Patient & Family Health Care Leadership

A Resource Compendium

DISCLAIMER: This Compendium has been prepared through the work of participants in the Patient & Family Health Care Leadership Network convened by the National Academy of Medicine. The statements and views expressed are those of the individual contributors and not necessarily of the contributors' organizations or of the National Academy of Medicine. This Compendium was created to assist and to inform volunteer patient & family council leaders who have from its inception, and continue to, contribute valuable feedback. It has not been subjected to formal review by the National Academy of Medicine and is not a report of the National Academy of Medicine or of the National Research Council.

Diedtra Henderson
Program Officer

Katherine D. Burns

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A [illegible] 11

B [illegible] 19

C [illegible] 27

D [illegible] 29

E [illegible] 3[illegible]

F [illegible] 41

G [illegible] 4[illegible]

H [illegible] [illegible]0

[illegible] [illegible]3

[illegible] [illegible]

[illegible] 61

[illegible] 68

- Provision of care, treatment, and services (PC)02.01.21—
- PC.02.02.01—
- PC.02.03.01—
- Rights and responsibilities of the individual (RI)01.01.03—
- RI.01.02.01—

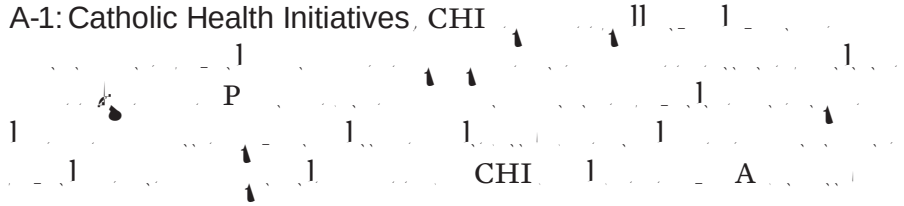
PFAC.

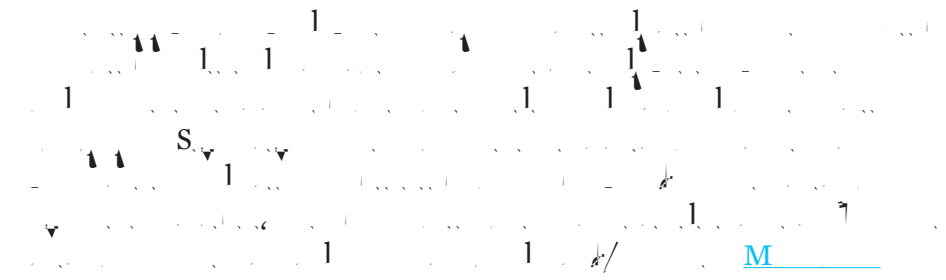
Competencies and roles

Increase the skills, knowledge, and understanding

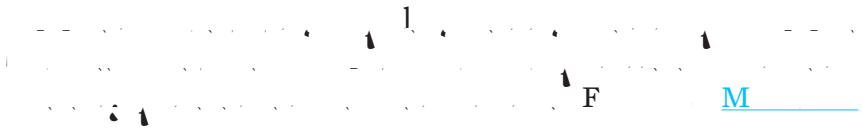
INFORMATION ON IMPACT

- A-1: Catholic Health Initiatives, CHI





- A-7: Kaiser Permanente
  Clostridium di cile C-di
  C-di
- A-8: Medicaid agency
- A-9: Beth Israel Deaconess Medical Center
- A-10:
  McKinsey & Company’s
- A-11:
  Robert Wood Johnson Foundation
- A-12: Fort Belvoir Community Hospital VA



- A-13: T Agency for Healthcare Research and Quality's
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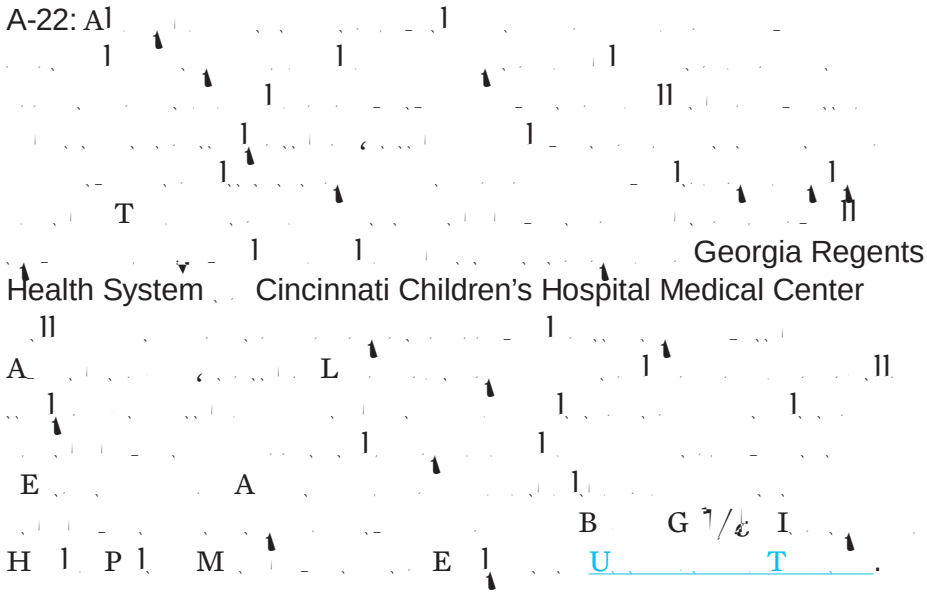
  C
  G R H
  C P H P
  M S B U H C H
- A-14: T Agency for Healthcare Research and Quality's
  P F E H Q S
  I
  E
  M
- A-15:

- A-22: Al



Georgia Regents Health System Cincinnati Children’s Hospital Medical Center

- A-23:

A-28: Anne Arundel Medical Center's MD

PFAC

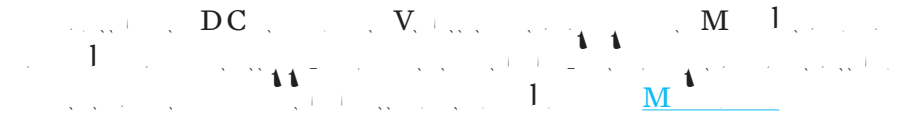
M

A-29: American Hospital Association

A-30: C.S. Mott Children's Hospital MI

M

A-31:



- A-34: A KLAS HFMA T P P F M
- A-35: Baystate Medical CenterMA T PFAC A E M
- A-36: Braintree Rehabilitation Hospital MA PFAC PFAC PFAC M
- A-37: P M G P C C O National Quality Forum M
- A-38: T Gordon and Betty Moore Foundation American Institutes for Research R P F E H P R M
- A-39: T Partnership for Patients'M S P P P F N P S F L L I
- A-40: I Shared Decision-Making Strategies for Best Care: Patient Decision Aids SDM T C

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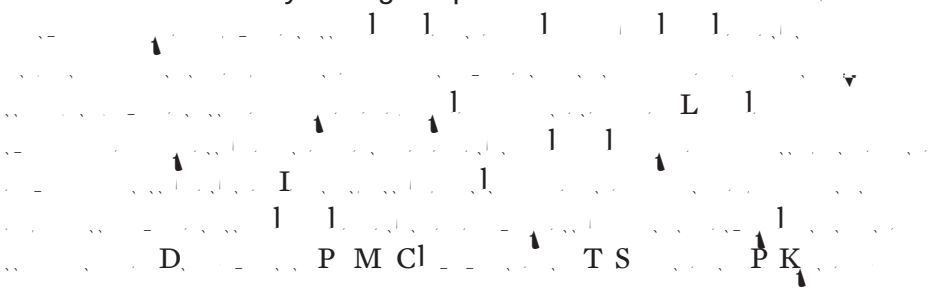
SDM

INFORMATION ON IMPACT

[illegible]

- B-1: Asthma control improved 3-fold. C C l H l M l C OH l T T A A B O P L B M A V J M P S J R P M T B Pediatrics
- B-2: Serious safety events reduced by 85%. V H l NC T C M M S J C H l C A H l P S V H l J E D A J L R Joint Commission Journal on Quality and Patient Safety
- B-3: Tools for limited English pro ciency patients. T E

B-4: Enhanced safety through improved medicine labels.



Pediatrics

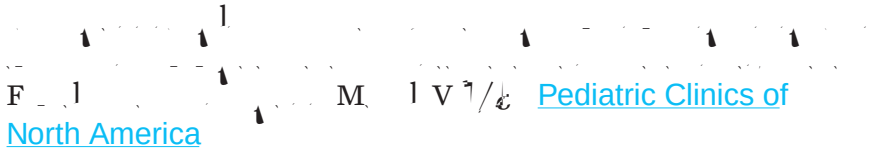
- B-8: PCMH-delivered care linked to cost savings.

Health Services Research

- B-9: Viewing care quality from patient's perspective.

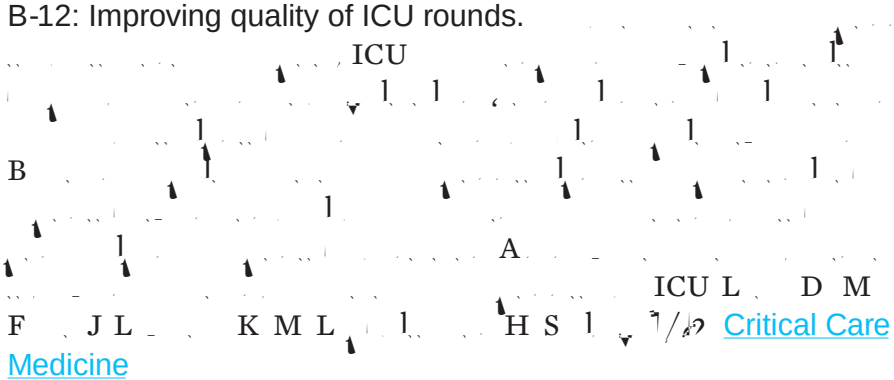
American Journal of Medical Quality

- B-10: Activation, literacy related to blood sugar control.



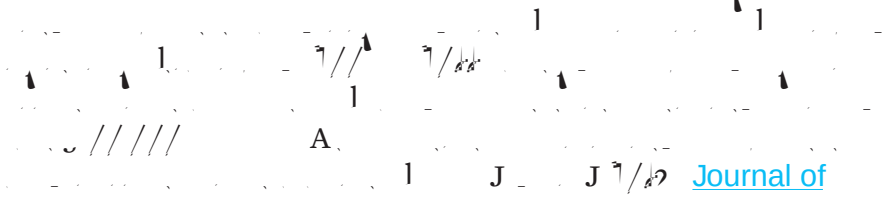
Pediatric Clinics of North America

- B-12: Improving quality of ICU rounds.



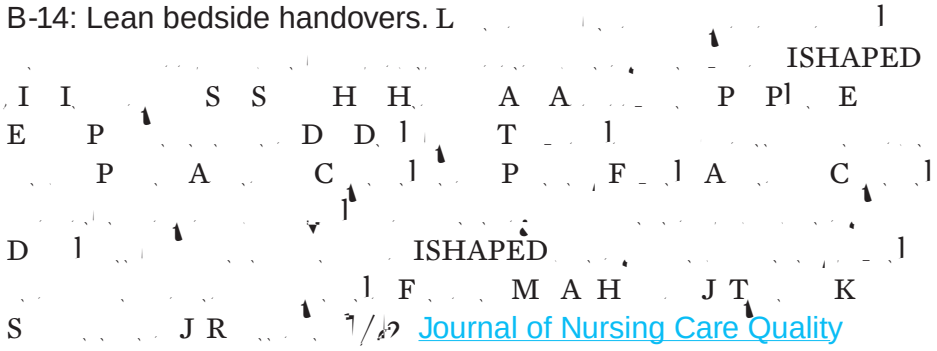
Critical Care Medicine

- B-13: 400,000 patients die due to medical errors.



Journal of Patient Safety

- B-14: Lean bedside handovers.

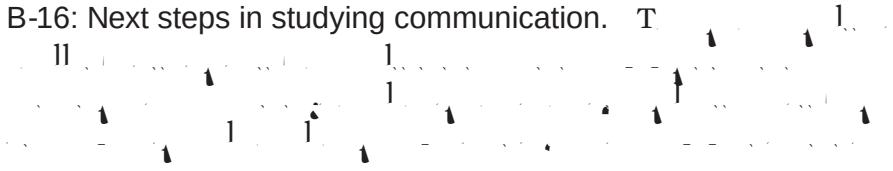


Journal of Nursing Care Quality

- B-15: Improving electronic handover tools.

International Journal of Medical Informatics

- B-16: Next steps in studying communication.

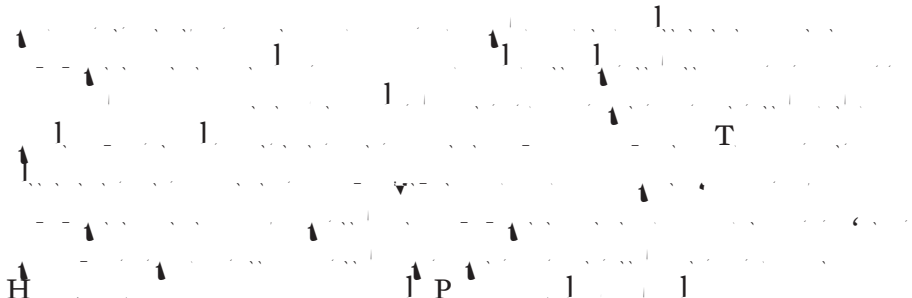


Patient Education and Counseling

B-17: Lean rounding speeds discharge, improves satisfaction.

Health Care Management Review

- B-21: The path from communication to outcomes.

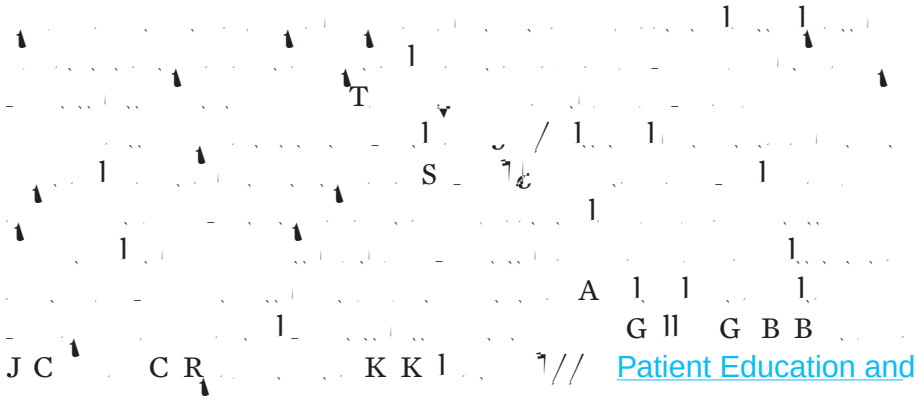


Patient Education and Counseling

- B-22: Enhanced use of RNs improves quality, increases costs.

Policy, Politics & Nursing Practice

- B-23: Deriving meaning from partnering with patients.



Patient Education and

- B-25: AHRQ spends $55 million on patient safety research. T
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C E ll
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l P Q l P S R
D E T US A H l
R Q l M
G J B l J H N T '//? International Journal for Quality in Health Care

- B-26: Patient-centered practices enhance e ciency. F
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S M J B A D I M J O
J J '/// Journal of Family Practice

- B-27: Banning handshakes to protect health? P
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L R A l '/ JAMA

- B-28: Partnering with patients to improve safety. T
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l S P '//? Hospitals & Health Networks

INFORMATION ON IMPACT

C

- C-1: Core measures for health care progress.

  [illegible] Vital Signs Core Metrics for Health and Health Care Progress

- C-2: Patients help detect quality gaps.

  [illegible] International Journal for Quality in Health Care

- C-3: Informal caregivers' roles in decision making.

  [illegible] BMC Health Services Research

- C-4: Older patients expect high-quality care.

INFORMATION ON IMPACT

D

- D-1: Hospital leaders key to patient/family engagement. T
A H A H R E
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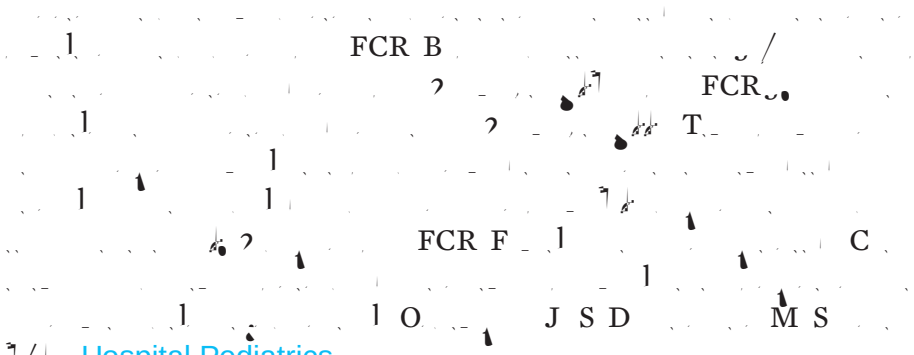
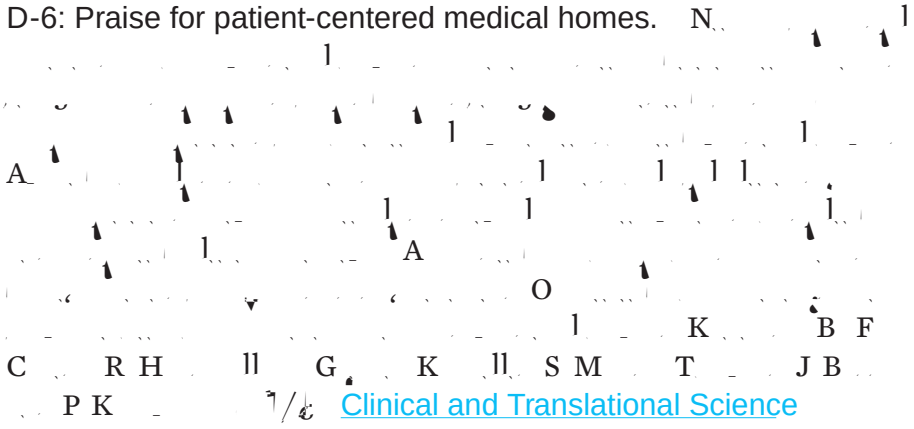
H J K H K K S H M
J D F BMJ Quality & Safety
- D-2: Engaged youth judiciously use care resources. I
E
R B M P H
K Archives of Disease in Childhood
- D-3: Patients' stories improve quality, safety. T
T
T
M L K
S The Permanente Journal
- D-4: Engaging PFACs to improve health. F
E
K Healthcare Financial Management
- D-5: Family-centered care improves discharge timing. T
FCR



Hospital Pediatrics

- D-6: Praise for patient-centered medical homes.



Clinical and Translational Science

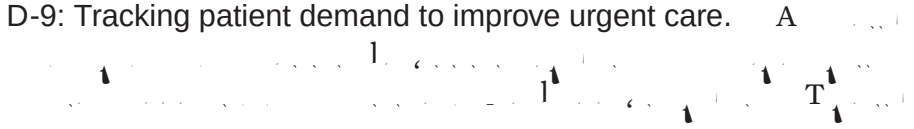
- D-7: Role of peer leaders in diabetes care

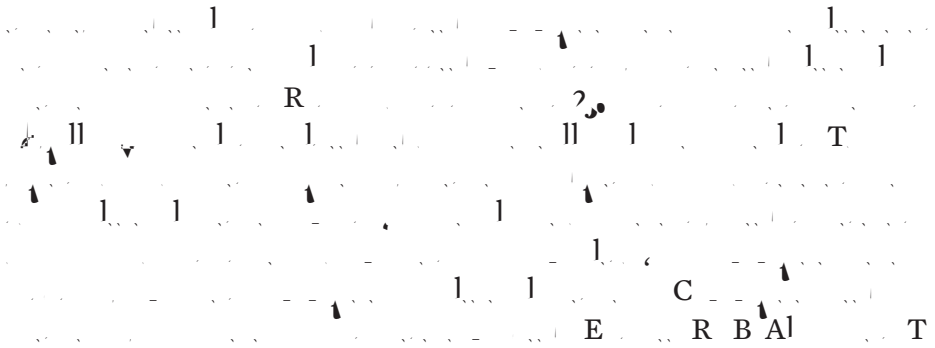
The Diabetes Educator

- D-8: Patients' safety attitudes di er from safety actions.

Medical Care Research and Review

- D-9: Tracking patient demand to improve urgent care.



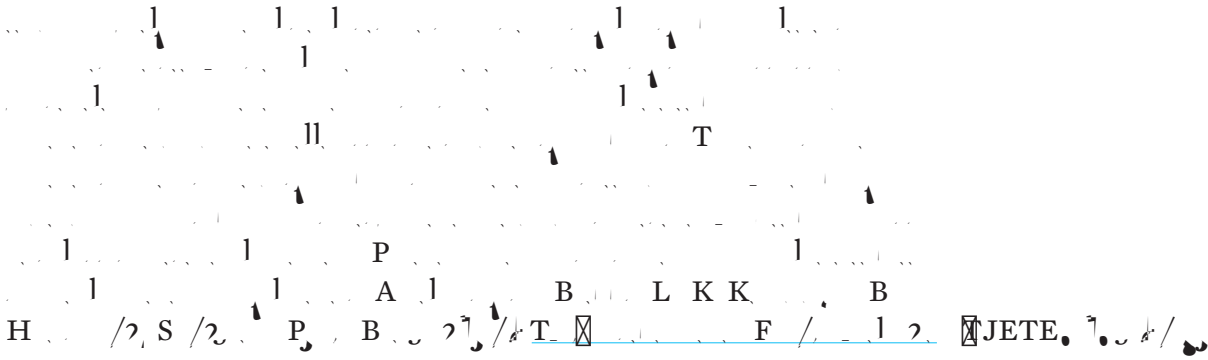


JAMA

D-15: Family-clinician relationships in the ICU.

Critical Care Medicine

D-16: Patient-centered advance care planning.



J M G E N J M P
B ////? Joint Commission Journal on Quality and Safety

- D-19: Improving care transition for older patients. T
O I
T
A
P C E C
J S J F A K ////? Home Health Care Services Quarterly
- D-20: Fully integrating the patients' perspective. T
M
A
P P G C J C S G C
M J N L S P B K C ////? The Journal of Nursing Administration
- D-21: Bridging communication gaps in the emergency department. D
I
P A L
F ////? Health Communication
- D-22: Leveraging systems approaches to improve care. T
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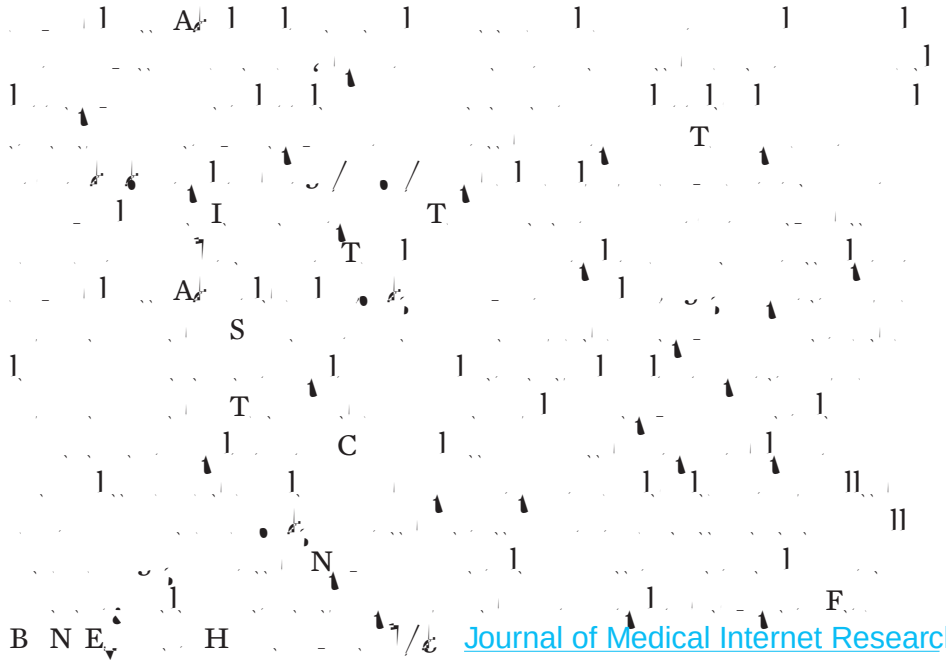
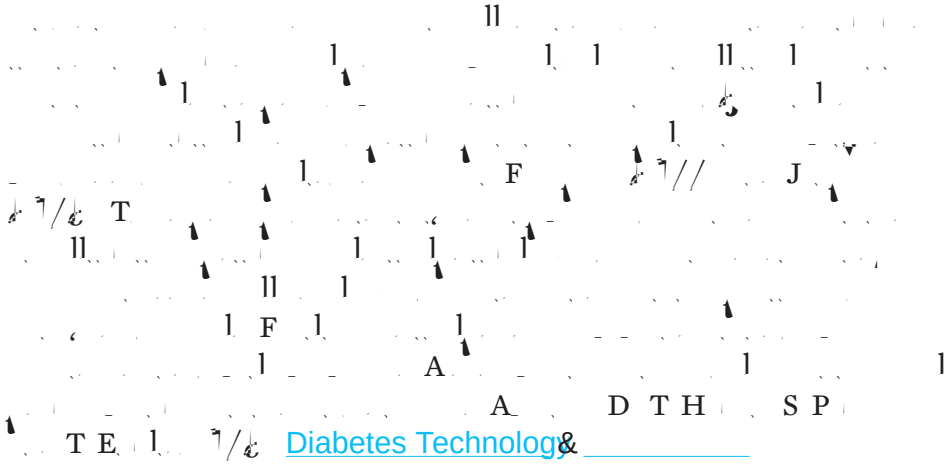
Crossing the quality chasm: A new health system for the 21st century ////.
DC N A P

INFORMATION ON IMPACT

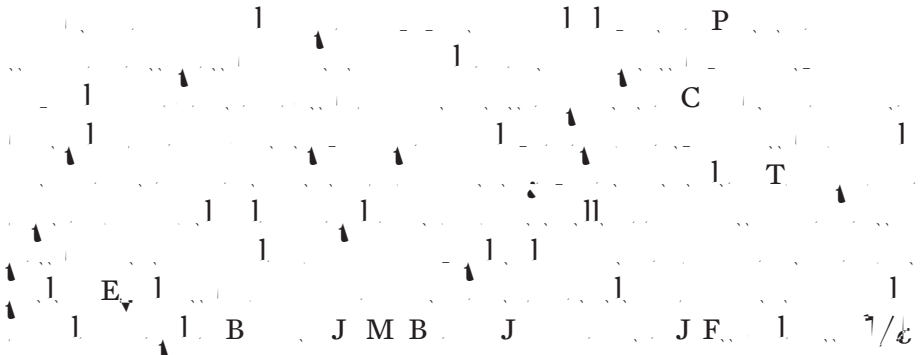


Journal of Medical Internet Research

E-5: Provider encouragement impacts patient portal use.

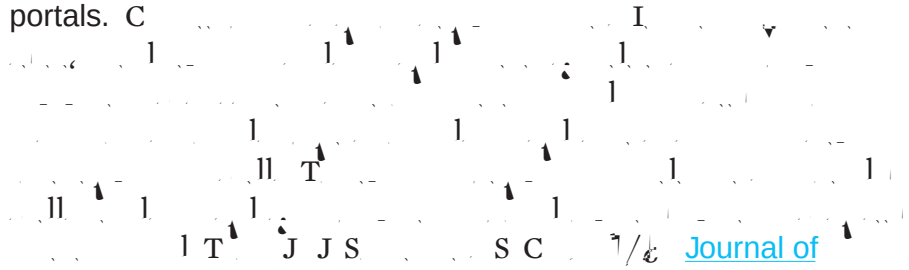


Diabetes Technology &



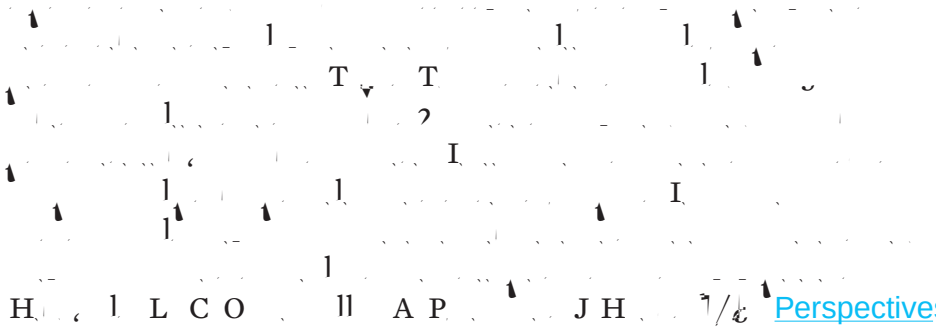
Studies in Health Technology and Informatics

- E-8: Numeracy, Internet uency impact performance on portals. C



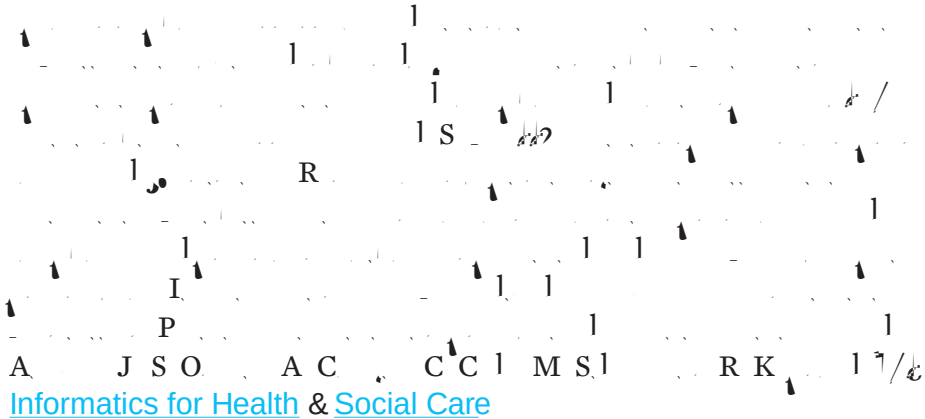
Journal of Applied Gerontology

- E-9: Texas patients nd redesigned portal more usable. T



Perspectives in Health Information Management

- E-10: Higher educated patients more likely to use portal. T



Informatics for Health & Social Care

- E-18: Digital access boosts patient satisfaction.

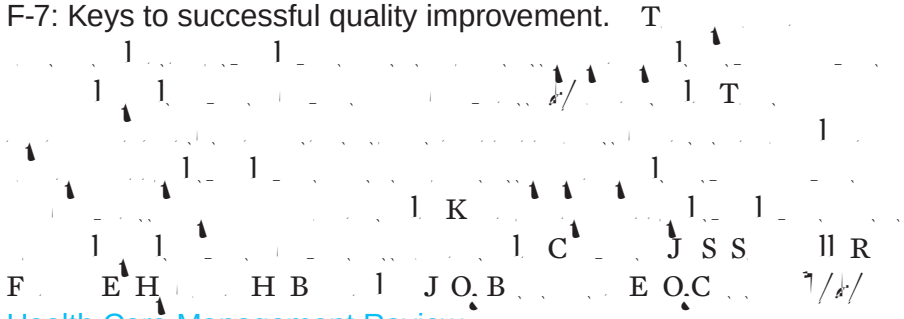
[Medical Care Research and Review]

INFORMATION ON IMPACT

C-

- F-1: Hospital leaders key to patient/family engagement. T

- F-7: Keys to successful quality improvement. T

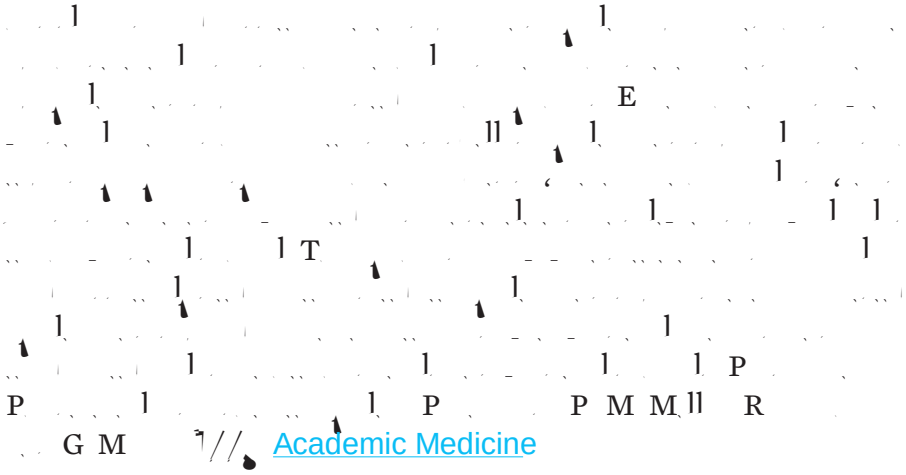


Health Care Management Review

- F-8: Leadership predicts degree of organizational learning. T

Healthcare Quarterly

F-11: Accelerating progress in leadership training.



Academic Medicine

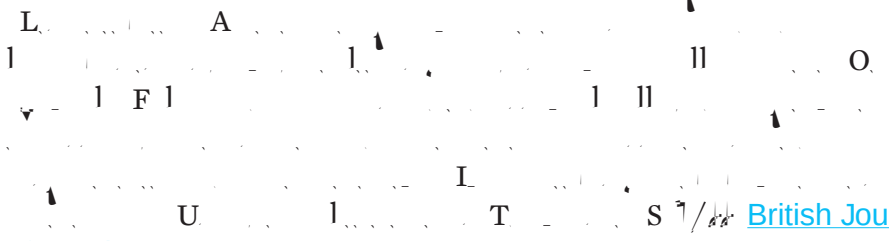
INFORMATION ON IMPACT

Nursing Administration Quarterly

G-5: Pediatricians' role in patient-centered care. A

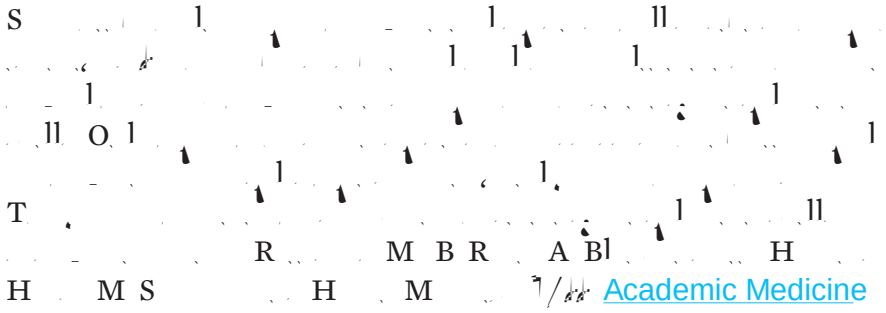
Health Care Management Review

- G-10: Learning lessons from frontline sta . T



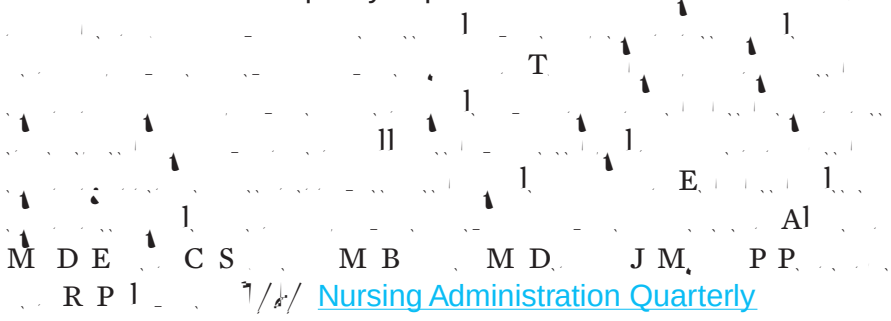
British Journal of Nursing

- G-11: Impact of patient feedback on clinician performance.



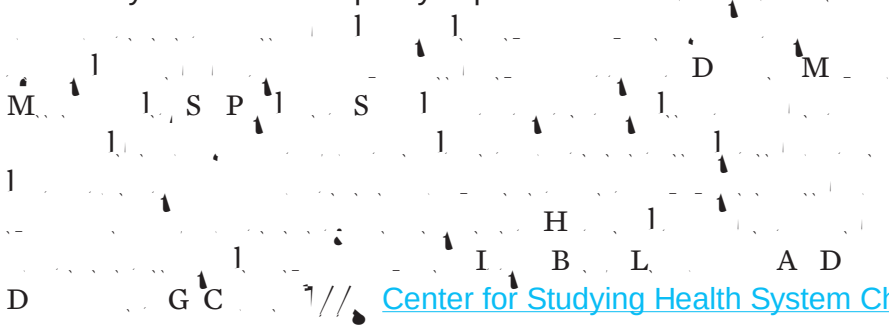
Academic Medicine

- G-12: Nurses' role in quality improvement. T



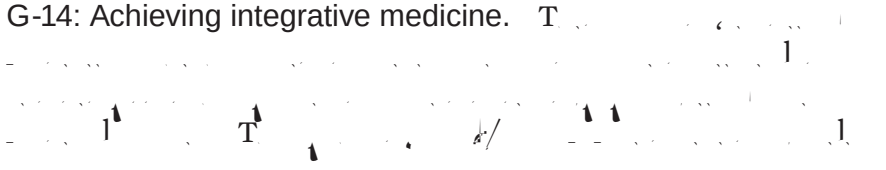
Nursing Administration Quarterly

- G-13: Physicians' role in quality improvement. T



Center for Studying Health System Change

- G-14: Achieving integrative medicine. T



M V D R C N . Explore (NY)

- G-15: Frontline sta driving improvement. L

T C B

T

R

N J S H . Health A airs

- G-16: Pediatric nurses' understanding of care partnership. T

I

L P . Journal of Clinical Nursing

- G-17: AAP: Core principles of family-centered care. T A

A P AAP

T AAP

F C

H C A A P . Pediatrics

- G-18: Physicians' views of surrogate decision making. A

A

S

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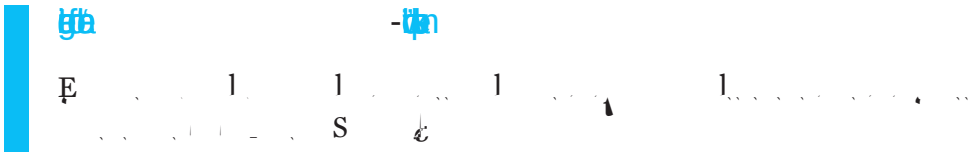
F

A

H G R T . Critical Care Medicine



INFORMATION ON IMPACT

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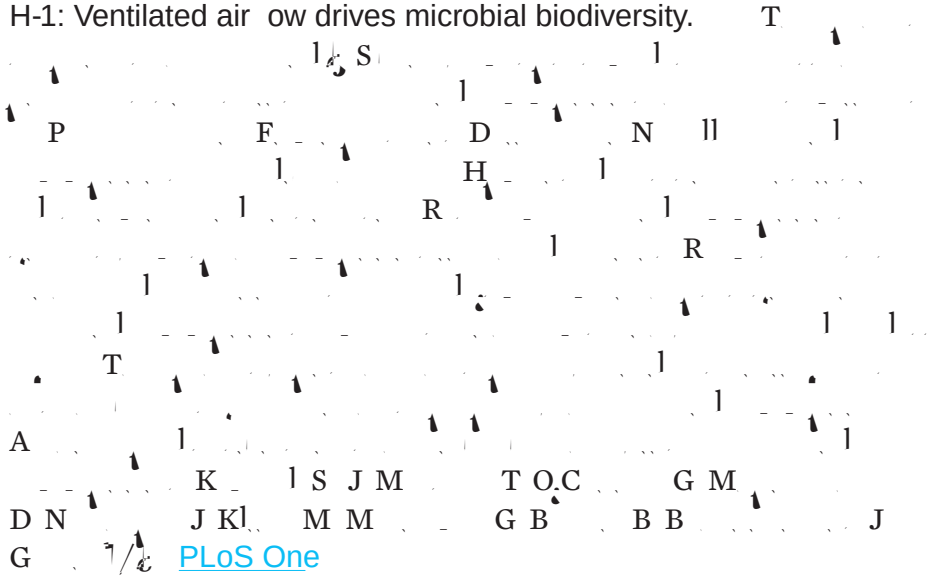
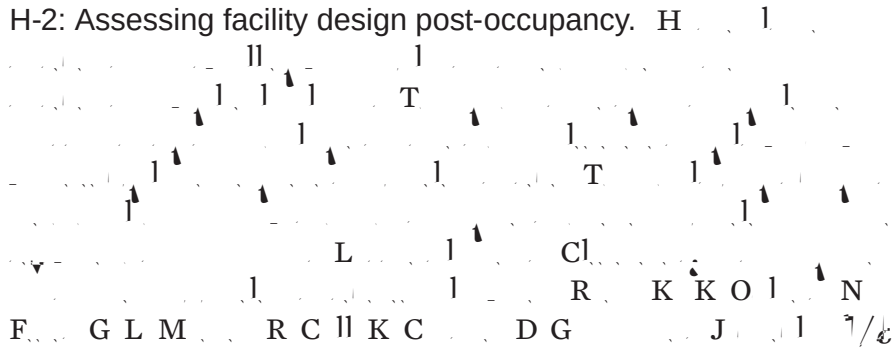
- H-1: Ventilated air ow drives microbial biodiversity. T



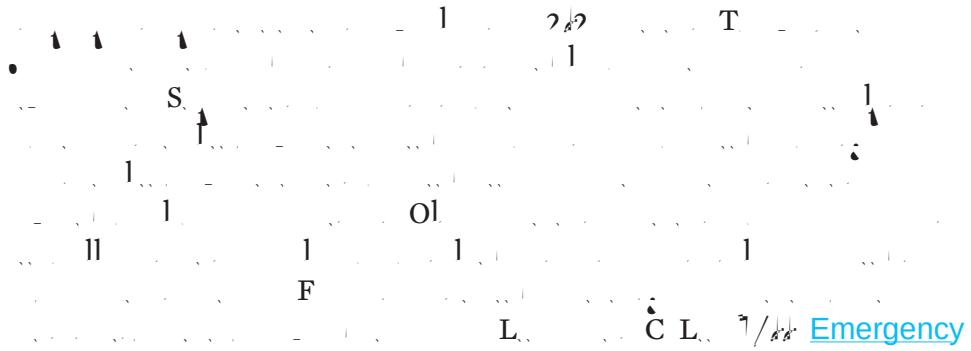
PLoS One

- H-2: Assessing facility design post-occupancy. H



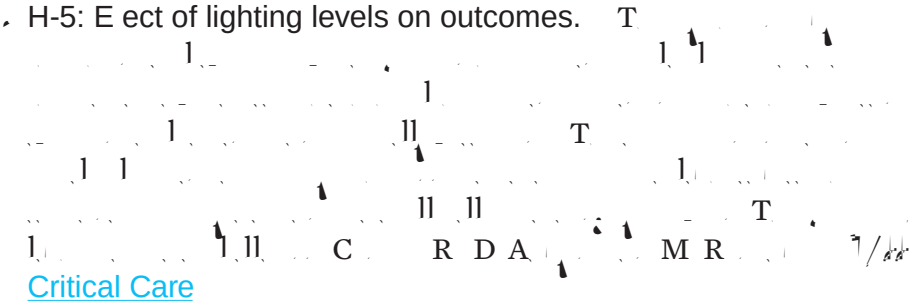
Health Environments Research & Design

- H-3: Decentralizing nurse stations improves patient satisfaction. N



Emergency Medicine Journal

- H-5: E ect of lighting levels on outcomes.



Critical Care

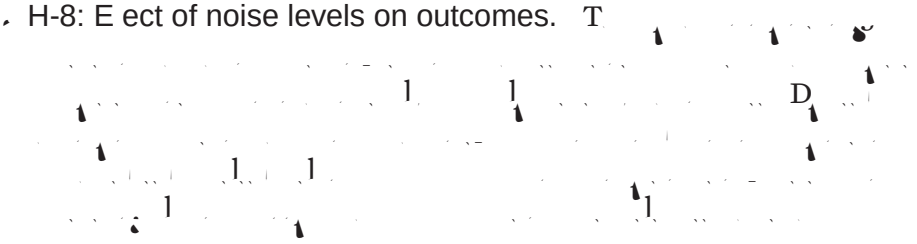
- H-6: Well-designed spaces help with safety.

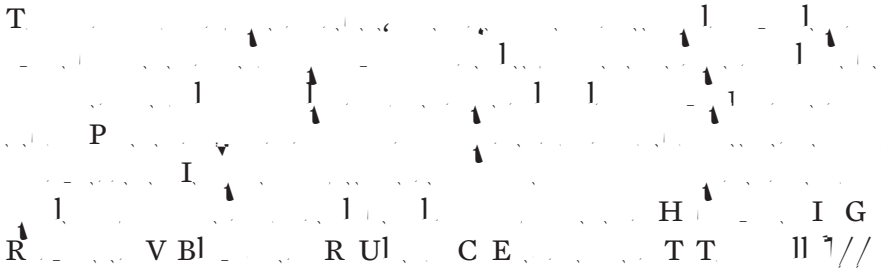
Health Environments Research & Design

- H-7: Ten steps toward a cost-e ective environment.

Health Environments Research & Design

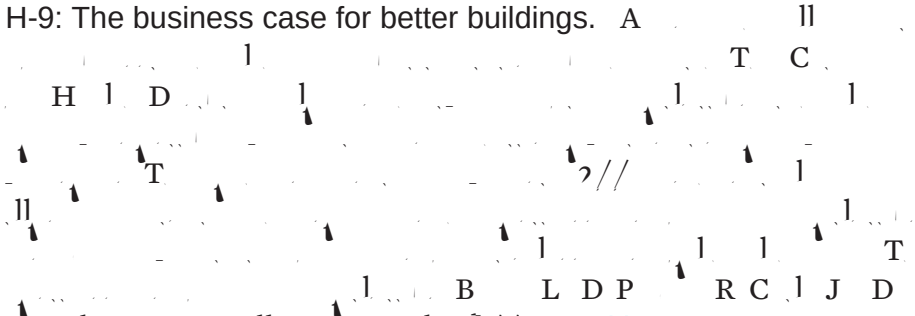
- H-8: E ect of noise levels on outcomes.





International Journal of Cardiology

- H-9: The business case for better buildings.



Healthcare Financial Management

VIDEO TESTIMONIALS:

RESOURCE ORGANIZATIONS

R &

- The Agency for Healthcare Research and Quality AHRQ
  H I C I E
  P F I A C I
- AHRQ Patient Safety Network I I I I
  II II
- American Hospital Association I /// I I
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  B I P P F I T PFAC
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  C
- Beryl Institute I I

- Patient Voice Institute
- PFANetwork
- Planetree

RESOURCE ORGANIZATIONS

AIDS United

Alzheimer's Association

American Cancer Society

American Diabetes Association

American Heart Association

HEARTORG

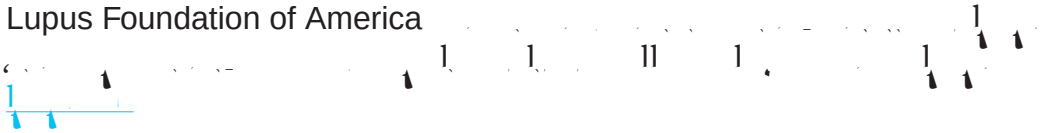
American Liver Foundation

American Lung Association

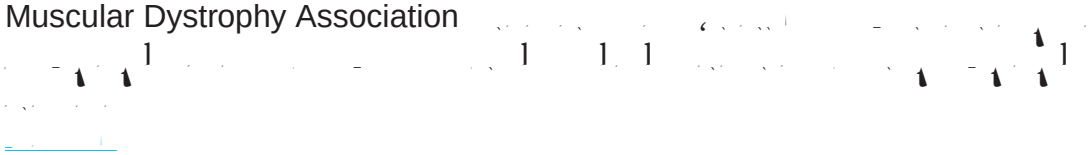
Asthma and Allergy Foundation of America

Epilepsy Foundation

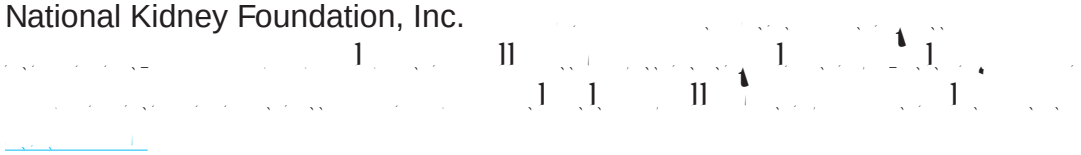
Lupus Foundation of America



Muscular Dystrophy Association

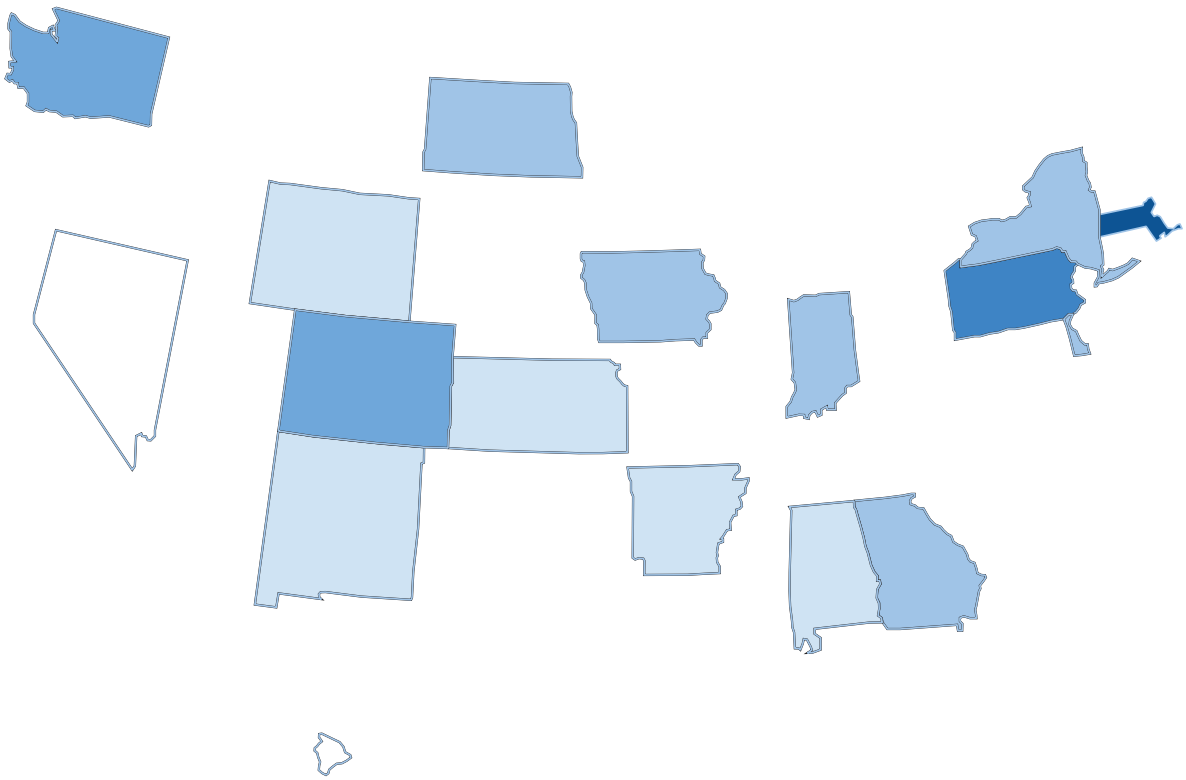


National Kidney Foundation, Inc.



E-COMMUNICATION CHANNELS AND FORUMS

PFHCLN: INSTITUTIONS IDENTIFIED



SNAPSHOTS

A &

Please be in touch
A

Contact:
D H NAM P Q DH

- Akron Children's Hospital OH P A C PAC
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- T P F A C Anna Jaques Hospital MA
  B Q C B
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- Anne Arundel Medical Center MD Better Together P
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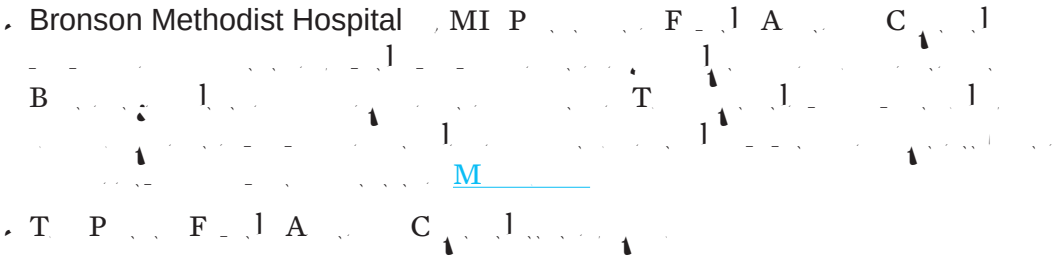
  M
- Baptist Health South Florida FL
  T P F A G
  M
- Barnes-Jewish St. Peters Hospital MO P F
  A C PFAC // PFAC
  M

- Baystate Children's Hospital, MA
- Berkshire Medical Center, MA
- Beth Israel Deaconess Medical Center, MA
- Beth Israel Deaconess Hospital-Milton, MA
- Boston Children's Hospital, MA
- Braintree & New England Rehabilitation Hospitals, MA

- Bronson Methodist Hospital



- Children's members arado

- Advisors and partners at Essentia Health, MN, I
- Fort Belvoir Community Hospital, VA
- Georgia Regents Medical Center, GA, AHRQ
- H. Lee Mo tt Cancer Center & Research Institute, FL
- Hallmark Health System, MA
- Health Central Hospital, FL, PFAC

HCAHPS

- Lawrence General Hospital, MA
- Lowell General Hospital, MA
- Mayo Clinic Health System, MN
- McLean Hospital, MA
- Long Beach Memorial Medical Center, CA

M

- Morgan Stanley Children's Hospital N I
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- A P F A C Nantucket Cottage Hospital MA T E S
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- Nemours DE FL N F A C FAC P H C T
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- T P F A C New England Baptist Hospital MA PFAC I P G J C
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- North Shore Medical Center FL T P F A C
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- T P F A C Norwood Hospital MA A

- NYU Langone's Center for Child and Family Experience
- PeaceHealth St. Joseph Medical Center
- Saint Anne's Hospital
- Smilow Cancer Hospital at Yale-New Haven's
- South Shore Hospital
- Stanford Hospital and Clinics

- The Children's Hospital at Dartmouth-Hitchcock NH F l A
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- The Milford Regional Medical Center MA PFAC l l
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- The Siteman Cancer Center at Barnes-Jewish St. Peters Hospital MO
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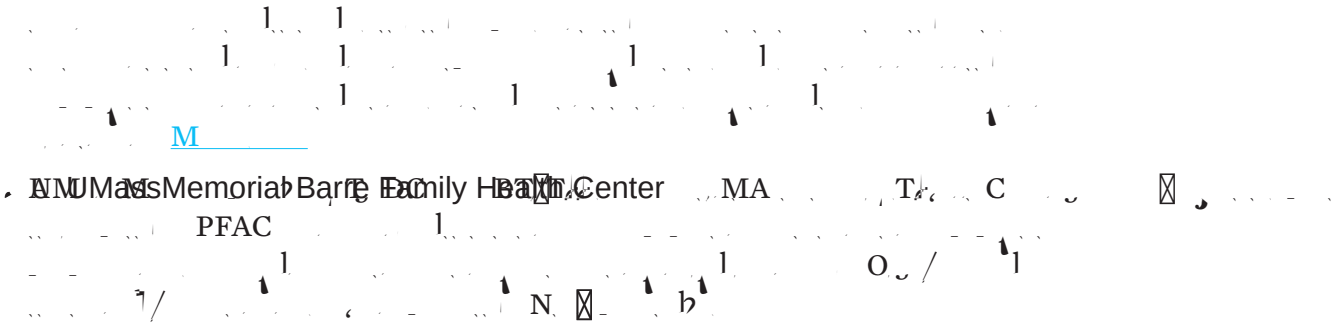
UMass Memorial Family Health Center
PFAC

- Vidant Health NC
- Whittier Rehabilitation Hospital MA

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