Creating a Sickle Cell Disease Learning and Improvement Network

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About NICHQ

Founded in 1999, NICHQ is an independent non-profit organization that partners with healthcare systems, foundations, government, payors, and family and community organizations to:

- Optimize healthcare system performance, and
- Identify and spread innovation and best practices
About NICHQ

_Vision_: A world in which all children receive the high quality health care they need.

_Mission_: To improve children’s health through improving the systems responsible for the delivery of children’s healthcare.
Two Certainties

- Care Varies
- Care not as good as it could be

- If you plotted a graph showing the results of all the centers treating any disease, what you tend to find is a bell curve: a handful of teams with disturbingly poor outcomes for their patients, a handful with remarkably good results, and a great undistinguished middle
- Atul Gawande, The Bell Curve
Third Belief

- Together—with patients and families—we can improve care and outcomes

% of Asthma Population with "Perfect Care"—CCHMC
WISCH Program Team

**NICHQ**
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**SCDAA**
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**Stanford/BMC**
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Transforming “National Coordinating Center” Model to Supporting a System of Improvement

National Coordinating Center (NCC) supports the capability of Network Sites to Implement Practices Effectively through HLC coaching and training.

Common Aims, Promising Practices, Common Measures

NCC provides a vehicle for learning across Sites through data about performance, learning sessions, website, individual coaching and group calls.

NCC synthesizes learning, modifies practices for further use by sites and broad dissemination.

Reports, public website

Sites learning more rapidly and achieving higher performance.

Sites implementing plans

CSCDC = COMPREHENSIVE SCD CENTERS
CBO = COMMUNITY BASED ORGANIZATIONS
FQHC = FEDERALLY QUALIFIED HEALTH CENTERS

WISH
Working to Improve Sickle Cell Healthcare
Integrating Two Programs—Common Content

**SCDTDP**
- Enhancing service delivery
- Improving access to care and decreasing barriers to care

**SCDNBSP**
- Increasing NBS follow-up
- Decreasing loss to follow-up
- Screening for emerging populations
- Trait counseling

- **Common systems of care**
- **Care coordination across networks**
- **Medical home for adults and children**
  - Transition of care
  - Increasing knowledge of SCD/SCT
- **Provision of recommended care**
Extended Collaborative or Improvement Network?

**Topic Selection**

- Enlist Teams

**EXPERT MEETING**

- Measures
- Aims
- Drivers & Change
- Faculty

**PRE WORK**

- Topic Selection

**FACULTY TEAM**

Available during Learning Sessions

- Coaching
- Performance Data
- Content Development
- Assessments
- Teaching

**Measurement and Feedback**

- LS 1 → LS 2 → LS 3 → LS 4 → LS 5 → LS 6

**SUPPORTS**

Available during Action Periods

- Listserv-faculty expertise
- Meeting Support
- Calls & Webinars-Faculty expertise
- Project logistics
- Extranet

**Dissemination**

**Sustaining Improvement**

**Spread**

**November 2011 to March 2014**

**Prepare Content**
Integrating Two Programs – Common Approach

SCDTDP
- Specific aims and project goals
- Measures
- Shared learnings regarding specific content
- Education materials

SCDNBSP
- Specific aims and project goals
- Measures
- Shared learnings regarding specific content
- Education materials

- Model for improvement
- Framework and care model
- Common aims and measures
  - Shared learnings
Improved outcomes and quality of life for individuals affected by SCD
- Decreased mortality
- Decreased morbidities, e.g.
  - Pain
  - Stroke
  - Acute chest syndrome
- Decreased utilization
- Improved function
- Humane patient experience

Primary Drivers

P1 Strong network vision, relationships, and plan

P2 Individuals, families and providers are knowledgeable & proactive

P3 PCP, CBO, HOSP: Reliable identification of SCD and trait, and follow-up

P4 PCP/HEME: care for persons with SCD is seamlessly co-managed

P5 ACUTE: Appropriate individualized treatment for acute episodes

Secondary Drivers

S1 Concurrent performance feedback

S2 Local leaders promote, recruit, organize

S3 Sustainable business model

S4 QI methods utilized routinely in strategy & operations

S5 Individual competence in self management

S6 Providers are prepared to treat SCD

S7 Reliable screening, counseling, and education for SCD and trait (>1 month old)

S8 Reliable newborn screening & follow-up

S9 Reliable provision of indicated treatment and immunizations

S10 Reliable annual health and healthcare assessment

S11 Care coordination based on individual care plan

S12 Access to care

S13 Timely triage and appropriate treatment in ED

S14 Practice- and community-level IT & decision support for planned & acute care
Keys to Success

- Early results
- Identify areas of common focus
- Champions
- Federal leadership
- Engagement of non-grant supported teams
- Data system—utility for care and improvement
“Better is possible. It does not take genius. It takes diligence. It takes moral clarity. It takes ingenuity. And above all, it takes a willingness to try.”

— Atul Gawande