

Output 1 – Synthesis Report

1. Introduction

Long-term outcomes for infants born with a cleft of the lip and/or palate are very variable and not well predicted by the severity of the cleft or effective aesthetic and functional treatment. To reach the goal of positive adjustment and successfully navigate the challenges associated with living with a cleft, key developmental tasks for children and their families include the acquisition of effective communication skills and the development of psychological resilience. With the aim of filling the gap left by inequalities in care provision for children with cleft lip and/or palate, this project focuses on the development of training materials designed to empower health care professionals to impart the knowledge and skills to parents and caregivers necessary to optimise the likelihood of positive outcomes for their children.

The project has been completed in collaboration with 6 partnering countries (Bulgaria, Estonia, Italy, Malta, Romania and Serbia). Each country has produced a national report, summarising key topics including the structure of their healthcare system, the availability and accessibility of cleft care, the availability of speech and language therapy (SLT) and psychological support for patients, and the challenges they face in delivering positive outcomes in these areas for their patients and families. Additionally, surveys (listed in Annex 1) were distributed to healthcare professionals (HCPs) and parents/caregivers of each partnering country, with the goal of ascertaining precisely what these individuals think about aspects of care for children with cleft lip and/or palate, such as the current level of SLT and psychological support provided and, crucially, whether parents would like more support to allow them to provide elements of care at home.

This report synthesises the results of the national reports and surveys, and will serve as a foundation from which a training curriculum, considering a breadth of country-specific issues, can be developed.

2. Diverse contexts

2.1 Healthcare systems and funding

Bulgaria has a combination of state and private healthcare structures. Health insurance contributions are mandatory for the working population, and insurance payers are entitled to free or subsidized state healthcare. Exemptions exist for the unemployed, the retired, students, soldiers, civil servants and vulnerable groups. In **Estonia**, health care is largely publicly financed, with the national health insurance scheme covering 95% of the population for their individual needs. There are 800 family physicians, and 65 public and private hospitals, including 35 nursing and rehabilitation hospitals. **Malta's** health care is readily available to the public, though many opt to access private sector primary care services as they offer better continuity of care. Services such as elective dental care, optical services, assistive devices such as hearing aids and some medicines, are means-tested. The private sector accounts for about two-thirds of the workload in primary care and is remunerated on a fee-for-service basis. **Romania** provides a social health insurance system. Citizens are entitled to free, unrestricted medical procedures, provided insurance is paid. If insurance is not paid, citizens are entitled solely to free emergency medical assistance. In 2017 there were 367 public and 209 private tertiary care hospitals. **Serbia's** health insurance provides contributors the right of health care, the right to compensation of related travelling expenses, and the right to salary compensation during temporary disablement. Additional voluntary/private health insurance is available which can provide a wider standard of rights. **Italy's** national health service is funded by the taxation system, however, a considerable proportion (479 of the 1155 hospitals), are private.

2.2 Cleft care availability and accessibility

Cleft care is not a priority in **Bulgaria's** healthcare system. The only treatment provided by the National Health Insurance Fund is surgical treatment. All additional multidisciplinary care is funded by an NGO, which provides cleft feeding support, specialized SL therapy, ENT follow-ups, orthodontic treatment and psychological support. In **Estonia**, cleft care is offered through the National Health Service (NHS) free of charge. Children born with a cleft are referred to the multidisciplinary cleft team, consisting of a surgeon, orthodontist, speech and language therapist, psychologist, and social worker, if needed. **Italy's** cleft care is offered through both its NHS and NGOs. Due to **Malta's** relatively small population, the prevalence of cleft lip and palate cases is low, with less than 5 cases per year. Cleft care is offered here through the NHS. A multidisciplinary team assess and review patients with cleft periodically. The team consists of an orthodontist, a dental surgeon, 2 plastic surgeons, and 2 SLTs. In **Romania**, surgical treatment is free of charge, however, multidisciplinary care including orthodontic treatment, speech therapy and psychological support are only covered by the national insurance system when these respective services are provided in public hospitals. Orthodontic treatment is mostly performed in private services. There are 6 cleft centres in Romania. Input into the surgical treatment of patients with cleft lip and palate comes from paediatric surgeons, plastic surgeons, oral and maxillofacial surgeons and sometimes ENT. The multidisciplinary team additionally consists of an orthodontic surgeon and the speech therapist, with additional involvement of a psychologist, geneticist, neonatologist, and paediatrician. In **Serbia**, there are no cleft centres offering multidisciplinary treatment. Beyond initial surgery, parents are not provided with guidance around multidisciplinary care and its benefits. Private sector costs deprive a substantial number of patients from treatment, resulting in poor speech and its detrimental psychosocial impacts.

2.3 Team resources and training – speech and psychology

There is a network of SLTs throughout Bulgaria, which is supported by the NGO. An SLT attends clinics, assesses the patients' needs and refers to SLTs the national network. However, there is very limited training for non specialist community therapists. Due to the country's NGO partnering in Erasmus+ projects such as *Face value*, *IHEM*, and *Cutting edge*, some well-received training was conducted for non-specialists on the psychosocial aspects of the cleft treatment. This was believed to enhance the whole treatment process of patients. In Estonia, SLT is provided through primary health centres, district clinics, day-care systems and schools. SLTs require a Master's degree, though there is no specific training for specialising in cleft. There are no psychologists in cleft teams and no training for non-specialists. In Malta, SLT is provided primarily through primary health centres and district clinics, though can also be offered through the child's school. SLTs are involved in the training of other health care professionals via seminars/lectures, though it is unlikely that cleft-specific SLT training is provided. A clinical psychologist is available at a general hospital, and children are referred to the psychologist if considered necessary. Though included in an SLT students' programme of studies, team members do not receive training in psychosocial aspects of care. In Romania, SLT is usually initiated in cleft centres and then continued in local speech therapy units affiliated to the public-school national network or in private practice. Psychological support is not available on a regular basis in the public healthcare system and training is not provided to non-specialists. Likewise, in Serbia, SLT training is not readily provided to non-specialists. Here, any training in the psychological aspects of care were through Erasmus+ projects.

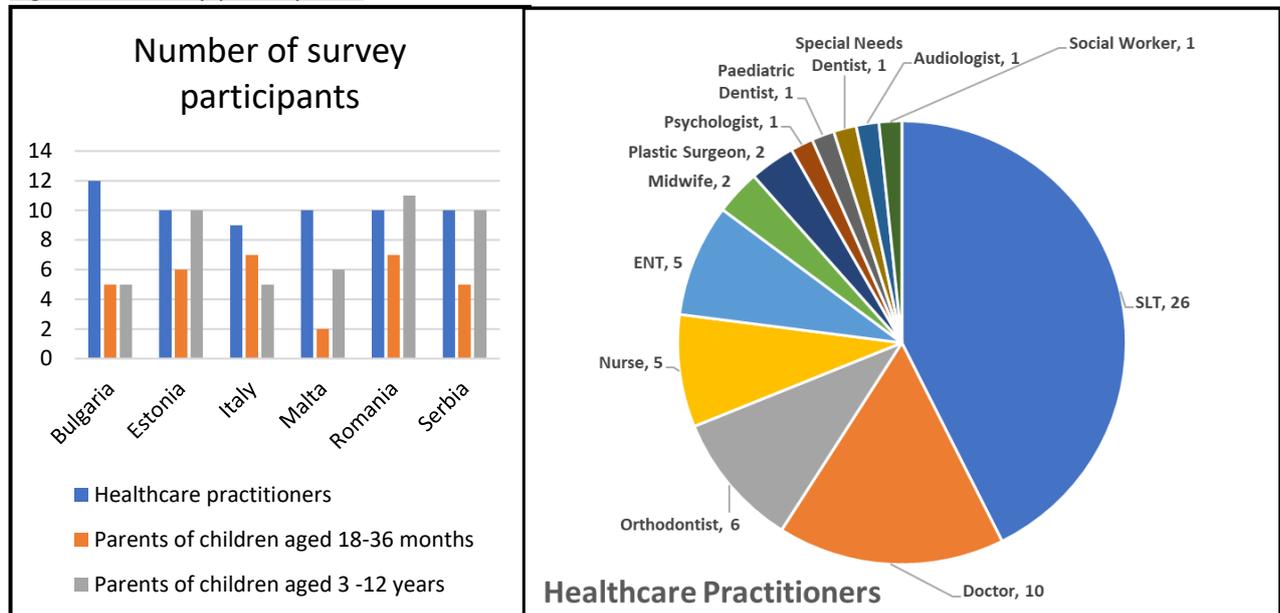
The level of SLT and psychological support available to patients clearly varies substantially due to geographical and financial constraints. The running theme throughout, however, is the lack of cleft-

specific SLT and psychological training for non-specialists which can be detrimental where there is no access to psychologists or speech and language therapists. Any relevant training that has occurred has been through the aforementioned Erasmus+ projects. This project aims to address this by providing training materials for non-specialists giving them the power to identify issues early, knowledge on how to address these issues and, crucially, be able to convey this knowledge to parents/caregivers.

3. Survey results

140 participants, composed of 61 healthcare practitioners, 32 parents of children aged 18-36 months and 47 parents of children aged 3-12 years, took part in the surveys (Appendix 1). Salient questions are summarised below.

Figure 1 – Survey participants



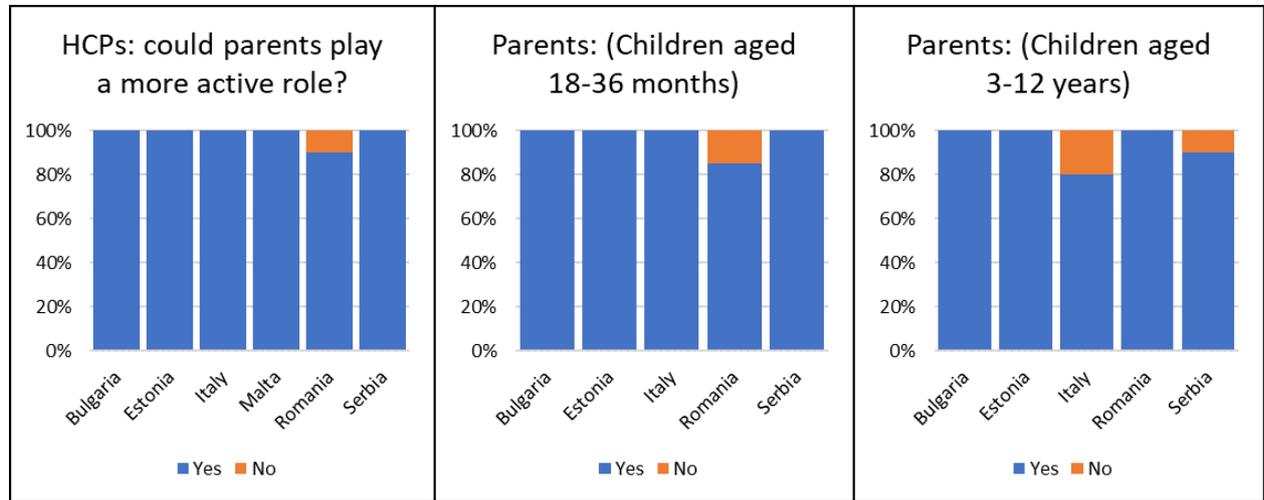
3.1 Involvement of parents/families in care

The overwhelming response was that HCPs wanted parents to become more involved in delivering care to their children from home (Figure 2). Quoting one surveyed HCP, “parents could be good co-therapists and actively involved in the therapeutic process if they are sufficiently prepared”. In parallel, almost all parents wanted more information to empower them to support their child from home. Comments from HCPs on the potential impact of this training included:

- Parents can feel more well equipped to actively participate in all types of therapy.
- Parents can identify children's [speech and/or psychological] problems as early as possible and know how to address these themselves or raise awareness.
- Parents will have strategies to reinforce the correct speech production, following the therapist's instructions at home through specific activities.
- Parent groups may be formed for sharing specific information.
- Parents may educate the rest of the family and other parents on SLT and with emotional and psychological support.

These points inform the themes that the training curriculum should abide by, allowing healthcare professionals empower parents in supporting their child from home, and educate their surrounding family.

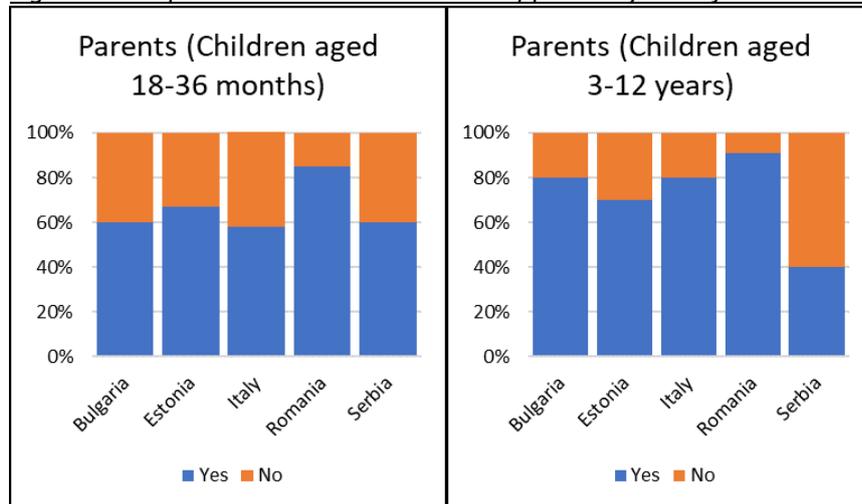
Figure 2 – Do healthcare practitioners believe parents can play a more active role, and do parents want more information on improving outcomes for their child?



3.2 Specific challenges for parents

Although parents of children aged 3-12 appear to, on average, feel that they have access to the support they need compared to parents of younger children (Figure 3), the overall picture is not good enough – too many families feel underserved.

Figure 3 - Do parents have access to the support they need for their child?



When partnering countries were asked *whether there are any problems accessing regular speech and language therapy (SLT), their responses, too, paint a similar theme:*

Bulgaria: As far as the multidisciplinary cleft treatment is not provided by the National health care system, the access to a regular cleft specific SLT is not granted. Thanks to ALA’s supported network of professionals, there is no problem for the families to access SLT in the biggest cities of Bulgaria. At

the same time in many small cities there are problems accessing regular speech therapy. The parents are referred to the closets professionals and sometimes it is very distant location.

Estonia: Yes, we do not have enough SLT's in Estonia. Especially in rural areas.

Italy: The main problem in accessing regular speech and language therapy in Italy – whether in a public structure or in a National Health System affiliated private clinic or practice – is the waiting lists; it's often quicker to have access in a private practice (there is a large number of them in every big city in Italy), but in this case the family would have to cope with the cost of a periodic speech and therapy treatment. For this reason, accessing speech and language therapy can be difficult for socially disadvantaged people.

Malta: No, we fall under the quality charter to have the first appointment following a referral within 15 days. Then, depending on the waiting list and client's needs a child may be seen once a week/fortnight or monthly. S/he may also be followed at school; at the moment SLPs are trying to engage in telepractice.

Serbia: There are some problems accessing regular speech and language therapy (SLT).

Similarly, when partnering countries were asked *whether there are other health care professionals delivering SLT services to children with cleft palate:*

Bulgaria: As far as we know there are no other specialists providing SLT.

Estonia: No

Italy: No, the only other figure involved in our same area of influence is the IBCLC (lactation consultant) who gives assistance to the mother during the first phases of feeding in newborns, in case of difficulties during initial latchment, nutrients shortage or lack of growth.

Malta: They can be referred to the Child Development Assessment Unit, where a team of allied health professionals assess the children, including clinical psychologist, OT, PT and paediatrician, issue reports and refer for respective services where necessary. The orthodontist and ENT specialist often sees these children also.

Serbia: No, there aren't. There are only speech therapists.

Regarding psychosocial aspects of life, the stigmatisation of children with cleft varies according to geography, but appears more widespread in rural areas and poorer communities. Access to psychological support is not available for all patients and families. The main problems are the visibility of the deformity, coupled with poor speech, which can act to establish and exacerbate an unhealthy mental state.

Parents have the dual challenge of achieving positive adjustment for themselves as well as in their children. One surveyed parent reported that they were withholding their child from attending nursery through fear of bullying. Indeed, not only may they feel unsure about how to promote resilience in their children, they may lack the attributes and resources associated with resilience themselves.

Little work currently exists specifically relating to the skills parents of children affected by cleft may usefully acquire to promote the development of key attributes, including resilience, in themselves

and also in their children. However, relevant research in related fields, including ways of promoting a positive outlook on life, self-compassion, a positive body image and speech and language development is available and should be utilised in the development of the training materials.

Conclusion

Children with clefts (and other craniofacial conditions) need help to deal with the challenges associated with their condition and its treatment and to develop into confident adults, however, there are considerable differences in the availability and access to SLT and psychological support services across Europe. Primary caregivers are considered key agents for change in their child's development and well-being, including communication and speech and language disorders, and they should be supported in their efforts by appropriate support from the HCPs. There is a growing body of evidence showing how trained parents can effectively deliver therapy for children with cleft-related speech and language problems.

This work will allow for the genesis of bespoke training materials to promote the acquisition of effective communication skills and psychosocial resilience in children affected by cleft. The need for this type of training material was already established through the ECCE's work on COST Action, 'CA 16234' (www.ecce.nu). Through this initial research, we now know precisely the audience/setting we need to adapt the training to, the specific challenges faced in these settings by HCPs and families, the proven willingness of HCPs to engage with families in improving outcomes, and the information and support needs of the families themselves.