

## **CLINICAL CARE CENTRES FOR SICKLE CELL DISEASE IN BELGIUM**

### **1. OBJECTIVE**

A map of centres where patients with sickle cell disease have their follow-up is not available.

The objective is to obtain information regarding the existence of clinical centres dedicated to patients with sickle cell disease and their available facilities.

### **2. STUDY PROTOCOL**

A survey was conducted in view to establish a map of the clinical centres where patients with sickle cell disease have their follow-up. Questions were also related to the services that are offered to the patients.

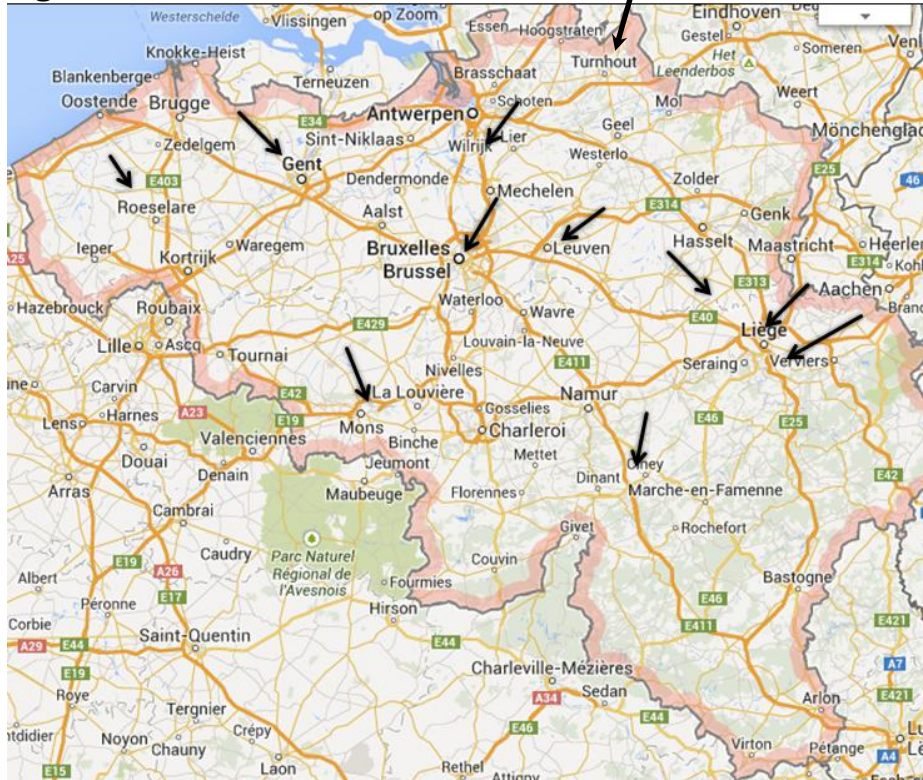
The questionnaire was sent to all members of the Belgian hematological society. The tool used was "QUALTRICS" (qualtrics.com)

It is certain that all centres have probably not been informed of this initiative.

### **3. RESULTS AND DISCUSSION**

Thirty-eight physicians responded. Among them, several responses were in doubles (same centre, same practice). The total number of responses included was 28 departments from 23 different hospitals. The distribution of those 23 hospitals in Belgium is presented below.

**Figure 1. Localisation of SCD centres**



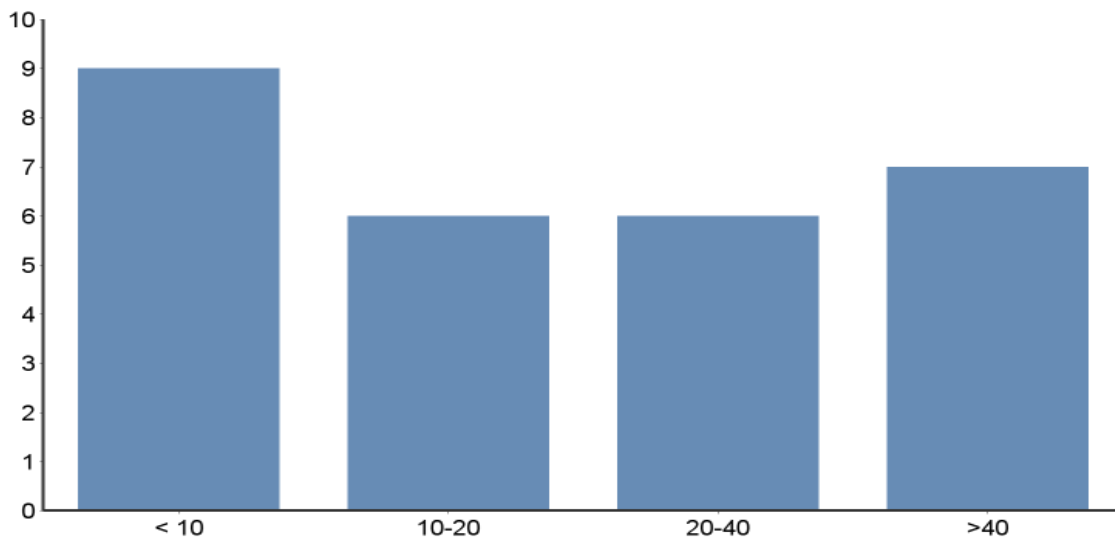
Eight, four and four centres are in Regions of Brussels, in Antwerpen and in Liège, respectively.

Among the responders, 10 are paediatricians (children to age 18) and 18 haematologists for adult patients. Two paediatricians follow both children and adults.

The number of patients followed regularly in each hospital is shown in Figure 2.

Nine of the 10 departments where less than 10 patients are monitored regularly, are clinical services for adult patients. In six of those nine departments, two to three physicians insure the clinical care for those patients.

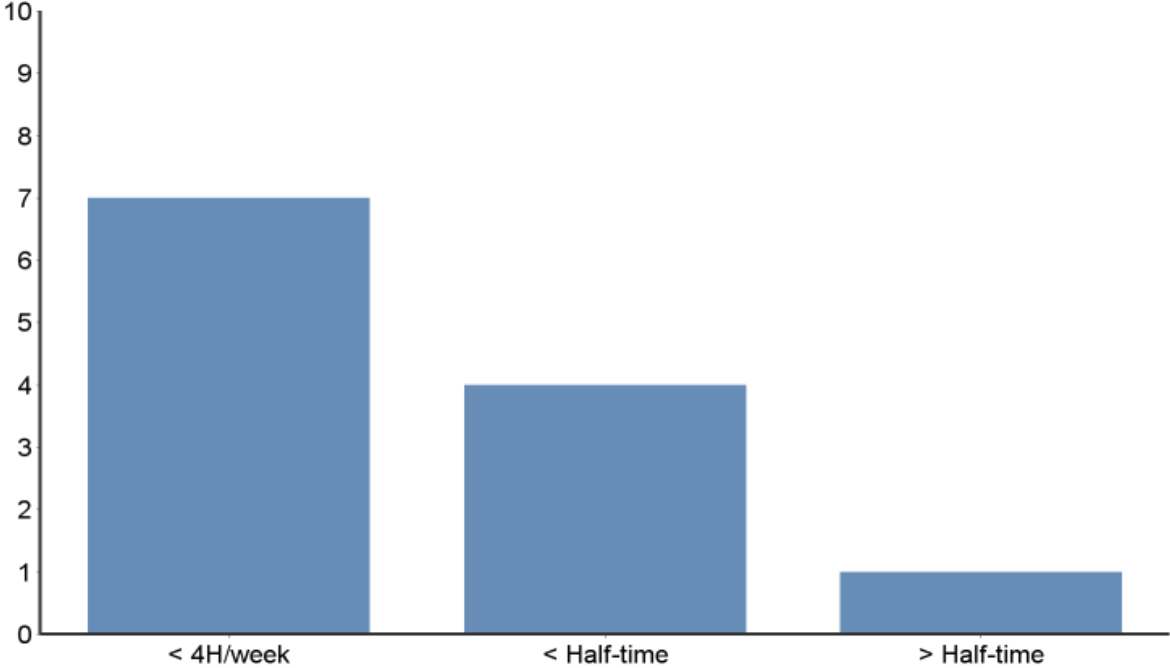
**Figure 2. Number of patients followed in each department.**



A dedicated day unit is available for patients with SCD (Specific procedures and dedicated staff) in 9/22 hospitals (41%); in 8/9 hospitals, it concerns a paediatric department.

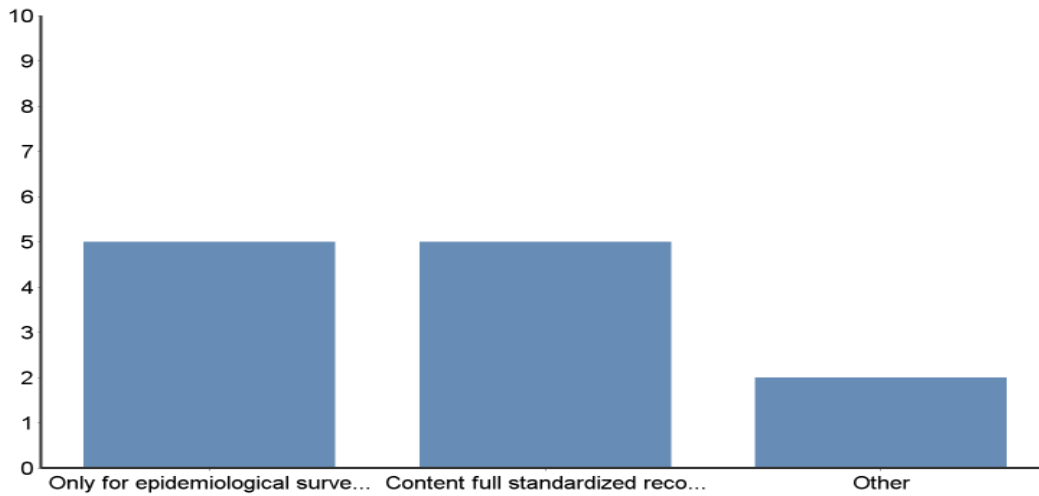
In 13/28 departments a nurse, for coordination of clinical care, is dedicated to patients with SCD. Five of them work in a paediatric department.

**Figure 3. Presence of a dedicated nurse for patients with SCD.**



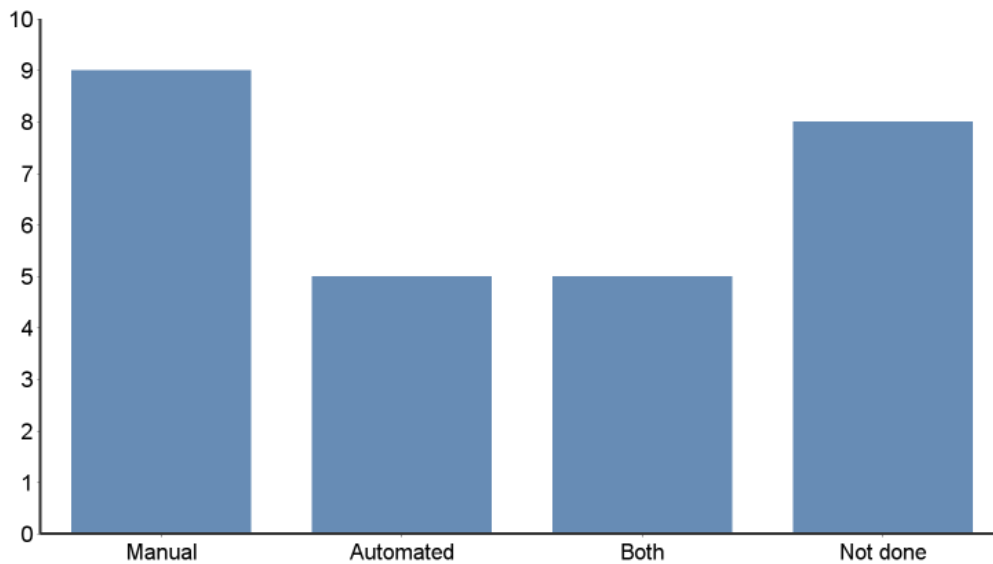
Fifteen departments know the existence of the national registry. A local patient registry exists also in 12 hospitals.

**Figure 4. Existence of a local patient registry.**



Red blood cell transfusion is one of the main treatments for patients with SCD. That procedure is performed in 20 departments; the procedure is performed using a sophisticated instrument (automated) in 5 departments.

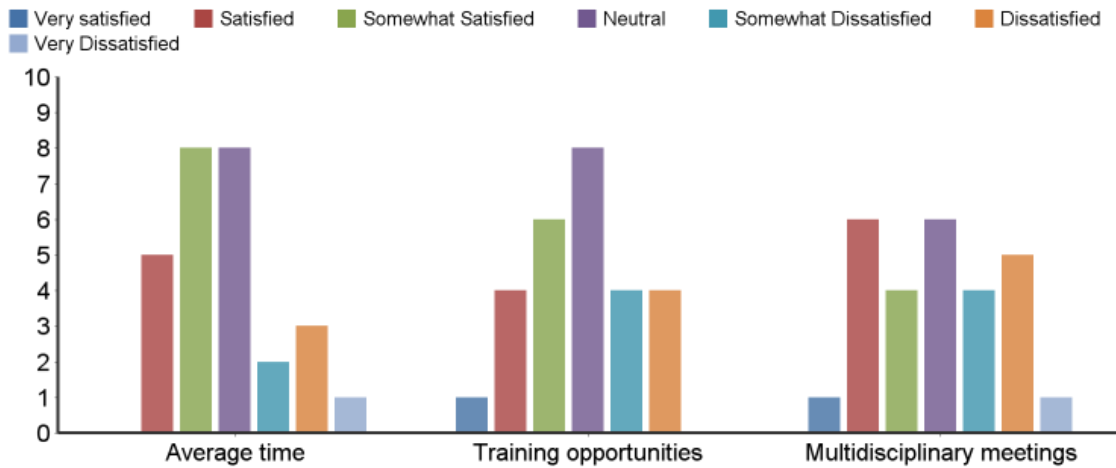
**Figure 5. Procedure used for red blood cell transfusion.**



Transcranial doppler ultrasonography is a non-invasive effective method for screening children with sickle cell disease at risk for first stroke. In all paediatric departments this procedure is available except two that sent children to centres where this method is available.

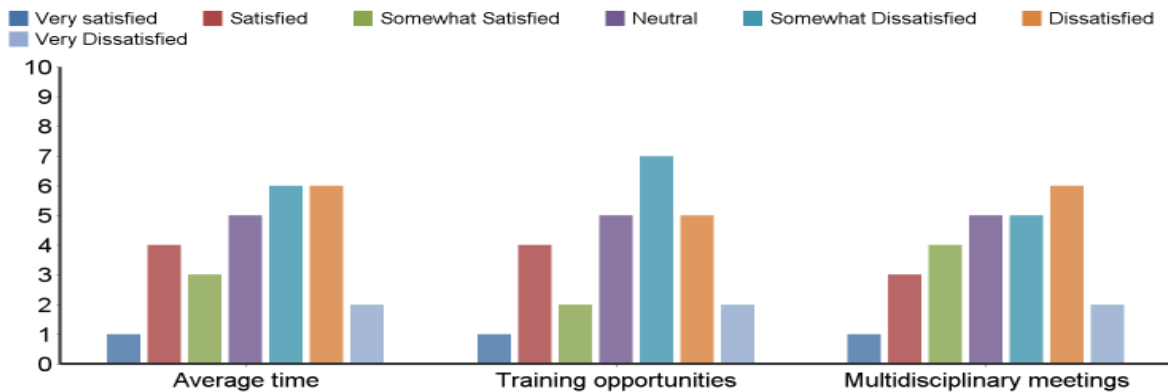
Six to 10 physicians were more or less dissatisfied with their average time, training opportunities, or multidisciplinary meetings dedicated to sickle cell.

**Figure 6. Physicians' self-assessment regarding the availability or opportunities for activities dedicated to sickle cell disease.**



The same question was asked about their nurse staff. Overall, more physicians reported their dissatisfaction (13 to 14 of them).

**Figure 7. . Physicians' self-assessment regarding the availability or opportunities for activities of nursing dedicated to sickle cell disease.**



## DISCUSSIONS

More than 50% of centres have less than 20 patients in follow-up. In most centres, no dedicated nursing staff is sufficiently available. On average, physicians are only moderately satisfied with respect to the time spent, training opportunities and multidisciplinary meetings related to these patients. As can be expected, centres are concentrated in hospitals in large cities where the amount of population at risk is significant.

## CONCLUSIONS

Based on these figures it can be concluded that the majority of patients with sickle cell disease have easy access to basic care. However, it is likely that in many centres the expertise for managing more complex cases is insufficient and this may impact on patient's survival and quality of life. To combine optimal local care with referral to expert centres of more complicated cases, the setup of "reference networks" may be a solution and a challenge for the Belgian haematology community.

A national plan for rare diseases is ongoing in Belgium. It is obvious that with a rare disease, few patients and sometimes geographic isolation, it is very complex to provide all the expected services. Nevertheless, patients could greatly benefit from the development of services and facilities for their disease. One way to achieve this is to define centres of expertise (laboratory and clinical level) and local centres. Recommendations for centres of expertise for rare anaemias exist ([www.enerca.org](http://www.enerca.org)) and should be applied to centres of expertise for SCD in Belgium. But in view to share tools and all aspects in the management of patients with SCD as well as to improve the knowledge of these diseases at all levels, networking between local and centres of expertise, as well as between centres of expertise should be encouraged.