

FOURTH EDITION OF THE ELECTRONIC MEDICAL
RECORD FOR FACIAL ANOMALIES – TEN YEARS
OF EXPERIENCE

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Abstract

Changes in outcomes during growth and subsequent treatment require not only a multidisciplinary approach but also a system enabling the follow-up of the patients. We present our ten years of experience with an innovative web-based platform that follows around 1500 patients born with facial anomalies on a national level. The degree of the full follow-up can be measured by the number of patients that drop out and the number of patients that have global assessment scores at a fixed period of age. At our actual level of integration of the filters, reminders, and statistics the level of coverage of the outcomes is between 18 to 39% based on the global assessment scores in different periods of age. Even if we had organized several pieces of training for parents in the last three years it is evident that we should improve in future the clarity of our messages in leaflets, training, and websites.

Key words: facial anomalies, cleft lip and palate, electronic medical record, workflow, follow-up patients

Introduction. Cleft lip and palate are common birth defects that occur in approximately one in every 500–800 births [1, 12]. In Bulgaria, this means that around 65 to 90 new cases are reported each year, with a total of 6000 to 8000 patients who have undergone treatment for this condition. These anomalies are

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considered rare diseases due to their genetic and phenotypic complexity [2]. Although there are some rare cases of life-threatening conditions, such as Pierre Robin sequence [3], abnormalities in the maxillofacial area can affect a person's quality of life due to visible differences and speech defects and comprehensive care is crucial [4, 5]. Furthermore, low public awareness and stigmatization of individuals with visible differences present additional challenges such as psychosocial support for the patient and the family. Other unresolved issues include the risk of dropping out from follow-up at certain ages, which can lead to missed opportunities for optimal correction of the palate due to velopharyngeal insufficiency, bone grafting, and orthodontic treatment. In 1997, the Association of Patients with Facial Anomalies and their Parents (ALA) was created to fill the gap in the care that the Government was not supplying. In 2013 ALA and the Plastic Reconstructive Unit of the Medical University of Plovdiv started the functioning of the Electronic Medical Record for Facial Anomalies (EMRFA) first as a database (DFA) and then as a system that enables improvement of the follow-up of the patients (<https://emrfa.org/>) (Fig. 1).

The main foreign partners of ALA are Smile Train <https://www.smiletrain.org/> from 2000, ECO <https://europeancleft.org/>, and Transforming Faces <https://transformingfaces.org/> from 2008. In 2008 started the building of a national network of feeding specialists, speech and language specialists, and orthodontists. ALA started co-funding programmes near the patient's home and through the EMRFA the Centre in Plovdiv controls the treatment done in the national network as each consultation and therapy is reported by a post "Consultation", "Start of therapy", and "End of therapy". In the experience of many

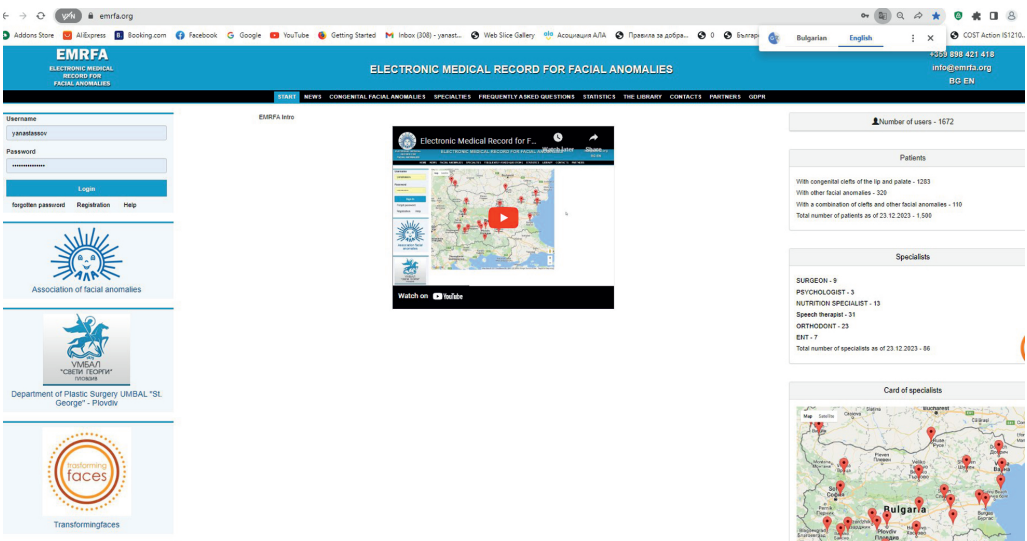


Fig. 1. Initial page of the EMRFA with 1500 registered patients and 86 specialists of a national network

specialized Centres, it is well known the problem of dropping out for these patients, and comprehensive treatment in the appropriate period of life has been omitted and optimal outcomes become more difficult or impossible.

The purpose of this paper is to present our experience in the Specialized Centre in Plovdiv, the national network of specialists through the evolution of the electronic medical record created by us, and the educational training for Parents-Patients and specialists. In the last three years, we organized several virtual and a pilot live training for families in middle or high risk for dropout. We realized that if we expect to raise the number of well-followed patients, we need to set up very clear messages for parents and specialists as the responsibilities of the parents and patients should be better defined and presented to the new families in our training and when a new family is presented to us. The EMRFA has been upgraded four times and the last upgrade was supported by a project from Transforming Faces and ALA between 2020 and 2023.

Material and methods. The last version of the EMRFA has been migrated from Visual Studio 2013 to 2019, MS.net framework Core 3.1, and from a server to a cloud server. The registration of a new patient is done most often when the child is presented to the Team, but also it is possible through emails and pictures sent by a nurse (feeding specialist in the network). There is a consent form that can be downloaded from the website and it should be signed by the parents and sent to us, but then, the case should be confirmed and filled with the detailed diagnosis of the anomaly by a surgeon of the Core Team. The participation of the Parents-Patients is voluntary and there is a clear procedure to unsubscribe and to anonymize the personal data of their files. All members of the Core Team have automatic access to the patient's files, but the family selects which specialists from the national network should have access and can write on the patient's wall. The patients and/or the parents can read and write on the wall comments uploading pictures and videos. Psychosocial risk factors are noted in the first meeting and also when necessary for example fixed age periods should be filled and/or updated data for the psychosocial aspects of the patient and family categorizing the families as low, medium, or high-risk for missing for follow-up. The questions related to these aspects are educational levels, family income, distance from a big city, other medical conditions in siblings or the family, etc. The different risk groups can be followed differently. Only a surgeon from the Core Team is allowed to determine the diagnosis of the facial anomaly using the ICD 11, for cleft lip and/or palate, the text-based notation such as LAHSHAL [6, 7], but also our severity score classification [8–11] (Fig. 2).

The follow-up of the patient is represented on the wall of the patient and each specialist can write a post “Comment”, “Therapy”, or “Consultation”. Each specialty – surgery, speech and language, orthodontics, ENT, feeding specialists, and psychology have different types of post “Therapy” and “Consultation”. For Cleft lip and palate pathology in the surgical aspect, the different types of defects



Fig. 3. Example on the wall of a patient with the post “Start of therapy” for the specialty of orthodontics

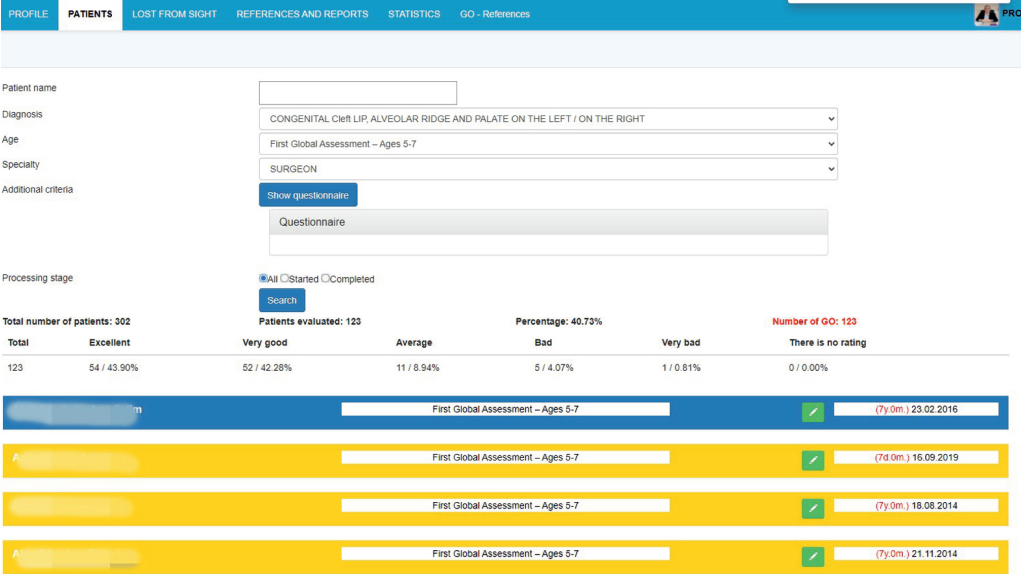


Fig. 4. Filter for global assessments for the age 5–7 for left or right cleft lip and palate

after a long period of absence. For this group of patients, we developed a Library Section.

Results and discussion. At the end of 2023, one year after we included the global assessment scores in the EMRFA, global scores for the age period of 5 to 7 years are present in 399 patients from 1004 patients (39%), for the age period 8–11

in 253 patients from 796 (32%), for the age period 12–14 in 149 from 525 patients (28%), for the age period 15–18 in 63 patients from 342 (18%). Surgical scores are always predominant in all ages. Full assessments in all specialties are present in only 51 of 1004 patients (5.1%). The work of the Core Team to categorize and evaluate the outcomes can be measured through the criteria of scores in each specialty.

It is difficult to motivate the members of the network to add posts “consultation” and “therapy” in the EMRFA only with idealistic arguments. The post “comment” does not measure the activity of the specialists, but they tend to use more often “comments” that we do not count as an activity that we can measure. Reimbursement to the members of the network is done when a post “Start” and another “End of therapy” are posted on the patient wall. This can be extended to all posts “consultation”, “therapy” or “global evaluation” done by the Core Team or the network specialists.

The number of new cases registered and treated by our Team from 2013 to 2016 is 70 to 81 new cases of cleft lip and/or palate per year (60 to 65000 newborn in Bulgaria in the last 10 years). In the end of 2023, the number of all registered patients is 1500. That means that the EMRFA and our Team cover more than 95% of the cases of cleft lip and/or palate born in the country and our experience could be a reference for future studies and long-term results.

It is well known that the treatment of facial anomalies could not be only surgical, but comprehensive and with full follow-up until the end of growth of individuals. The EUROCLEFT project 1996–2000 [12] has shown the wide variety of treatment protocols in Europe and showed examples of the minimal documentation that can help to compare the outcomes. Follow-up until the end of the growth is a challenging matter and a few Teams in the world can affirm that they have full data until the end of the growth of all their patients. The Core Team and ALA organized several online virtual trainings for parents divided into groups of ages. In each virtual training, 30 to 50 families have participated. Records of videos of these trainings are available in the library section of the EMRFA. We realized that unfortunately, the ones that are missing from follow-up are the middle or high-risk families. So, we tried to call by phone 30 families that are considered middle or high-risk and have been missing consultations for more than four years in the age group 5 to 11. We found that most of them had changed their phone number and succeeded in organizing a two-day training on the expenses of ALA for only five families (16.67%).

On the first day, we addressed to the parents a questionnaire with questions trying to understand the reasons why they have been missing regular consultations and 20 questions on the basic responsibilities of the parents of a child born with a facial anomaly (at what age your child should see a speech therapist, an ENT doctor, a dentist, the difference between a dentist and an orthodontist, the optimal age for bone graft, how can growth influence speech, etc.) We compared their

answers before and after and saw improvement in the scores after the training of course. The main reasons for missing regular consultations were health problems in the family, but this may not be the reason in the group of 25 families that we could not find (they had changed their phone numbers and were not reachable).

Conclusion. The reasons for dropping out of regular consultations are various and some of them are out of our control, but if we pretend to expect a responsible attitude from parents and patients and give them the chance to have comprehensive care, especially for the poorest ones, we should address clear messages in the educational training (showing examples of what is the optimal treatment, optimal ages and requirements for that). In the era of digitalization and accessible internet a responsible parent can participate in implementing the documentation of the EMRFA by uploading pictures and videos at different ages and this activity can be measured by a filter created by us. The parents can upload pictures and videos asking for a virtual consultation, a valuable opportunity in the period of COVID pandemic. As our network of specialists is supported only by ALA through the co-funding programs of Transforming Faces and needs expansion to provide more options for treatment near the homes of the patients, we count on parents to promote the adhesion of new specialists in the network. This is also a role to play for the responsible parent.

REFERENCES

- [1] WHO Meetings on International Collaborative Research on Craniofacial Anomalies, Global strategies to reduce the health-care burden of craniofacial anomalies, Geneva, Switzerland, 5–8 November 2000; Park City, Utah, USA, 24–26 May 2001.
- [2] MOSSEY P. A., J. LITTLE, R. G. MUNGER et al. (2009) Cleft lip and palate, *Lancet*, **374**(9703), 1773–1785, [https://doi.org/10.1016/S0140-6736\(09\)60695-4](https://doi.org/10.1016/S0140-6736(09)60695-4).
- [3] SANTORO M., E. GARNE, A. COI et al. (2023) Survival, hospitalization, and surgery in children born with Pierre Robin sequence: a European population-based cohort study, *Arch. Dis. Child.*, **108**(7), 550–555.
- [4] SOMMER C. L., A. P. WANKIER, S. OBIRI-YEBOAH et al. (2021) Qualitative analysis of factors impacting comprehensive cleft lip and palate care in Ghana, *Cleft Palate-Craniofac. J.*, **58**(6), 746–754, <https://doi.org/10.1177/1055665620959995>.
- [5] ALONSO N., C. A. RAPOSO-AMARAL (Eds) (2018) *Cleft Lip and Palate Treatment: A Comprehensive Guide*, Springer, <https://doi.org/10.1007/978-3-319-63290-2>.
- [6] HOUKES R., J. SMIT, P. MOSSEY et al. (2023) Classification Systems of Cleft Lip, Alveolus and Palate: Results of an International Survey, *Cleft Palate-Craniofac. J.*, **60**(2), 189–196, <https://doi.org/10.1177/10556656211057368>.
- [7] PIETRUSKI P., M. MAJAK, T. DEBSKI, B. ANTOSZEWSKI (2017) A novel computer system for the evaluation of nasolabial morphology, symmetry, and aesthet-

ics after cleft lip and palate treatment. Part 1: General concept and validation, J. Cranio-Maxillofac. Surg., **45**(4), 491–504.

- [8] MORTIER P., V. MARTINOT, Y. ANASTASSOV et al. (1997) Evaluation of the results of Cleft Lip and Palate Surgical Treatment: Preliminary Report, Cleft Palate-Craniofac. J., **34**(3), 247–255.
- [9] ANASTASSOV Y., C. CHIPKOV (2000) Analysis of the nasal deformities in cleft lip and palate patients by a new rating scale: a preliminary report, J. Cranio-Maxillofac. Surg., **28**, Suppl. 1.
- [10] ANASTASSOV Y. (2016) Un registre clinique des anomalies de la face en Bulgarie, Editions universitaires européennes, ISSN 978-3-639-54031-4.
- [11] ANASTASSOV Y., K. GIGOV, R. KHATER et al. (2017) A web-based national registry for facial anomalies (DFA) in Bulgaria: An Electronic Medical Record for Facial Anomalies, JCLPCA (ISSN 2348-2125), **4**(1), S118–S125.
- [12] SHAW W. C., G. SEMB, P. A. NELSON et al. (2001) The Eurocleft Project 1996–2000: overview, J. Maxillofac. Surg., **29**(3), 131–140.

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