

For immediate release:

**International Experts Launch a Foundational Set of Standards
to Measure and Improve Preterm and Hospitalized Newborn Health Globally**

BOSTON, Massachusetts, August, 13, 2020: The International Consortium for Health Outcomes Measurement (ICHOM) announced the release of their Preterm and Hospitalized Newborn Health Standard Set (NEO-SS) today.

Health professionals, patient advisors, and recognized leaders from across Europe, Africa, the Americas, Asia and Australia have joined forces to establish and launch a global set of outcomes that reflect what matters most to the parents of preterm and hospitalized newborns - independent of treatment or diagnosis, from birth to 5 years of age.

This collaboration is facilitated by ICHOM and made possible by the generous contribution of the European Foundation for the Care of Newborn Infants (EFCNI). The NEO-SS was developed by the ICHOM Preterm and Hospitalized Newborn Health Working Group, comprised of 21 international experts and patient representatives, from 20 organizations across 15 countries. A full list of organizations and representatives involved in the ICHOM Preterm and Hospitalized Newborn Health Working Group is available [here](#).

Patient Advisor and NEO Working Group Member Silke Mader, European Foundation for the Care of Newborn Infants, Germany shares: "As a patient representative, but first and foremost as a mother of a son born preterm over 20 years ago, I very much appreciate that the ICHOM project took great care to engage with patients and parents from the very beginning. To develop standards of optimal care for hospitalised newborns requires the input and feedback from those who have experienced the immediate impact of preterm birth and the sometimes lifelong consequences that follow. For children born preterm and their parents, it is one thing to survive but quite another to thrive and be happy and healthy. Therefore, I am very pleased with the patient- and parent-centred perspective that has been used in this project. I really hope this will be an example to follow for future medical research projects – for the sake of both patients and professionals."

The Preterm and Hospitalized Newborn Health Standard Set

The NEO-SS is a minimum core set of standards, comprised of Patient and Clinician - Reported Outcome Measures already being collected by many practices in routine clinical care. The NEO-SS measures 21 outcomes under the ICHOM framework for comprehensive outcomes measurement. These overarching domains are Social Functioning, Mental Functioning, and Physical Functioning.

To help ensure the Standard Set is relevant across contexts, the Working Group also recommended a series of Case-Mix, risk adjustment factors, to be collected along with the outcomes measured. These cover baseline clinical, treatment-related, demographic and lifestyle factors to ensure that patient populations can be compared between settings.

In order to minimize the burden placed on clinicians to collect the outcomes of the set, these were chosen to be measured during the initial hospitalization period, at 2 and then 5 years of age. Packages of

clinician- and patient-reported measures were recommended at each of these timepoints . Measuring, reporting, and comparing these outcomes can help develop best practices in preterm and hospitalized newborn care; ultimately generating value and better outcomes for patients worldwide. With the chosen measures available in several languages, the Standard Set is slated to have increased adoption across countries.

An open-source [Reference Guide](#) has also been created, outlining recommendations for administering the set, time points, and a data dictionary for organizations to begin implementation.

Consumer Review Period:

The Outcomes recommended by the Working Group were also validated during an Open Review period. 92% of patient and caregiver respondents from a diverse range of cultural and economic backgrounds agreed that all important outcomes are covered.

Of the professionals and administrators surveyed across 15 countries, 96% approved of the outcomes chosen for the set, 90% of the measures recommended for each timepoint and 88% of the case-mix variables. There was over 78% agreement that there were no critical concepts missing from the outcomes or packages of measures being recommended by the Working Group.

The Future of NEO-SS:

From its inception, ICHOM has made Standard Sets open source. Now that this recommendation is finalized, the real work can begin, ushering in a new season for Value Based Health Care for preterm and hospitalized newborns. It will be invaluable to learn from implementation pilots that may emerge across the globe and inform future iterations of this global set of standards.

The Chair of the Working Group, Andreas Flemmer, MD, Ludwig Maximilians University of Munich says, “When I agreed to chair the working group for the ICHOM Standard Set for Preterm and Hospitalized Neonates, I was quite curious where this work would lead us. The subsequent preparation and discussions with working group members, patient and parent representatives during the journey towards the final set were an exciting experience. Thanks to the participation of specialists, parents and previously preterm, as well as an excellent ICHOM team, I am confident that we were able to agree upon a set of important outcomes that may now help centers caring for this vulnerable group of patients. The goal would be to assess outcomes prospectively and thus make it possible to evaluate daily practice as well as post-discharge support for these infants.

It was a pleasure to work in this team and I am very much looking forward to seeing how the set will be introduced into clinics.”

For more information on the NEO-SS, the standard set flyer can be downloaded [here](#) and the reference guide [here](#).

More Information on The International Consortium for Health Outcomes Measurement:

ICHOM’s mission is to unlock the potential of value-based health care by defining global standard sets of outcome measures that matter most to patients and driving adoption and reporting of these measures worldwide to create better value for all stakeholders. ICHOM was founded in 2012 by Professor Michael E. Porter of Harvard Business School, the Boston Consulting Group, and Karolinska Institute.

Visit www.ichom.org for more details.