

Patient and Family Engagement : Paradigms and Models

Engagement is a mutual relationship.



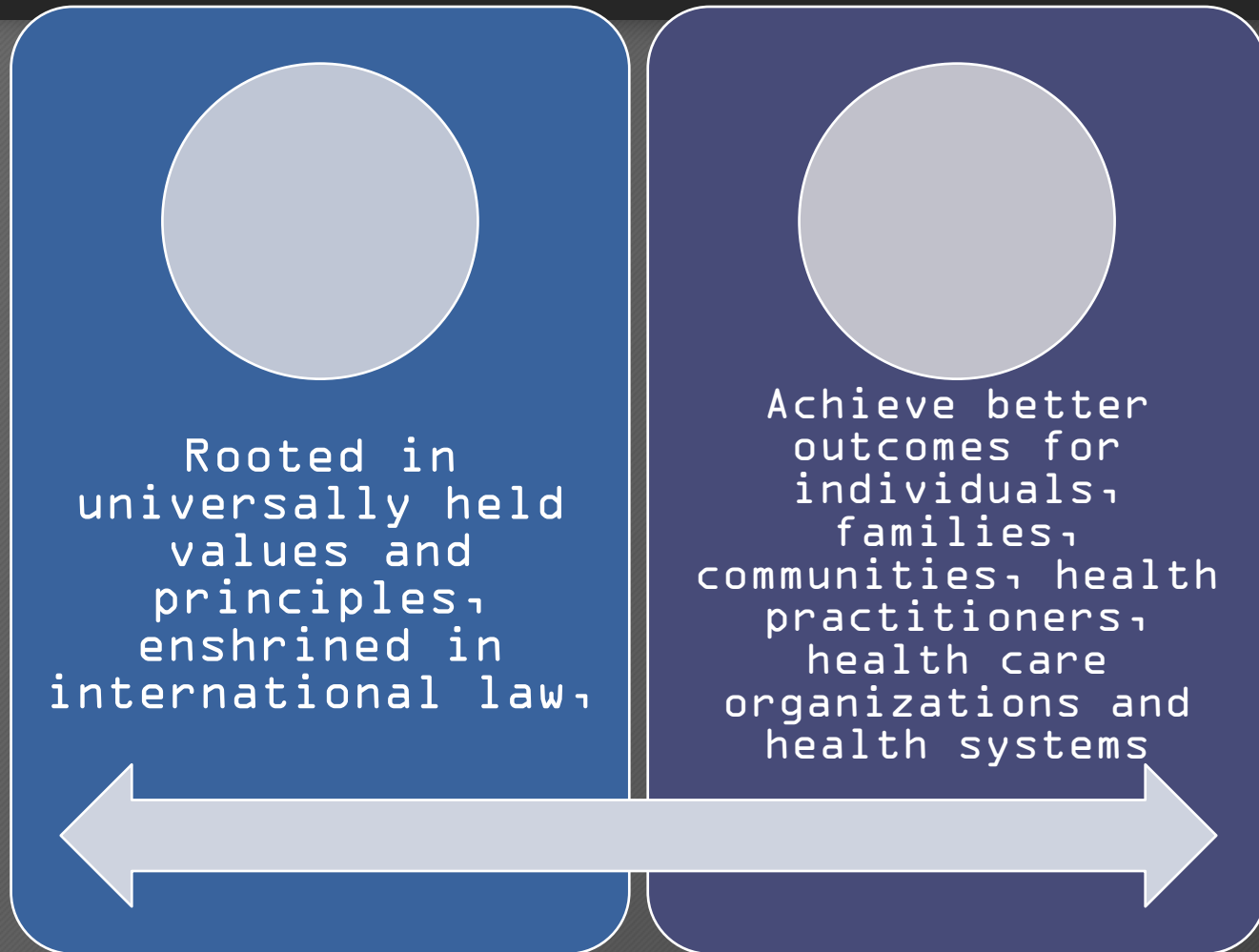
Whatever form it takes,

Engagement changes the focus,

*from taking action to
improve health and healthcare
for the people,*

*to taking action
with the people – a simple
yet radical notion*

People-centred health care (WHO)



Promotes :

Culture of care and communication

Responsible, responsive, accountable services and institutions

Supportive and positive health care environments

Patient and Family Centered Care

- a partnership among practitioners, patients, and their families to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care (Institute of Medicine, Washington, DC).



Patient and Family Centered Care

- A core value of an organization
- that guides its planning, delivery, and evaluation of health care and is
- grounded in mutually beneficial partnerships among health care providers, patients, and families.



Why Patients and Families Matter



the greatest untapped resource in our quest to achieve the triple aim of better health, better care, and lower costs

The most valuable untapped resource for improving healthcare is the knowledge, wisdom, and energy of individuals, families, and communities who face challenging health issues in their everyday lives.

Patients and families are key stakeholders in health care, they have the most at stake

A growing body of evidence shows that their engagement leads to better health outcomes

We believe it is imperative to be explicit and consistent in the inclusion and use of the word family .

Families are key to promoting health and wellness of patients.

Families are the most effective supportive care structure for patients.

Systems need to be in place encouraging and supporting patients and families to define how they want to be involved.

A broad definition of family “a group of individuals with a continuing legal, genetic and/or emotional relationship, critical to ensuring that a patient’s choices about who will participate in their care are respected.”

Patient and Family Engagement

A set of beliefs and behaviors
by patients,
family
members, and
health
professionals

*organizational
policies,
procedures and
interventions
that ensure
both*

- the inclusion of patients and families as central members of the healthcare team and
- active and collaborative partnerships with providers and provider organizations

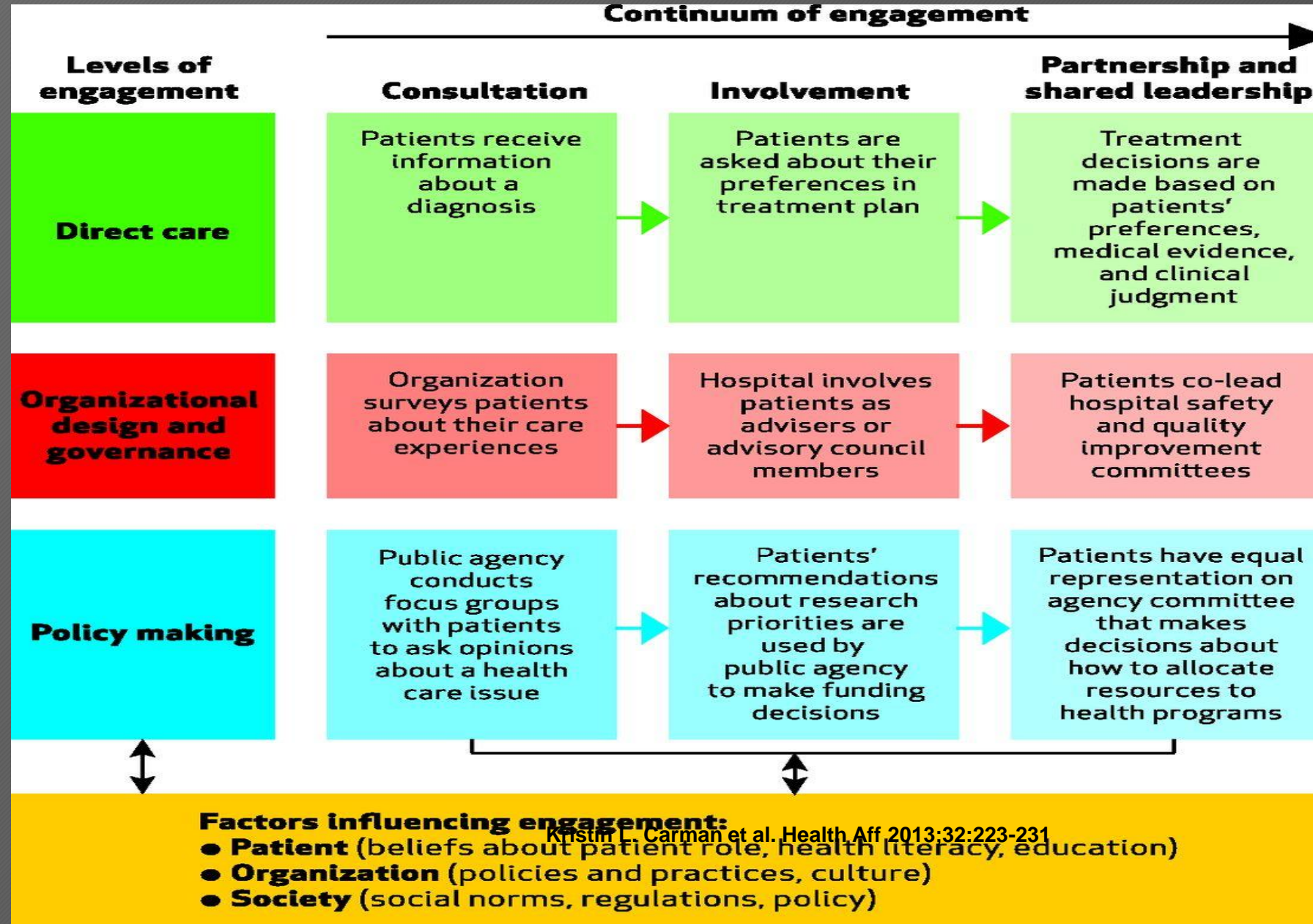
Patients, Families, Health Professionals

Working in active partnership at various levels across the health care system—

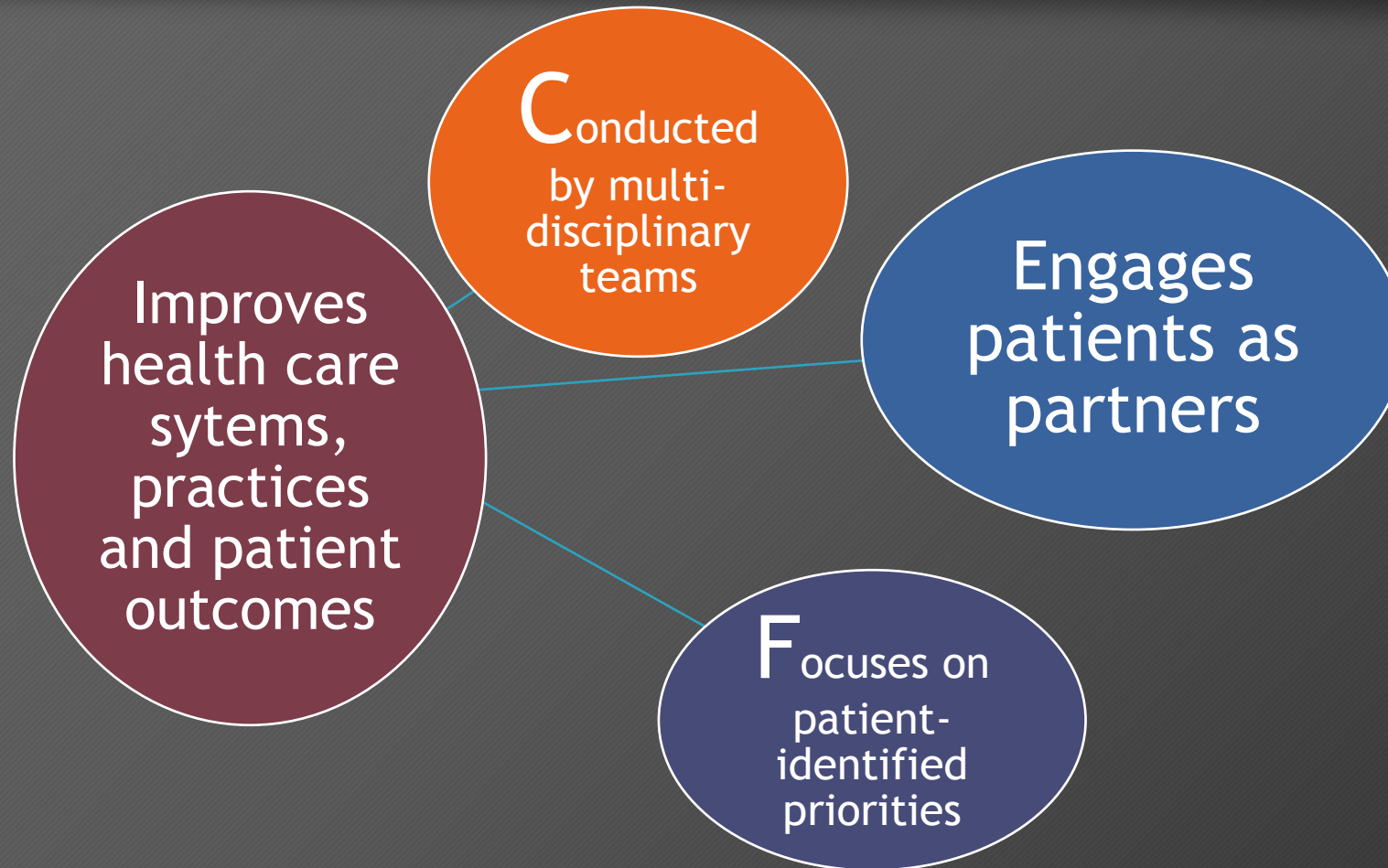
Direct Governance and Policy Making

Organizational Design

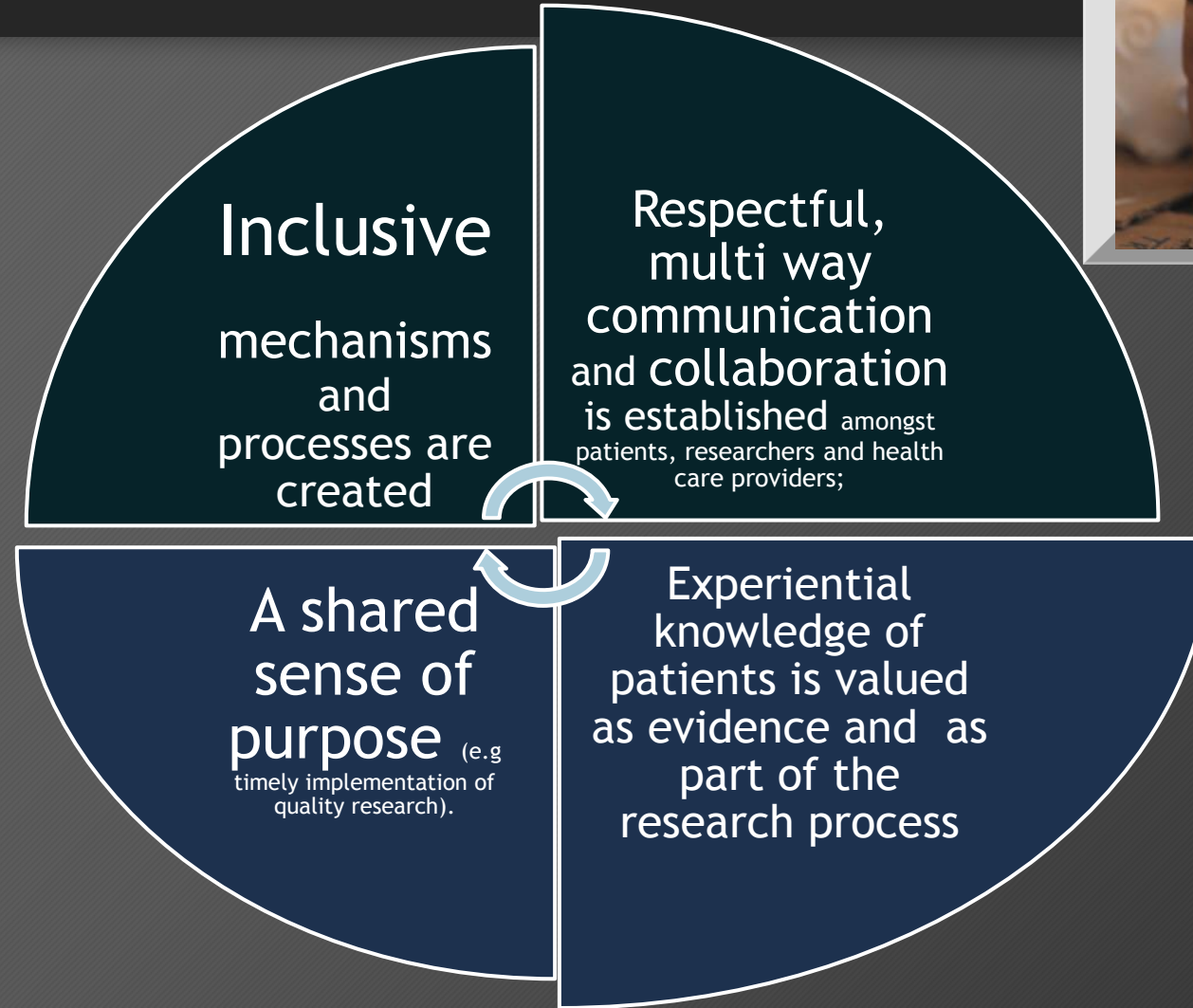
A Multidimensional Framework For Patient And Family Engagement In Health And Health Care.



Patient Oriented Research



Desired Outcomes of Patient Oriented Research



Patient and Family Engagement in Research occurs when they meaningfully and actively collaborate in



Governance
, priority
setting

Conduct
of
research

Knowledge
translation
(summarizing,
distributing,
sharing and
applying the
resulting
knowledge)

Improved patient experience with the health system and health outcomes

Patients and Families influence decision making, accelerate knowledge translation and uptake of new policies and practices

Research is conducted in areas patients and families value/find meaningful

Researchers understand the value of patient and family engagement and patients and families appreciate the value of research

Provide input on identifying health research priorities

Participate in the design and undertaking of research projects

Patients and Families
Patients

Researchers, health care professionals and policy makers work together with patients and families to ensure an integrated people centered approach that improves policy, practice and health outcomes



Sample of Guide Keystone Questions

Does proposal describe how patients and families were or will be identified and engaged in the research?

Are roles of patients and families significant in formulating the study's research questions, hypotheses and design and in the study's conduct and dissemination of results?

Are the roles proposed for patients and families in the planned dissemination or implementation plans meaningful and likely to be effective?

If engagement is not applicable in the proposed research, does the application justify why it is not?





Sample guide key questions in data analysis and interpretation (even when PF are not directly involved)

Do patient/family stakeholders have same interpretation of study findings as researchers?

Are there findings that would benefit from patient/family stakeholder explanation/contextualization?



Benefits of patient and family engagement in health research

Provides new insights that could lead to innovative discoveries

Development of new forms of research

Increased adoption of research results

Makes investment in research more accountable and transparent

Ensures that research is relevant to patients and families concerns and needs

Benefits to patients and families



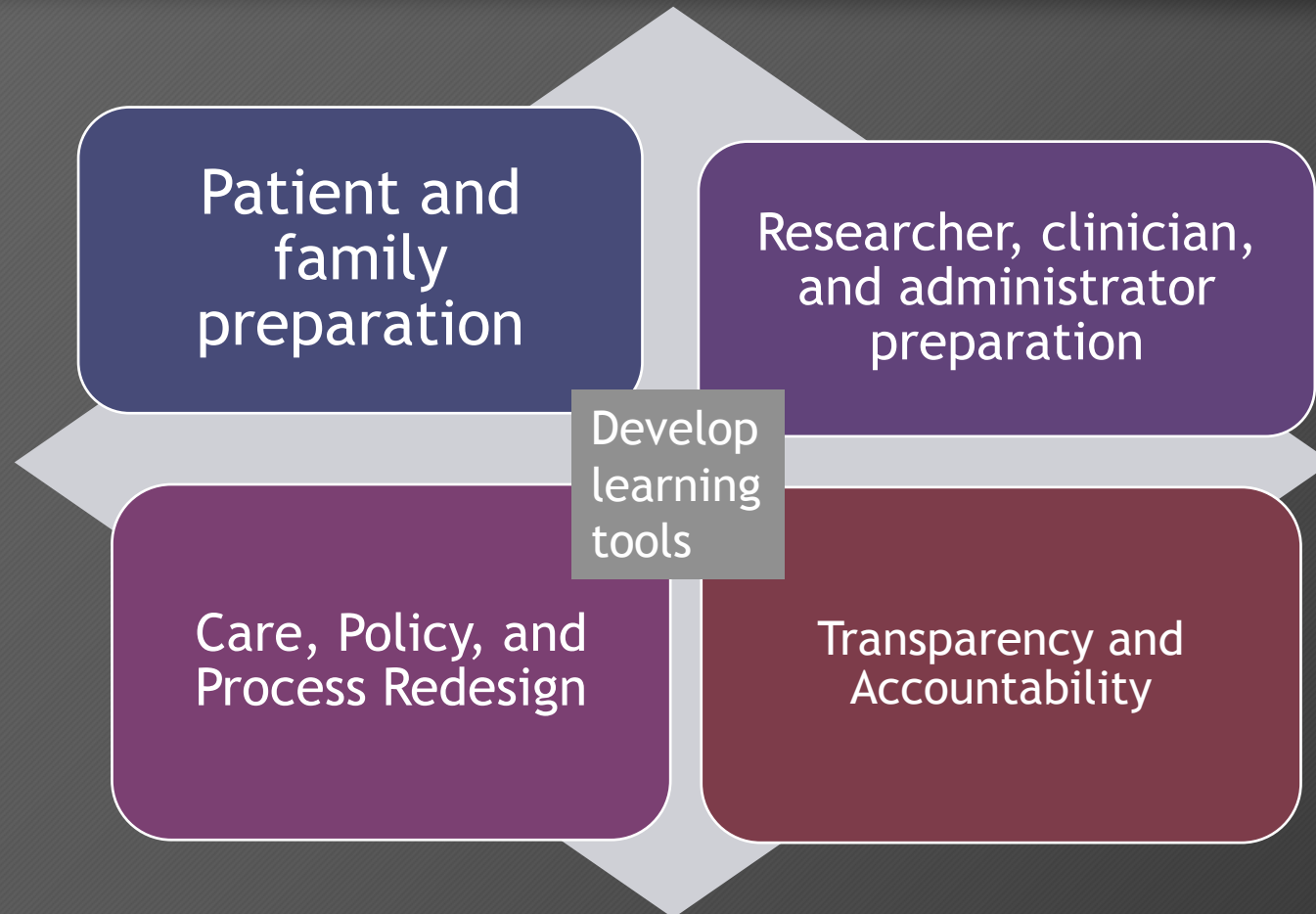
Increased confidence

Development and enhancement of new skills

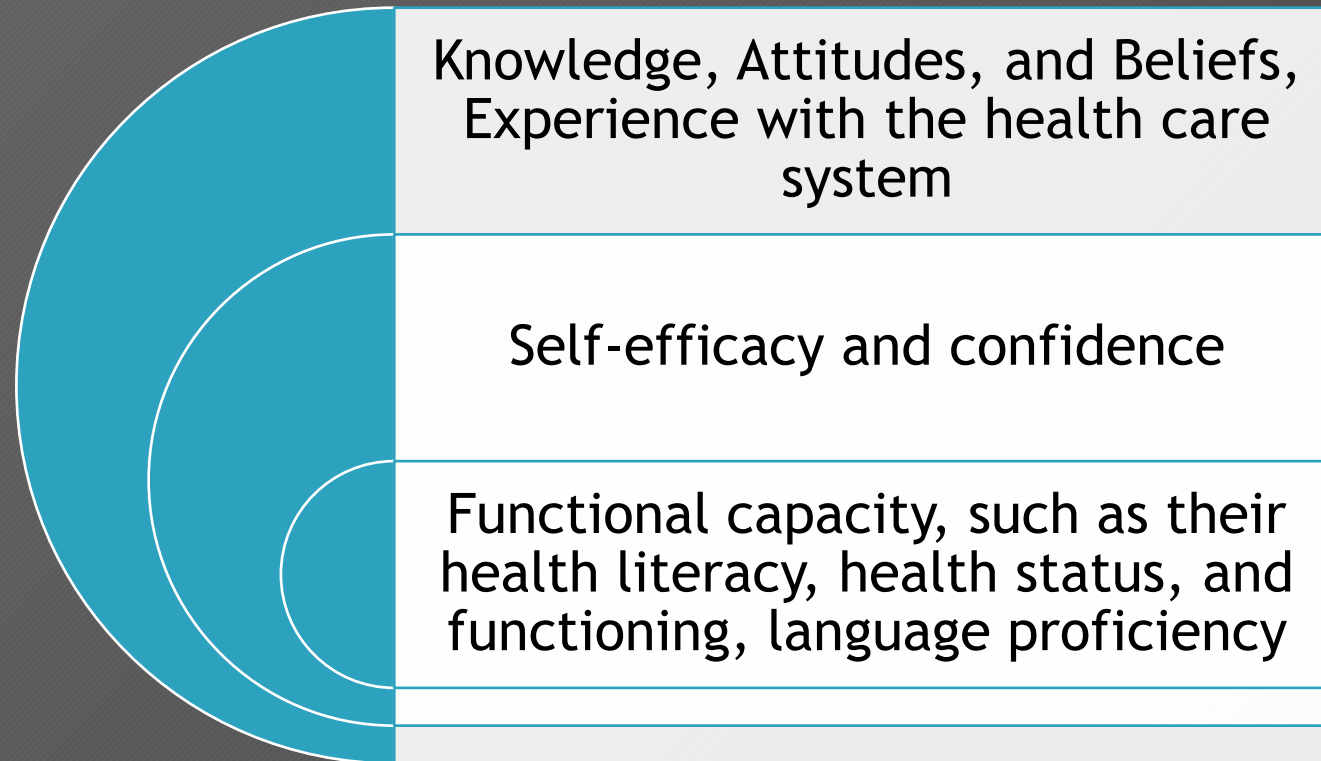
Access to information they can understand and use

A feeling of accomplishment from contributing to research relevant to their needs.

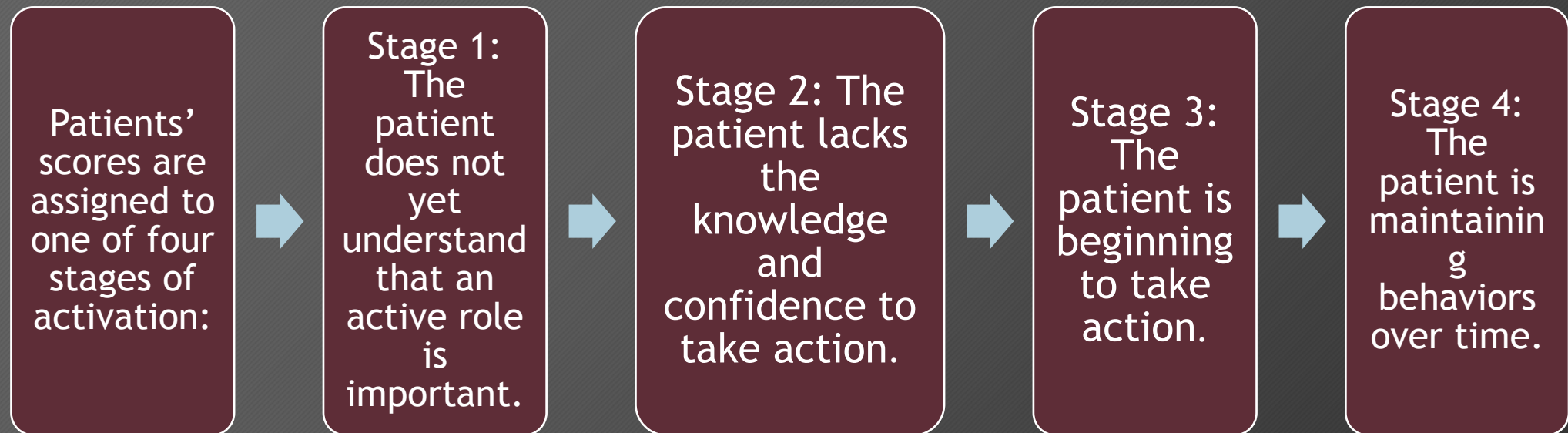
Key Tasks for Pursuing Patient and Family Engagement



Key Factors that affect patient and family motivation, willingness and ability to engage



Sample Tool that can be adapted : Patient Activation Measure (PAM) quantifies an individual's level of activation, or engagement, in their care



Readiness to Partner With Patient and Family

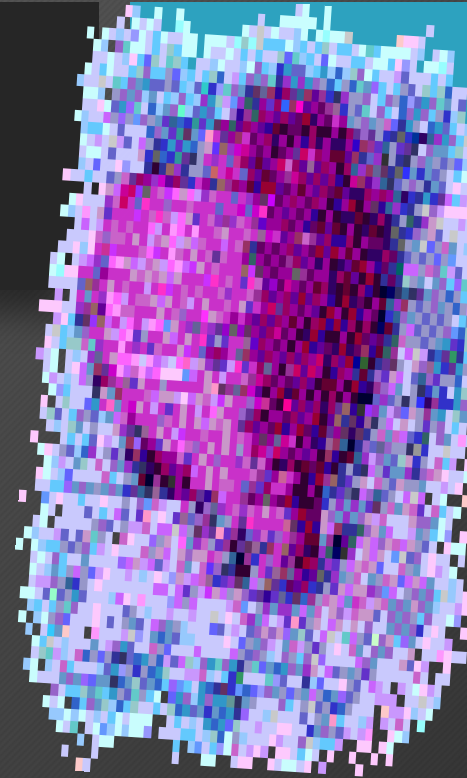
I am ready to work with patient and family when

- I believe in the importance of patient and family participation in planning and decision making at the program and policy level
- I believe that the perspectives and opinions of patient and family advisors, staff, and clinicians are equally valid in planning and decision making at the program and policy level
- I believe that patients and family members bring a perspective to a project that no one else can provide
- I consistently let colleagues know that I value the insights and experiences of patients and family members

I enjoy working with people who are different from me

I am willing to talk about my experiences with patient and family advisors and to share suggestions, ideas, and potential solutions that will help improve hospital care

I am comfortable requesting that patient and family advisors be invited to participate in improvement initiatives in which I am involved



What do patients and families need in order to participate effectively in health research ?

We must know it's important (i.e., the why behind the what).

We must know it's possible (i.e., the ways or avenues we can take that are within our ability).

We must know it's safe (i.e., we can't be punished, ignored, or made more fearful)

We must know its benefits and advantages to us personally, to our patient and family and to other patients and their families

