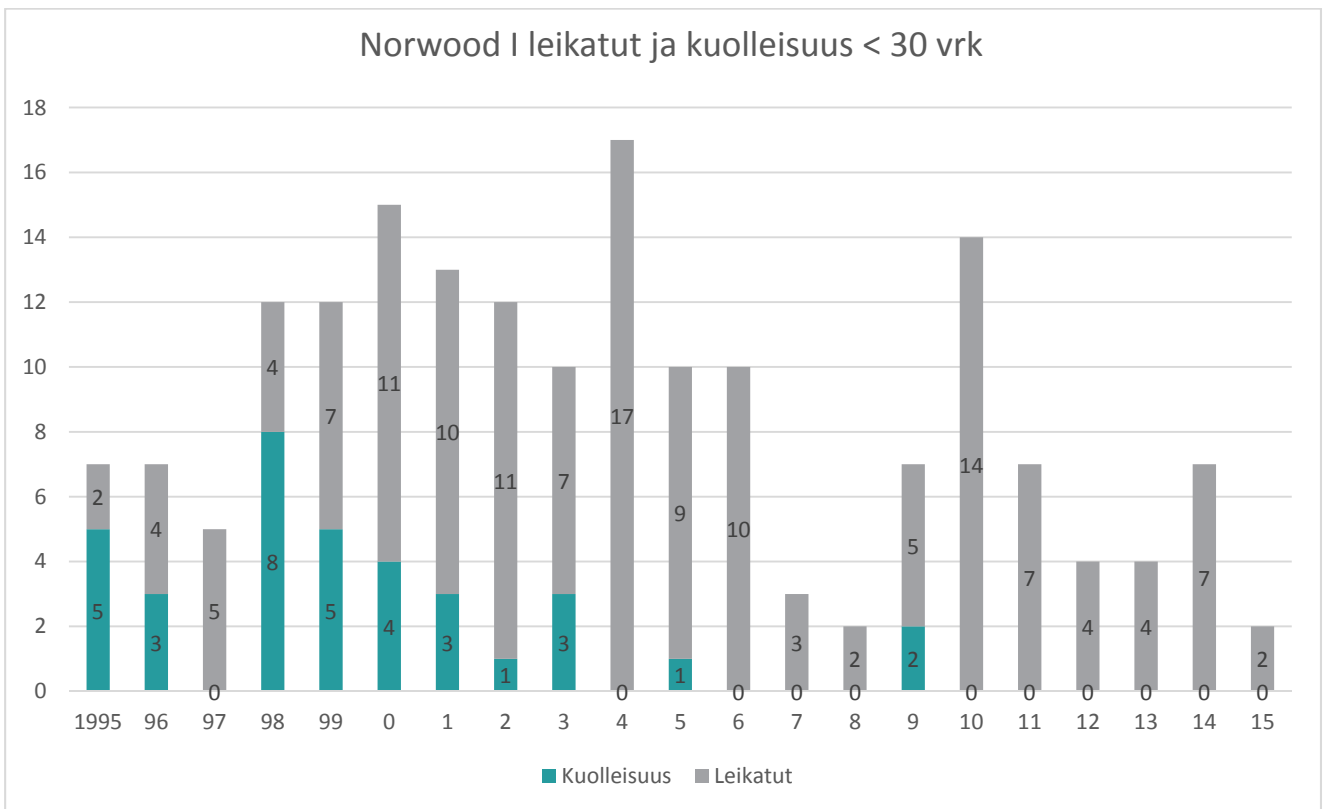


Figure 5. The number of Norwood operations for HLHS during 1995-2015 (grey) and associated operative mortality rate (< 30 days after surgery) (green).

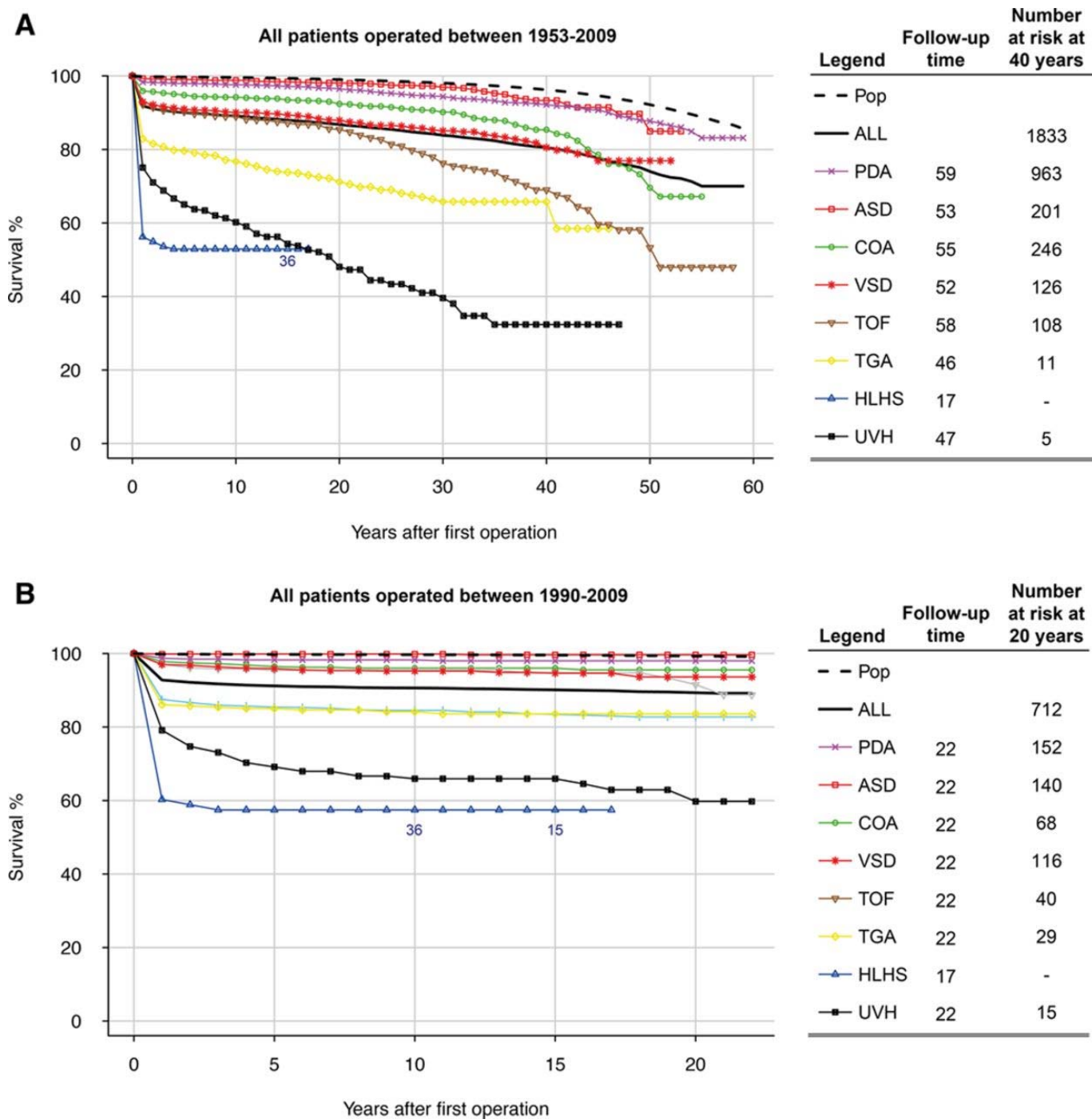


Figure 6. Late follow-up results of all children operated in Finland 1953–2009 of childhood age (< 15 years), 13 876 operations on 10 964 children. Follow-up comprehensiveness 98 %. (Raissadati A, Nieminen H, Jokinen E, Sairanen H. Progress in Late Results Among Pediatric Cardiac Surgery Patients: A Population-Based Six-Decade Study with 98 % Follow-Up. *Circulation* 131(4): 347-53, 2015).

Intensive Care Unit K9

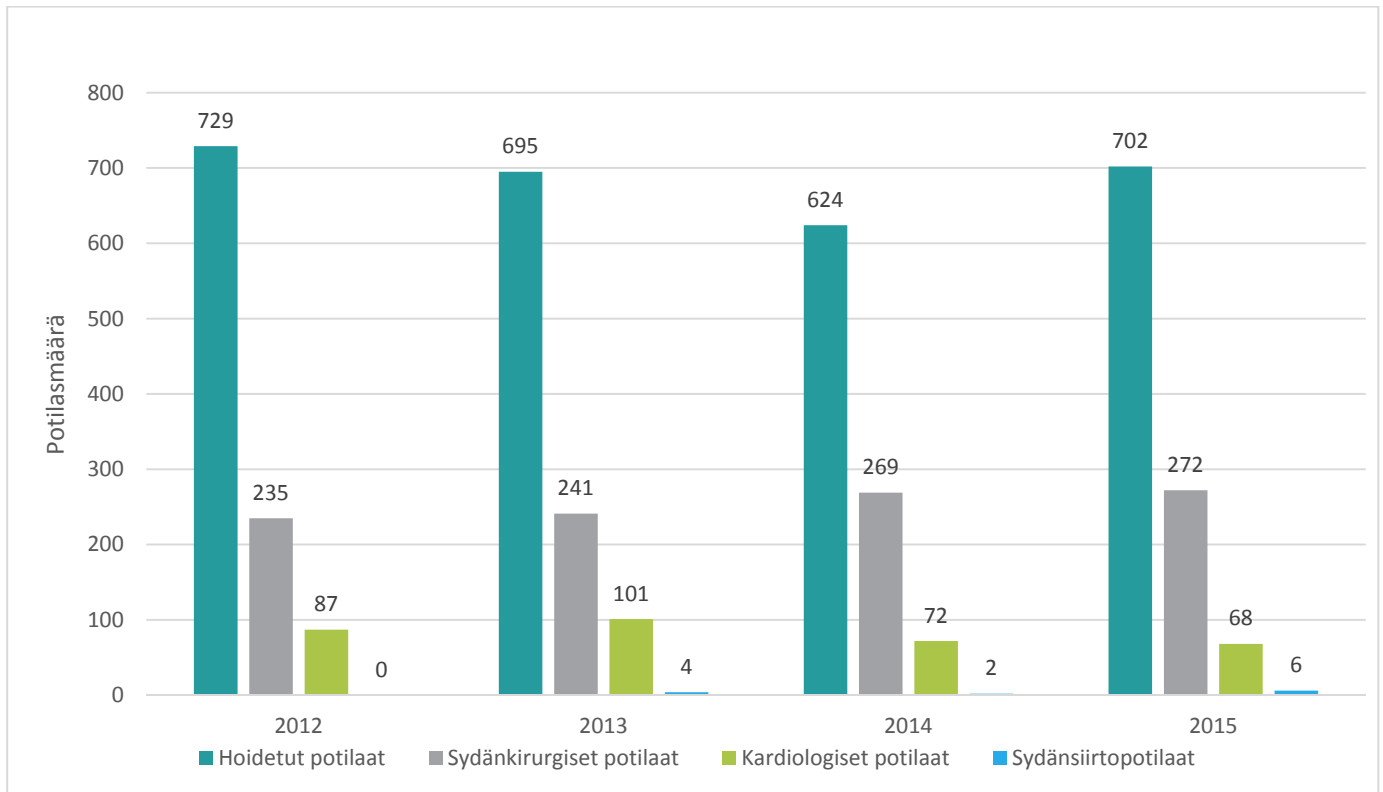


Figure 7. Total number of patients treated in the Intensive Care Unit K9 and the numbers of heart surgery patients, cardiological patients and cardiac transplantation patients from 2012 to 2015.

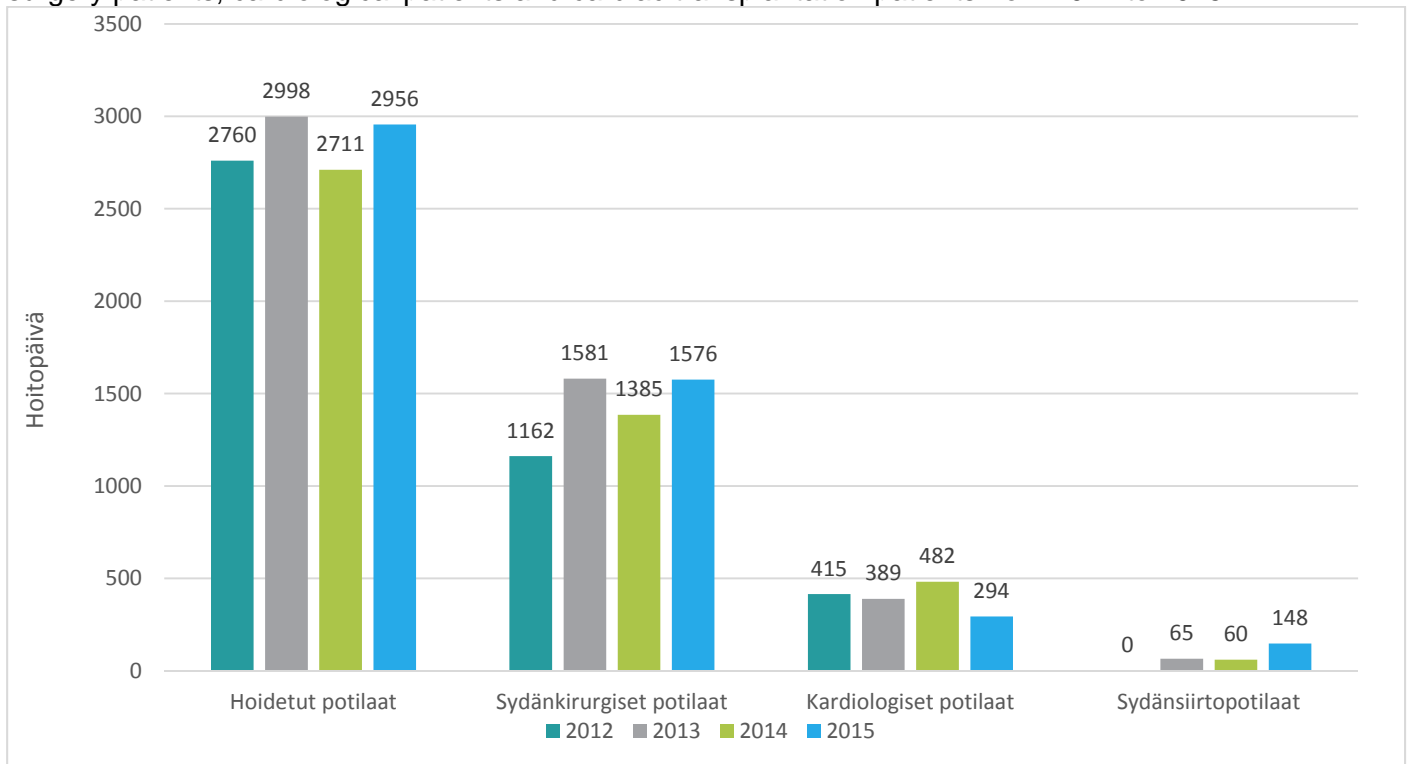


Figure 8. Length of stay in the Intensive Care Unit K9: total number of patients (Hoidetut potilaat) and the numbers of cardiac surgical patients (Sydänkirurgiset potilaat), cardiological patients (Kardiologiset potilaat) and cardiac transplantation patients (Sydänsiirtopotilaat) during 2012–2015.

Patients	2012	2013	2014	2015
Heart surgery patients	49	56	55	57
Cardiological patients	15	14	17	9
Heart transplantation patients	0	3	3	8
Others	36	27	25	26

Table 2. Distribution of Therapeutic Intervention Scores (TISS) at the Intensive Care Unit K9 during 2012–2015.

Catheterization laboratory

All invasive pediatric cardiology in Finland – i.e. heart catheterizations – is centralized to the Children’s Hospital, Helsinki University Hospital. These procedures comprise diagnostic hemodynamic and angiographic examinations, interventional catheterizations, electrophysiological examinations and arrhythmia ablation treatments as well as endocardial pacemaker installations. Additionally, pre- and post-operative cardiac catheterizations are performed on Estonian patients annually (about 5–10). In the figure and table below, the key figures describing procedures from the years 2010–2015 are presented.

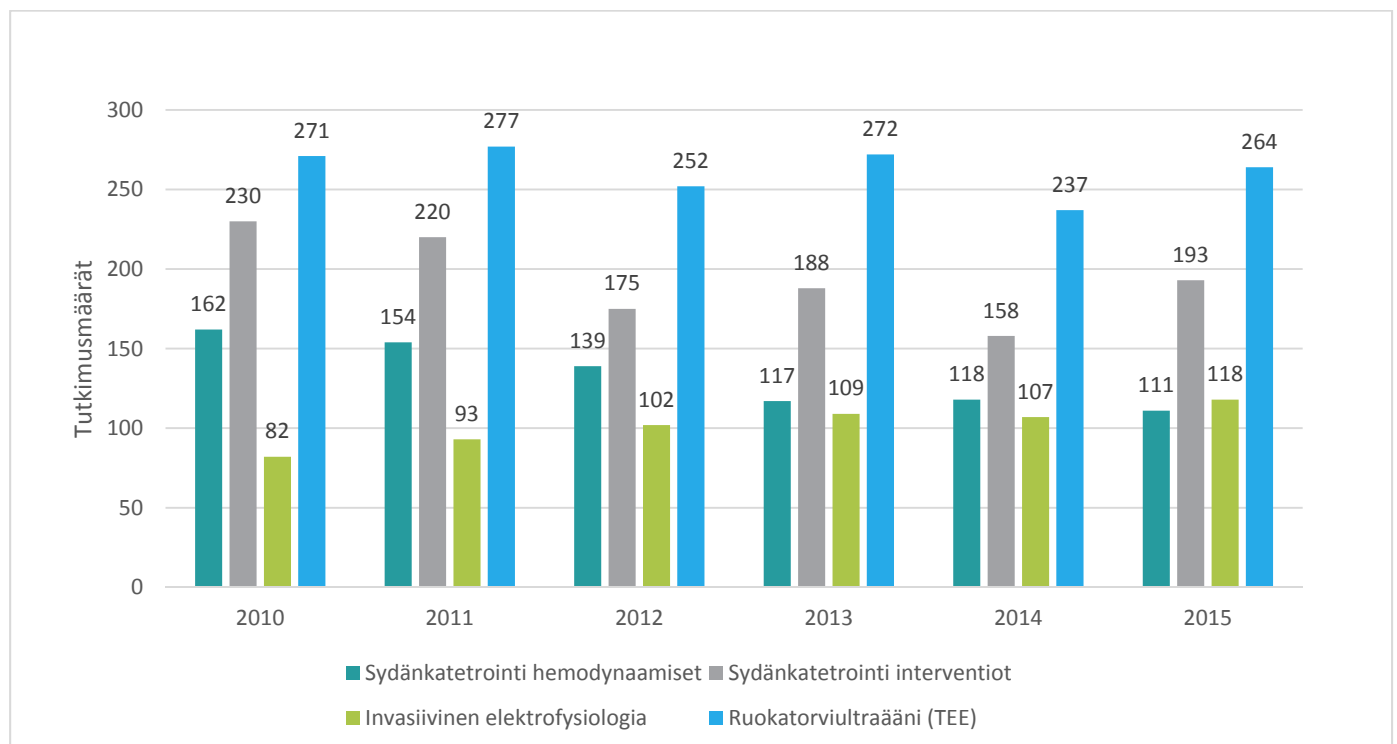


Figure 9. Total numbers of hemodynamic catheterizations (green), interventional catheterizations (grey), invasive electrophysiological examinations (light green) and transesophageal echocardiographic examinations (blue) performed in the cardiac catheterization laboratory during 2010–2015.

Cardiac outpatient care

Pediatric cardiology outpatient visits take place in three locations: Cardiac Outpatient Clinic at the Children's Hospital (Helsinki), Pediatric Outpatient Clinic at the Children's Hospital (Helsinki), and Jorvi Hospital Pediatric Outpatient Clinic. The fetal cardiac outpatient clinic takes place at the Cardiac Outpatient Clinic two days a week. Cardiologist consultation services are provided for all outpatient clinics, hospital wards, intensive care units K7 and K9, and for the OR.

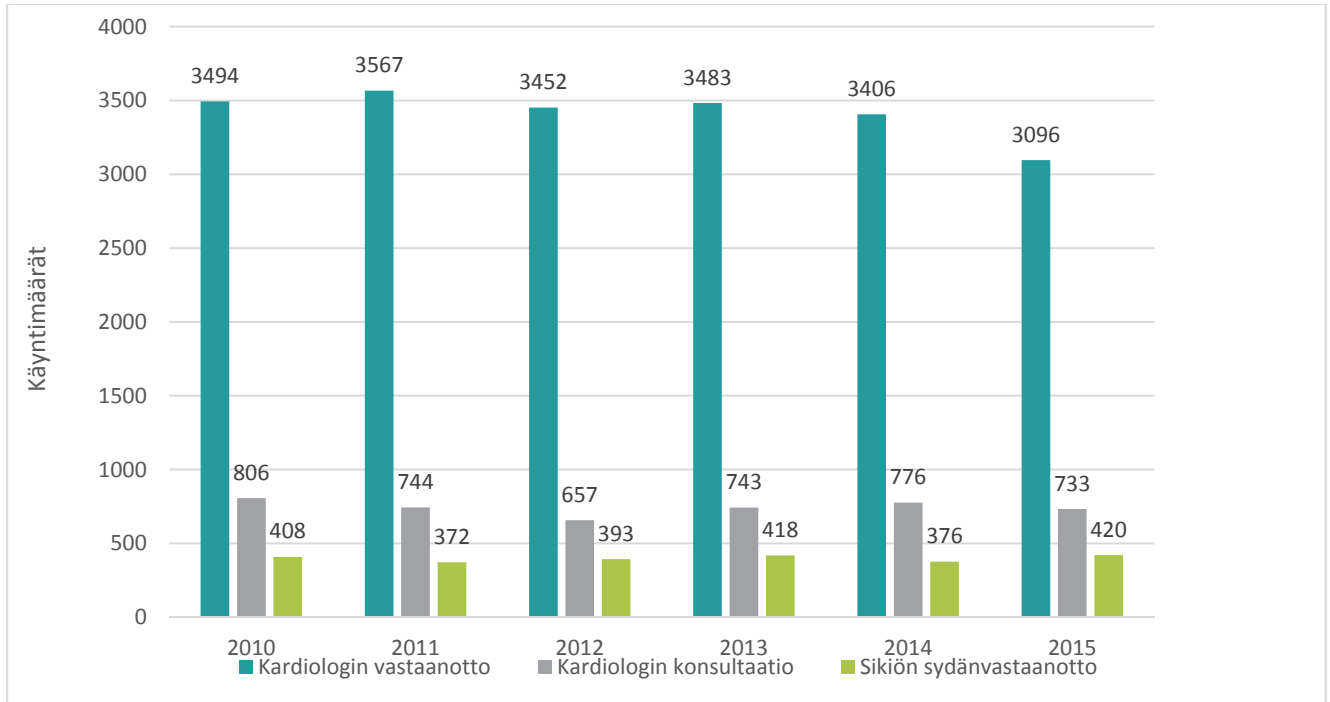


Figure 10. Total numbers of patients: pediatric cardiology outpatient visits (green), cardiology consultations (grey) and fetal cardiac visits (light green) during 2010–2015.

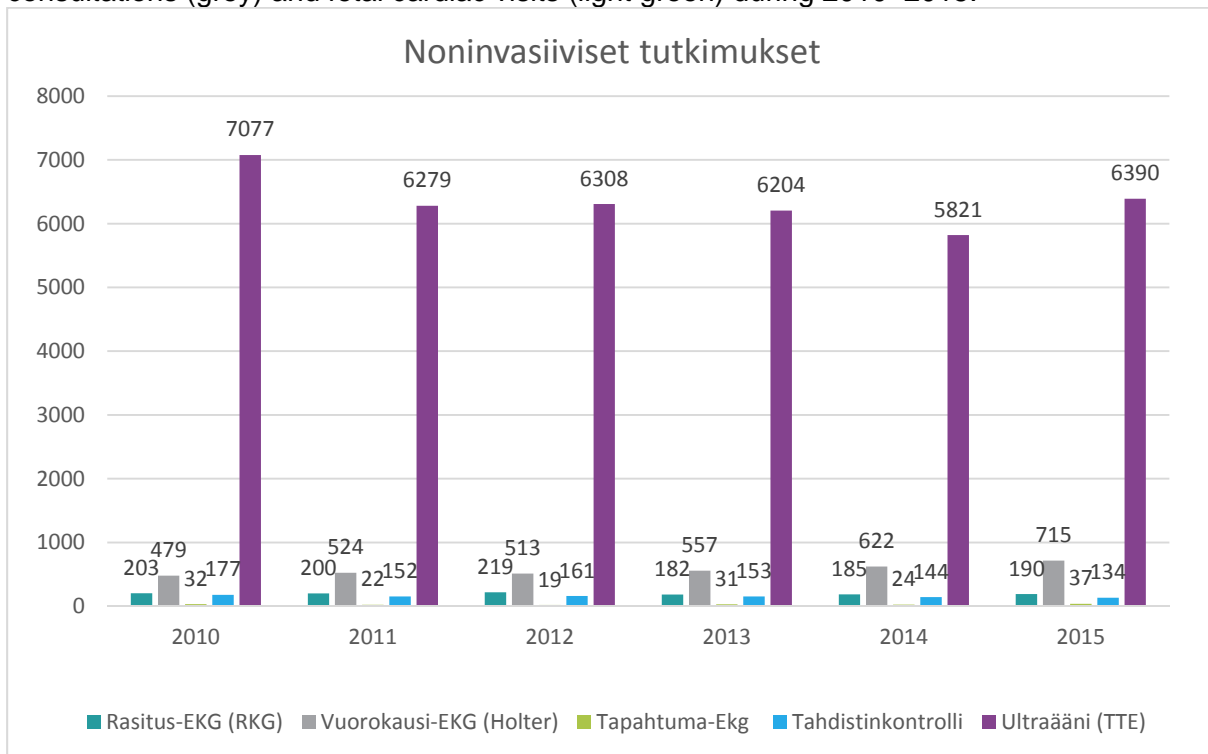


Figure 11. Total number of non-invasive examinations performed by pediatric cardiologists during 2010–2015: exercise tests (green), 24-hour ECG-recording (grey), event monitor (light green), pacemaker control (blue), transthoracic echocardiography (violet)

New in 2015

In September 2015, nurses from wards K9 and K4 began practicing job rotation. Job rotation is planned from the perspective of the Heart Child Process and our functional know-how. The most essential goals of job rotation are widening the range of professional skills, obtaining new information and skills, and strengthening co-operation. Job rotation between the two units will continue systematically in the future.

The Fetomaternal Medical Center launched fortnightly patient case conferences in 2015. These conferences cover patients with structural defects discovered through fetal diagnostics that require multi-professional expertise. The conferences are partaken by specialists in perinatology, neonatology, pediatric surgery, pediatric neurology and pediatric cardiology.

The Rare Diseases Center (HAKE) was founded within HUS in 2015. Rare cardiac diseases are a part of the Rare Diseases (HAKE) program at the Children's Hospital. The program is aimed at strengthening the networks of professionals who have experience in rare diseases and bringing patients' experiences into the development process for better care. In 2015, the Heart Child Process began preparing for a proposal to enter the Rare Diseases program. The team has produced material for a net portal regarding rare heart diseases and participated in the planning and development of the HAKE program. On 18 January, 2016, HUS Joint Authority Chief Medical Officer Markku Mäkijärvi confirmed the proposed HUH HAKE Rare Heart Diseases program. Head of Pediatric Cardiology Department Jaana Pihkala was appointed as program director. At first, the program will only cover congenital heart defects, but it is intended to expand to cover all rare heart diseases that manifest in childhood or in adulthood.

Research work

The Heart Child Process. Physicians' publications in 2015

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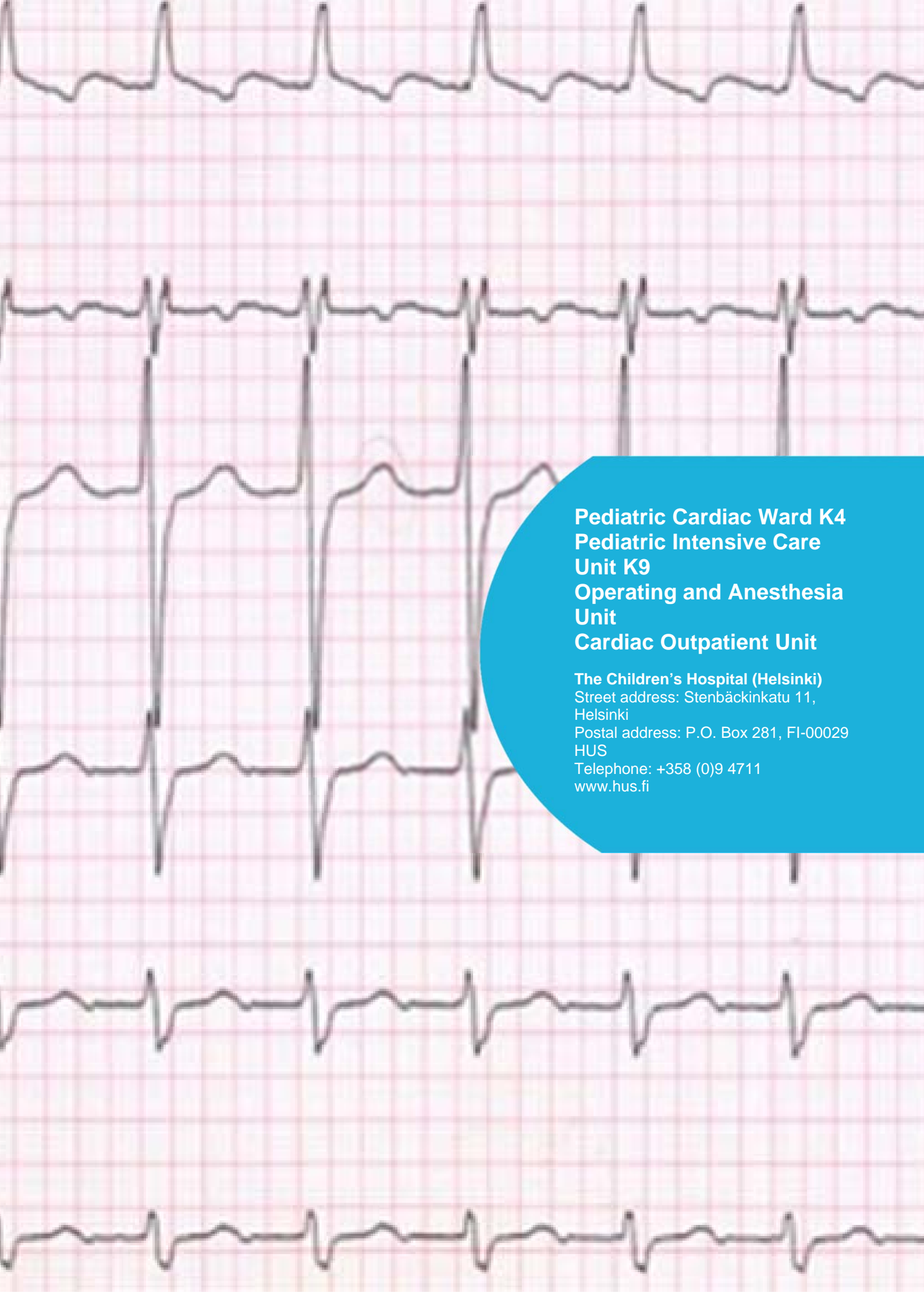
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Summary

Pediatric cardiac surgery was initiated in Finland in 1953. In 2015, 229 open heart surgeries and 70 closed heart surgeries were performed at the Children's Hospital. 61 (20.4%) of the operations were performed on children under the age of one month, and 162 (54.2%) on children under the age of 12 months. Six heart transplants were performed in 2015. The large share of infants and demanding cardiac surgery place special challenges on surgical care as well as on intensive care and ward care. This is also illustrated by the fact that the share of heart patients in intensive care unit according to Therapeutic Intervention Scoring System (TISS) points has in recent years been in the approximate range of 75 %. The total number of reoperations is significant: more than 30 % of all operations. This frequently derives from the fact that the patient's heart defect is initially planned for correction in several stages: e.g. as a series of three-stage palliative operations for a univentricular heart defect. Occasionally residual defects require a reoperation. Surgical mortality in Finland in recent years has been below the average European level – last year in the range of one per cent, regardless of the fact that even the most complicated defects have come within the sphere of surgical treatment. The late prognosis of heart children who have been operated on is monitored with comprehensive follow-up research study. The long-term follow-up results of patients who have been treated surgically during the years 1953–2009 published recently (Raissadati et. al *Circulation* 2015) reflect procedures performed with early perfusion and surgical techniques. It does appear that with the modern techniques, the long-term results from operations performed between 1990 and 2010 have improved.

Catheter procedures in the treatment of congenital heart defects were initiated during the 1960s. The quality and total number of procedures and instruments have developed rapidly, and these days within the sphere of catheter techniques-based treatment are even preterm infants. Currently in a large part of all the pediatric cardiologic units, interventional catheterizations form the biggest group of catheterization procedures. At the Children's Hospital (Helsinki), these totaled 158 last year. Some diagnostic catheterizations are also conducted in interventional readiness. The indications for catheter procedures are the same as for the surgical treatment of similar defects. The benefits of catheterization procedures compared to surgery are rapid recovery and smaller cosmetic detriment. Cost-wise as well, a catheter procedure is almost always more economical than the corresponding surgical operation. In addition, endocardial pacemaker installations are actively performed in the heart catheterization laboratory as well as arrhythmia catheter ablation treatments, whose quantity has increased in recent years.

The net loading of the pediatric cardiologic ward K4 is continuously in the range of 70 %. Most of the patients come from outside the HUS catchment area for highly specialized medical care, which sets exceptional requirements on the arrangements. Approximately 4500 patients visit the pediatric cardiologist's reception per year, and echocardiographic examinations are performed to the total of almost 6000 annually. Some of the patients are anesthetized for the examinations. A fetal heart clinic operates at the Cardiac outpatient unit in Children's hospital two days a week. It employs three pediatric cardiologists who are specialised in fetal cardiology. The fetal cardiac clinic works closely together with the Fetomaternal Medical Center in Women's Hospital. The total number of special examinations, such as exercise tests, pacemaker testing and Holter recordings, is high, which also imposes requirements on the special expertise of the care staff. The total number of visits to outpatient clinics has remained almost the same in recent years, and no significant changes are being planned with regard to the next few years.

The background of the entire page is a light pink grid with a black ECG (heart rate) line. The line shows a regular rhythm with distinct P waves, QRS complexes, and T waves. A large, semi-circular teal shape is positioned on the right side of the page, containing white text.

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Pediatric Intensive Care
Unit K9
Operating and Anesthesia
Unit
Cardiac Outpatient Unit**

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