
Patient Activation as a Health Literacy Tool: Is It Missing From Your Toolbox?

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Learning Goals Roadmap

1. Define 'patient activation' and establish its relationship to health literacy.
2. Describe uses for the research-validated Patient Activation Measurement (PAM) tool.
3. Explain how to integrate and use patient activation and health literacy tools to empower patients, improve outcomes, and reduce costs.
4. Incorporate one new concept from this presentation related to patient activation into your daily practice.

Patient Activation

‘Patient activation’ (PA) describes the degree to which individuals have the knowledge, skills and confidence to manage one’s health/health care and share responsibility for health decisions with providers.

Hibbard & Greene, 2013

Health literacy (HL) describes activities associated w/finding, understanding, and using information and services to improve health & navigate health organizations.

Liu, et al, 2020

When providers address their patient’s HL, they are not focused (explicitly) on self-efficacy (confidence) or shared decision-making. Instead, they adopt **best communication practices** utilizing:

- [Universal Precautions in Health Literacy](#)
- [Plain Language Guidelines](#)
- [Teach Back](#)

Activation: Assumptions & Questions

If activated patients manage their health and health care more effectively than those who are passive.

How can patients become confident informed managers of their health and health care?

What knowledge, attitudes, and skills (KSA) do they need to become activated?



The Patient-Provider Dyad

Persons living with chronic disease face difficult and complex decisions about their health, such as:

- following complex treatment regimens
- monitoring their health conditions
- making lifestyle changes
- knowing what to do to self-manage chronic disease
- recognizing when to involve health professionals

Patient Empowerment

Empowering patients to manage health is an essential element of **high-quality patient care**.

Those with high activation levels understand their role in the care process and feel capable of fulfilling it.

Patients should play a major role in determining both their need for care and the outcome of care.

There is a growing awareness that patients should be more active and more effective managers of their own health and health care.



Patient Activation Measure (PAM)

The Patient Activation Measure (PAM) is a 22-item *validated* tool that assesses patient *knowledge, skills, and confidence* for self-management. Shortened forms have 13 and 10 items, respectively.

PAM scores range from 0-100.

Providers who know their patient's activation level can use the information to personalize a plan of care with the patient's input (shared decision making).

Knowing your patient's PAM score enables patient-centered care and interventions that build an individual's *knowledge, skills and confidence*

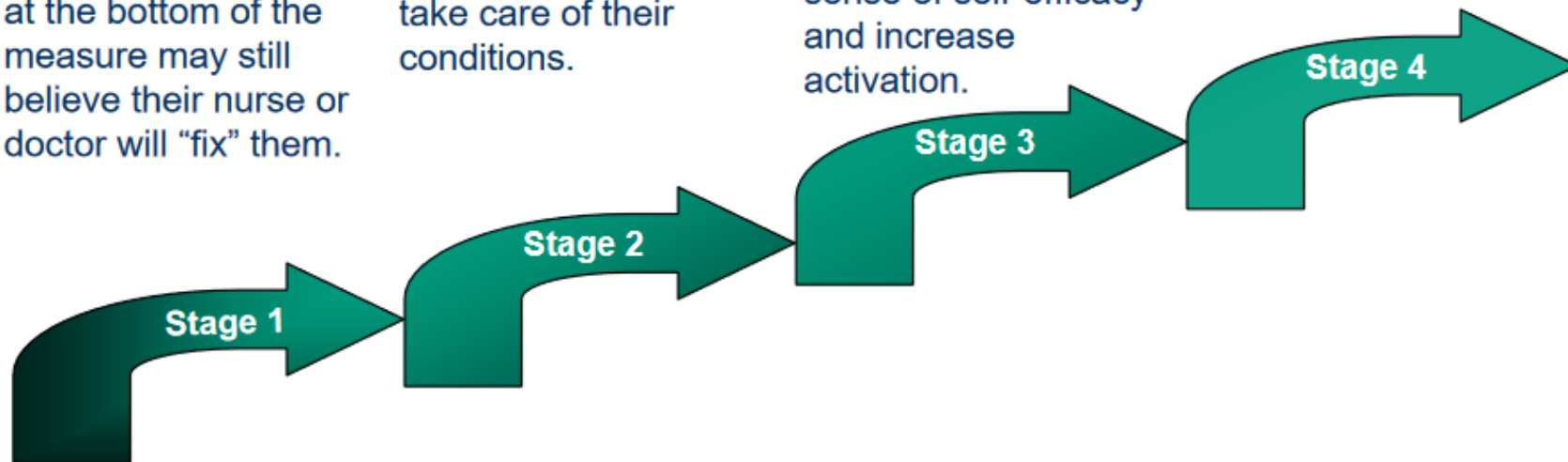
Four Stages of PAM

Members who score at the bottom of the measure may still believe their nurse or doctor will “fix” them.

Members who score somewhat higher, may understand they must be involved in their healthcare, but lack the knowledge and confidence to take care of their conditions.

Members who score in the upper half are beginning to gain confidence to take on self-management behaviors and need to experience small successes to build a sense of self-efficacy and increase activation.

Members scoring in the upper range have the confidence and skills to manage their health, but may need help with maintaining their progress during stressful times.



Level 1

DISENGAGED AND OVERWHELMED

"My doctor is in charge of my health."

Individuals are passive and lack confidence. Knowledge is low, goal-orientation is weak, and adherence is poor.

Healthcare utilization:
Very high ED/ER use, very high risk of Ambulatory Care Sensitive (ACS) utilization, very high risk of readmission, very low use of preventive care and screens.

Level 2

BECOMING AWARE BUT STILL STRUGGLING

"I could be doing more for my health."

Individuals have some knowledge, but large gaps remain. They believe health is largely out of their control, but can set simple goals.

Healthcare utilization:
High ED/ER use, high risk of ACS utilization, high risk of readmission, low use of preventive care and screens.

Level 3

TAKING ACTION AND GAINING CONTROL

"I'm part of my health care team."

Individuals have the key facts and are building self-management skills. They strive for best practice behaviors, and are goal-oriented.

Healthcare utilization:
Low ED/ER use, low risk of ACS utilization, low risk of readmission, good use of preventive care and screens.

Level 4

MAINTAINING BEHAVIORS AND PUSHING FURTHER

"I'm my own health advocate."

Individuals have adopted new behaviors, but may struggle in times of stress or change. Maintaining a healthy lifestyle is a key focus.

Healthcare utilization:
Very low ED/ER use, very low risk of ACS utilization, very low risk of readmission, very good use of preventive care and screens.

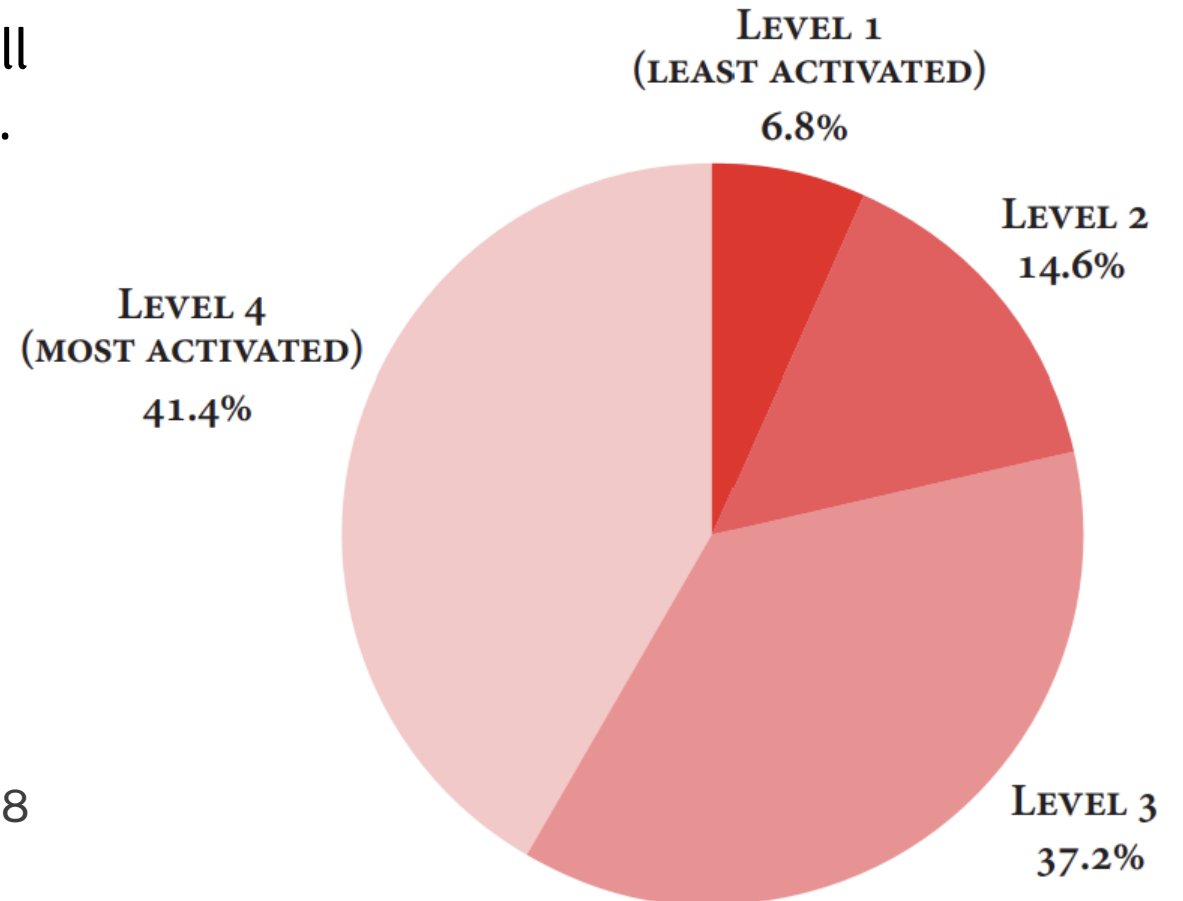
Estimated Activation Levels U.S. Adults

Activation levels reflect an individual's beliefs about their role in managing their health as well as their knowledge and confidence in doing so.

Activated patients are proactive managers.

Even at the highest level of activation, people struggle to maintain healthy behaviors but the keys to success are that activated patients: (1) will develop the skills needed and (2) have confidence they can manage their health.

Hibbard, Cunningham, 2008



Patient Activation Measure (PAM – 13)

Assess the belief that an active role is important	1. I am the person responsible for taking charge of my health.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
	2. Taking an active role in my health care is the most important thing that affects my health.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
Measure the degree of knowledge and confidence to <u>take action</u>	3. I am confident I can help prevent or reduce problems associated with my health.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
	4. I know what each of my prescribed medications does.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
	5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
	6. I am confident that I can tell a doctor or nurse concerns I have even when <u>he or she does</u> not ask.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
	7. I am confident that I can <u>carry out</u> medical treatments I may need to do at home.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
	8. I understand my health problems and what causes them.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
Assess the ability to <u>take action</u>	9. I know what treatments are available for my health problem.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
	10. I have been able to maintain lifestyle changes, like healthy eating or exercising.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
	11. I know how to prevent problems with my health.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
Assess the ability to stay the course under stress	12. I am confident I can work out solutions when <u>new problems</u> arise with my health.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
	13. I am confident that I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A

Brief Health Literacy Screen

1. How confident are you filling out medical forms?
2. How often do you have problems learning about your medical condition because of difficulty understanding written information?
3. How often do you need help reading or filling out medical forms?
4. How often do you have someone help you read hospital materials?
5. How often do you have a problem understanding what is told to you about your medical condition?

Chew, et al, 2004

Since its origins in 1999, HL assessment has focused on literacy skills, note this early definition as the “ability to perform basic reading and numerical tasks required to function in the health care environment.”

Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, AMA

Response	Score	Assessment
Always/Extremely	5	Limited skills
Often/Quite a bit	4	Limited skills/Will need assistance
Usually/Somewhat	3	Marginal skills/ Needs supervised assistance
Sometimes/Occasional	2	Adequate skills
Never/Not at all	1	Adequate/Functions independently

Higher Activation Levels Predict Behavior

Individuals with higher activation levels are:

- more likely to engage in preventive care (health screenings and immunizations)
- practice positive health behaviors (good diet and exercise)
- practice self-management behaviors (monitor health conditions and adhere to treatment protocols)
- seek health information (ask questions in medical encounters and use quality information to select providers)

Hibbard, Mahoney, et al, 2007

Activation Level and Access to Resources

How does patient activation level predict ability to access resources after controlling for differences in economic status, education, health status and insurance status among a group of adults living with chronic health conditions?

	All adults with a Chronic Condition	PAM Level 1	PAM Level 2	PAM Level 3	PAM Level 4
Regular Source of Care	91.0%	88.4%	88.5%*	91.3%	92.4%
Unmet Medical Need	12.2%	26.8%*	15.2%*	10.2%	9.4%
Delayed Care	15.5%	47.1%*	39.1%*	30.2%*	25.2%
Did Not Get Prescription Drug Due to Cost	21.0%	37.4%*	26.3%*	19.9%	20.0%

For every variable, adults with higher levels of activation experienced fewer barriers and utilized more creative problem-solving solutions to access care and the SDOH.

Source: Health System Change Research Brief No. 8 October 2008. Judith Hibbard and Peter J. Cunningham

*Differences with Level 4 statistically significant at $p < .05$.

Note. All estimates are based on regression-adjusted means controlling for age, gender, family income, education, health insurance status, race/ethnicity, number of chronic conditions, perceived health status, body mass index, urban vs. rural residence, and census region.



Complementary Tools for Patient Empowerment

Patient Activation Research

Patient activation focuses on knowledge, skills, and confidence. Persons with higher levels of activation have been shown to have better health outcomes, lower health care costs and better patient experiences.

Research shows that activated patients are more likely to engage in information-seeking, preventive, and maintain self-management behaviors. Once they develop the knowledge, skills and confidence to practice preventive behaviors, they are also inclined to maintain them over the long term.

Hibbard, Mahoney, et al, 2007

Quality Improvement Goal	Intervention	K	S	C
Improving health literacy	<ul style="list-style-type: none"> Written health information Alternative format resources (e.g. internet) Targeted low literacy initiatives Targeted mass media campaigns 	✓ ✓ ✓ ✓		
Improving clinical decision making	<ul style="list-style-type: none"> Communication skills training for clinicians Coaching and question prompts for patients Patient decision aids 	✓	✓ ✓ ✓	✓ ✓
Improving self-care	<ul style="list-style-type: none"> Self-management education Self-monitoring and treatment Self-help groups and peer support Patient access to personal medical information Patient-centred telecare 	✓ ✓	✓ ✓ ✓	✓ ✓ ✓ ✓
Improving patient safety	<ul style="list-style-type: none"> Infection control Adherence to treatment regimes Patient reporting of adverse drug events Equipping patients for safer healthcare Preventing wrong site surgery 	✓ ✓ ✓	✓ ✓ ✓	✓ ✓ ✓
Improving access	<ul style="list-style-type: none"> New modes of communication Remote teleconsultation 	✓ ✓		

Knowledge, Skills, and Confidence (K, S, C) Activities Evaluated Using the Patient Activation Measure

Create A Patient Activation Plan

Patients with low activation levels also have higher rates of avoidable ED visits and have a harder time managing complex transitions of care.

Their hospital readmission rate is more than twice the unplanned healthcare utilization rate at 30-days post-discharge than patients with high activation.

Fisher, 2022

Consider creating an activation plan to move individuals interested in moving from lower to higher levels of activation by following these steps.

Step #1 Know Your Patients: Use PAM-13

Start by administering the PAM-13 to get a baseline activation level for each patient. Review the results with each one. Engage them in a conversation about “patient activation.” Use motivational interviewing to discuss areas of change that might be easiest as starting points.

Develop a plan with short term realistic goals for improving knowledge, skills, and confidence. The goal is to become a proactive manager of one’s health.

Share decision-making. Use health literacy tools to improve communication and ensure comprehension.

- [Ask Me 3](#)
- [Teach Back](#)

Step #2 Activate Using Digital Outreach Tools

Activate patients using digital outreach tools that enable them to engage seamlessly with you and/or clinic staff:

Manage clinical care and prevent disease

- schedule appointments
- send messages and appt reminders
- schedule lab work, tests, other procedures
- preventive health screenings
- immunizations

Manage education and health literacy

- learn about health conditions
- track and manage symptoms
- medication management

Remote care

- telehealth
- telemonitoring
- health coaching

Step #3 Enlist a Health Coach

Health coaches support patients as they make decisions and implement changes that improve health.

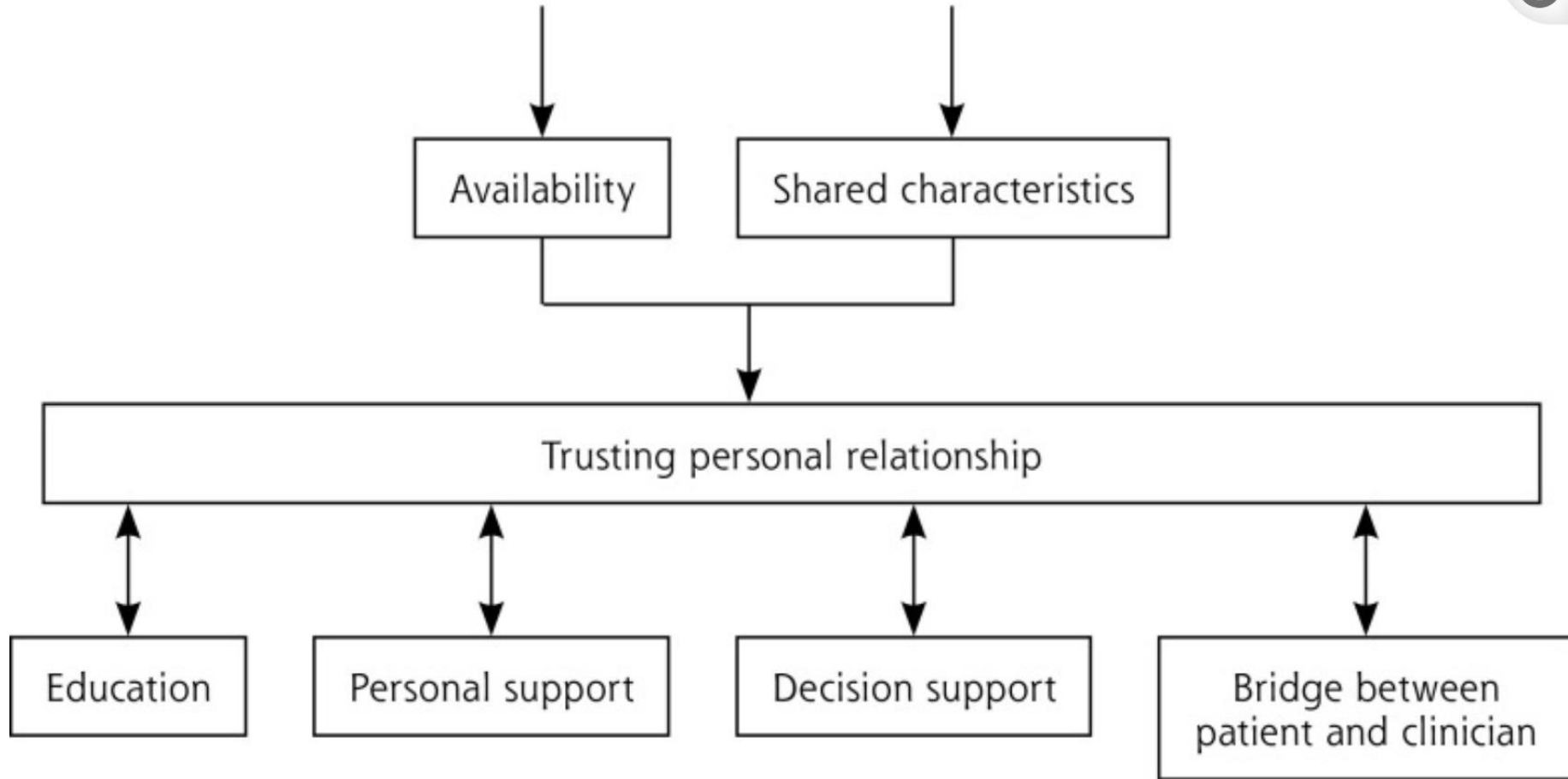
They have a growing role as community-based patient advocates.

Efforts to deliver more integrated, patient-centered primary care have included patient activation, patient education and engagement, shared decision making, and self-management support.

Health coaches are working in many of these interprofessional areas and may be emerging as a new profession/para-profession.

Thom, et al, 2018

Context of health coaching to support patient decision making



Health coaches' activities that support patient decision making

Step#4 Utilize Digital Communication

Use digital media to help patients move from one activation level to higher levels. Increase knowledge about health, develop skills, and build confidence following best practices:

- [Social Media Best Practices Checklist \(CDC\)](#)
information adapted for Facebook, X (formerly Twitter) and Instagram
- [How To Evaluate Health Information on the Internet: Questions and Answers](#)
- [A Community Toolkit for Addressing Health Misinformation](#)

Step #5 Survey Participant Experiences

Patient/participant surveys are a key confidence-building intervention activities that are often overlooked.

When individuals have time to confidently reflect on their health care experience and provide meaningful feedback, they become engaged with the process of their care. Their patient activation level increases.

It is even more meaningful when providers have conversations about their patient's experiences with health care and the health care system. This is an opportunity to provide instruction, information for skill building, and affirmation to build confidence, too.

Thanks for joining me today!

Do you have any questions?

Contact me: lkguyer@ufl.edu



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