**CoULD Research Strategy**

The mission of CoULD is to describe epidemiology, clinical characteristics, and health status of children with congenital upper limb differences, as well as quantify changes to function and health status with non-operative and surgical care.

The goal of the Research Committee is to oversee and guide scientific research and education related to CoULD. Committee charges include vetting and providing feedback for study proposals.

One challenge for the research committee is to determine when studies should be executed. The enthusiasm to be productive and disseminate early research must be balanced against our desire to maximize study power, produce valid findings based upon patient- (not parent-) centered measures, and assess longer-term outcomes. This balance is particularly important, as underpowered, parent-based, and short-term research findings may be invalidated by our own longer-term, patient-centered results.

To this end, we propose a strategy in which research would be conducted in three phases over time:

Phase I: Early studies based upon enrollment data and early follow-up

* Demographics
* Classification
* Reliability
* Health-status of non-operative conditions in older patients
* Research Process investigation

Phase II: Mid-term studies based upon surgical and non-operative treatment

* Prevalence of disease
* Cross-sectional studies- useful for evaluating associations including findings during procedures, surgeon’s choices at surgery, and patient characteristics and procedures performed.
* Surgical decision-making
* Treatment complications
* Comparisons of parent- and patient-reported health measures
* Value-based studies
* Research Process investigation

Phase III: Long-term studies based upon PRO’s into adolescence and adulthood

* Longer term outcomes of treatment (e.g. recurrent deformity, pain, arthrosis, function)
* Comparative analyses of different treatment

Phase I Phase II Phase III

Time 🡪