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ECHO Measurement Framework for Assessing Environmental Influences on Child Health

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Abstract

Purpose of review—Diverse methodologic approaches pose significant challenges to assessing environmental exposures effects on child health outcomes. While transdisciplinary research efforts offer unique opportunities for understanding the complex and multidimensional facets of lifespan health and disease trajectories, a shared measurement strategy is necessary for ensuring cohesion and comprehensibility across disciplines and domains.

Recent findings—Exposure science often focuses on one life stage, one primary outcome domain, and/or one environmental context without regard for understanding the complexity of exposome pathways and outcomes across a developmental continuum. As part of the National Institutes of Health (NIH) Environmental influences on Children’s Health Outcomes (ECHO) Program, the Person Reported Outcomes (PRO) Core developed a unifying measurement framework that takes a lifespan development approach to assessing physical, mental, and social health outcomes within the complex matrix of environmental exposure pathways.

Summary—The proposed framework offers a shared methodological approach to health outcome assessment, with a particular emphasis on PROs. This framework will be instrumental for future large-scale consortia and transdisciplinary team science efforts by providing a common structure, measurement guidance, and consistent terminology.

Keywords

Measurement; Person Reported Outcomes; ECHO; lifespan development

Introduction

Environmental exposures profoundly shape lifespan health and disease trajectories [1, 2]. Robust evidence from pre-clinical and clinical studies shows that pre- and perinatal exposure can permanently alter the developing brain and associated regulatory systems to increase

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susceptibility to a host of diseases and developmental challenges, at levels of exposure not generally toxic to adults [3–5]. Adverse environmental exposures have short- and long-term consequences for children’s health [6]. Conversely, positive exposures, such as early childhood high-quality caregiving [6, 7], can promote health and well-being [8]. However, because prior research emanates from diverse disciplines with varied methodologic approaches (e.g., behavioral teratology, environmental epidemiology, sociology, pediatrics), a comprehensive measurement framework for assessing the impact of exposures on child health and disease outcomes is lacking. Such an absence impedes cross-study comparisons and replications, as well as the ability to draw causal conclusions so vital to prevention.

As part of the Environmental influences on Children’s Health Outcomes (ECHO) Program, the Person Reported Outcomes (PRO) Core addresses this deficiency by employing state-of-the-art measurement science strategies to develop a unifying measurement framework for assessing a range of environmental exposures on diverse child health outcomes. This framework has guided the creation of the ECHO-wide Cohort Data Collection Protocol, which unites 83 individual cohort studies via a common set of data elements and measures driven by high-impact scientific questions addressing ECHO’s five primary child health outcomes: obesity; upper and lower airways (e.g., asthma); neurodevelopment; pre-, peri-, and postnatal health; and positive health (assets that strengthen an individual’s capacity to adapt, satisfy needs, fulfill goals) as well as the recent addition of an ECHO focus on Neonatal Opioid Withdrawal Syndrome (for an overview of ECHO, see Gillman & Blaisdell p. X in this issue).

Framework Overview

The overall aim of the proposed measurement framework is to provide structure and guidance regarding assessment of child health outcomes within their biological, psychological, social, and environmental contexts and to use exposomics, the comprehensive measurement of exposures and associated biological response pathways over development, to assess cumulative risks and promote health. This multi-level approach accounts for the complex matrix of exposures and the downstream effects on child health from preconception through early adulthood by recognizing health as continuous and transactional, resulting from multiple interactions with levels and types of environmental contexts. This will optimize discovery of exposure-related heterogeneity in disease expression across development and across socioeconomic or geographic boundaries.

The following framework for lifespan health outcomes (including parent and developing child), builds on the PROMIS and NIH Toolbox initiatives and incorporates the World Health Organization’s domains of physical, mental, and social health [9]. Particular emphasis is placed on person-reported outcomes (PROs) as a complement to exposure and biological response biomarkers, with laboratory analysis occurring simultaneously to provide the most holistic understanding of child health outcomes. [10, 11]. Broadly defined as *any measures of an attribute of a person that requires assessment*, PROs are cross-cutting as they focus on both health *and* disease, as opposed to the traditional binary framing of presence/absence of disease. PROs also encompass developmentally-based measurement strategies; and enable precise tracing of the impact of children’s exposure history [12, 13].

The measurement framework outlined here emphasizes Child Health Outcomes (Figure 1) and Parent Health and Functioning (Figure 2), as parents represent a proximal bio-ecological environment that affects child health (for a review of the broad spectrum of exposome measurement, see [14, 15]). While this framework was developed as part of ECHO, the core components (i.e., domains and organizing constructs) apply to broader research endeavors assessing environmental exposures on child health outcomes. Further, specific measurement examples from ECHO help contextualize the framework as well as provide foundational strategies for common measurement selection in future large-scale consortia research. Key considerations include balancing 1) exposure biomarkers; 2) developmentally sensitive measures with lifespan coherence—both “tried and true” legacy measures as well as innovative advancements in measurement approaches and techniques (e.g., dimensional assessments that capture the full range of normal/abnormal variation, computer adaptive testing); and 3) efficiency of PROs with nuanced performance-based and observational assessments.

Child Health Outcomes - Physical Health

This domain focuses on the structural, functional, and somatic aspects of physical health, beginning in utero and extending throughout childhood and adolescence. This approach allows for detection of early fetal abnormalities as well as identification of malformations that may not present until childhood [16] while also acknowledging the experiential component (i.e., symptoms) associated with physical health. The two organizing constructs within this domain are 1) *Growth and Development*; and 2) *Somatic Experience and Physiological Functioning*. Within this domain, ECHO places primary emphasis on three outcome areas reflecting: (a) perinatal outcomes proximal to exposure; (b) pediatric health risk pathway (i.e., obesity) that presages chronic diseases of the lifespan; and (c) a prevalent pediatric health condition (i.e., asthma) strongly tied to adverse exposures.

Growth and Development includes assessing attributes related to body size (e.g., length/height, weight, waist circumference) and composition (e.g., percent lean body mass, fat distribution), as well as growth trajectories and subsequent childhood obesity outcomes. ECHO has a particular focus on perinatal growth and development given the presaging developmental health risks associated with structural and functional neonatal abnormalities including more vulnerable organ systems and childhood obesity [17]. Attributes of neonatal growth include: 1) neonatal body composition measured via the Pondral index and biometry; 2) birth defects or congenital anomalies using medical records and, when valid, parental report; 3) birthweight, with specific indicators for low birthweight (<2500 grams); and 4) gestational age at delivery, particularly for preterm birth (<37 weeks post-Last Menstrual Period [LMP]).

Somatic Experience & Physiological Functioning refers to somatic and physical disabilities where effects can be direct and indirect (through disease onset), with particular sensitivity to adverse early exposures [17–21]. Components include: 1) motor development (e.g., reflexes, gross/fine motor development, strength, and endurance); 2) sleep health and ecology (e.g., regulation of sleep/wake cycles and circadian rhythm); 3) neuro-sensory functioning (e.g., vision, hearing, taste/olfaction, and vestibular balance); 4) organ system

function (e.g., cardiac, pulmonary, kidney, liver, and gastrointestinal functioning); and 5) symptoms (e.g., pain, fatigue).

While all components of this domain are covered in ECHO using such methods as PRO measures to assess how physical disabilities interfere with a child's everyday life and physical functioning (e.g., PROMIS Pediatric Asthma Impact [22]) or performance-based assessments to measure actual physical functioning (e.g., NIH Toolbox Motor Battery [23]), one area of particular interest to ECHO investigators is sleep health. Measured from birth through adolescence, sleep *health* captures timing, chronotype, duration, quality, and satisfaction. Sleep *ecology* assesses sleep routines and practices. In addition to novel measurement approaches with wearable technology, sleep health and ecology are primarily assessed in ECHO by self-report. The Brief Infant Sleep Questionnaire – Extended (BISQ-E) Parent Report [24] assesses this construct in infancy (0–2yrs), while age-appropriate versions of the PROMIS Pediatric Parent Proxy Sleep-Related Impairment and Disturbance scales are used in early and middle childhood (2–7yrs); from age 8 through adolescence, parallel PROMIS scales developed for child self-reporting are used [25].

Child Health Outcomes - Mental Health

This domain captures how the child organizes, regulates, and processes information from, as well as through interactions with, the environment, including atypical neurodevelopmental processes and their clinical expression (e.g., autism, oppositional defiant disorder, depression, ADHD) as affected by exposures [26–29]. Measurement involves child self-report, parent proxy report, observation, and performance-based measures. Special attention is paid to innovative measurement approaches and instruments that are sensitive to development, or those that assess skills, processes, and outcomes across the full range of normative variation, and atypical functioning defined in relation to age-graded capacities [13, 30]. This domain is organized around three concepts: 1) externalizing and internalizing spectrums; 2) social cognitive processes; and 3) cognition, all of which have been robustly linked to early life exposures [31–34]. Although prior behavioral teratologic research has relied on traditional clinical classification systems, it is increasingly evident that exposure-related problems in this domain require sensitive, developmentally-based measurement of dimensional constructs [35–37].

Behavioral and Emotional Self-Regulation reflects a child's capacities for behavioral, attentional, and emotional control in response to demands of the real-world environment [38] as well as volitional deployment of cognitive resources in the face of competing stimuli [39, 40]. Development of such capacities manifests as emotional and behavioral self-regulatory competency and positive health outcomes [41, 42]. When these capacities do not develop well, mental health problems tend to occur [41, 43]. On the “externalizing” side, normative developmental processes are those underpinning behavioral regulation, including compliance, attention orienting, self-control, and persistence [41, 43]. Clinically, atypical patterns are encompassed within an externalizing spectrum reflecting syndromes of under-control, including ADHD, Oppositional Defiant Disorder, Conduct Disorder, and substance use/abuse [43–46]. On the “internalizing” side, normative developmental processes support emotion regulation including both temperamental differences in affectivity and regulatory

strategies [43, 47, 48]. Clinical manifestations reflect the emotion dysregulation of the internalizing spectrum such as depression, anxiety, and post-traumatic syndromes [49, 50].

ECHO employs a developmental framework that captures assessment of early developmental processes that may serve as precursors to psychopathology (e.g., The Infant and Child Behavior Questionnaires [51, 52]), traditional symptom-based behavioral checklists (e.g., BASC [53] and CBCL [54]), and developmentally-based dimensional assessments emphasizing normal/abnormal differentiation within developmental context (e.g., Multidimensional Assessment Profile of Disruptive Behavior [MAP-DB][55]). For more nuanced assessment during early childhood when children cannot be interviewed, performance-based assessments are recommended, such as the as the Berkeley Puppet Interview Symptomology Scales (BPI-S)[56], as are standardized diagnostic observations, such as the Disruptive Behavior Diagnostic Observation Schedule (DB-DOS) [57] and the Anxiety Diagnostic Observation Schedule (ANX-DOS) [58]. These in-depth observational assessments provide unique, developmentally-appropriate complements to parental report of externalizing and internalizing patterns.

Social Cognition focuses on the development of intrapersonal social abilities, and includes sociability, social responsiveness, and social capacity. These measures are distinguished from those measured in the Social Functioning domain because they are intrinsic to the child. A child's level of social responsiveness, for example, reflects *intrapersonal* neurodevelopmental functioning, not *interpersonal* interactions. Normative capacities include joint attention, theory of mind, and shared positive affect, while atypical processes include the clinical features of Autism Spectrum Disorder (ASD) [59].

In ECHO, the majority of cohorts do not include ASD as a main outcome focus, thus requiring a measurement approach that balances efficiency with depth to assess the social cognition domain. To achieve this, ECHO includes the full version of the Social Responsiveness Scale (SRS) [60] as well as an option to use the newly-developed SRS short form [61], both of which are dimensional measures of underlying ASD-related phenotypes. These parent report questionnaires enable feasible and meaningful data contributions from every child in ECHO, with ASD-specific risk screeners (e.g., M-CHAT) [62] and in-depth measures (e.g., Autism Symptom Interview [63], video-referenced Reciprocal Social Behavior scale [vr-RSB] [64]) recommended for more specialized studies seeking the full range of variation in early manifestations of ASD-related impairment in early childhood.

Cognition refers to neurocognitive development and information processing and is typically evaluated using experimental performance-based discrete tasks that measure a range of specific sub-concepts of general intelligence. Within our framework, the organizing facets of cognition are: 1) *receptive and expressive language*, including symbolic communication and pre-language, word learning, lexical, syntactic, and pragmatic development, and the language/cognition interface in which words acquire generalizable meaning [65, 66]; 2) *fluid reasoning*, or the ability to apply logical thinking to solve novel problems, including visual-spatial processing and pattern recognition [67]; and 3) *executive function*, or cognitive processes serving goal-oriented behavior, including working memory, cognitive flexibility, and inhibitory/effortful control of pre-potent responses [41, 68].

At the earliest ages (0 to 36 months), measurement focuses on key developmental milestones via such performance-based instruments as the Mullen Scales of Early Learning [69], Bayley Scales of Infant and Toddler Development [70], as well as parent-report measures such as the Ages and Stages Questionnaire [71]. Cognition measures at older ages include full-scale and abbreviated scales of intelligence (e.g., Wechsler [72] and Stanford-Binet Intelligence Scales [73]), as well as newer touchscreen-based cognition batteries such as the NIH Toolbox Cognition Battery [74–76]. For executive function measurement in particular, performance-based measures are favored due to relatively poor correspondence of parental rating measures with performance-based tasks [77].

Child Health Outcomes - Social Health

This domain describes the developmental processes and perceived functioning of social relationships and the enactment of social interactions and broader role performances in a range of social contexts. Conceptually organized around the most proximal social ecologies [78] (e.g., family, peers, school, and community), the social health domain is characterized by both the *quality* of social interactions as well as the *competencies* of social participation, with two primary organizing constructs: *Social Relationships* and *Social Role Functioning & Performance* (Figure 1).

Social Relationships describe the structure and quality of interactions an individual has with others in a range of social contexts. Positive relationships are fundamental to child attainment of short and long-term health and developmental outcomes [79], with the quality of such relationships representing the basic human needs of care and affiliation. ECHO emphasizes three types of social relationships: 1) *family relationships*, which includes the stressors and supports between and with all family members, with particular emphasis on the unique features of the child-parent relationship and caregiving quality; 2) *peer relationships*, including feelings of being accepted and supported by peers as well as social withdrawal, peer rejection, and bully victimization; and 3) *teacher connectedness*, which describes the child's perceptions that teachers are invested in their personal and academic lives.

Measurement for all three social facets emphasizes the child's subjective experience of feeling accepted, cared for, and supported by others, as well as feeling that others can be trusted and depended on for help and understanding [80]. Particularly in early development, observed parent-child interaction is a key assessment tool to enable measurement of dyadic processes that transcend individual behaviors [81, 82]; in ECHO tools such as the NICHD Parent-Child Interaction Observation [83] and the HOME Inventory [84] are used to capture caregiving quality in the early years. Such direct observation measures are complemented with parent questionnaires describing various components of family relationships, such as cohesion and conflict (e.g., Family Environment Scale [85]). In subsequent life stages, measurement focuses on parent proxy and child self-report measures, including several PROMIS and NIH Toolbox Social Health Domain questionnaires (e.g., PROMIS Peer and Family Relationships scales [86, 87] and the NIH Toolbox Positive Peer Interactions scale [88]) as well as the Panorama Student-Teacher Relationships scale to assess teacher connectedness [89].

Social Role Functioning & Performance reflects performance in life areas that are socially and culturally recognized as important for people given their developmental level. Individuals adjust how such “performances” based on the social roles of importance to specific cultural contexts, audiences, and developmental level, and through such performances, develop their social identity [90].

For children and adolescents, one of the most salient contexts for social role performance and functioning is the school environment. This includes both *academic performance*, or how well a child is doing in school and in specific subject areas, as well as *student engagement*, which represents a child’s interest in school and motivation to succeed. Measurement focuses on PROs starting in the preschool years (ages 2 to 5) with the National Children’s Health Survey parent report of early academic abilities [91] and continuing with parent proxy and child self-report measures using the Healthy Pathways Academic Performance scales [12, 92]. Student engagement assessment draws on the Panorama School Engagement Scales for 3rd–12th graders to capture children’s own attitudes toward school [89].

Parent Health and Functioning

As both a biological risk transmission and the most proximal environmental influence on children’s physical, social, and mental health, parents represent a particularly salient pathway through which exposures are transmitted. Parents are also an environmental exposure in and of themselves and can mediate (both positively and negatively) the extent to which the full range of environmental exposures ultimately affect such child health outcomes. Measurement of parent health and functioning parallels that of child health, with physical, mental, and social domains. Given ECHO’s focus on child health outcomes, we highlight representative measurements from each component to exemplify exposure risk, biological and social risk transmission, and the extent to which the parent exposure pathway ultimately adversely affects children’s health.

Parent Physical Health focuses on 1) *physical functioning*, which focuses on structural components including height, weight, body composition, and obesity status; and 2) *somatic experience and physiological functioning*, which captures an individual’s experience of symptoms such as pain, fatigue, and sleep health, as well as organ system functioning (e.g., motor, neuro-sensory, sexual function and need for assisted reproduction). In addition to physical exams and medical record data, parent physical health is assessed via PROs, including the PROMIS Sleep Disturbance and Sleep-Related Impairment scales as well as the PROMIS Global Health scale, which includes specific items related to an individual’s self-reported overall physical health [93, 94].

Parent Mental Health includes measures of negative and positive affect, experiences of stress and well-being, health risk behaviors such as smoking and substance abuse, and cognitive function. Of the three parent health domains, mental health is emphasized the most in ECHO, given associations between parents’ neuropsychological health and a wide range of child health and developmental outcomes [2, 3, 34]. In particular, maternal mental health in the preconception, prenatal, and postnatal time period is highlighted, including measures

of childhood trauma, depression, anxiety, and stress, which represent adverse risks to fetal and infant development. Additional measures of health risk behaviors, such as smoking, alcohol use, and other substance use/abuse, are also included in this domain. PROs are the primary measurement strategy, and ECHO leverages the unique features of PROMIS Mental Health domain scales (e.g., depression, anxiety) and NIH Toolbox Emotion domain scales (e.g., Perceived Stress Scale), as scientifically rigorous, low burden assessments – including options for short forms and CATs –that are harmonized with or identical to legacy measures [88, 95–98].

Parent Social Health refers to social functioning within and outside the family, and the quantity and quality of social relationships, ranging from conflict and isolation to companionship and intimacy. Given the negative impact of prenatal stress on subsequent child health outcomes [27, 32, 33, 44], ECHO emphasizes *social support* and *paternal engagement* during pregnancy, which provide buffers for and promote healthy child development. PRO measures include maternal reports via PROMIS Emotional, Informational, and Instrumental Support scales [93, 94] and the Early Childhood Longitudinal Study-Birth Cohort (ECLS-B) Paternal Involvement scale [99].

Conclusion

Exposure science often focuses on one life stage, one primary outcome domain, and/or one environmental context (e.g., built environment and associated chemical exposures), without regard for the complexity of understanding exposome pathways and outcomes across a developmental continuum. The proposed framework addresses this need by not only capturing the three primary domains of physical, mental, and social health within life stages, but also *across* life stages, with particular emphasis on consistent, developmentally-sensitive measurement to provide coherence from birth through early adulthood. Using a developmentally-based model of continuous outcome measurement across life stages provides opportunities to assess facets of child health in a manner sensitive to developmental capacities and constraints, while enabling meaningful linkages across all life stages. Overall, this framework provides a shared understanding of measurement strategies for conducting large scale consortia research and can be an impetus for future transdisciplinary team science efforts within ECHO and across the broader scientific research community.

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Key points

- The proposed measurement framework provides shared methodology to assessing children's physical, mental, and social health outcomes in large-scale, transdisciplinary research consortia.
- Key measurement considerations include balancing exposure biomarkers, developmentally sensitive measures with lifespan coherence, and efficiency of Person-Reported Outcomes (PROs) with nuanced performance-based and observational assessments.
- PROs offer opportunities to complement biomarker assessments and provide the most holistic understanding of child health outcomes in the context of diverse environmental exposures.

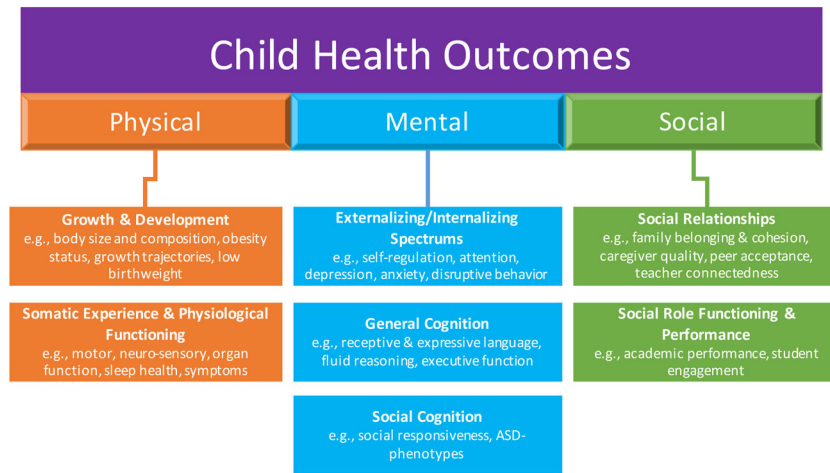


Figure 1. Child Health Outcomes Measurement Framework
 Adapted with permission from the PROMIS measurement framework, developed as part of the NIH-funded Patient-Reported Outcomes Measurement Information System (PROMIS®) (U01AR052177).

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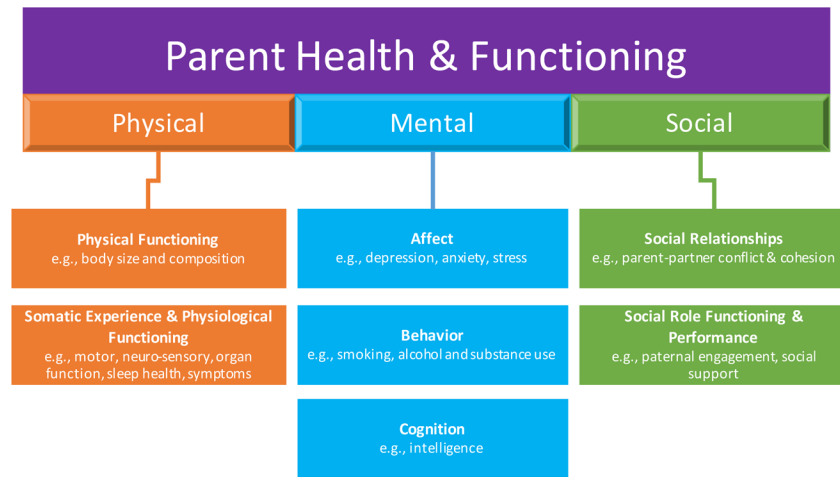


Figure 2. Parent Health & Functioning Measurement Framework
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