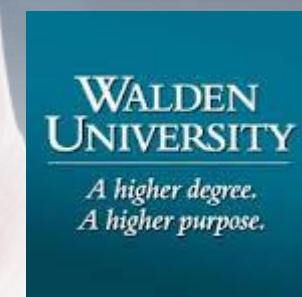




Understanding Health Literacy Skills in Patients With Cardiovascular Disease and Diabetes

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Understanding Health Literacy Skills in Patients with Cardiovascular Disease and Diabetes

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Health literacy is the ability to understand and act on health information and is linked to health outcomes. It is unclear how health literacy skills are developed in patients with complex conditions, such as cardiovascular disease and diabetes. The purpose of this grounded theory study was to gain perspectives of both patients and healthcare professionals on how health literacy skills were developed in patients with cardiovascular disease or diabetes. The research questions addressed how knowledge and skills were acquired, the role of digital tools, instructional strategies used by healthcare professionals, and how the instructional strategies of the healthcare professionals matched the learning preferences and needs of the patients. A social ecological framework was used, which underscored the importance of understanding health literacy from multiple sources. Semistructured

What is health literacy?



Healthcare professionals



Education

Blood pressure

Decision making

Health apps

PROSIE

Social networking

Navigation

Personalized, interactive, social, & relevant

Diabetes

Health Literacy

Heart disease

Numeracy

Heart failure

Cholesterol

Internet searches

Wearables

Linguistics

Trusted sources

Chronic conditions

Communication

Apps

Knowledge

Connected health devices



Digital tools & technology

DOCUMENT



Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Ratzan and Parker).



Background

Health literacy is a public health priority (Nielsen-Bohlman, Panzer, & Kindig, 2004)

90 million Americans have below basic health literacy skills (Kutner, Greenberg, Jin, & Paulsen, 2006)

Low health literacy is linked to poorer health outcomes (Berkman et al., 2011)

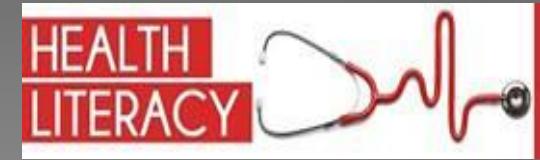
HHS developed a National Action Plan to improve health literacy (2010)



My Journey in Health Literacy:

- *30+ years as a clinical exercise physiologist working primarily in a cardiac rehabilitation setting;*
- *Inpatient and outpatient*
- *One on one, small groups*
- *Community and corporate educational sessions*
- *Degree in Education*
- *Stories*



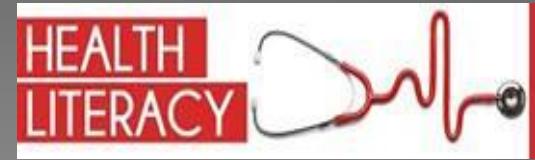


Story 1:

Can't use "big" words like "cholesterol", "carbohydrates", or "saturated fats" because it makes the reading level too high

If we used that approach with our kids, instead of teaching them to read, we would live in a world in which reading was not necessary

Patient education



Definitions:

Educator: (1) one skilled in teaching; (2) a student of the theory and practice of education (*Merriam-Webster Dictionary*)

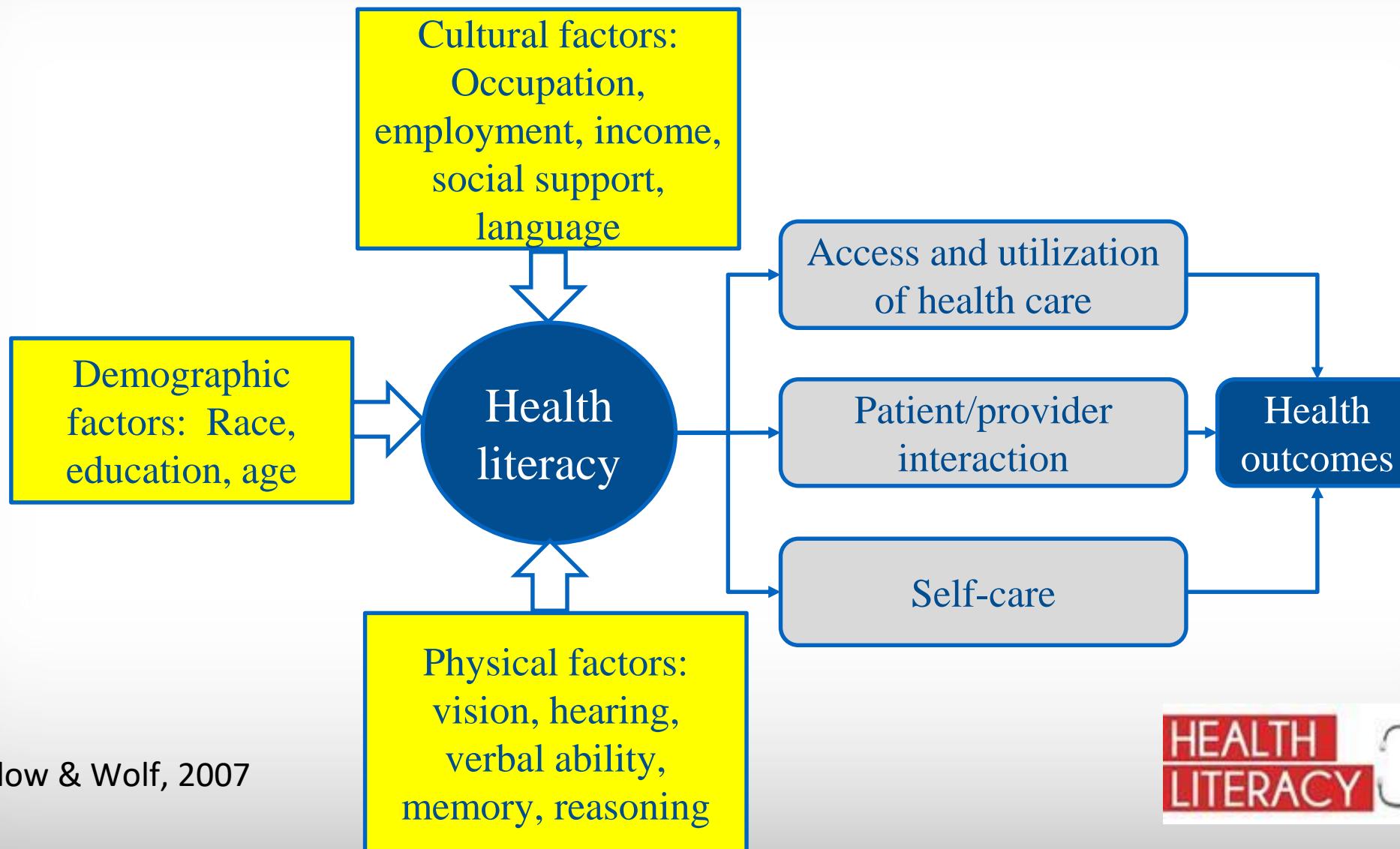
Who is that?

- Doctors
- Nurses
- Other healthcare professionals
- Health educators and coaches



Only 1 of 19 healthcare professionals met the definition

Health literacy and health outcomes pathway



Paasche-Orlow & Wolf, 2007





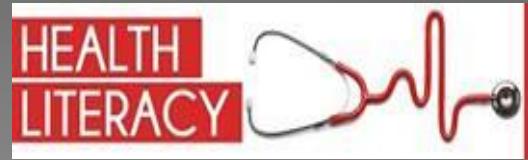
Focus on low literacy

low health literacy associated with poorer outcomes

- **Heart disease**
- **Heart failure**
- **High blood pressure**
- **Lipoprotein disorders**
- **Diabetes**

In most cases, health literacy was a dichotomous, independent variable, with a biometric or health outcome as the dependent variable.

Very little research on the impact of building health literacy skills.



The Challenge

Heart disease and diabetes are complex conditions that require a high level of patient involvement



Interpreting lifestyle instructions

Physical activity and nutrition guidelines



Understanding the condition

Names and implications of conditions, diagnostic tests, and treatments

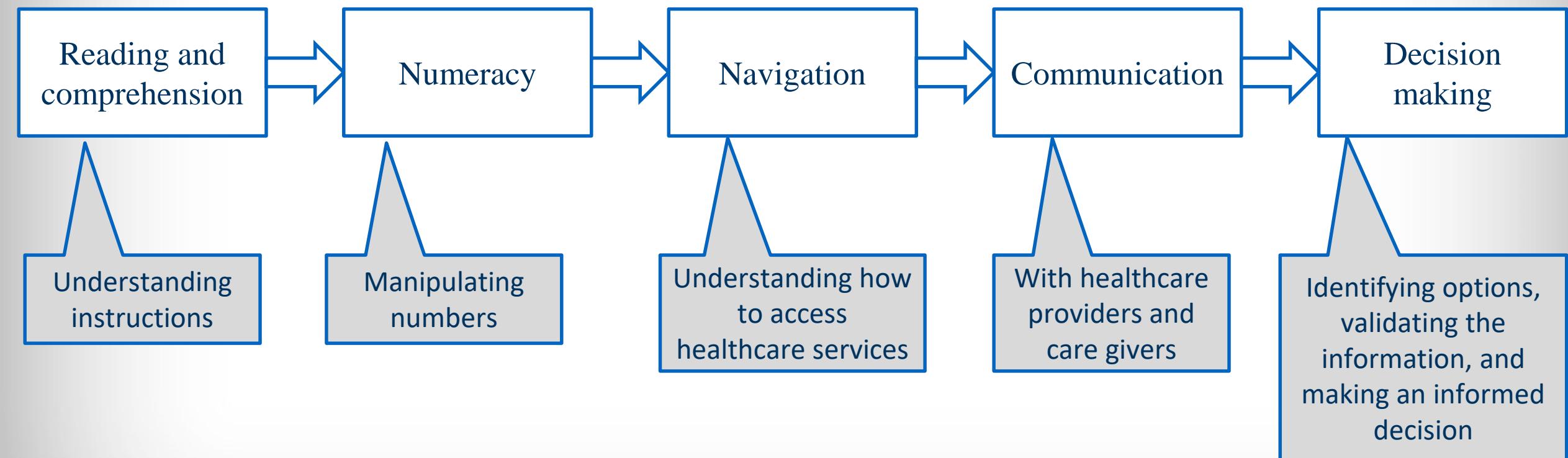


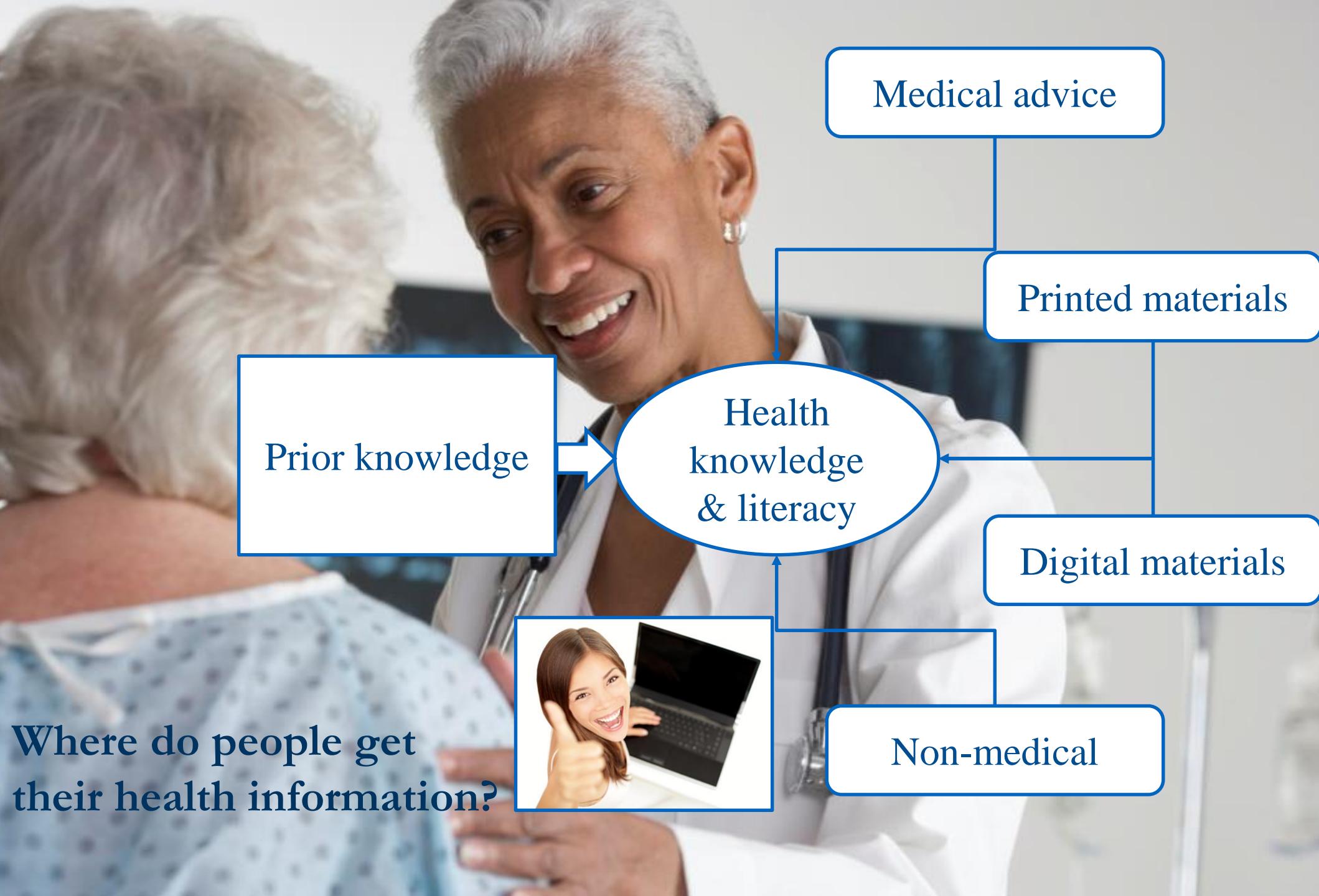
Instructions from the healthcare provider

Medications, symptoms, and follow up

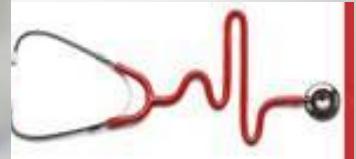
Including the use of large words and concepts, such as cholesterol, saturated fat, carbohydrates, insulin resistance, and angina pectoris

Progression of health literacy skills in chronic diseases





Where do people get their health information?

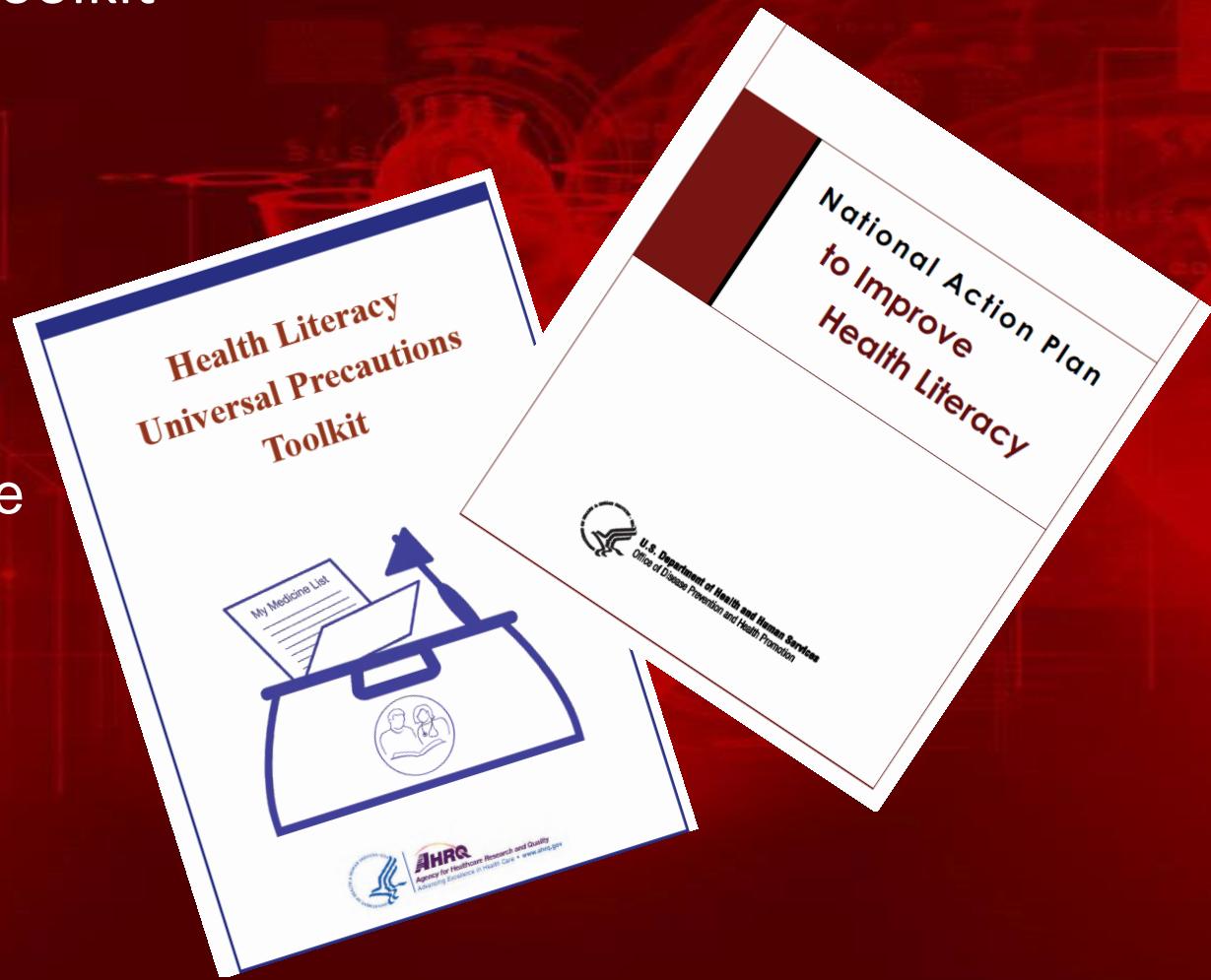




Resources:

National Action Plan to Improve Health Literacy Health Literacy Toolkit

- Strategies:
 - Plain language
 - Teach-back



Role of Qualitative research in the medical literature

Promoting Publication of Research Editor's Perspective Harlan M. Krumholz

Perspective

Implementation of Rigorous Qualitative Research

In M. Krumholz, MD, SM; Elizabeth H. Bradley, PhD; Leslie A. Curry, PhD

In the basic sciences, investigators frequently conduct descriptive studies as a prelude to formulating and testing hypotheses. These discovery studies can be quite unbounded at the outset as investigators accumulate novel information that will serve as the building blocks for future studies. In the clinical sciences, descriptive studies are also common, but they are almost always based on data collected as standardized variables using quantitative methods. Such an approach implies either that available data are sufficient or that we have enough knowledge to define the precise data that are required. However, in many cases, we are in a more formative phase of understanding a given research area, particularly when we study healthcare delivery and issues relating to complex clinical care, rather than whether a drug, device, or clinical strategy produces a specific effect.¹ When we are in an early phase of understanding a research question, qualitative methods may be the best approach. And yet, research that uses qualitative methods is frequently published in the mainstream medical literature.

There are many possible explanations for this relative absence. Few individuals may be gaining the necessary skills to pursue this type of research, as training opportunities and resources are scarce in typical research training programs. Investigators may be obtaining funds to pursue qualitative research, as large medical research funds funding organizations only a small number of direct calls for this type of work. Finally, journals may not be interested in research based on qualitative methods.

I believe that, when used appropriately, rigorous, qualitative methods can contribute to the development of the fields of healthcare research, outcome research, and quality improvement. Qualitative research, which is similar to other reporting checklists (Consolidated Standards for Reporting Trials and Quality of Reporting Meta-Analyses) to support the aim of transparency in research methods, a 32-item checklist recommends that authors report content in the 3 key domains of research team and reflexivity, study design, and data analysis. When a research question would best involve qualitative research methods and a study is conducted according to these standards, this journal would welcome this approach.^{4,5}

Qualitative research is disciplined by a substantial body of literature from multiple disciplines⁶⁻¹³ and has been applied in the study of health and health care since the mid-1990s.^{14,15} The methods can be used to understand complex social processes, organizational change, individual health behaviors, and nuanced aspects of environmental, and health outcomes for quality of care, healthcare delivery, and health outcomes of individuals and populations.¹⁶⁻²⁰ The role that qualitative research can play is exemplified in our National Institutes of Health-funded study on strategies to improve door-to-balloon times. At the time of the study, there was considerable uncertainty about the determinants of timely reperfusion. Not much was known which questions to ask, what processes were required, and how to replicate findings.

We believe that, when used appropriately and with scientific rigor, qualitative methods can play a critical role in advancing the fields of biomedical research, health services research, outcomes research, and implementation science. The well-established standards for qualitative methods provide guidance about what constitutes a high-quality design.²⁻⁶ More than 22 guidelines that address the publication of qualitative studies have been synthesized to produce the Consolidated Criteria for Reporting Qualitative Studies,⁷ the opinions expressed in this article are not necessarily those of the American Heart Association. Cardiovascular Medicine (H.M.), from the Section of Clinical Scholars Program at the University of Connecticut, Wood Johnson Clinical Scholars Program, New Haven, CT; Department of Health Services Research, University of Health Sciences, New Haven, CT.

The opinions expressed in this article are not necessarily those of the American Heart Association.

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Promoting Publication of Rigorous Qualitative Research

Editor's Perspective

Harlan M. Krumholz, MD, SM; Elizabeth H. Bradley, PhD; Leslie A. Curry, PhD

which is similar to Standardized Descriptive studies are also based on data collected over more time.

age to define the precise data that are required, however, many cases, we are in a more formative period when we study health delivery and issues relating to complex clinical care, than whether a drug, device, or clinical strategy produces a specific effect. When we are in an early phase of understanding a research question, qualitative methods may be the best approach. And yet, research that uses qualitative methods, frequently published in the mainstream medical literature, there are many possible explanations for this relative absence. Few individuals may be gaining the necessary skills to pursue this type of research, as training research training programs, and researchers are scarce in typical research funding organizations. Investigators may be obtaining funds to pursue qualitative research, as large medical research funding organizations, by only a small number of direct calls for this type of work, journals may not be interested in research based on qualitative methods.

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We believe that, when used appropriately and with scientific rigor, qualitative methods can play a critical role in advancing the fields of biomedical research, health services research, outcomes research, and implementation science. The well-established standards for qualitative methods provide guidance about what constitutes a high-quality design.²⁻⁶ More than 22 guidelines that address the publication of qualitative studies have been synthesized to form the Consolidated Criteria for Reporting Qualitative Research (see Table 1).

improvement in the timeliness of treatment,²¹⁻²³ and subsequent quantitative studies and formed a combination of national initiatives that contributed to a remarkable improvement in the timeliness of qualitative and mixed methods research.^{24,25} Moreover, we gained critical information on the production of qualitative designs that could not have been possible without the experience of our reviewers. Finally, we gained critical information on the production of quantitative designs that could not have been possible without the experience of our reviewers. Moreover, we gained critical information on the production of quantitative designs that could not have been possible without the experience of our reviewers.

At a systems level, efforts to integrate narrative data with interpretive text and impact of qualitative methods on research and depth that are characteristic of some qualitative research; and ineffective writing, including excessive jargon and failure to cite sources.

At a systems level, efforts to increase the quality, visibility, and impact of qualitative research and awareness within the clinical narrative data with interpretive text.

Key Issues in Outcomes Research

Mixed Methods Provide Outcomes Research

Key Issues in Outcomes Research

Qualitative and Mixed Methods Provide Unique Contributions to Outcomes Research

Defining Qualitative Research

Qualitative and Mixed Methods Research: Contributions to Outcomes Research

Key Issues in Qualitative and Mixed Methods Research

Leslie A. Curry, PhD, MPH; Ingrid M. Nemphard, PhD, MS; Elizabeth H. Turner, PhD

Qualitative research examines the effects of medical care interventions and policies on the health outcomes of individuals and society.¹ Investigators conducting outcomes research seek to inform the development of clinical practice guidelines, to evaluate the quality of medical care, and to foster effective interventions to improve the quality of care.² Outcomes research has traditionally used quantitative methods to examine the utilization, cost, and clinical effectiveness of medical care through randomized and nonrandomized experimental designs. Quantitative methods are not as well suited to measure other complex aspects of the healthcare delivery system, such as organizational change, clinical leadership in implementing evidence-based guidelines, and patient perceptions of quality of care, which are also critical issues in outcomes research.³⁻⁷ These more nuanced aspects of healthcare delivery may be most appropriately examined with qualitative research methods.⁸⁻¹⁰

Qualitative approaches are becoming more common in healthcare and health services research.^{2,11-13} Federal agencies issued by the National Institutes of Health, the National Science Foundation, and the National Science Foundation have funded qualitative research projects with prede-

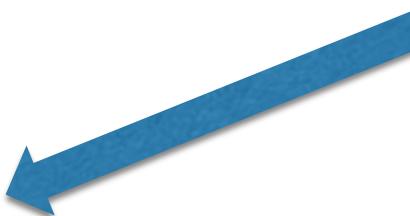
Quantitative clinical medicine has been encouraged by the announcement of a new funding program by the National Institutes of Health.¹⁶ For more than a decade, foundations such as the National Science Foundation have demonstrated a commitment to supporting qualitative research through funding scientific conferences,¹⁷⁻²⁰ workshops, and monographs on this field of inquiry.²¹⁻²³ Despite this steady growth in qualitative research, outcomes workshops, and monographs on this field of inquiry.¹⁷⁻²⁰ Despite this steady growth in qualitative research, outcomes investigators in cardiology have relatively little guidance on when and how best to implement these methods in their investigations.

The purpose of the present report is to introduce qualitative methods as providing unique and critical contributions to outcomes research. This report will describe the situations in which qualitative approaches are most helpful; summarize the primary principles and practices in study design, sampling, data collection, and data analysis for qualitative studies; present representative examples of cardiovascular outcomes research that uses qualitative methods; and synthesize current standards for ensuring rigor and enhancing credibility of qualitative research.

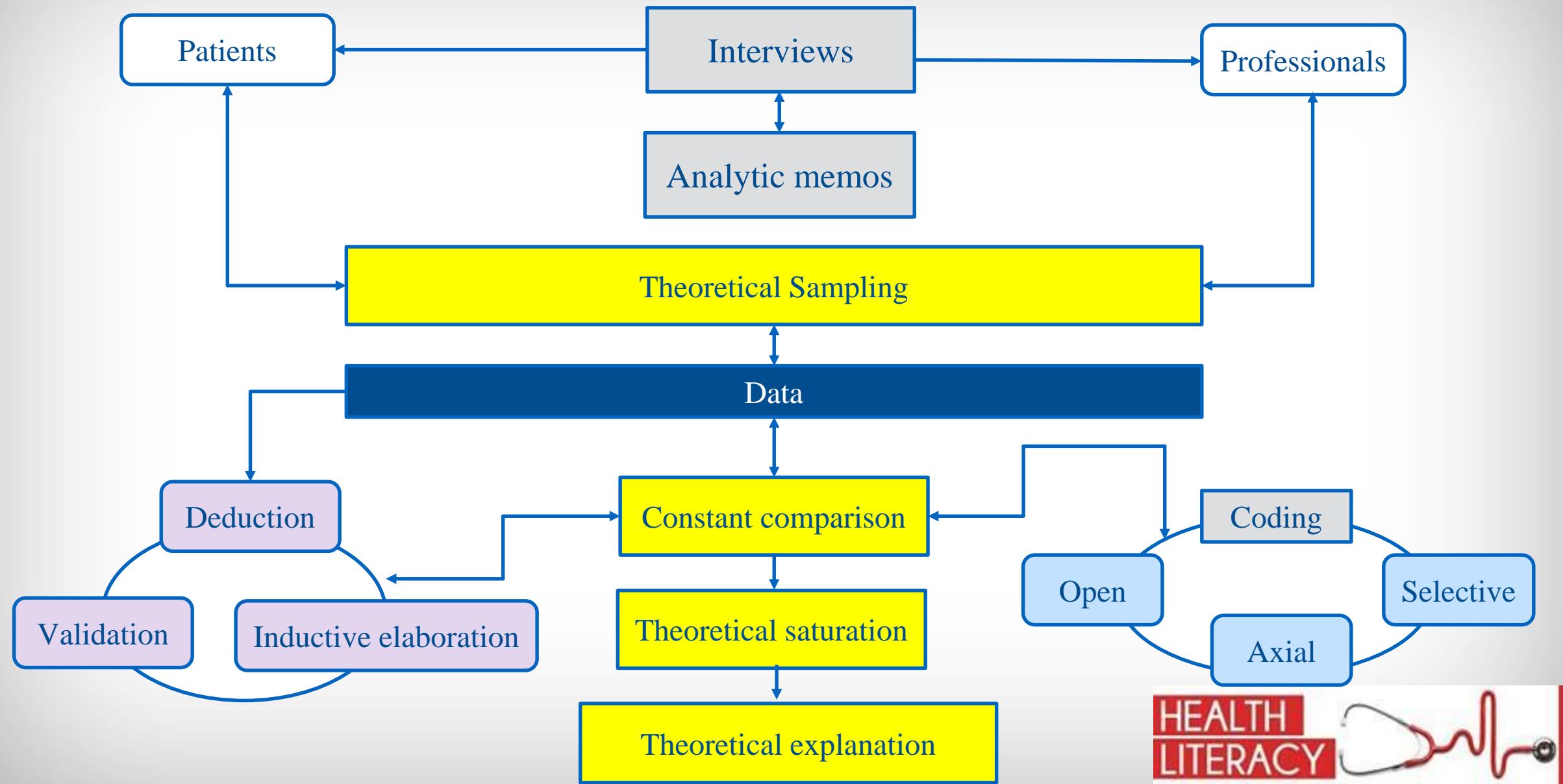
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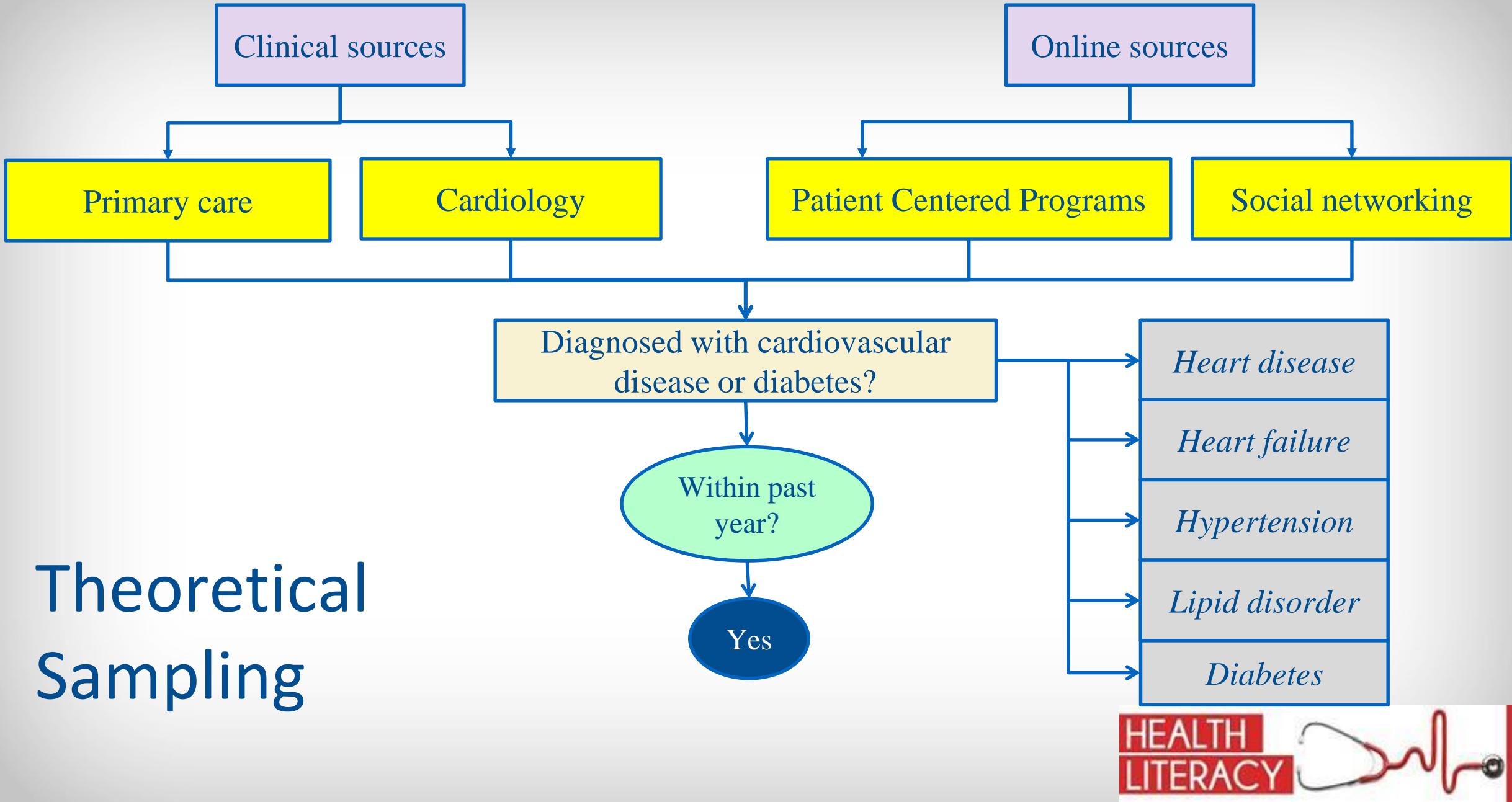


TQR 7th Annual Conference Presentations

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1. Use of Grounded Theory in Medical Research By Patrick Dunn
 2. What if a Robot Could Help Me Care for My Parents? Using Photo Elicitation with Pre-Users of Remote Monitoring Technologies By Martha M. Snyder and Laurie P. Dringus
 3. Qualitative Inquiry in a Distance-based Environment: Thoughts and Tips By Yulia Watters, Darren Adamson, and Deborah Bell
 4. Student Veterans' Experiences in Negotiating Student Services in Higher Education: A Phenomenological Inquiry By Christina Alexander
 5. Visions in Our Heads: Lived Experiences of US Counsellors-in-Training in Study Abroad Programs By Cristen C. Wathen & David Kleist
 6. Hearing Minority Parent Voice: Education for All By Barbara R. Wilson
 7. The Science Fiction of Qualitative Inquiries By Johnny Saldaña
 8. New Windows on Patient Experience in Health Care: Blogs, Vlogs, Facebook, and more By Rikki Mangrum
 9. Reflections of Choice: Turning to the Arts to Foster Preservice Teachers' Reflexive Dispositions about Literacy By Janet C. Richards, Shetay Ashford, Elaine Cerrato Fisher, and Christiana Succar
 10. Playing Well with Others: The Rise of Transdisciplinary Qualitative Research By Racine Brown
 11. Contemplative Qualitative Inquiry: Zen Principles for the Qualitative Researcher By Valerie J. Janesick
 12. Occupational Health Stress in the Service Sector By Fozia Malik and Shaan Shahabuddin
 13. Sampling in Qualitative Research: Insights from an Overview of the Methods Literature By Stephen Gentles
 14. Shared Experiences and Discovery on the Science Teaching Journey: A Voyage of Discovery for Two Science Teachers By David Thorton
 15. A Holistic Approach to Reducing the High Rate of Recidivism for Ex-Offenders By Cheryl White
 16. Introducing Qualitative Analysis Software with Quirkos By Daniel Turner
 17. Guidelines for Evaluating and Quality Reviewing Qualitative Research By Daniel Turner

Grounded Theory





Patients



Characteristic	Number	Sources	Number
Total number	16	Medical group	7
Male	6	Patient focused programs	8
Female	10	Social media	1
		Type	Number
Under age 40	2	Heart attack	4
40-65	10	Heart failure	4
Over 65	4	High blood pressure	4
High school graduate	9	Dyslipidemia	4
College graduate	5	Diabetes	4
Master's degree	2	Congenital heart defect	1
		Care giver	1
		Irregular heart beat	1

Healthcare professionals



Characteristic	Number	Professional type	Number
Total	19	Physician	5
Male	5	Nurse	5
Female	14	Nurse practitioner	1
Average age	50.4	Physician assistant	1
Under 40	4	Pharmacist	1
40-65	13	Dietitian	1
Over 65	2	Social worker	1
Average years of experience	24.4	Medical Assistant	1
		Health educator/coach/designer	4

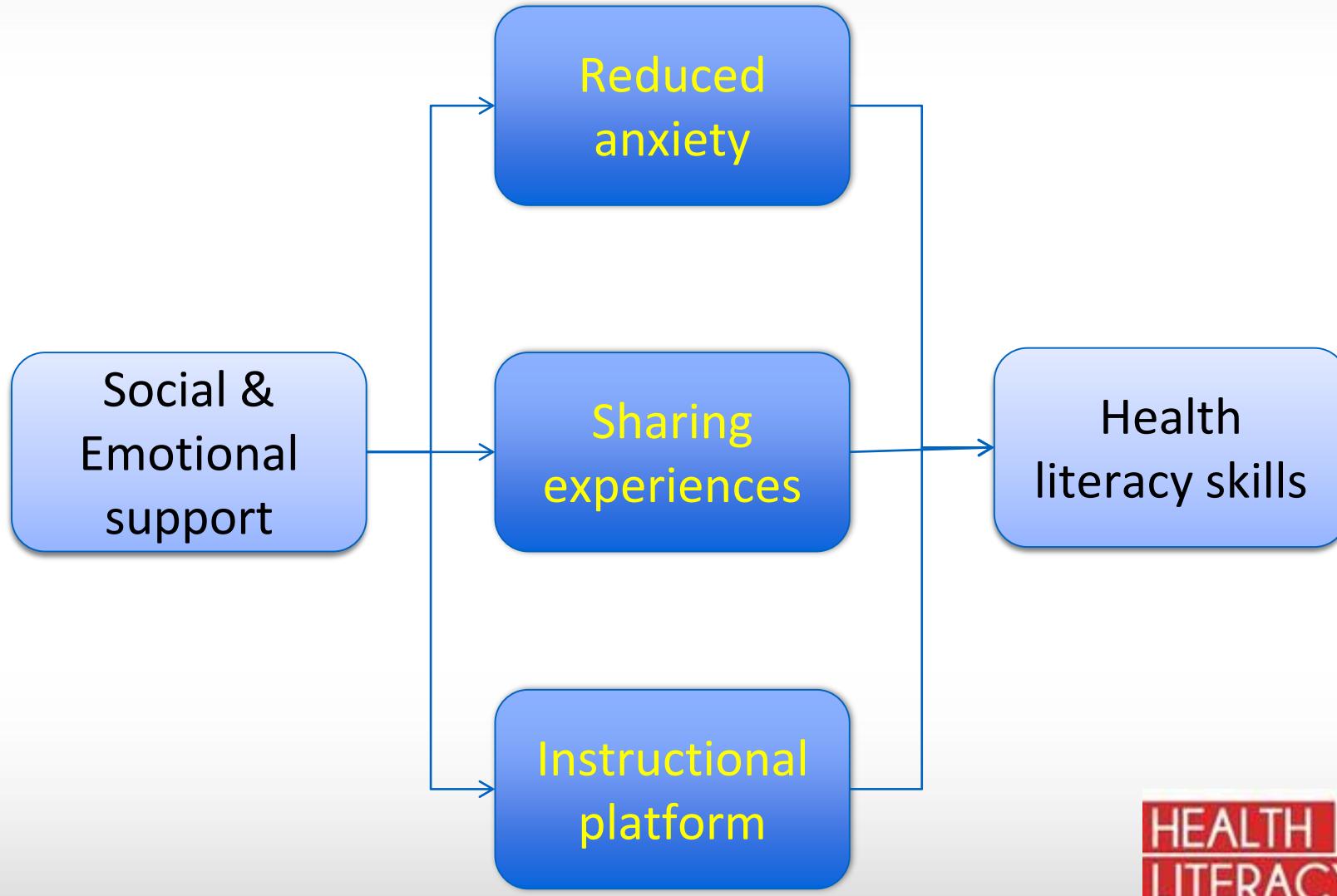
Categories	Patients	Healthcare professionals
Resources and technology	106	60
Programs and interventions	36	6
Teaching methods	23	88
Influencers	14	5
Emotions	40	37
Behaviors	10	30
Personalized	31	36
Process	8	36

Research question 1: What are the perspectives of patients and healthcare professionals in the development of health literacy skills in patients that have been recently diagnosed with a coronary artery disease, heart failure, hypertension, a lipoprotein disorder, or diabetes?

Key Theme: Social support is a learning opportunity

Categories	Selected extract
Emotional support	<p>The support groups help me to learn. The buddy forms and patient forms, you get to talk to other people. When you hear the same thing from multiple forms, it helps you to start to make sense. I learned about studies that had been done, and the results. I would never have known without being connected to those groups. You find out little details that might not be important to the doctor, but helps to explain things. <i>P12.</i></p> <p>So I think there is some kind of personal connection, and reassurance that there are other people out there going through a similar experience. <i>HP5</i></p>
Behavioral	<p>A lot of the behavior I observed is expected, and made sense to me. At the same time, I have been impressed by it, because you read so many things that people are just lazy and they don't care about their health, but it was absolutely not the case. It was an older population, every one of them was over 55, and they were all well informed, it seemed like. <i>HP7.</i></p> <p>Understanding what they actually did. I did not really know medically what was going on, so that I was more aware of my choices. I felt at the time like everything was bleak, because I did not know the choices. <i>P2</i></p>
Programs	<p>Cardiac rehab had the biggest impact because emotionally, I was a mess, a mess, I mean just don't know how people do it, I didn't even conceptualize that, you know, I didn't die, but I wasn't, I had a lot of fear. <i>P1</i></p> <p>He directed me to the Game of Health. He was able to keep track us and a lot better. It was the camaraderie of the group, people that were losing and not losing and I learned things I forgot I knew. I was depressed myself. Because I would gain weight, I would chastise myself. <i>P4</i></p>

How does the support system impact health literacy?



Research question 2: What are the perspectives of patients and healthcare professionals in the use of new technologies to build health literacy skills?

Key Theme: Google is a health system

Categories	Selected extract
Self directed/ personal experience	I get most of my information from the internet . I have been misdiagnosed, so I do a lot of my own research . <i>P16.</i> A lot of them turned to journals and really reliable resources , such as the Mayo Clinic, or medical journals. So they were reading what I would consider very high level stuff. The selection of these sources was based on the credibility of the source , and the visibility of the source. So people know about the Mayo Clinic, they know about Harvard Medical. The other place they got information from was friends and family. Some of them would have medical professionals in the family they would turn to, and since they trusted the person, they trusted the information they gave . <i>HP7</i>
Role of tools	I see such as natural fit, in my experience, when someone was diagnosed they would turn to digital tools for more information . On a day to day routine, where we all engaged digitally, throughout the day, that seemed to be a comfortable form of information, for many age demographics, not all. I would say the need for validated instruments, for trustworthy resources, that was always huge . It was not a google search, but a warehouse of vetted, and validated knowledge, similar to going to the heart.org website. Knowing that you have a stamp of approval and thorough science review really does give people comfort as they are taking in all of this information. <i>HP2</i> I use google and put in key words until I find what I am looking for. I kind of already know, from my family history what I am looking for and what I need to do. <i>P6</i>
New tech confusion/digital divide	I was using a Fitbit until I killed it. <i>P4</i> I don't even have a cell phone. <i>P2</i>

Research question 3: How do healthcare professionals and health educators assess and build health literacy skills in their patients?

Key theme: Instructional strategies should be personalized, interactive, social, and relevant.

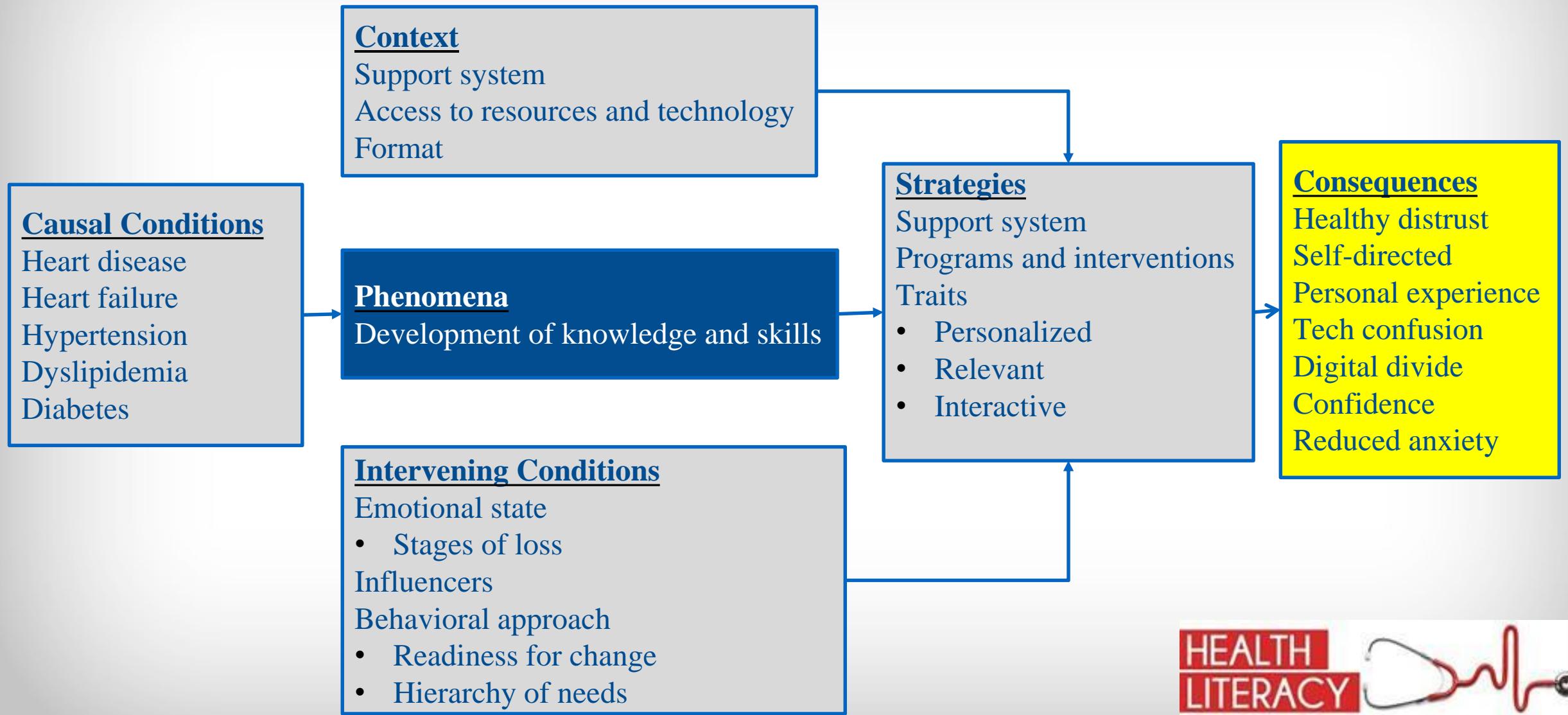
Categories	Selected extract
Traits	So it has to be personalized and individualized , so that it is relevant to their lives. I think you have to go to where the person is, and meet them there and find out what works for them, but I think it is going to be more specific and customized . <i>HP1</i>
Integration	Do I try to give patients very practical examples? I tell them stories, patients remember stories. And it sticks with them. And I give them examples of other patients that were successful , and kind of how they thought through things so they can see, ok this is the process. It tells them, it is time to learn. It is so overwhelming. I assess where they are emotionally . If they are overwhelmed, we can't get complicated at all. We need to go over the basics. <i>HP3</i>
Format	The information I received from my doctor was good, but I was curious to learn more . The print material was helpful, but too general. <i>P8</i>

Research question 4: How are instructional strategies designed to build knowledge and health literacy used by healthcare professionals? aligned with the process of learning described by the patients?

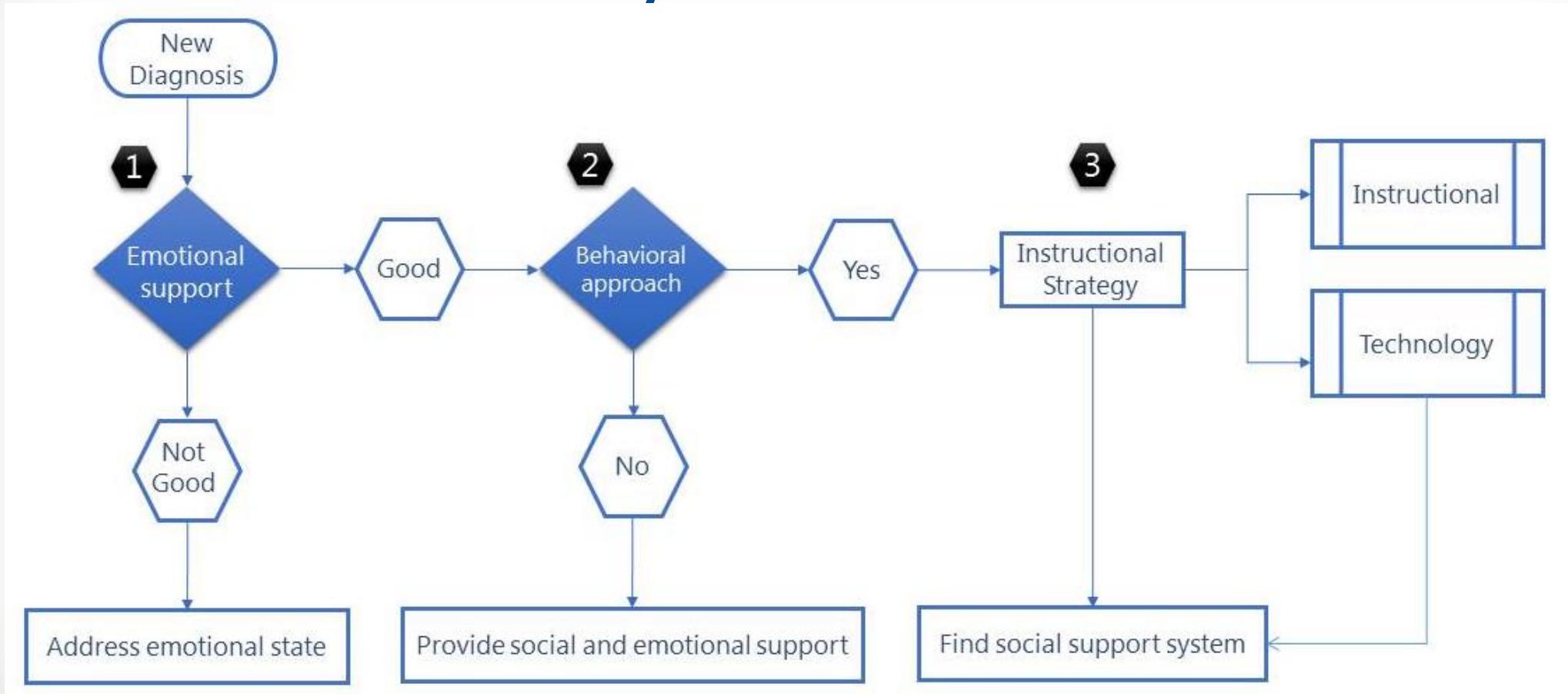
Key theme: Patients are self-directed learners

Categories	Selected extract
No patient left behind	It depends on the condition, but if they are not making changes and are not motivated he does not like to keep them as a patient. We will have them find another doctor. <i>HP9</i>
Healthy distrust	...question their doctor very closely. If they don't have a sympathetic ear, leave it, because you need all the support you can get. <i>P2</i>

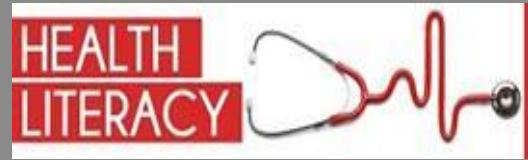
Axial Coding



Theoretical explanation: Health literacy instructional model



Implications?



What is needed?

- ✓ Better understanding of the relationship between social and emotional support and health literacy
- ✓ Development of more effective tools and programs
- ✓ Development of more effective strategies for healthcare professionals
- ✓ Need for better options for unmotivated, non-self-directed learners – leaving no patient behind.

Thank you! Questions?