Pediatric Terminology Summit

Introduction

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Goals

1. Provide an update on the progress of the pediatric terminology initiative since 2012
2. Illustrate utility and develop specifications of terms through use cases
3. Discuss dissemination and uptake opportunities
4. Plan for next steps
Background Context

• Providing data is a gift of time, effort, privacy, and other factors
• Collecting data is a responsibility and an investment
• How can we respect the gift and protect the investment?
• Data can continue to be of value if:
  – Permission is granted to reuse the data
  – The data has content and format that allows others to accurately interpret it
  – The data can be combined with other data
Health Care Delivery & Clinical Research Systems

- Practice Guidelines & Policy
- Communication Plan & Incentives
- Individual Volunteer Education about research goals and risks & Permission to participate
- Individual Volunteer Transition Plan to return to Health Care Delivery System & Individual sharing of Study Results

HEALTHCARE DELIVERY SYSTEM

T2 Translational Research

CLINICAL RESEARCH SYSTEM

T1 Translational Research

Data & Specimen Repositories
- Data Sharing
- Aggregate Data & Specimens
- Data Pooling & Analysis
- Individual Data & Specimens

Exploratory & Efficacy Studies
- Individual Data & Specimen Acquisition under Regulatory Protection & Risk Management Plan
- Effectiveness Studies

Meta-analyses
- Publications
- Non-clinical laboratory and model studies

Effectiveness Studies
- Exploratory & Efficacy Studies
- Data Sharing
- Aggregate Data & Specimens
- Data Pooling & Analysis
- Individual Data & Specimens

Publications
- Meta-analyses
- Non-clinical laboratory and model studies

Non-clinical laboratory and model studies
- T2 Translational Research

T1 Translational Research
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- Aggregate Data & Specimens
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Effectiveness Studies
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T1 Translational Research
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NICHD Terminology Initiative

The NICHD terminology initiative is based on the following model

• Precise concepts -> defined terms to describe the concept
• Terms can be:
  – Mapped to other terms in other systems, if applicable
  – Inserted into a hierarchal framework
  – Linked to a developmental timeline
  – Used in many ways such as:
    • Variable names
    • Outcomes
    • Metadata
    • Values for tags
Need for human-machine interaction

• Data quantity and complexity require machines to compile, analyze, store, retrieve, and represent the data

• Interface between humans and machines is imperfect- humans interpret terms and their underlying concepts dependent on context, learning, and history

• Machines require instructions
Some concepts and terms defined

- **Typology** = classification or grouping based on common characteristics
- **Taxonomy** = classification or grouping based on origin
- **Ontology** = full listing of what exists in a system, how the entities can be grouped, related within a hierarchy, and subdivided according to similarities and differences = spectrum of child health specific concepts
- **Semantics** = how to describe or represent what exists = child health terminology
- **Syntax** = the formal relationships among the elements of the system = relationships among the child health concepts and terms