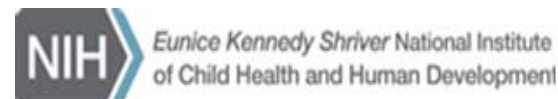


Pediatric Terminology Summit Introduction

Steven Hirschfeld, MD PhD
Captain, USPHS

Associate Director for Clinical Research
Eunice Kennedy Shriver National Institute of Child
Health and Human Development



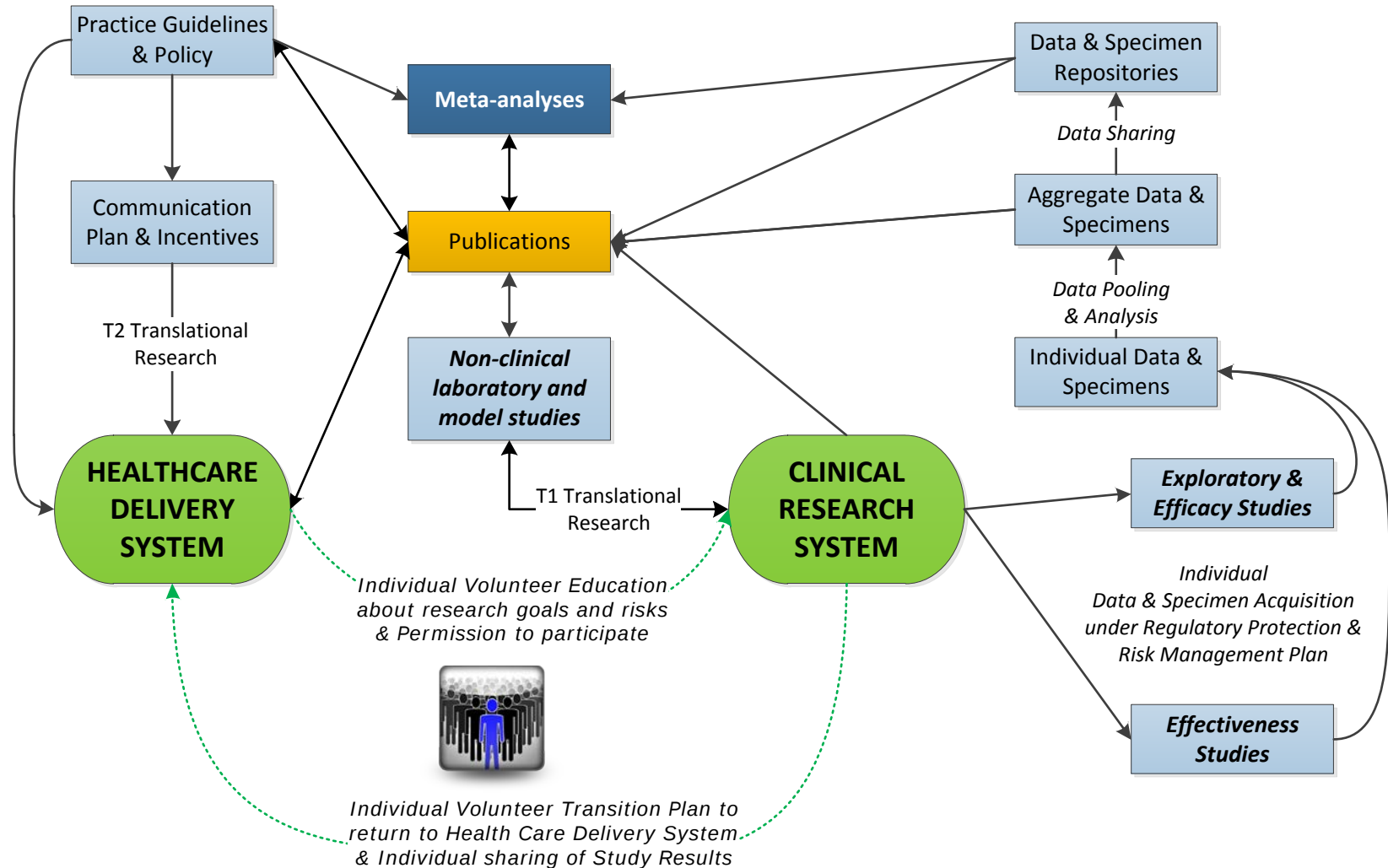
Goals

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



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 hierarchical 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

