

# What Will it Take to Get it Right?

## *Helping Patients Achieve Literacy in Health Care*

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# Overview

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- Health literacy in health care delivery context
- Emerging models to improve health system health literacy
- Implications of health literacy goals for health systems

# Health Literacy\*

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- Degree to which individuals have the capacity to **obtain, communicate, process, and understand** basic health information and services needed **to make appropriate health decisions**
- Influenced by individual capacity, provider skills, and system demands and complexities

\*Patient Protection and Affordable Care act of 2010

<http://health.gov/communication/literacy/quickguide/factsbasic.htm>

<http://www.cdc.gov/healthliteracy/learn/>

\*Ratzan R.C. and Parker R.M., 2000 in *National Library of Medicine current bibliographies in medicine: Health Literacy*. U.S. Department of health and Human Services.

# Health Literacy Skills Key in Ensuring Effective Health Care

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- Help consumers make sense of health information and services
- Help providers convey health information and services to consumers

# Consumer Health Literacy Skills

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- Find information
- Communicate needs and obtain services
- Understand the meaning and usefulness of information and services
- Consider choices and consequences of information and services
- Decide which information and treatment options align with their needs and values
- Make informed decisions and act

# Provider Health Literacy Skills

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- Help people find information and services
- Communicate about health and health care
- Process what people are explicitly and implicitly asking for
- Understand how to provide useful information and services
- Decide which information and services work best for different situations and people so they can act

# Health Literate Organizations

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- Remove barriers to health literacy
- Recognize
  - Miscommunication that negatively affects patient care and outcomes is very common
  - Miscommunications arise from range of clinical to operational situations
  - Individuals who ordinarily have adequate health literacy may have difficulty processing and using information when sick, frightened, or impaired
  - Literacy, language, and culture are intertwined and linked to cultural competency and health equity

<http://www.cdc.gov/healthliteracy/learn/>

IOM Roundtable on Health Literacy. Ten Attributes of Health Literate Health Care Organizations, 2012.

[https://nam.edu/wp-content/uploads/2015/06/BPH\\_Ten\\_HLit\\_Attributes.pdf](https://nam.edu/wp-content/uploads/2015/06/BPH_Ten_HLit_Attributes.pdf)



# 10 attributes of health literate health care organizations

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1. Leadership
2. Integration into planning, evaluation and quality improvement
3. Prepares workforce
4. Includes consumers in evaluating services and information
5. Meets needs of all
6. Communicates effectively
7. Ensures easy access
8. Designs easy to use materials
9. Addresses Health Literacy in high-risk situations
10. Explains coverage and costs



# 1. Leadership

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- Efforts not limited to a few projects or programs
- Leadership establishes a culture through ongoing language, expectations, and behavior
- Implement evidence based strategies and work with researchers to develop and test new ones
- Activities include:
  - Delegating authority for oversight
  - Setting organizational goals
  - Allocating resources
  - Cultivating organizational champions

## 2. Integrate health literacy into planning, evaluation and quality improvement

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- Ongoing needs assessments reflecting organizational performance
- Develop metrics, routinely collect data
- Design and conduct rigorous program evaluations
- Track and report communication failures and conduct root cause analyses to uncover systematic sources of error
- Harmonize health literacy with other organizational priorities (e.g., pursuing health equity)

### 3. Prepare workforce to be health literate

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- Hire diverse workforce with expertise in health literacy
- Incorporate health literacy into orientation sessions
- Augment in-house training resources
- Identify and implement appropriate new curricula

## 4. Include populations served in information and services design, implementation and evaluation

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- Include members of populations on governing bodies
- Establish advisory groups that involve individuals with limited health literacy, adult educators, and experts in health literacy
- Collaborate with members of community in design and testing of interventions and development of materials
- Obtain and incorporate feedback on health information and services from consumers
- Enlist community members in evaluation teams

## 5. Meet needs of populations with range of health literacy skills yet avoid stigmatization

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- Adopt health literacy universal precautions
- Create an environment that does not impose high literacy demands
- Streamline information collection
- Provide extra assistance (health educators, navigators, case management)
- Ask about problems with paying for medicine, provide assistance with applying for drug coverage
- Use written information to reinforce spoken communication and provide audiovisual alternatives

## 6. Use health literacy strategies in interpersonal communications, confirms understanding at all points of contact

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- Culture that emphasizes verification of every communication
- Allow adequate time for all interactions
- Plan for language assistance
- Provide technology that facilitate communications (e.g., talking touchscreens)
- Treat communication failures as safety issues

## 7. Provide easy access to health information and services, navigation assistance

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- Design health care facilities with features that help people find their way
- Use easily understood language and symbols on signage
- Train staff to respond to navigational inquiries
- Integrate and co-locate multiple services in the same facility
- Help consumers and families understand what health care benefits and services are offered
- Supply navigators to answer questions, problem solve, advocate, lend support and give guidance and assistance

## 8. Provide print, audiovisual, and social media content that is easy to understand and act on

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- Consider educational materials a supplement to, not a substitute for, in person education
- Stock high-quality educational materials for limited literacy in multiple ways (e.g., DVDs, patient portals)
- Evaluate materials using state of the art tools Make materials available in commonly read languages
- Employ staff and consultants with health literacy expertise when developing new materials
- Involve target audience in testing and evaluation of materials



## 9. Address health literacy in high risk situations, including care transitions and medication discussions

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- Establish and implement plans to ensure safe communication during high-risk situations (e.g., meaningful informed consent)
- Using aids (pill boxes, pill cards) to remind individuals how to take medicines correctly
- Educating patients and caregivers and confirming understanding about hospital stays
- Providing easy to understand discharge instructions

## 10. Communicate clearly what health plans cover and what individuals will have to pay

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- Provide staff and resources to find out what treatments are covered
- Communicate costs of care in advance
- Are familiar with and take into consideration insurance drug coverage that affects costs of medicines prior to prescribing
- Refer individuals to health insurance consumer and navigator programs



**Task is  
daunting!!**

**How do we  
implement?**

# Many Best Practices

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- Health Literate Materials
- Health educators
- Navigators
- Interpreters
- Routine literacy assessment
- Provider training
- Communication
  - Campaigns that encourage question asking
  - Using common language
  - Verify comprehension with teach-back or show me, teach to goal, chunk



- What is my main problem?
- What do I need to do?
- Why is it important for me to do this?

**The 10 Questions You Should Know**  
Questions Are the Answer



**\*National Patient Safety Foundation.** Ask Me 3: good questions for your good health.

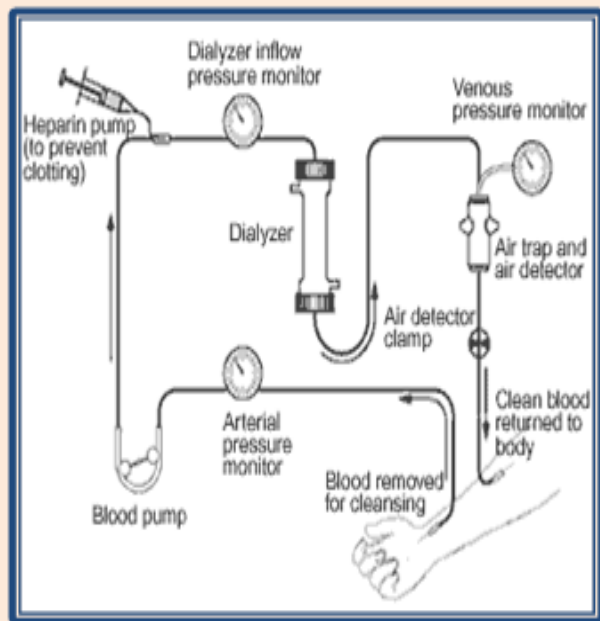
<http://www.npsf.org/?page=askme3>

**\*AHRQ.** Questions to ask your doctor.

<http://www.ahrq.gov/patients-consumers/patient-involvement/ask-your-doctor/index.html>

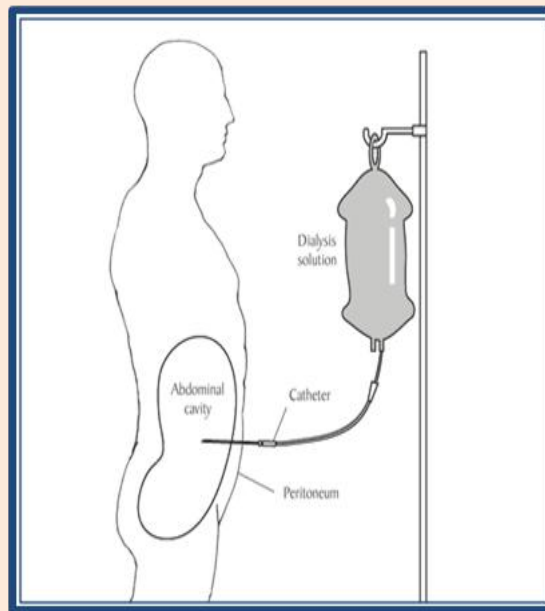
# Putting it Into Practice: Kidney Disease Treatments

## Hemodialysis (HD)



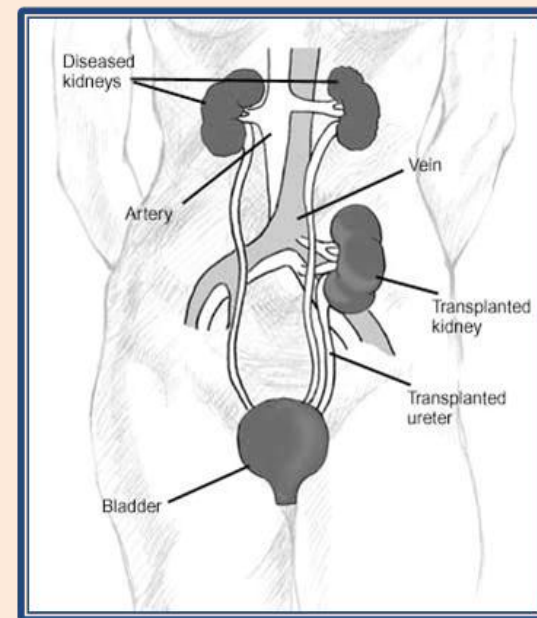
- In Center
- At home

## Peritoneal Dialysis (PD)



- At home

## Transplant



- Living
- Deceased

# Patients and their Families on Health System Experiences

(20 Focus Groups)

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- Frequently urgent dialysis initiation
- Little time for decision-making
- Poor awareness of alternative treatment options
- Inaccurate understanding of treatments
- Family members needed for support

Sheu J, Ephraim PL, Powe NR, Rabb H, Senga M, Evans KE, Jaar BG, Crews DC, Greer RC, Boulware LE. African American and non-African American patients' and families' decision making about renal replacement therapies. Qual Health Res. 2012 Jul;22(7):997-1006. PubMed PMID: 22645225.

# System Fails to Support Education and Decision Making

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**Patient:** *"I didn't know anything about it; I just did what they told me. I didn't even know what the catheter was for. And the nurse said, she says do you understand? I says, well they had the thing in my side first, the access thing before they put the catheter in. No, I didn't know anything."*

**Family Member:** *"Not at all because it was, they gave me brochures. They didn't tell me what I was going to expect or what to look for or what to do. I learned 11 years on my own."*

# System Fails to Help Patients Understand Treatment Alternatives

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**Patient:** *"I was vaguely aware of all the treatment options but nobody in my medical team had talked to me... I was on my chair one day on hemo and the manager of the unit was nearby...he looked at me and he said, you're having some trouble dealing with this aren't you? I said, yeah. He said, you ought to look at the peritoneal dialysis, and that was the first I heard of it."*

**Family member:** *"At the time, I wish we could have been given more information and more at the time, but I was told that he just had to have it, had to go on the dialysis immediately. So I don't think it was enough time to get enough information to make a choice."*



# Patients and Families think Others Should Know About

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- **Morbidity and mortality** (*e.g., trips to hospital*)
- **Autonomy** (*e.g., control over treatment schedule*)
- **Symptoms** (*e.g., gaining or losing weight*)
- **Treatment delivery and frequency**
- **Relationships** (*e.g., sexual relations*)
- **Psychological** (*e.g., sadness, anxiety*)
- **Finances** (*e.g., out of pocket expenses*)

# Literacy Tailored PREPARED Educational Materials (English and Spanish)

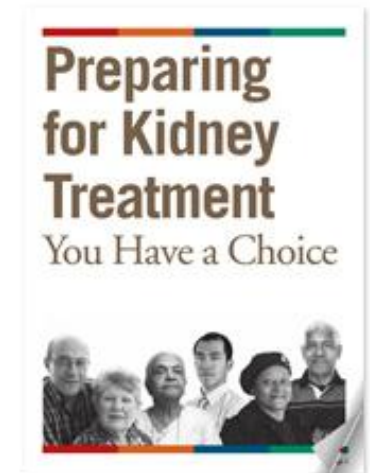


[Play Video](#)

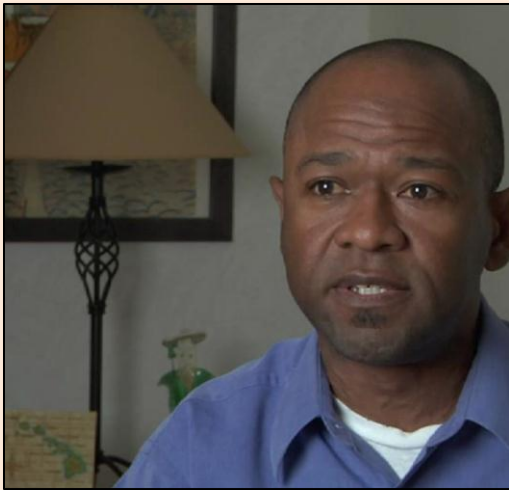
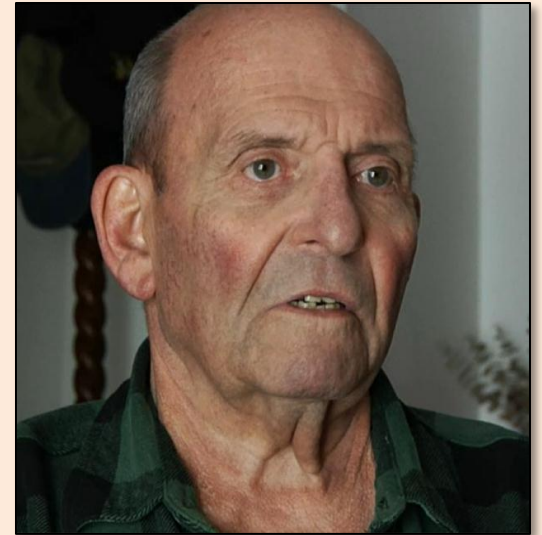
**All The Facts:**



**Book:**



<http://diseasemanagementboulware.org/prepared-materials/>



## Freedom to Do Things



Will my treatment choice affect how free I feel to do things?

It could.



**Transplant** may be better than **peritoneal dialysis**.

Studies' Rating ★★★★★

**Transplant** may be better than **in-center hemodialysis**.

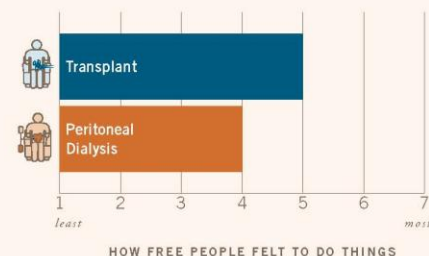
Studies' Rating ★★★★★

**In-center hemodialysis** may be about the same or better than **peritoneal dialysis**.

Studies' Rating ★★★★★

## Freedom to Do Things

In one study, people with a transplant felt freer to do things than people on peritoneal dialysis.

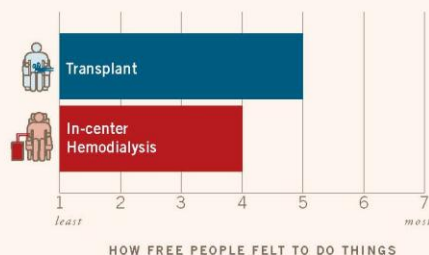


**Transplant** may be better than **peritoneal dialysis**.

Studies show some people on peritoneal dialysis feel a little less free to do things than people with a transplant. Others on peritoneal dialysis feel a lot less free.

Here's what one of these studies showed:

In one study, people with a transplant felt freer to do things than people on hemodialysis.



**Transplant** better than **in-center hemodialysis**.

Studies show some people on hemodialysis feel somewhat less free to do things than people with a transplant. Others on hemodialysis feel a lot less free.

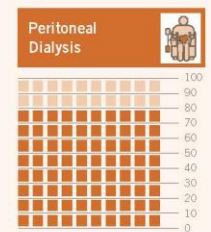
Here's what one of these studies showed:

**In-center hemodialysis** may be about the same or better than **peritoneal dialysis**.

Studies show some people on peritoneal dialysis feel just as free to do things as people on hemodialysis. Others on peritoneal dialysis feel a little less free.

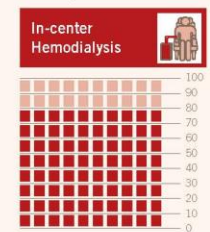
Here's what one of these studies showed:

80 out of 100 people on **peritoneal dialysis** felt freer to do things after one year.



■ = 1 person who felt freer to do things  
■ = 1 person who did not feel freer to do things

80 out of 100 people on **in-center hemodialysis** felt freer to do things after one year.



■ = 1 person who felt freer to do things  
■ = 1 person who did not feel freer to do things

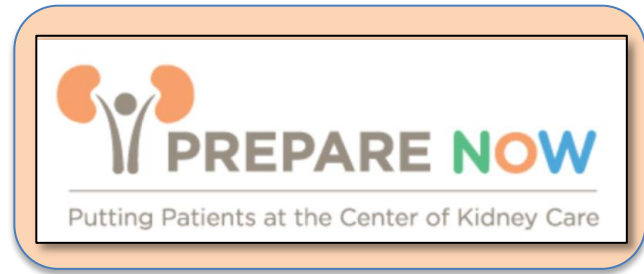
# Great! But... “Not Enough!”

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**Patient:** *“So, I think it’s really important that ... the caregivers, and I’m talking about nursing, physicians, social workers, all of the support staff needs to be able to [educate you] when you walk through the door, say that’s what your diagnosis is.”*



# Enhancing Health System Literacy for Kidney Care





Putting Patients at the Center of Kidney Care

**Providing**  
**Resources to**  
**Enhance**  
**Patients'**  
**And Families'**  
**Readiness to**  
**Engage in Kidney Care**

**Break the NEWS**  
**Review your OPTIONS**  
**Weigh the Pros and Cons**

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## Example Key System Literacy Components

- Health system investment with leadership and \$\$ commitment
- Create a culture change
- Improve team engagement with patients and care partners
- Navigation supported by literate materials and tools
- Coordinating care
- Meets range of needs of population served (blind/low and high literate/social needs)
- Focus on vulnerable care transitions
- Developed with consumer input



Putting Patients at the Center of Kidney Care

## Outcomes

### Clinic

- Advance directives
- Patient values-aligned orders documented in health record
- Navigation effectiveness

### Patient

- Empowerment
- Self-efficacy
- Decision-making



Putting patients at the center of kidney care transitions. PI: Boulware

<http://www.pcori.org/research-results/2015/putting-patients-center-kidney-care-transitions>



# How do we measure and Track Health System Progress?

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- Systematic review of measures to assess 10 attributes of organizational health literacy
- MEDLINE and other databases
- Reviewed measures for content, validity, reliability and potential uses
- Identified 68 measures of at least 1 attribute, **2 measures assessing all 10 attributes**



Agency for Healthcare Research and Quality  
Advancing Excellence in Health Care

# Health Literacy Universal Precautions Toolkit

## Health literacy universal precautions

- Simplifying communication
- Confirming comprehension
- Making the health care system easier to navigate
- Supporting patients' efforts to improve their health

## 21 Tools to help improve

- Spoken and written communication
- Self-management and empowerment
- Supportive systems

## Primary Care Health Literacy Assessment\*

Please select **one answer** that most accurately describes your practice:

- Doing Well** Our practice is doing this well  
**Needs Improvement** Our practice is doing this, but could do it better  
**Not Doing** Our practice is not doing this  
**Not Sure OR N/A** I don't know the answer to this question **OR**  
 This is not applicable to our practice

### 1. Prepare for Practice Change

	Doing Well	Needs Improvement	Not Doing	Not Sure or N/A	Tools to Help
1. Our health literacy team meets regularly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1-Form Team
2. Our practice regularly re-assesses our health literacy environment and updates our health literacy improvement goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2-Create a Health Literacy Improvement Plan 13-Welcome Patients
3. Our practice has a written Health Literacy Improvement Plan and collects data to see if objectives are being met.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2-Create a Health Literacy Improvement Plan
4. All staff members have received health literacy education.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	3-Raise Awareness
5. All levels of practice staff have agreed to support changes to make it easier for patients to navigate, understand, and use health information and services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	3-Raise Awareness
6. All staff members understand that limited health literacy is common and can affect all individuals at one time or another.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	3-Raise Awareness
7. Our Health Literacy Team understands how to implement and test changes designed to improve performance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2-Create a Health Literacy Improvement Plan

\*Electronic version available from Survey Monkey®

# Organisational Health Literacy Self-assessment Resource

- 10 checklists
- assess presence of attributes outlined in IOM Roundtable report
- Encourages planning for future action
  - Responsibility
  - Timelines
  - Etc



Enliven Organisational health literacy self assessment resource>.

<http://www.enliven.org.au/sites/default/files/Enliven%20Health%20Literacy%20Audit%20Resource.pdf>

## Attribute 1 – Details and Resources cont.

Checklist of attributes of a health literate organisation: **Attribute 1**

Assessor name: \_\_\_\_\_

Date assessment completed: \_\_\_\_\_

### Attribute 1:

A health literate organisation has leadership that makes health literacy integral to its mission, structure and operations

A health literate organisation ...		Currently Present ✓	Notes/plans for future action (responsibility, time lines, etc.)
a.	Has an explicit commitment to health literacy in the mission statement, policies and programs		
b.	Develops and implements health literacy policies and procedures related to language access		
c.	Established policies and procedures for receiving and addressing language assistance concerns or complaints from consumers		
d.	Prioritises clear and effective communication across all levels of the organisation and across all communication channels		
e.	Assigns a designate with responsibility and authority for health literacy oversight		
f.	Conducts annual assessments of health literacy across the organisation		
g.	Sets health literacy improvement goals and accountability measures		
h.	Allocates resources (fiscal and human) to meet health literacy improvement goals		
i.	Identifies and trains health literacy champions throughout the organisation		
j.	Creates a culture that places equal value on professional and consumer perspectives, and that emphasises that communication is made up of two-way interactions		
k.	Redesigns systems to maximise an individual's capacity to learn how to maintain good health, manage illness or disease, communicate effectively and make informed decisions		
l.	Designs (or re-designs) physical spaces to support effective communication		
m.	Contributes to local, state and national efforts to improve organisational responses to health literacy		
n.	Sponsors research to extend the evidence base		
o.	Encourages other organisations to be health literate		

Enliven Organizational health literacy self assessment resource>.

[http://www.enliven.org.au/sites/default/files/Enliven%20Health%20Literacy%20Audit%20Resource](http://www.enliven.org.au/sites/default/files/Enliven%20Health%20Literacy%20Audit%20Resource.pdf)

# Summing Up: Challenges and Promises

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## Challenges

- Many moving parts
- Tremendous organizational commitment required
- Difficult to measure
- Need process measures of incremental success
- Focus on individual diseases or care process may detract from broad health system changes needed
- Payment and compliance policies not yet fully aligned to influence change

## Promises

- Embracing the whole mission will address many of the most pressing health care delivery issues
  - Safety
  - Quality
  - Fragmentation
  - Patient Centeredness

# Conclusion

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- To 'get it right' will take a lot!!
  - Full commitment of health care delivery systems to embrace health literacy as a core value
- Frameworks exist and are being operationalized
- Measurement standards and policy alignment will be key
- All stakeholders (*including patients, care partners, providers, administrators, payers*) can take part and lead the way