

# Planning early childhood audiologic intervention programs on a regional scale: introduction to an Italian study

## *Pianificare su base regionale un programma di intervento audiologico precoce dell'ipoacusia infantile: introduzione a uno studio italiano*

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### SUMMARY

Non-uniform, late, or inappropriate care of childhood with permanent hearing impairment (PHI) predisposes many children to develop communicative-behaviour problems and impaired psychosocial adjustment that can persist in adolescence and adulthood. In March 2014, the CCM (Centro Controllo Malattie or Disease Control Centre) of the Italian Ministry of Health funded a project entitled "Preventing Communication Disorders: a Regional Program for Early Identification, Intervention and Care of Hearing Impaired Children". The project involved 5 tertiary centres with UNHS programs formally approved by the Region. The main purpose of the project is to define and launch an integrated regionally-based public health model for identification, diagnosis and intervention of childhood PHI. The first phase of the project investigated the state of art and produced recommendations for positive changes in identification, diagnosis, therapy and care of childhood PHI in Italy, taking into account diagnostic and treatment innovations, family empowerment, treatment alliance and an interdisciplinary approach. Recommendations drawn from this initial phase will represent the basis for a regional system for early intervention that is validated, integrated and shared between the five regions.

**KEY WORDS:** Universal newborn hearing screening • Childhood auditory surveillance • Early intervention program • Health service planning • SWOT analysis

### RIASSUNTO

*Una presa in carico non uniforme, tardiva o inappropriata dei bambini con deficit uditivo aumenta il rischio di sviluppare difficoltà comunicative-comportamentali e psicosociali che possono persistere fino all'adolescenza o all'età adulta. Nel Marzo 2014 il Centro di Controllo Malattie (CCM) del Ministero della Salute Italiano ha finanziato il progetto "Programma regionale di identificazione, intervento e presa in carico precoci per la prevenzione dei disturbi comunicativi nei bambini con deficit di udito". Il progetto coinvolge 5 centri di III livello in cui il programma di screening uditivo neonatale è stato approvato dalla regione di appartenenza. Lo scopo principale del progetto è quello di definire e proporre un modello di salute pubblica su base regionale per l'identificazione delle ipoacusie infantili permanenti, la diagnosi e l'intervento. La prima fase del progetto prevede di indagare lo stato dell'arte e di produrre raccomandazioni che possano portare a cambiamenti positivi nell'identificazione, nella diagnosi, nella terapia e nella presa in carico dei bambini con deficit uditivo, tenendo presenti le innovazioni diagnostiche-riabilitative, il sostegno e l'alleanza terapeutica con la famiglia, un approccio interdisciplinare. Le raccomandazioni emerse da questa prima fase rappresenteranno le basi per un sistema regionale di intervento precoce che sia valido, integrato e condiviso da tutte le cinque regioni coinvolte.*

**PAROLE CHIAVE:** Screening uditivo neonatale • Sorveglianza uditiva pediatrica • Programma di intervento precoce • Pianificazione del servizio sanitario • Analisi SWOT

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## Introduction

Permanent hearing impairment (PHI) is the most common sensory defect in childhood. A significant degree of PHI occurs in 1-3 per thousand births in industrialised countries. Its prevalence can double by age of school entry and can increase by 3 to 10 times in at-risk paediatric populations or in poor countries<sup>1,2</sup>.

A childhood auditory deficit is typically of cochlear origin and is severe to profound in about a third of cases,

and eventually requires cochlear implantation. The condition harbours a high risk of language learning impairment and language-based learning disabilities because functional development of the auditory cortex critically depends on auditory experience<sup>3</sup>. Sensory deprivation during periods of maximal receptiveness (known as sensitive periods) impairs the auditory system function and compromises cortical and cognitive development, affecting the mutual interaction of the cortical areas<sup>4</sup>. As

a result of the decoupling of the auditory system from other systems in the brain, there is a compromise of key cognitive functions, such as working memory, attention and sequence learning<sup>5</sup>.

Fortunately, developments in scientific, clinical and medical technology have shown remarkable progress in the last 15-20 years. Valid diagnostic and intervention procedures linked with fitting of sophisticated hearing aids or cochlear implants have outlined courses and processes that are today applicable, feasible, effective and sustainable<sup>6</sup>. Timing, appropriateness and quality of interventions have been shown to be crucial factors: the better conceived, the greater the chances of avoiding the negative impact associated with PHI<sup>17</sup>. This knowledge has internationally encouraged the development of newborn hearing screening (UNHS) and surveillance programs with the aim of identifying congenital and delayed-onset PHI within the first 3 months of life or immediately after occurrence<sup>12,8,9</sup>. Several Italian regions have now regional policies specifically aimed at detection of childhood PHI<sup>10-14</sup>. The majority have been demonstrated to be highly practical, and excellent results in terms of coverage and reduced age of hearing impairment identification have been reported<sup>15-17</sup>. Yet, at this point, it is necessary to build an integration with further steps of diagnostic, therapeutic and rehabilitative intervention, in order to not miss the opportunity to achieve early management as well. This achievement is still problematic in most national and international programs. As an example, an audit on the effects related to US UNHS programs published in 2010 reported excellent result in terms of national coverage, but also showed that about 40% of infants who screened positive did not get the required audiologic evaluation within 3 months, thus producing a high percentage of children that could not initiate early management<sup>18</sup>.

Diagnostic, treatment, rehabilitative and educational interventions are often late or inappropriate in Italy, predisposing many children to communicative-behaviour problems and impaired psychosocial adjustment that can persist into adolescence and adulthood. In addition to clinical and educational issues, this highly jeopardised situation restrains rehabilitation, educational and legislative interventions, forcing them towards a *support-based* rather than *prevention-based* approach<sup>10-14</sup>.

In March 2014, the CCM (Centro Controllo Malattie or Disease Control Centre) of the Italian Ministry of Health funded a project entitled "Preventing Communication Disorders: a Regional Program for early Identification, Intervention and Care of Hearing Impaired Children". The vision of the project is to lessen and prevent communication delays that typically occur in the event of late care. The program's policy is to upgrade and uniform current public health practices, taking into account diagnostic and treatment innovations, family empowerment and treatment alliance, and an interdisciplinary approach. The main purpose of the project is to define and launch an integrated,

regionally-based public health model for identification, diagnosis and intervention of childhood PHI. The project will be carried out in five Audiology and Otolaryngology Units that coordinate and represent a tertiary centre for UNHS programs approved by each participating Region and that provide audiologic assessment, cochlear implant surgery and rehabilitation. The centres are the following: (1) Audiology and Otolaryngology Unit, Department of Pediatrics, Research Institute and Hospital for Maternal and Child Health - IRCCS "Burlo Garofolo" – Trieste (Head of the Unit, Scientific coordinator and local supervisor of the project: Dr. Eva Orzan); (2) Department of Head and Neck Surgery, Department of Head and Neck Surgery – Otorhinolaryngology Catholic University of the Sacred Heart "A. Gemelli" Hospital, Rome (Local Supervisor of the project Prof. Guido Conti, Director of Department: Prof. Gaetano Paludetti,) (3) Otorhinolaryngology Clinic, University of Perugia, Perugia (Local Supervisor of the project and Director of the Clinic Prof. Giampietro Ricci); (4) Otology and Cochlear Implant Unit, Santobono-Pausilipon Children's Hospital, Naples (Local project Supervisor and Head of Unit Dr. Antonio Della Volpe; project collaborator Dr. P. Siani) (5) Operative Unit of Otorhinolaryngology, Audiology and Phoniatrics, University of Pisa, Pisa (Local Supervisor of the project and Head of Unit: Prof. Stefano Berrettini).

The first phase of the project included the identification of areas for which it is necessary to plan innovative organisation. Overall and specific objectives were set for each area of activity and a structured planning method was employed to identify the internal and external factors that are favourable and unfavourable to the aims, i.e. evaluate the capabilities of the organisation and to identify where the greatest opportunities lie within a realistic context. This phase has been carried out using the principles of a SWOT analysis. Recommendations drawn from the strategic analysis will represent the basis for a regional system for early intervention that is validated, integrated and shared between the five regions. The results of this first stage of the project are conveyed in this series of articles.

## Materials and methods

SWOT analysis can help identifying an organization's Strengths, Weaknesses, Opportunities and Threats. It was developed at the Stanford Research Institute in the 1960's and was designed to engage all staff who affect a company's achievements in systems for positive change<sup>19</sup>. Although it was originally designed to provide a thorough analysis of private sectors, its benefits have prompted its use in health-care organisations as well<sup>19,20</sup>. In principle, SWOT analysis offers a model to systemise compilation and assessment of key data, such as present status of medical technology, sources of professional training and state of the art, to obtain recommendations to be considered for future planning.

**Table I.** Overall and specific objectives for the 9 SWOT analyses performed.

Themes	Overall objective	Specific objective for SWOT analysis
Newborn hearing screening	Optimise UNHS processes	Universal screening and re-screening test to be done by 1st month of age, preferably before hospital discharge
Hearing surveillance activity	Recognise childhood PHI that are not identified by the UNHS	Minimise loss to follow up cases and achieve an early identification of late onset or progressive PHI
Aetiologic diagnosis	Obtain an early aetiological diagnosis through the implementation of uniform and timely procedures, particularly with regards to common causes (CMV, GJB2 mutations/GJB6, inner ear malformations)	Apply a shared diagnostic protocol that can identify the cause in at least 70% of PHI
Audiologic diagnosis	Obtain an audiologic definition of PHI through the implementation of uniform and timely audiometric protocols, functional to the subsequent early hearing aid fitting.	Define the type, severity and morphology of PHI within 3-6 months of life if the child has been referred from the UNHS, or within one month if the child has been referred from hearing surveillance activity
Hearing aid fitting	Achieve an early amplification in all cases of significant PHI	Achieve an optimal hearing aid fitting in case of significant bilateral PHI within one month after audiologic diagnosis
Follow-up	Harmonise criteria for outcome evaluation	Schedule a follow-up protocol that supports an effective feedback within tertiary centres and primary care
Family support	Foster the natural communicative development of the child by strengthening the therapeutic alliance and the empowerment of the family	Coordinate professional activities that involve and empower families in the first three months after identification of PHI
Rehabilitation	Promote the global development of children with PHI by means of an early rehabilitation project based on shared knowledge and scientific evidence	Define the features and modes of access to a precise and specialised rehabilitation project for the small hearing-impaired child within three months from audiologic diagnosis
Cochlear implant fitting	Early cochlear implantation for children with severe to profound PHI	Obtain a hearing threshold within 35 dB HL within 3-6 months from the cochlear implant activation

A SWOT facilitator was identified for each analysis. The first step involved formulating overall and specific analysis objectives to help focus thinking and problem-solving, as listed in Table I. A group of professionals working in the aforementioned 5 tertiary care referral centres for childhood PHI was asked to report at least two strengths, weaknesses, opportunities and threats for each of the 9 themes of discussion. The facilitator introduced the SWOT matrix, which is divided into four quadrants, labeled “Strengths”, “Weaknesses”, “Opportunities” and “Threats”.

Strengths and weaknesses can be defined as internal to the setting. Internal factors at the healthcare centre include resources and experience. Human resources encompass staff, volunteers and the centre’s target population. Physical resources include location, building and equipment. Financial resources may cover grants and other sources of income. Experience may involve the centre’s successful

programs and even the centre’s reputation in the community. Opportunities and threats are external. Opportunities are external to the setting and can involve the future. Some examples include collaborations with different healthcare organisations, development of new healthcare programs and increased funds for better healthcare informatics. Factors that could harm the performance of healthcare organisations are considered threats. Examples include economic or political insecurity, increased demand for expensive medical technology, budget deficit and increased pressure for reductions in healthcare costs.

Participants were asked to write down their initial ideas on paper and to suggest items from their own lists to favour discussion, revisit the list and consolidate related suggestions. Table II lists possible questions that helped participants to identify strengths, weaknesses, opportunities and threats for each discussion theme.

**Table II.** SWOT matrix with useful questions for identifying strengths, weaknesses, opportunities and threats.

<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• What do we do well?</li> <li>• What advantages do we have?</li> <li>• What relevant resources do we have access to?</li> <li>• What do others see as our strengths?</li> </ul> <p><b>Opportunities</b></p> <ul style="list-style-type: none"> <li>• What good opportunities are facing us?</li> <li>• What trends might be helpful to observe?</li> </ul>	<p><b>Weaknesses</b></p> <ul style="list-style-type: none"> <li>• What aren’t we doing well?</li> <li>• What can we improve?</li> <li>• What should we avoid?</li> </ul> <p><b>Threats</b></p> <ul style="list-style-type: none"> <li>• What obstacles do we face?</li> <li>• Is technology changing faster than we are adapting to the changes?</li> </ul>
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Next, the SWOT facilitator summarised priorities by calculating the frequency of items collected during SWOT analysis. The review of the most frequently cited items were used to make a TOWS (Threats-Opportunities-Weaknesses-Strength) matrix, which matches the external threats and opportunities with internal weaknesses and strengths of the specific activity <sup>20</sup>.

A TOWS matrix compares strengths-opportunities, weaknesses-threats and weaknesses-opportunities:

(1) S-O strategy: Strengths can be used to employ the opportunities offered by external elements; (2) W-O strategy: Weaknesses internal to the system can be overcome by empowering and taking advantage of opportunities offered by external elements; (3) S-T strategy: The risks from external elements can be minimised by employing the strengths points efficiently; (4) W-T strategy: A good plan to minimise internal weaknesses can be useful to prevent the effects of risks arising from external elements.

This type of analysis makes it possible to extrapolate recommendations and guidelines for each theme. Analysing and discussing the data, some main recommendations were obtained that can represent food for thought for tertiary care audiology centres, to optimise resources and generate positive changes.

## Results

The flow diagram of the SWOT and TOWS analysis processes is outlined in Figure 1.

A SWOT analysis facilitator was selected between the members of the working group for each of the theme of discussion (see also Table I). The facilitator conducted a preliminary literature search on the assigned topic. Subsequently, before beginning SWOT process, the facilitator explained and focused the overall and specific objectives (see also Table I) that should drive the strategic study to the working group. For three themes (Hearing aid fitting, Family support and Rehabilitation) the facilitators decided to run a “first round” analysis that was proposed also to other professionals or families not included in the working group, to foster a subsequent discussion that could better reflect the Italian reality. This preliminary survey was conducted by mail with the same principles of the SWOT analysis or with questionnaires specifically developed to assess positive and negative aspects of the procedures or protocols available at the tertiary care centres. The working group included from 17 to 24 professionals involved in prevention, diagnosis, treatment and rehabilitation of childhood PHI, all working in the 5 above mentioned tertiary care centers. All analyzes were conducted at project

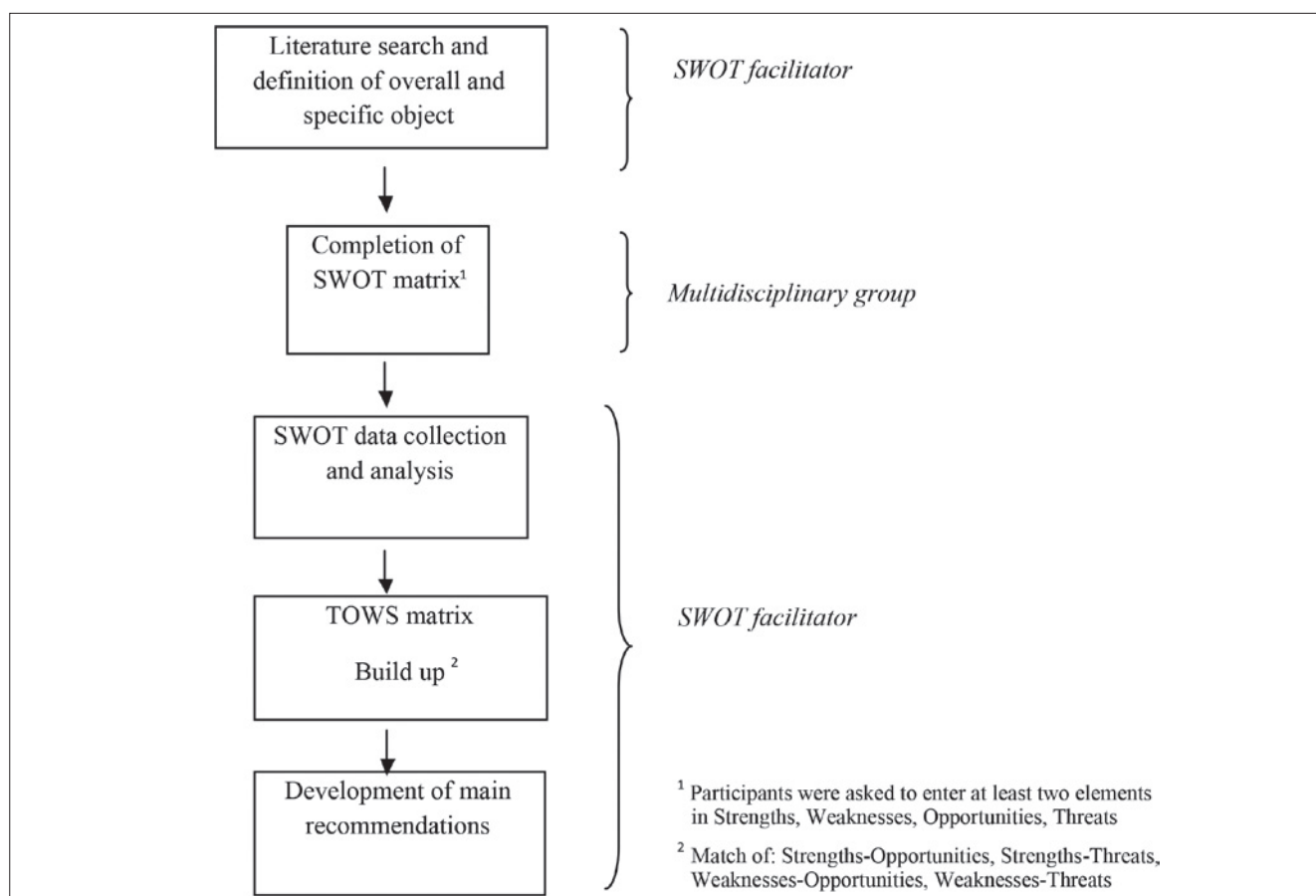


Fig. 1. Flowchart with all the steps of collecting, processing and discussing the details of each work area.

meetings, with all participants present, each one completing his or her own SWOT matrix. After completion of the matrices, the facilitator collected all the data. Overall, 486 items were identified for Strength (S) category, 513 items in the Weakness (W), 421 items in the Opportunity (O) and 434 items in the Threats (T) category, for a total of 1854 items. Subsequently all items were reviewed and grouped in main key points. Finally, a TOWS matrix was created for each theme, which compares and combines Strengths with Opportunities (S-O), Weaknesses with Opportunities (W-O), Strengths with Threats (S-T) and Weaknesses with Threats (W-T), eventually offering recommendations and directions that can constitute an effective starting point for prospective planning and innovation, in particular for tertiary care centres. A total of 103 suggestions or proposals were obtained as to the best course of action for the 9 fundamental themes and objectives of early childhood hearing loss care.

## Discussion

Implementation of UNHS programs in most Italian regions has been a major healthcare advance<sup>21,22</sup>. An additional step consists in systematising an early intervention process that can facilitate language, social and cognitive skills development, eventually allowing children to fully achieve educational and social opportunities<sup>7,23</sup>. This potential has not been uniformly and fully realised in Italy. The team of professionals involved in the project is convinced that it is necessary to improve the system of services needed to serve hearing impaired children and their families according to centres' experiences, along with the evolution of technology and in parallel with the application of healthcare reforms.

Restructuring of the healthcare sector is taking place in many Italian regions, and healthcare organisations face many new challenges: defining services, securing the means and understanding expectations and sustainability. UNHS programs have already been demonstrated to be efficient with a high level of quality. It is now necessary to ensure that every child with PHI has an equal chance to receive access to all critical care within a realistic context: timely identification; follow-up diagnostic testing; communication of results to family and other involved professionals; start of auditory stimulation; early rehabilitative intervention; long-term follow-up.

When planning services it is advisable to define and agree on the goals and objectives, analyse the current situation (including resources and obstacles), predict trends and finally define the activities and strategies to reach the desired goal. To do this, there are several options. One is SWOT analysis. This method is advantageous mainly because it encourages proactive and "positive" thinking, rather than reacting to actions in habitual ways<sup>19</sup>.

The outcome of our SWOT analyses are the main recom-

mendations for specific goals and will be used within the CCM national project as a call to action plan: activities to be undertaken, who should be responsible for each activity and when and how the activity should be completed. A strength of this project is that all units involved coordinate and/or represent a tertiary centre for UNHS programs formally approved by each Region. Moreover, all centres take care of children and families from first diagnosis, hearing aids fitting and potential cochlear implant surgery, up to evaluation of outcomes. The analysis and implementation of procedures, since they are carried out by the units that are actually involved in the realisation of the project, can guarantee the transfer of results at the local, regional and supra-regional levels. The healthcare models developed, agreed and implemented will be made available to other regions or organisations for similar programs. Other Regions will be added to the activity.

The present work in the course of the project has some limitations. SWOT analysis is only one way to generate ideas for improvement. It is a subjective instrument that depends on points of view, experiences and biases of those who participate. Sometimes, participants confused "strengths" and "opportunities" and "weaknesses" and "threats". Strengths are considered internal to the organisation, and opportunities are external. The coordinators and facilitators of SWOT analyses placed the suggestion in the appropriate quadrant when necessary, keeping in mind that the "correct" placement was always considered less important than capturing the idea. SWOT analysis is most effective if as many stakeholders as possible are involved in the process<sup>19</sup>. Each person on staff has a different perspective about the strengths and weaknesses of the health centre's efforts. On this occasion, it was an interdisciplinary group of professionals working in tertiary centres with daily experience in early childhood PHI management. There are, however, other professionals that can provide a useful contribution such as healthcare coordinators and policy makers. These individuals may provide other ideas for networks, need of cooperation, with a clear distinction between internal and external factors.

A further drawback can be that regions, albeit with regional laws, initiated their programs with different organisational backgrounds. Therefore, the strengths of one group can be seen as weaknesses of another group. This aspect highlighted a strong need for interdisciplinary training as a requisite for future effective networks. All contributors to SWOT analyses indeed favoured greater collaboration and communication between the various professionals that are involved with the child and also between the team and the family, especially if the child and the family live far away from the tertiary centre. A team that is affected by ambiguous competence assignments, uneven sharing of information and lack of working meetings, not only is ineffective, but also leads to incoherent information given to families.

The early intervention system involves the partnership of many professionals, hospital and primary providers, associations and specialised teams to monitor and assure proper functioning of all aspects of the system. Audiologic services operators, rehabilitation technicians, family and later even the school must share the needs and solutions aimed at achieving overall well-being of the child. As for other healthcare organisations, even the paediatric PHI care system needs to transform itself into professional network organisations that are influenced by many stakeholders. Resources should be available, and SWOT analyses foresee that resources can be found not only within the organisation itself, but also in its network. Finally, the following SWOT analyses should not be viewed as a conclusion, but rather as a starting point within a specific “historical moment” of Italian childhood PHI care. It can help healthcare managers and policy makers to know what the expectations of their stakeholders are now and in the near future in order to prioritise them and, hopefully, fully realise the promise of UNHS.

## Conclusions

Non-uniform, late or inappropriate care of childhood PHI predisposes many children to develop communicative-behaviour problems and impaired psychosocial adjustment that can persist in adolescence and adulthood. In Italy, this highly jeopardised situation is still confining rehabilitation, education and legislation towards a *support-based* rather than *prevention-based* approach.

In March 2014, the CCM (Centro Controllo Malattie or Disease Control Centre) of the Italian Ministry of Health funded a project entitled “Preventing Communication Disorders: a Regional Program for early Identification, Intervention and Care of Hearing Impaired Children”. The program policy aims to upgrade and harmonise current public healthcare practices, taking into account diagnostic and treatment innovations, family empowerment and treatment alliance, and an interdisciplinary approach. The first phase of the project, described in the following series of articles, is intended to investigate the state of art and produce recommendations for positive changes and innovation in identification, diagnosis, therapy and care of childhood PHI. A specific target that can drive SWOT analysis has been identified for each area of childhood PHI management process. A group of professionals working in tertiary centres performed 9 SWOT analyses to evaluate capabilities of the organisation and to identify opportunities within a realistic context. Recommendations were identified for several themes regarding the early PHI intervention process, and will represent the basis for a region-based early intervention system that is integrated and shared between stakeholders. The need for an effective professional network organisation has been highlighted in all 9 analyses presented, emphasizing that

communication and training are the most effective levers in healthcare organisations.

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