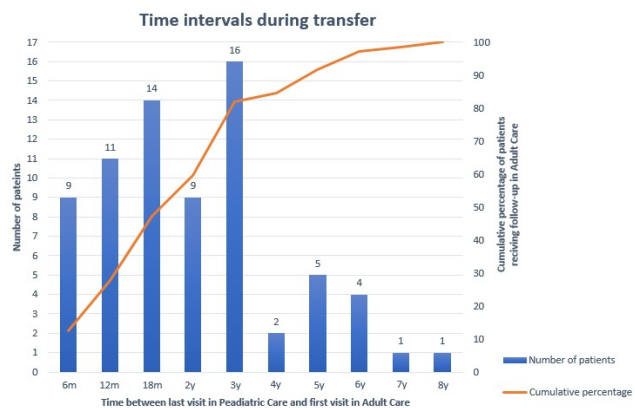


## Successful transfer to adult care: A nationwide study in patients with complex congenital heart lesions in Sweden

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### Introduction

Patients with complex congenital heart lesions are in need of life-long medical follow-up. International guidelines advice that patients with complex lesions should be transferred to specialist ACHD care within 12 months after leaving pediatric cardiology. The combination of appropriate care level and appropriate time intervals during transfer to adult care can be considered as successful transfer. Unsuccessful transfer of care in patients with CHD might increase the risk for urgent interventions and long-term complications. The aim of the present study was to determine proportions of successful transfer in patients with complex congenital heart lesions in Sweden.

### Methods

Seventy-two patients, born in 1991, 1992, or 1993 and diagnosed with complex congenital heart disease from six university hospitals in Sweden have been enrolled. Predominant diagnosis among the included patients were TGA 42%, DORV 18%, Truncus arteriosus 9.7%, and 12.5% Univentricular heart defects. Data were collected from hospital administrative databases, medical files and registries. The time interval between last visit at paediatric cardiology and first visit at ACHD care was calculated. Transfer destinations were categorized as either appropriate (i.e., at ACHD level) or not appropriate (i.e., at non-specialized adult level). Successful transfer was defined as a transfer of care towards the appropriate level and within the recommended time interval.

### Results

In total, 68 patients (94%) were transferred to the appropriate level of care (i.e., ACHD care). Twenty patients (28%) had their first visit in adult care within 12 months, and 34 patients (47%) within 18 months (Figure 1). Successful transfer, being transferred to the appropriate care level and within the recommended 12 months, was observed in only 19 patients (26%). If a more liberal time interval of 18 months would be used, 33 patients (45%) were considered to be successfully transferred.

### Conclusion

The vast majority of patients was transferred to ACHD care. Still, 6% were not followed up at the appropriate care level. Furthermore, the majority of the patients were not followed up at the recommended time interval, according to guidelines. Indeed, even with a more generous time interval of 18 months, less than half of the patients were successfully transferred.