**Appendix 1 Patients’** **and** **parents’** **perspectives**

The text below is derived from the 2010 guideline

Opinions of patients and of the parents of patients are important when it comes to creating guidelines. The working group felt the need to enter into dialogue with parents and patients in a focus group addressing their experiences with the care and counselling of the child with craniosynostosis. Furthermore, we wished to make an inventory of the wishes and expectations about this counselling.

Via patient association LAPOSA, parents of children with craniosynostosis as well as older patients themselves were invited to participate in the focus group. Our aim was to provide for as much diversity as possible; i.e.: different treatment location, both non-syndromic and syndromic craniosynostosis, different treatment techniques, and variety in ages. In the end, we held two evening sessions. In the first session, 9 parents of young children (1-6 years) attended. The second session was with parents of school-going children (6-18 years) and older patients (15+) and partners. The number of participants was 8 and we interviewed two externally.

The focus group discussions were mediated by an advisor in the department of Professional Quality of the Dutch Order of Medical Specialists and involved in the development of the guideline. Both a social worker and nurse practitioner, working in craniofacial care, attended as well. The topics addressed were the topics dealt with in the guideline:

Intake/diagnosis; treatment; aftercare.

A summary of these sessions is presented below:

**Intake**

Even before intake, there was often considerable uncertainty about the condition, resulting in:

* many referrals (general practitioner>> pediatrician>> specialized center);
* late referrals;
* unnecessary or inaccurate or incorrect diagnostics;
* receiving incomplete or incorrect information;

All this is a source of great agitation/stress for the parents. It forces them to solve everything on their own.

***Wishes/needs***

* education to child health clinics; obstetricians, general practitioners, pediatricians
* short interval between suspicion of craniosynostosis to first contact
* clear information (written/internet) alongside the opportunity to ask questions and guidance when processing the information.
* easy access to a member of the team. This contact must be able to handle coordination issues but also medical/psychosocially emotional issues.

**Diagnosis** **and** **treatment**

Different treatment methods are available, but the how, what and why of each method are unclear for the parents. This brings uncertainty and makes it difficult to make a well-balanced choice. Some parents indicated that the period between first contact and intervention was very long. They started to worry increasingly about the health of their child. Furthermore, the effect that the diagnosis can have on the family and the future raises concern. Even after the first treatment of children with syndromic craniosynostosis, the parents are still worried.

Then, many questions arise, for example on the child’s development, auditory perceptions and visual acuity. Parents notice that quite some things tend to go wrong or almost wrong, due to insufficient knowledge of other disciplines (e.g. technicians). Moreover, in general they were not satisfied with the postoperative pain management as well.

***Wishes/needs***

* being able to choose the treatment. This means that they want to hear objectively from their treating physician which possible treatments are available, with all advantages and disadvantages.
* once again, easy access to a member of the team. This contact should have an overview of all medical/psychosocial aspects. In addition, he or she should be able and allowed to independently undertake steps outlined in the treatment plan. To be able to coordinate multidisciplinary care is seen as important.
* clear information from the physicians involved (which includes being able to talk to everybody), a personal approach.
* the need for social work. This is more important for parents with children with syndromic craniosynostosis. The team has to become actively involved here.
* contact with a clinical geneticist should be offered whenever relevant.
* contact with peers. This may be via the Internet (e.g. Hyves, Facebook, blogs) or via patient associations.
* educating disciplines involved in the treatment.
* good postoperative pain management.

**Aftercare**

In this period, child and parents are still being confronted with the consequences of the condition. Questions and/or problems arise especially about choosing a school, dealing with practical issues, accepting the abnormal appearance, resilience, and the physical/mental limitations. It is not always easy to smooth the contact between the care and educational sectors.

In the case of invasive procedures, active preparation and counselling by the team both in the home or home substituting situation and at school are highly appreciated.

When a child is being managed in multiple healthcare facilities, it is not easy to keep track. Sometimes the parents and patient are even confused who should be doing what and when. Regarding insurance: this usually gives the necessary problems. The Dutch Exceptional Medical Expenses Act (AWBZ) always is a source of problems. The basic health insurance package usually presents no problems. There appear to be many differences between the various health insurance packages.

The transition from child to adult care is a complex topic (e.g.: Who is the contact, which care can be left to the child itself?), The transfer to the adult hospital is certainly experienced as very sudden.

In general, parents indicated that they managed to find their way in handling the situation. However, support from the team in dealing with this process can be valuable.

***Wishes/needs***

* also in the aftercare period there is a need for a contact person to whom questions can be addressed, even if these do not seem to be directly related to craniosynostosis.
* proactive involvement of the (psychosocial team) during the periods of treatment and the transition periods of the different developmental stages of the child.
* guidance in choosing a school; with behavioral/mental issues. Guidance may also be provided in a peripheral setting, but the team should give active attention to this issue.
* communication between peripheral treatment providers and the team.
* easy access to social work.
* contact with a clinical geneticist when planning a new pregnancy.
* preparation and guidance for the transition process.