Proposal for a new SOSORT Consensus on comprehensive care and habilitation of children with non surgical idiopathic scoliosis

Background

In the history of SOSORT, we have always sought to advance our understanding of what was best for our patients through qualitative studies (the Consensuses) that explored and converged different experiences across various parts of the world. In some cases, these were followed by quantitative studies, whereas in others, quantitative studies were simply not possible (e.g., regarding the aims of treatment - Negrini 2005).

Treatments for disorders that arise during growth aim to 1) prevent an immediate or future impact on health and 2) allow the proper development of other body structures and functions (e.g., in the case of scoliosis, pulmonary and psychological function or mental health). For the latter, the term “habilitation” is used because these functions are not yet established, and to distinguish it from “rehabilitation”. In the field of children with idiopathic scoliosis, all non-surgical treatments are defined and grouped in various ways, such as “conservative”, “non-operative”, and, more recently, “comprehensive care”. While these terms already show the wide range of activities performed within the field, beyond the classical “treatments” of bracing and Scoliosis Specific Exercises (SSE), the umbrella term “habilitation”, commonly used in pediatrics, would also encompass the understanding of allowing proper development of children beyond their spine - that is a primary aim in the “non-surgical” community.

Beyond terminology, SOSORT has already highlighted the complexity of the field by describing the two main “classical” treatments: bracing and SSEs. Concerning bracing, SOSORT initially focused on biomechanical action (Rigo 2005) but found no Consensus: in practice, each expert uses different braces, and each brace implements different biomechanics. We later understood that there was uniformity (and Consensus) in managing patients with braces, and we produced specific Guidelines on this topic (Negrini 2009) that emphasise the importance of expertise and the behaviours of all practitioners involved. After that, we did not advance further in our understanding of what we do in clinics to make braces work. Also, the last SOSORT advancement, the classification of braces (Negrini 2022), helps to describe but does not further our understanding. The current literature reports a wide variation in brace results. The BRaIST study clearly showed that braces work (Weinstein 2013) but also reported a failure rate as high as 28%. In the SOSORT Community, in the same population, this rate is below 5%, as reported by many authors (Aulisa, De Mauroy, Dolan, Negrini). Compliance could be a factor in this variation, but very few studies have examined how to increase it (Negrini 2024).

Regarding exercise-based treatment for idiopathic scoliosis, SOSORT defined the characteristics of these exercises (Weiss 2005) and subsequently considered the rationale for defining SSEs: the combination of autocorrection and stabilisation. Nevertheless, in that Consensus, it was already clear that the exercise-based intervention should not focus solely on the "physical" actions of exercise (autocorrection, stabilisation, etc.), but should also include a lot more, such as information for the family, activities of daily living, and psychological aspects (Figure).

Autocorrection 3D	97%	90%	0%	7%
Theoretical information for the patient and family	87%	53%	27%	7%
Stabilisation	87%	50%	23%	13%
Self perception	87%	43%	33%	10%
Activities of daily living	83%	53%	20%	10%
Muscular endurance	83%	30%	33%	20%
Psychological aspects	77%	43%	20%	13%
Respiratory education	77%	27%	27%	23%
Neuromotorial control of the spine	70%	33%	30%	7%
Proprioception and tactile	70%	27%	33%	10%
Equilibrium	70%	20%	37%	13%
Restoring of physiological spinal curvatures (sagittal plane)	67%	57%	7%	3%

Later, when publishing the first SOSORT Guidelines, we added the term "physiotherapic" not to introduce a professional role, but to emphasise that exercise-based treatment is more than simple exercises (Negrini 2011). Since then, no further progress has been made in our understanding, and studies have mostly focused on the "physical" aspects of exercises, while the comprehensive approach to children with idiopathic scoliosis is not currently in focus.

One possible way forward is to consider the approach to children with idiopathic scoliosis as a complex intervention (UK Medical Research Council (MRC) 2021), in which multiple factors play a crucial role in determining the final outcomes. Studying complex interventions requires a clear description of the intervention (Levack 2024). Recently, Cochrane Rehabilitation developed a Reporting Guideline to provide a complete and thorough description of interventions in the field of rehabilitation (and habilitation), called GUIDE-Rehab (Guideline for Interventions Description in Rehabilitation) (Negrini 2025), entirely based on the Rehabilitation Treatment Specification System developed over 20 years and supported by the American Congress of Rehabilitation Medicine (Van Stan 2021). GUIDE-Rehab aims to open the so-called "black box" of rehabilitation interventions

and can offer us a framework for describing in detail what we do in our daily practice to achieve the best possible results through a complete treatment.

We propose using GUIDE-Rehab to develop a new SOSORT Consensus and to describe comprehensive care and habilitation of children with non surgical idiopathic scoliosis that focuses not solely on the spinal deformity but also on the child and their proper and complete development. Such a Consensus could enable the SOSORT community to take another step forward in delivering the best possible treatment for our patients.

Methods

Design: qualitative study including a Delphi process and Consensus.

Directors: Sabrina Donzelli, SOSORT President; Dariusz Caprowski, SOSORT Chair of the Consensus Committee; Stefano Negrini, expert in GUIDE-Rehab. Secretary: Prachi Bakarania, SOSORT General Secretary.

Participants: they are divided into two groups:

- The multiprofessional expert panel shall direct the Consensus and shall include people with strong clinical and scientific expertise covering the whole spectrum of treatments (braces and exercises).
- Participants in the Delphi round take part in the Consensus process and include people with strong clinical expertise, preferably covering the whole spectrum of treatments (braces and exercises).

The expert panel includes a maximum of 8 people, other than the Directors and the Secretary, chosen in response to a call and subsequent ranking, in accordance with the following criteria:

- Minimum 2, maximum 4 panelists per type of provision (prescribers, brace providers, SSE providers)
- Maximum 2 persons per country
- Balanced coverage of the 3 world regions (Americas, Eurafrica, Australasia)
- Inclusion of at least 1 patient, who must not be a prescriber or provider of scoliosis treatment

The inclusion criteria for the expert panel will be differentiated by provider type as follows.

expertise	Clinical	Scientific
	Last 15 years	Last 10 years
Prescribers	Minimum 500 patients per year with a prescription of brace + SSE	First/Last/Corresponding author of published papers on braces or SSE

SSE providers	Minimum 100 patients per year treated with SSE and wearing a brace	First/Last/Corresponding author of published papers OR presenter at SOSORT or other international Meetings on SSE
Brace providers	Minimum 500 braced patients per year with minimum 10% performing SSE	First/Last/Corresponding author of published papers OR presenter at SOSORT or other international Meetings on braces
Patients	3 years of treatment with braces and SSE	

The participants in the Delphi Rounds and the final Consensus must also be experts, with the difference that only the clinical criteria from the last 10 years are considered

expertise	Clinical Last 10 years
Prescribers	Minimum 500 patients per year with a prescription of brace and/or SSE
SSE providers	Minimum 100 patients per year treated with SSE
Brace providers	Minimum 500 braced patients per year
Patients	3 years of treatment with braces and SSE

Procedure: The meetings will involve the expert panel, while the Delphi rounds will involve all the experts. Each item will be approved if 80% agreement is reached. As per our previous Consensus, the research steps could be as follows.

STEP	METHOD	DEADLINES	MEETING
DEFINITION OF THE PANEL	Call	11/1	
DEFINITION OF THE METHODOLOGY AND PRESENTATION OF GUIDE-REHAB	120' Meeting	18/1	TBD
BRAINSTORM TO DEFINE THE PRELIMINARY LIST OF TARGETS	90' Meeting	25/1	TBD
IDENTIFICATION OF THE TARGETS AND COLLECTION OF OTHER PROPOSALS	Delphi	8/2	
PRESENTATION OF THE RESULTS BRAINSTORM TO DEFINE THE INGREDIENTS TO ACHIEVE THE FIRST SET OF IDENTIFIED TARGETS	120' Meeting	22/2	TBD
IDENTIFICATION OF THE INGREDIENTS OF THE FIRST SET OF IDENTIFIED TARGETS AND COLLECTION OF OTHER PROPOSALS	Delphi	1/3	
BRAINSTORM TO DEFINE THE INGREDIENTS TO ACHIEVE THE SECOND SET OF IDENTIFIED TARGETS	120' Meeting	15/3	TBD

Identification of the ingredients of the second set of identified targets and collection of other proposals	Delphi	22/3	
Presentation of the results and agreement on elements to discuss at the final Consensus Meeting	120' Meeting	5/4	TBD
Consensus Conference		29/4	

Authorship criteria: the directors and secretary will be main authors; the expert panel and Delphi Round participants will co-author the paper, provided they participate in ALL the stages (all Meetings and Delphi Rounds for the expert panel, all Delphi Rounds for participants). Who will participate in at least one stage will be listed as contributor under the common name “participants to the 2026 SOSORT Consensus”.