Engaging Patients, Families & Stakeholders to Improve Hospital Care: Experiences with the i-HOPE Study

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Road Map

- Background to I-HOPE
- Approach & Methods
- I-HOPE Study Findings
- Dissemination
- Reflections on patient partnerships

Agenda

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Background: Why our study was needed

- Hospitalization is a vulnerable time for patients and caregivers

Background: Why our study was needed

- Hospitalization is a vulnerable time for patients and caregivers

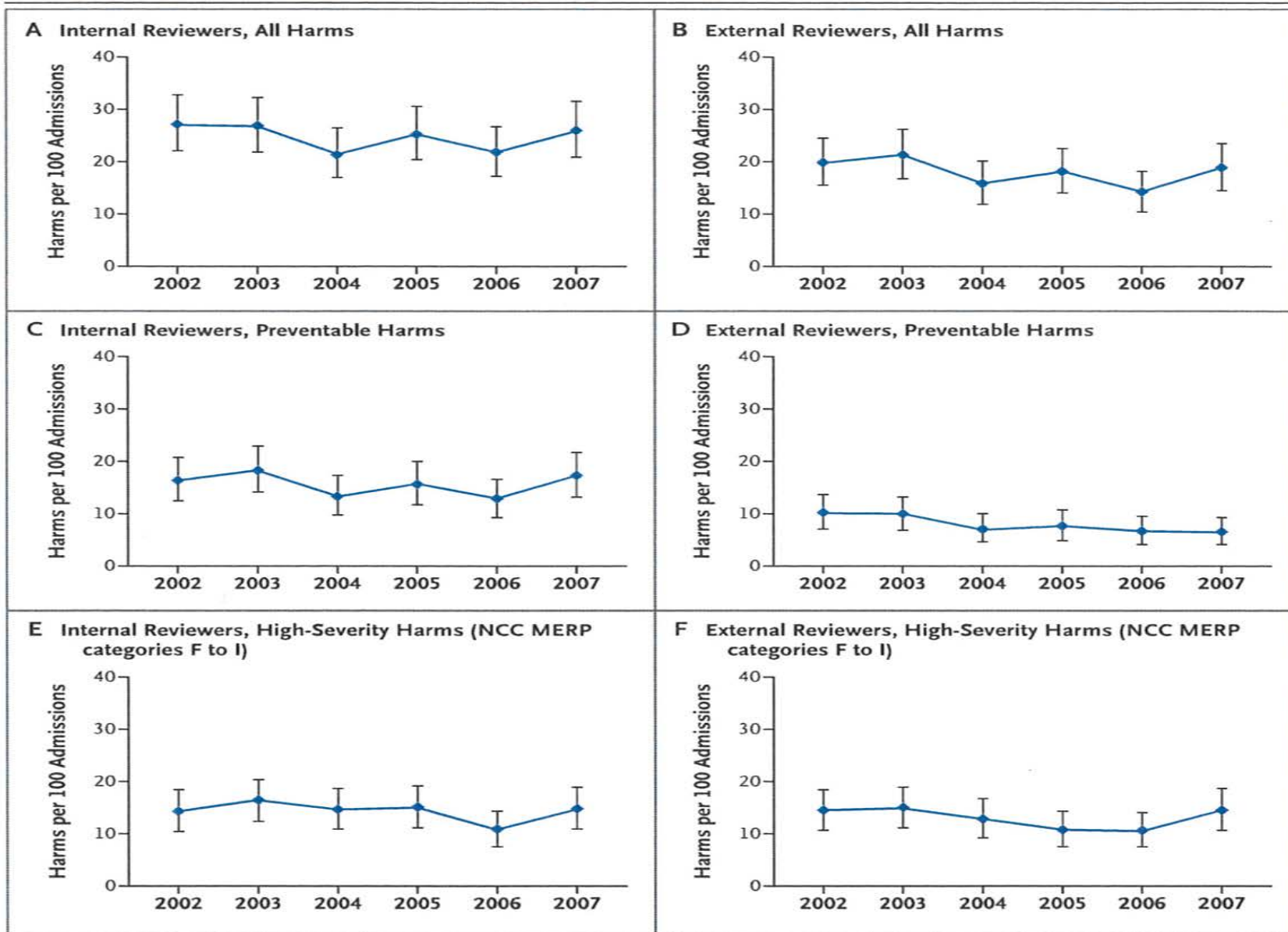- Gaps in care quality are well documented, and difficult to close

Trends in adverse events

A Internal Reviewers, All Harms

B External Reviewers, All Harms

C Internal Reviewers, Preventable Harms

D External Reviewers, Preventable Harms

E Internal Reviewers, High-Severity Harms (NCC MERP categories F to I)

F External Reviewers, High-Severity Harms (NCC MERP categories F to I)

Figure 3. Rates of All Harms, Preventable Harms, and High-Severity Harms per 100 Admissions, Identified by Internal and External Reviewers, According to Year.

All reviews were performed with the use of the Institute for Healthcare Improvement's Global Trigger Tool. High-severity harms were those reported in categories F through I of the National Coordinating Council for Medication Error Reporting and Prevention (NCC MERP) Index, ranging from harm requiring initial or prolonged hospitalization to harm causing death. The I bars indicate 95% confidence intervals.

Value based purchasing

- MS-DRG payments reduced by 2%
- Hospitals receive payments based on performance
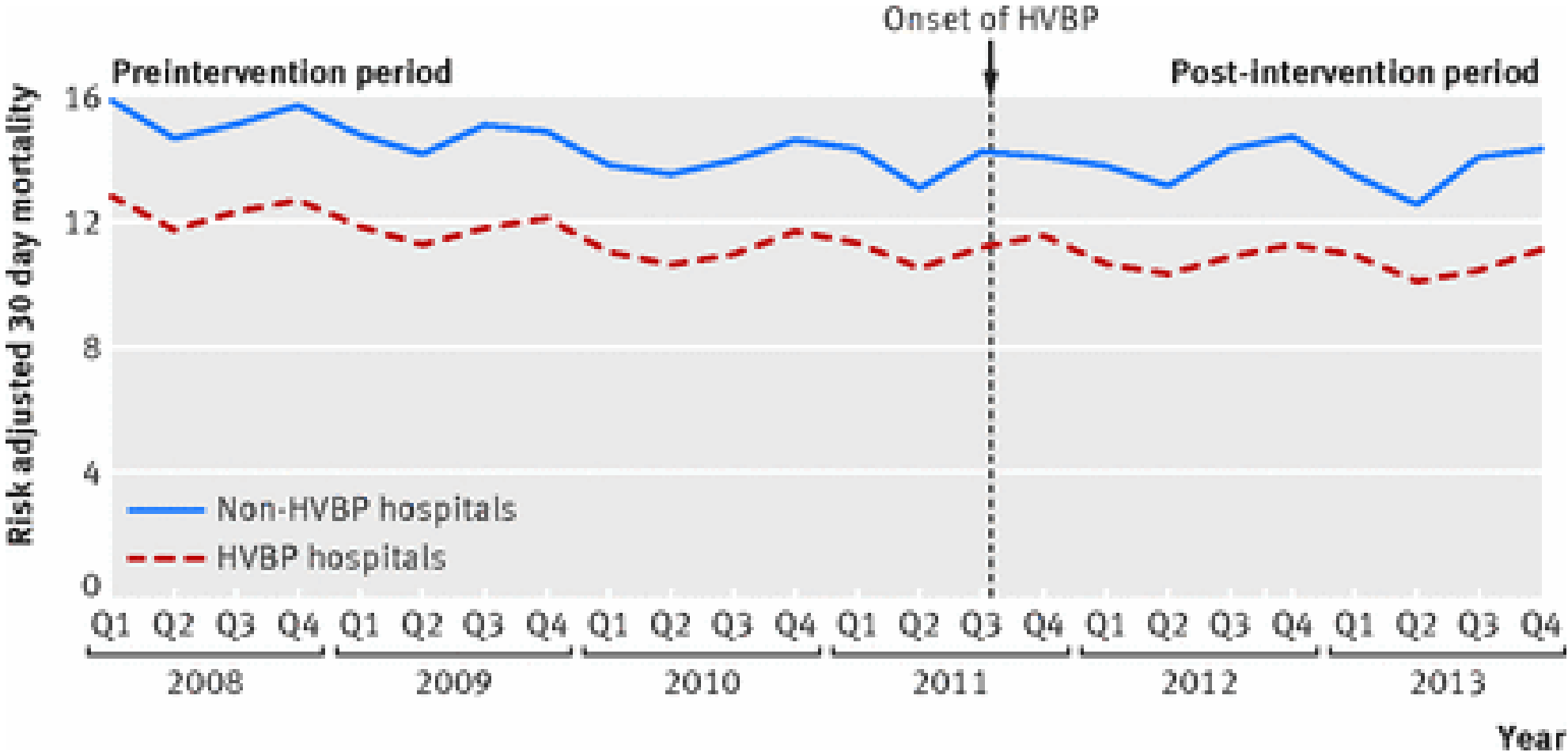
Background: Why our study was needed

Patient and caregiver priorities with regard to improving hospital care were unknown

We believed engagement was central to effectively improving hospital care

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Our Aim

To systematically engage
patients, caregivers and other stakeholders
to create a prioritized list of questions
to guide research and improvement efforts
for the care of hospitalized patients.

Road Map
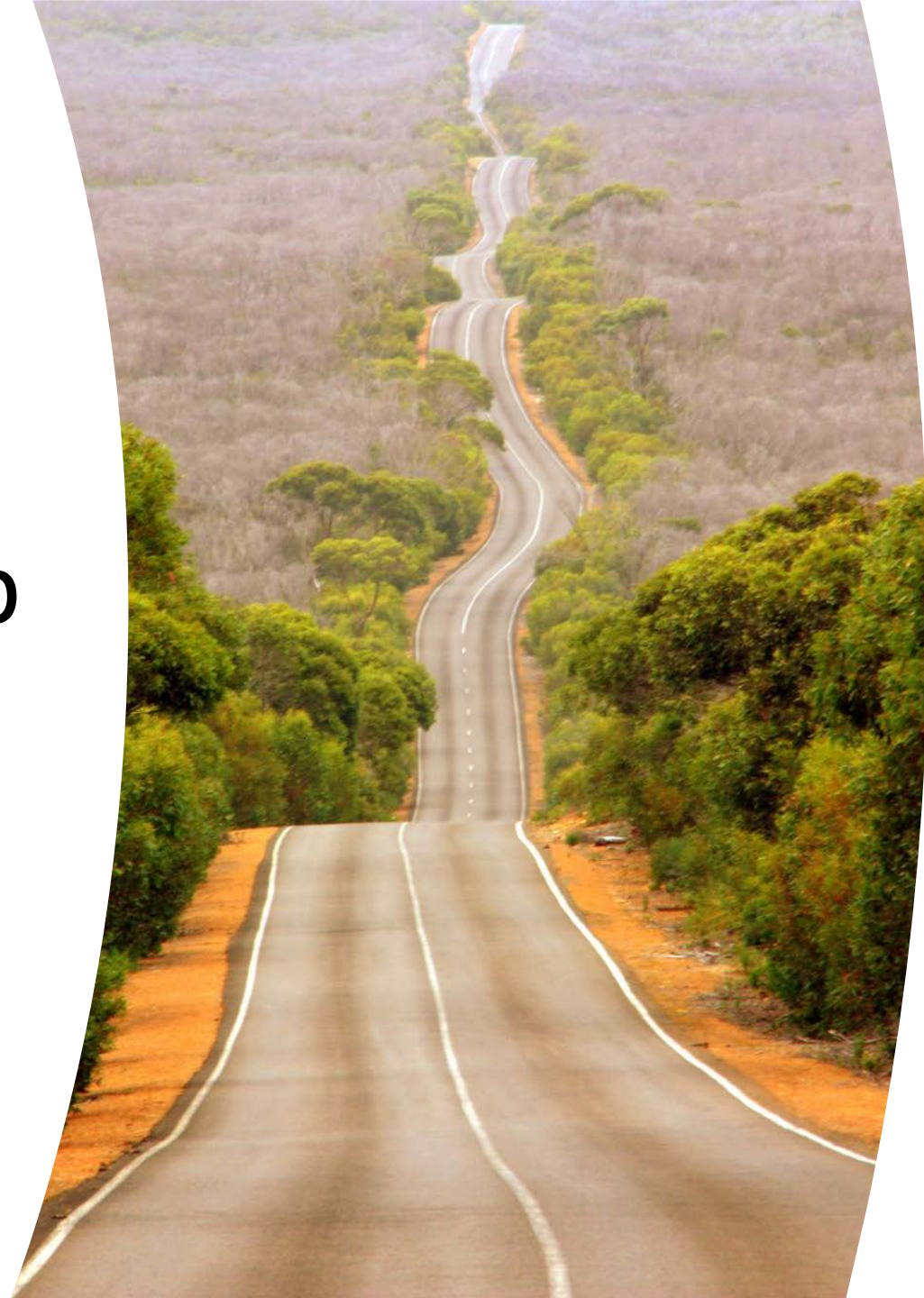
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Approach

Approach

Guided by:

- PCORI standards for formulating research questions

- James Lind Alliance Methods for Stakeholder Engagement

1. Steering Committee formation

2. Stakeholder identification and training

3. Online Survey

4. Refining Survey Responses

5. In-person prioritization

PCORI Research Standards

- Identify gaps in evidence
- Develop a formal protocol
- Measure outcomes that people care about
- Identify / engage patients and stakeholders
- Use patient reported outcomes

James Lind Alliance

- Sets standards for priority setting partnerships
- Process for identifying & prioritizing questions

| Collect potential questions | → | Categorize questions | → | Rank questions | → | Develop prioritized list |
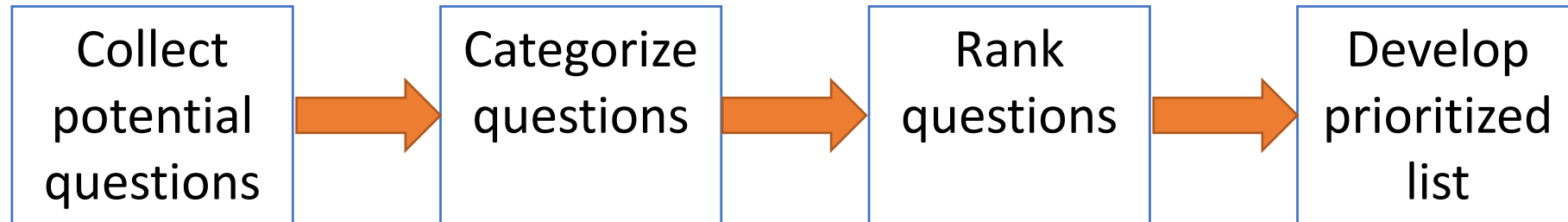
The James Lind Alliance

The James Lind Alliance (JLA) is a non-profit making initiative established in 2004. It brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 uncertainties, or unanswered questions, about the effects of treatments.

The aim of this is to make sure that health research funders are aware of the issues that matter most to patients and clinicians.
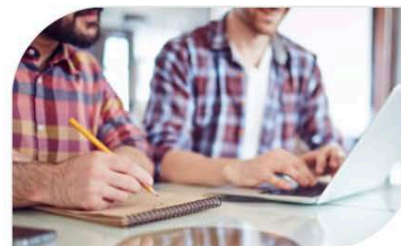

The PSPs

Find out about the areas in which Priority Setting Partnerships identify the uncertainties which really matter.
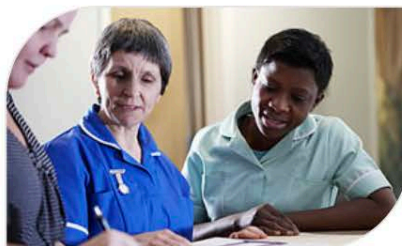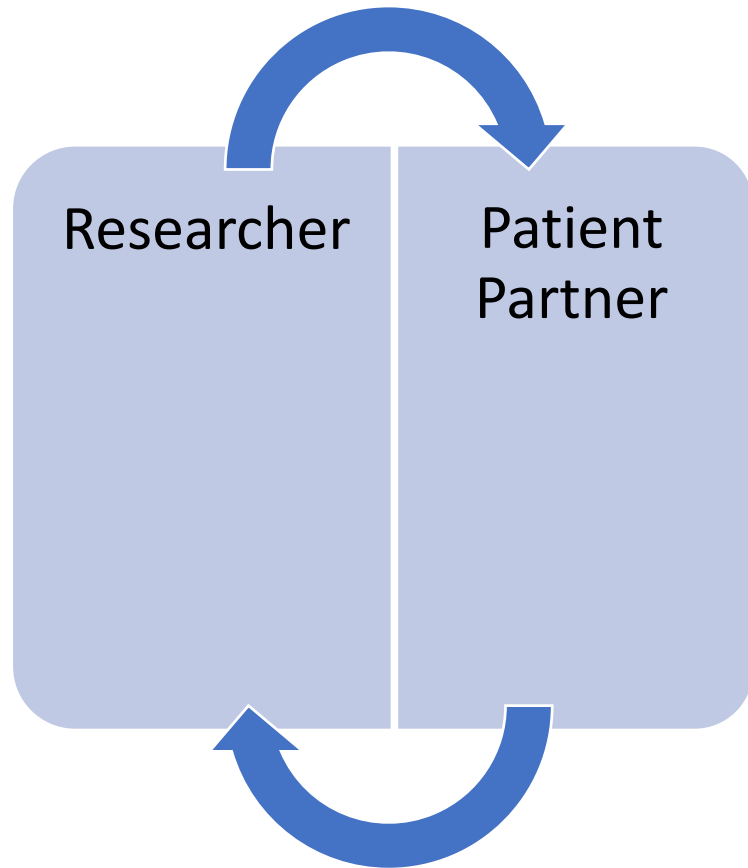

Top 10s

See the top priorities for future research, agreed by patients, carers and health professionals working with Priority Setting Partnerships.

The JLA Guidebook

Read a step-by-step guide to the processes involved in a Priority Setting Partnership.

Methods: Steering Committee Formation

Seven Academic Medical Centers

Supporting and Dissemination Partner

Methods: Stakeholder Identification & Training

- 37 stakeholder organizations identified:
  - Patient & Caregiver Organizations
  - Patient & Family Advisory Councils
  - Medical/Professional Societies
  - Research and Quality Improvement Organizations

- Stakeholder representative(s) identified

- Leaders from stakeholder organizations participated in orientation webinars

Our i-HOPE partners:

- Agency for Health Research and Quality Evidence Based Practice Centers Scientific Resource Center
- Alzheimer's Association
- American Academy of Hospice & Palliative Medicine
- American Academy of Neurology
- American Academy of Physical Medicine & Rehabilitation
- American Association of Neurological Surgeons
- American Association of Nurse Practitioners
- American College of Clinical Pharmacy
- American Geriatrics Society
- American Nurses Credentialing Center

- American Society of Plastic Surgeons
- Community First Health Plans
- Congress of Neurological Surgeons
- Health Hats
- Health Research & Educational Trust - American Hospital Association
- Institute for Healthcare Communication
- Institute for Healthcare Excellence
- Institute for Patient and Family Centered Care
- Living Beyond Breast Cancer
- Louise H. Batz Patient Safety Foundation
- Minnesota Hospital Association

- National Alliance for Caregiving
- Partnership to Improve Patient Care
- Patient Centered Outcomes Research Institute Ambassador Program
- Planetree International
- Society for Post-Acute and Long-Term Care Medicine
- Society of General Internal Medicine
- Society for Medical Decision Making
- US Department of Veterans Affairs, Hospitalist Field Advisory Committee
- US Department of Veterans Affairs, Health Services Research & Development

Methods: Online Survey

- Stakeholder organizations surveyed their leadership and/or members:*

  - Questions they had about hospitalization
  - Suggestions for hospital care improvement

- Representative sent electronic survey invitation and link to group's constituents.

Hospital Questions Survey

Have you ever left the hospital with unanswered questions?

This survey will help research teams learn the questions that patients, families, caregivers, and other healthcare stakeholders want answered.

How to complete this survey

Are you a patient or caregiver? Think about your experience during and after any hospital stay. Think about the questions that you had <u>during</u> the hospital stay or <u>after</u> you left the hospital that were left unanswered or that were confusing.

REDCap

Research Electronic Data Capture

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Methods: Refining Survey Responses

- 499 respondents
  - 117 patients
  - 127 caregivers
  - 267 healthcare providers
  - 63 researchers
  - 10 policy makers
  - 4 industry
  - 4 payors

Methods: Refining Survey Responses

- 782 questions/areas of improvement submitted

- Categorized into 73 topics/themes
  - 53 health system
  - 20 disease specific

Health System

| |
|---|
| Care Transitions: Discharges |
| Medications |
| Patient understanding |
| Evidence-based medicine/practice |
| Management practices |
| Communication |
| Post-acute care |
| Patient education |
| Models of Care |
| Patient experience |
| Post-acute care: What do I do? |
| What to expect |
| Post-acute care: Who do I call? |
| Financial / Insurance Matter |

Disease Specific

Surgery
Dementia
Pain management
CHF
Other Diseases

Methods: Refining Survey Responses

- 782 questions/areas of improvement submitted

- Categorized into 73 topics/themes
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  - 20 disease specific

- 36 commonly submitted questions identified

Methods: In-person prioritization meeting
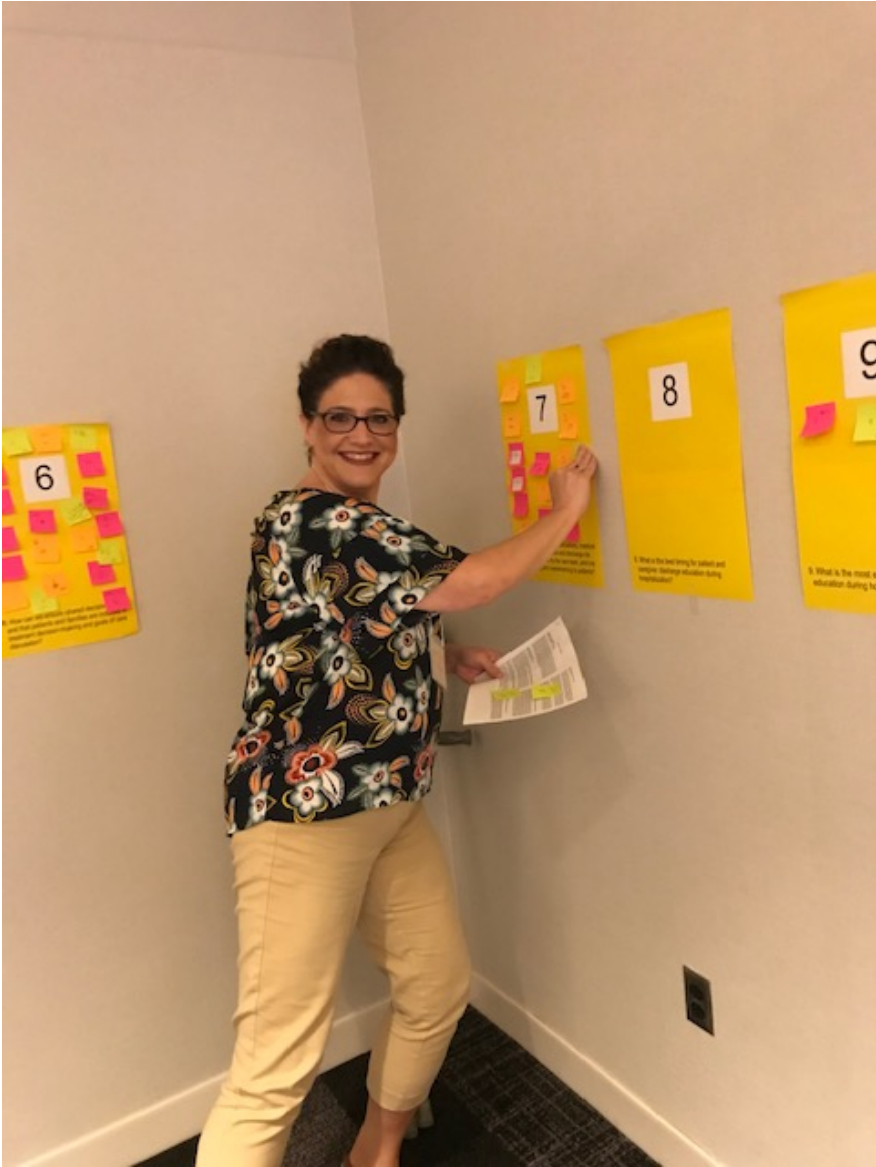
Methods: In-person prioritization meeting

Priority	i-HOPE Survey Responses Prioritized July 2018	i-HOPE Prioritized Research Questions *Patient* refers to patients, families, caregivers, surrogates
1	How can we ensure shared decision-making and that patients and families are included in treatment decision-making and goals of care discussion?	What interventions ensure that *patients* share in decision making regarding their goals and plans of care?
2	How can the hospital discharge hand off to other care facilities (e.g. SNFs), primary care providers and specialists be made smoother?	What are the most effective discharge handoff practices between hospitals and other providers?
3	How can education on medications, medical conditions, hospital care and discharge be better coordinated by the care team, and not so confusing and overwhelming to patients?	How can the care team best coordinate education on medications, medical conditions, hospital care and discharge for hospitalized *patients* to minimize confusion?
4	How can patients, family members, other caregivers and heath care teams work together to create effective discharge experiences that allow patients to feel empowered to manage their health once they get home?	For inpatients, what comprises a collaborative discharge process that fosters understanding, empowerment, and effective management of their health at home?

6.	Can telemedicine technology be used to reduce readmissions or improve transitions of care in hospitalized patients?

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8.	What are the most effective ways for patients and providers to partner in understanding information about diagnosis, steps taken to explore it, treatments undertaken, and what needs to happen after discharge?

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9.	What are patient's expectations related to the treatment of pain?

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10.	What are the best interventions to achieve medication optimization throughout the patient's care trajectory?

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9.	What are patient's expectations related to the treatment of pain?
10.	What are the best interventions to achieve medication optimization throughout the patient's care trajectory?
11.	Would providing more clear and accessible information regarding hospital practices result in improved patient experiences compared to current practices?

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Dissemination

- Patients, Families, and Caregivers
  - PFAC Networks
  - PCORI Ambassador
  - Healthcare providers
  - Healthcare systems

- Clinicians and Researchers
  - Publications and presentations
  - Funding agencies

- Stakeholder Organizations

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Patient Partner Experiences

- Partners involved every step of the project:
  - Bi-weekly Steering Committee calls
  - Survey design
  - Analyses
  - In-person prioritization
  - Dissemination

*"True partnership with researchers –
Not checking a box"*

Impact of collaboration with patient partners

- Survey tool development

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Impact of collaboration with patient partners

- Data analysis and codebook development

| Being known as a person	A patient being known as a unique individual outside of their illnesses, knowing about a patient's priorities and life goals, outside of their care goals.	Q68.1- Why do they use cookie-cutter methods versus 'know your patient'?

Impact of starting with the patient perspective

- Relationships, not processes

- Patient perspective versus patient understanding

Implications for improving hospital care
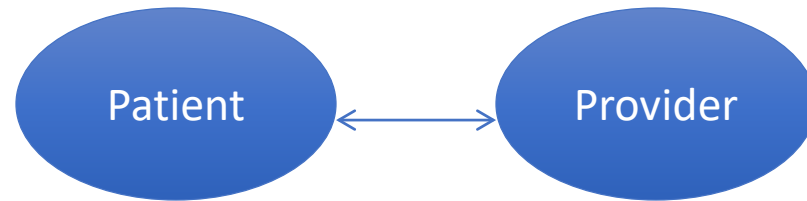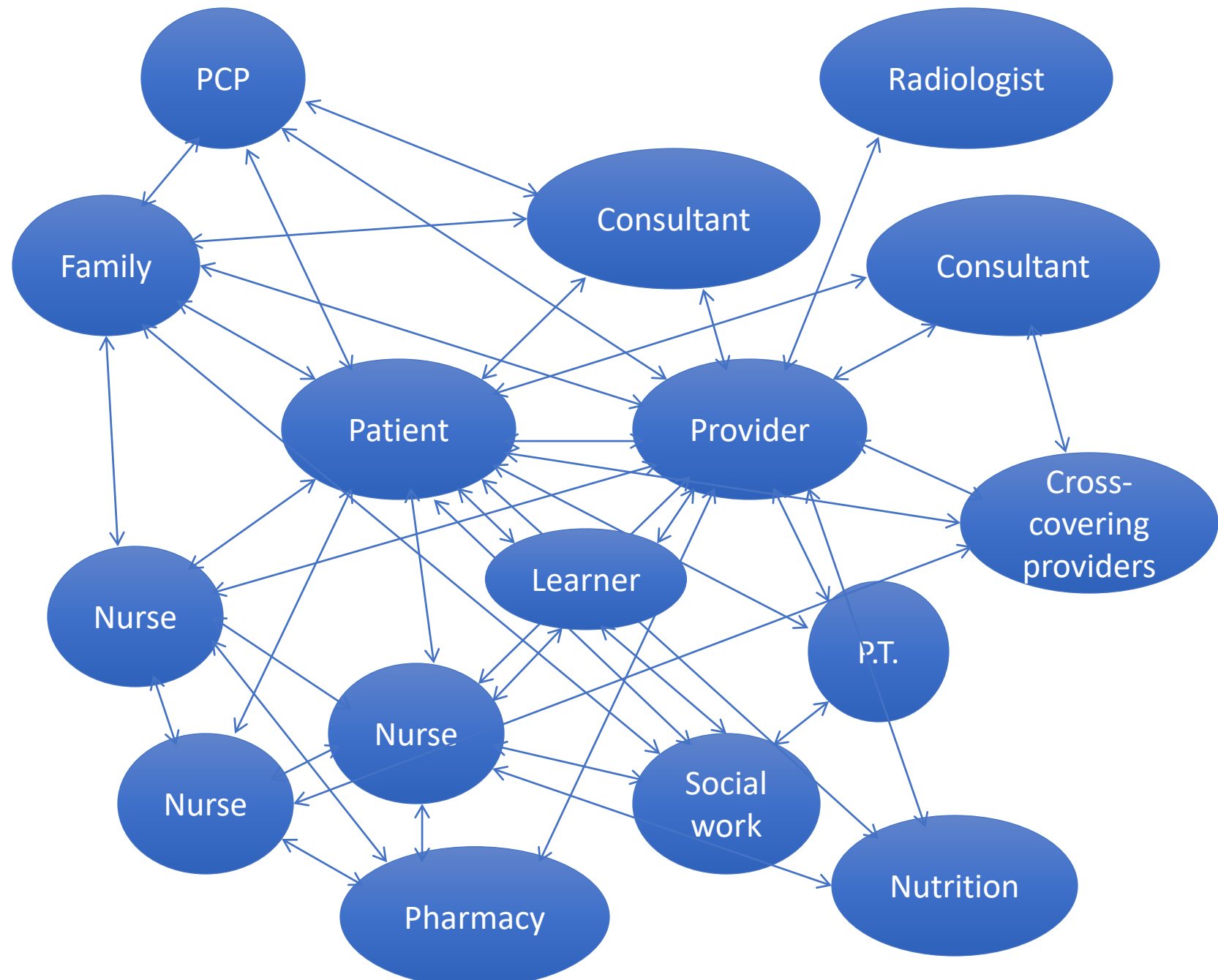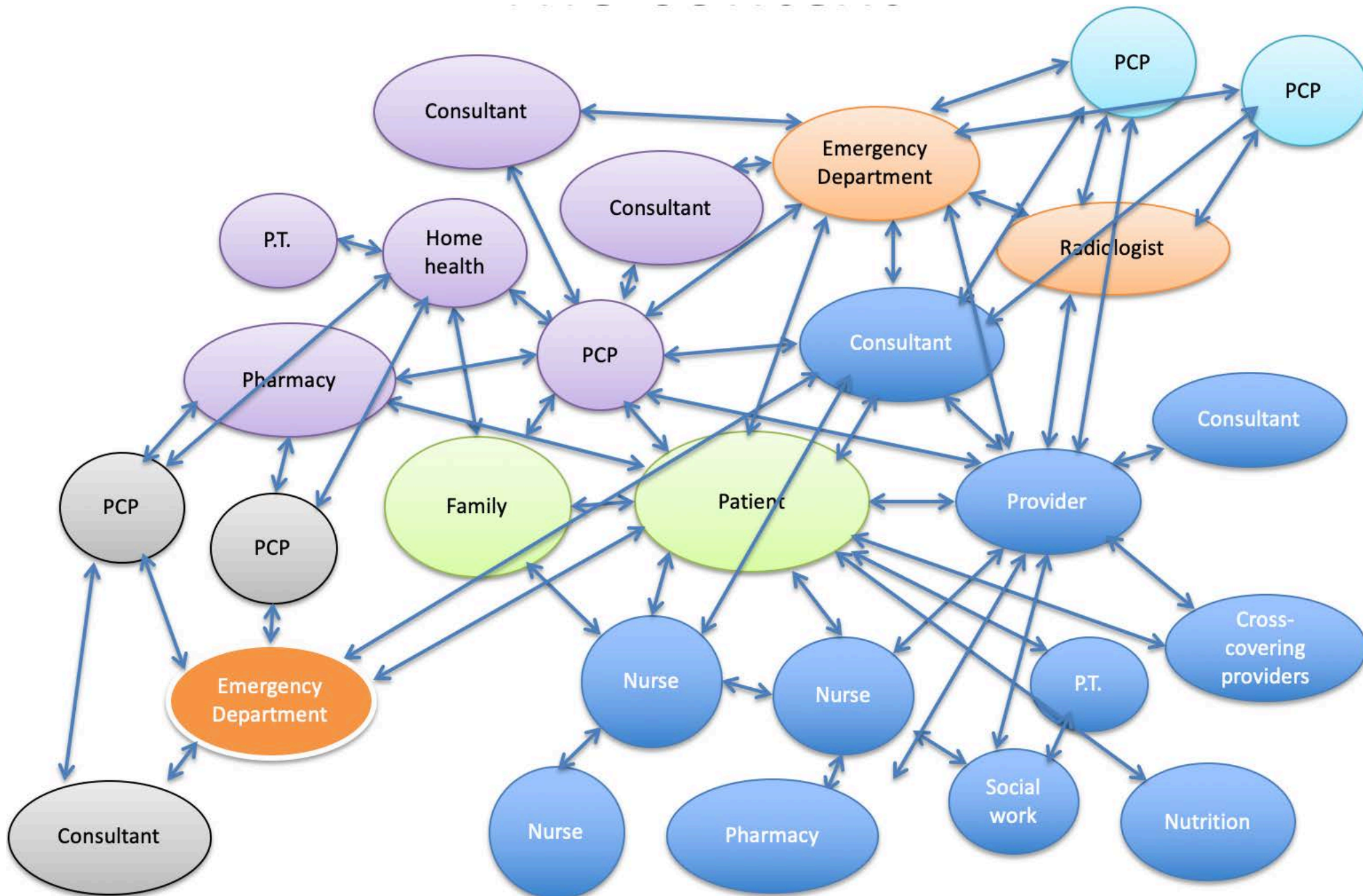
Implications for improving hospital care

Processes

Relationships

Resources

I-HOPE Steering Committee and Study Team

- Esther Avitia, Luci Leykum, Becky Coker (STVHCS / UTHSCSA)
  - Michelle Archuleta & Marisha Burden (UC Denver)
  - Jim Banta, Margaret Fang & James Harrison (UCSF)
- Joy Benn, Lali Silva, Jawali Jaranilla (Health East Care System)
  - Julie Hagan & Shaker Eid (John Hopkins University)
- Melissa Wurst & Mona Mullick (University of Washington in St Louis)
  - Georgiann Ziegler, Vineet Chopra (University of Michigan)
  - Kathlyn Fletcher (Medical College of Wisconsin)
  - Christopher Nyenpan (Society of Hospital Medicine)

https://www.hospitalmedicine.org/clinical-topics/i-HOPE-study