

# ***Advancing Child & Family-Centred Care at SickKids: Grounded by an Organizational Assessment***

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# Child & Family-Centred Care Project

- **C&FCC is**

- Reflective of respect for, and partnership with, the child and family in health care delivery

- **C&FCC Project was designed to**

- Build from previous success and
- Provide a base from which to *advance* C&FCC across SickKids



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# Acknowledgements

**Family-Centred Care Advisory Council**

**Children & Youth Advisory Council**

**C&FCC Recommendations Development Team**

**SickKids Executive and Senior Leadership**



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# C&FCC Project Aims

To explore:

1. What is the **state** of C&FCC at SickKids?
2. What are the **leading practices** (internal & external) of C&FCC?
3. What practices, if extended or initiated, **promise optimal advancement** of C&FCC within SickKids?



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# Definition: Promising Practices in C&FCC

- **Care practices** (e.g family-centred rounding, joint care planning)
- **Processes** (e.g. system navigation, procedures like family presence @ induction)
- **Related structures & systems** (e.g. family representation on committees, administrative policies)



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# Methodology and Data Sources

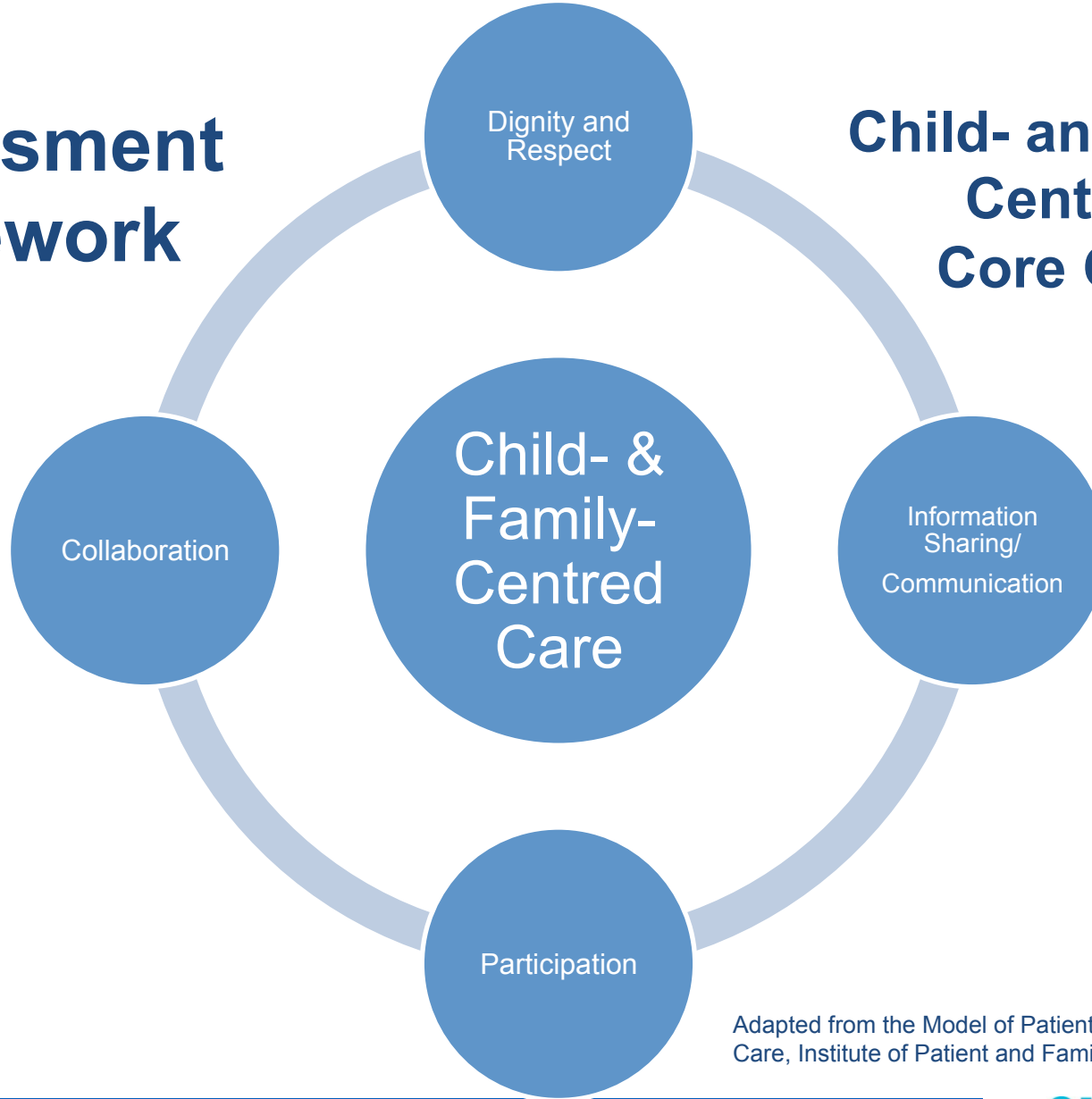
Internal	External
<b>Surveys</b> <ul style="list-style-type: none"><li>• 80% + managers submitted</li></ul>	<b>Literature Review</b> <ul style="list-style-type: none"><li>• Peer reviewed and web-based</li></ul>
<b>1:1 Interviews</b> <ul style="list-style-type: none"><li>• Physicians, key stakeholders</li></ul>	<b>External consultations</b> <ul style="list-style-type: none"><li>• Leading centres</li></ul>
<b>Focus Groups</b> <ul style="list-style-type: none"><li>• Children, families, teams, professional groups</li></ul>	



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# Assessment Framework

# Child- and Family-Centred Care: Core Concepts



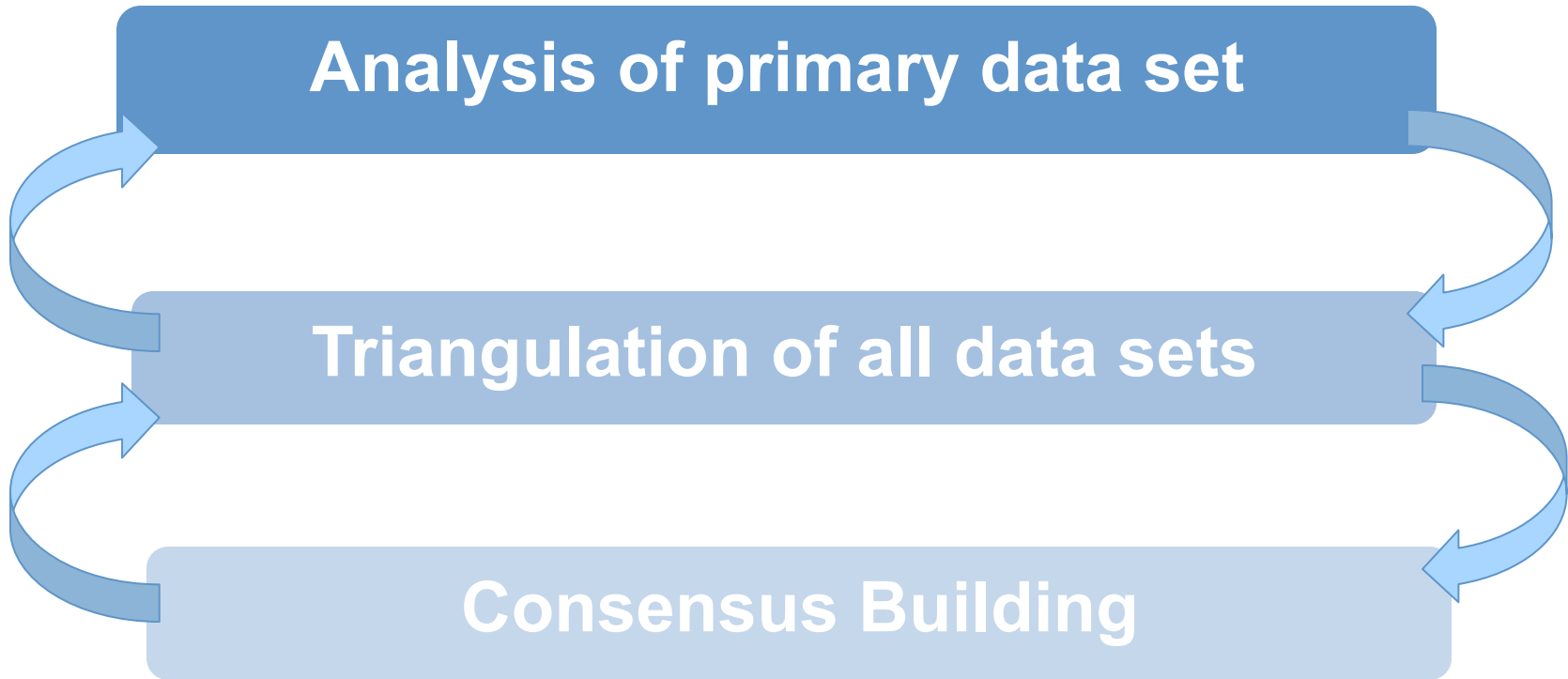
Adapted from the Model of Patient and Family-Centred Care, Institute of Patient and Family Centred Care, U.S.A



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# Information Gathering and Synthesis



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# Survey Design

## 8 categories, 144 items: primary data set

- 1) **level of agreement** on SickKids performance
- 2) **level of priority** for improvement or change at SickKids
  - leadership(8)
  - mission and definition of quality(17)
  - patients and families as advisors(22)
  - patterns of care(35)
  - information/education for patients and families (19)
  - charting and documentation (2)
  - patient and family support (7)
  - quality improvement(3)
  - environment & design(31)

Adapted from the Model of Patient and Family-Centred Care, Institute of Patient and Family Centred Care, U.S.A



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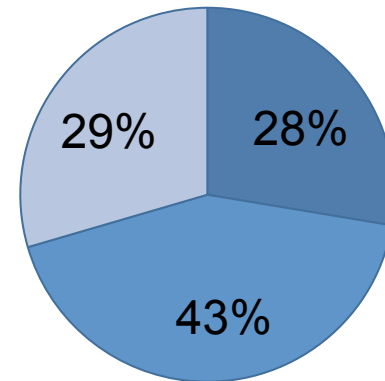
# Survey Responses

**Strong agreement**  
for minority (28%) of  
items

**Limited to Moderate  
agreement**  
for vast majority (>70%)  
of items

## Agreement with C&FCC practices

- STRONG (>80%)
- MODERATE (51-79%)
- LIMITED (<50%)



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# Strong agreement: exemplars

Based on the Managers ' assessment	
The SickKids <b>mission statement</b> articulates a commitment to the concepts of patient-and family-centered care	92.1 %
How SickKids describes <b>patient care</b> articulates the principles of patient-and family-centred care	97.4%
The importance of conveying <b>respect and preserving the dignity</b> of each patient and family	92.1%
There is continual, open, and honest <b>communication</b> among patients, families, and staff	94.8%



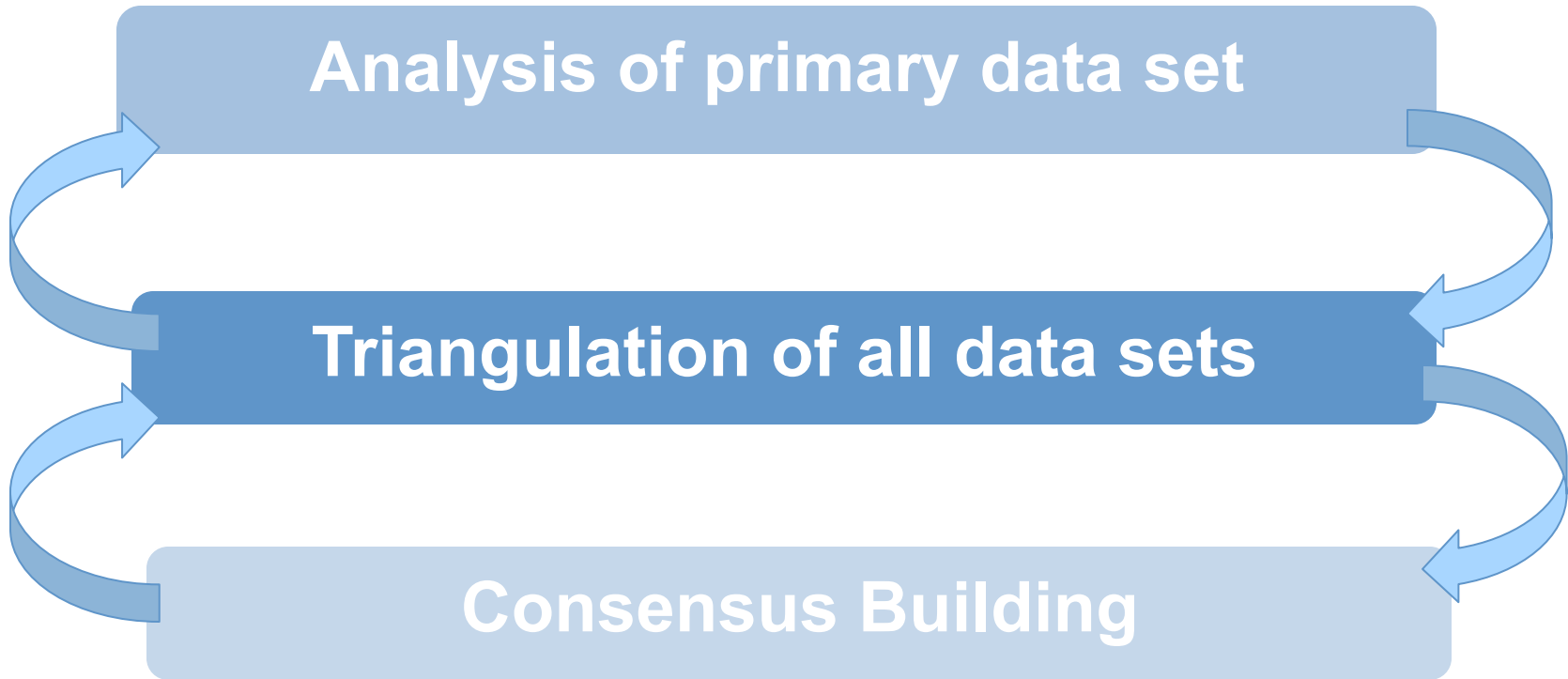
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# Limited agreement: exemplars

<b>Based on the Managers' assessment</b>	*high priority for improvement ** didn't know
Patients and families are involved in <b>orientation</b> and continuing <b>education</b>	8.1%**
Each patient has a single, identified <b>coordinator</b> of care.	39.5%*
Patients and families are involved in developing and evaluating <b>peer support</b> programs	28.5%
Patients and families are involved in <b>quality improvement</b> initiatives	42.1 %*
<b>Signage</b> is: helpful to patients and families, in the languages of the communities served	<30%*



# Information Gathering and Synthesis



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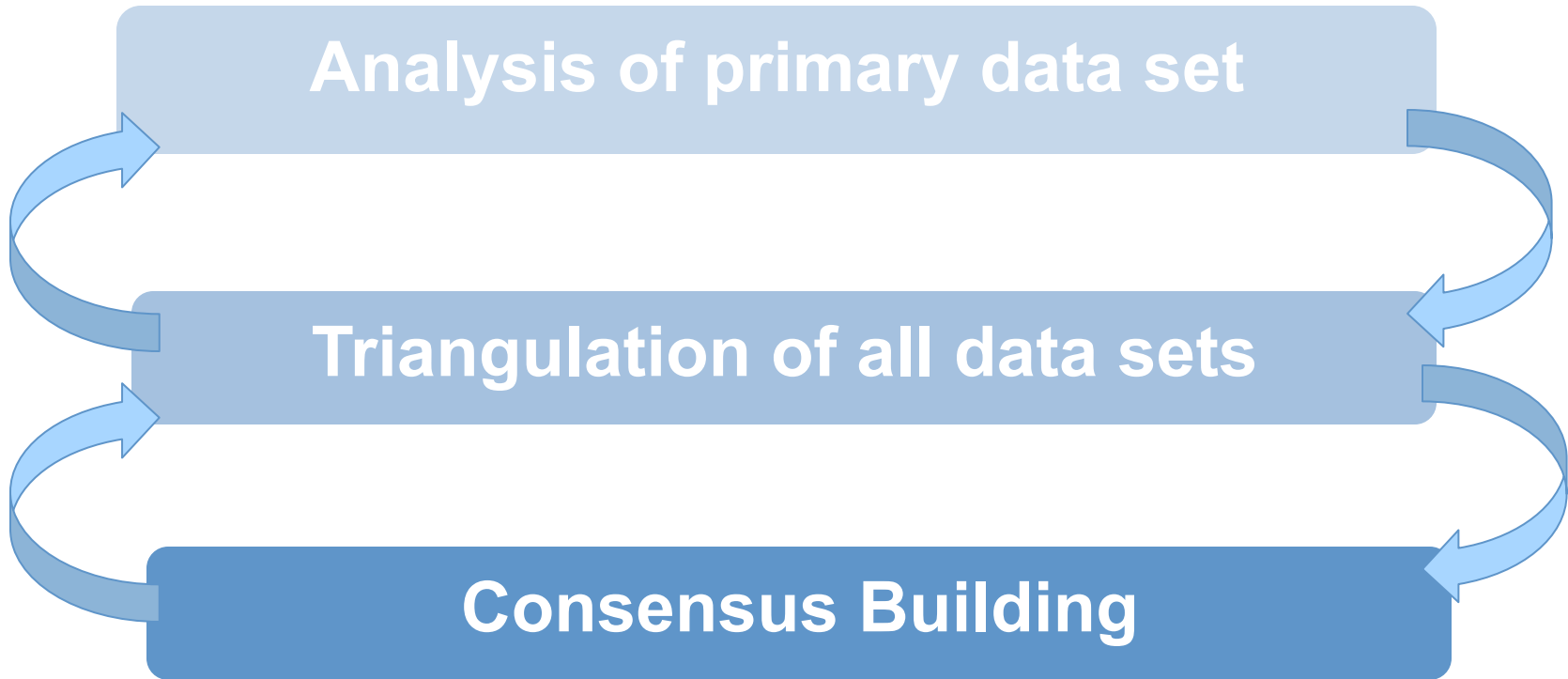
# Interim Considerations

- **Many leading practices & high engagement**
  - Suggesting **strong 'state' of C&FCC** with areas for improvement
- **Number of practices**
  - Too many to enable focus and promote action
- **Contextual information not ideally captured**
  - Specific ideas for improvement
- **Diversity and breadth of child/family perspective**



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# Information Gathering and Synthesis



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# Consensus Building

## Ranking

- Top 3 priority practices

## Among

- Family-Centred Care Advisory Council
- Children & Youth Advisory Council
- Recommendations Development Team



Photo by J. Blumberg (Sept 2012)  
SickKids Family-Centred Care  
Advisory Council



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# Challenges and Limitations

## Participants told us:

*“they are all important...we cannot (easily) choose”*

*“we know that we can always do better...”*



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# Project Team Considerations

- Feasibility, acceptability, sustainability
- Based in best evidence (if available)
- Access to ‘champion(s)’ and/or supportive infrastructure
- Potential costs: time and expense
- Balancing ‘quick wins’ vs. longer term aims
- Organizational or unit/front-line level practices
- Timely, ‘good fit’ with strategy



# Recommendations

- **12 priority practices recommended to advance C&FCC at SickKids**
  
- **Cross 4 core components of C&FCC and include:**
  - works in progress
  - inviting further exploration
  - merit action



# Dignity & Respect

Increased capacity  
for language  
interpretation &  
translation

- Family-activated service
- Translation at admission & discharge

Enhanced sibling  
support- to promote  
growth &  
development

- Physical recreation
- Parent/child play and learn
- Sibling celebrations



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# Information Sharing & Communication

More accessible health care records

- Family experience
- Informed decision making
- Storage and utility of information

Promoting family presence at nursing shift-handover

- Family preferences
- Standardize components, customize others
- Research & evaluation

Communicating with children in a way that they understand and are understood

- Competency based education
- Enhanced 'white boards'
- Document preferences

# Participation

Improved access to high quality peer support

- Host family/community events
- Inventory: multi-modes
- Enable, monitor & coach

Enhanced coordination & navigation of care

- Explore 'self-scheduling' portal
- Combined clinics
- Key worker roles

Enhanced discharge engagement

- Post-discharge phone calls
- 'Concierge style' ambulatory care

Presence of families at induction of anaesthesia

- Policy & procedures
- Family readiness & success

# Collaboration

Family representation: committees

- Family Advisory Network
- Diverse representation

Family engagement: education & performance

- Formalize 'Family as Faculty Program'
- Family members input into performance reviews

Family spaces: to be together, quiet reflection, learning on a unit

- Open Ronald McDonald Room
- Hospital-wide memorial service

# Findings of the C&FCC Project

- **Validate key objectives of The Centre**
- **Indicate SickKids is in a strong position to *advance* C&FCC through:**
  - **Innovation**
  - **Extension**
  - **Evaluation**

**...of select priority practices**



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# Towards Successful Implementation

## Dissemination of results

## Development of implementation plan

- Establish work-groups
- Identify priority practice leads, sites
- Synergies with others

## Research & Evaluation

- Setting priorities for quality improvement & research
- Seek funding for research



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# Comments/ Questions



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