

Health Literacy and Empowerment

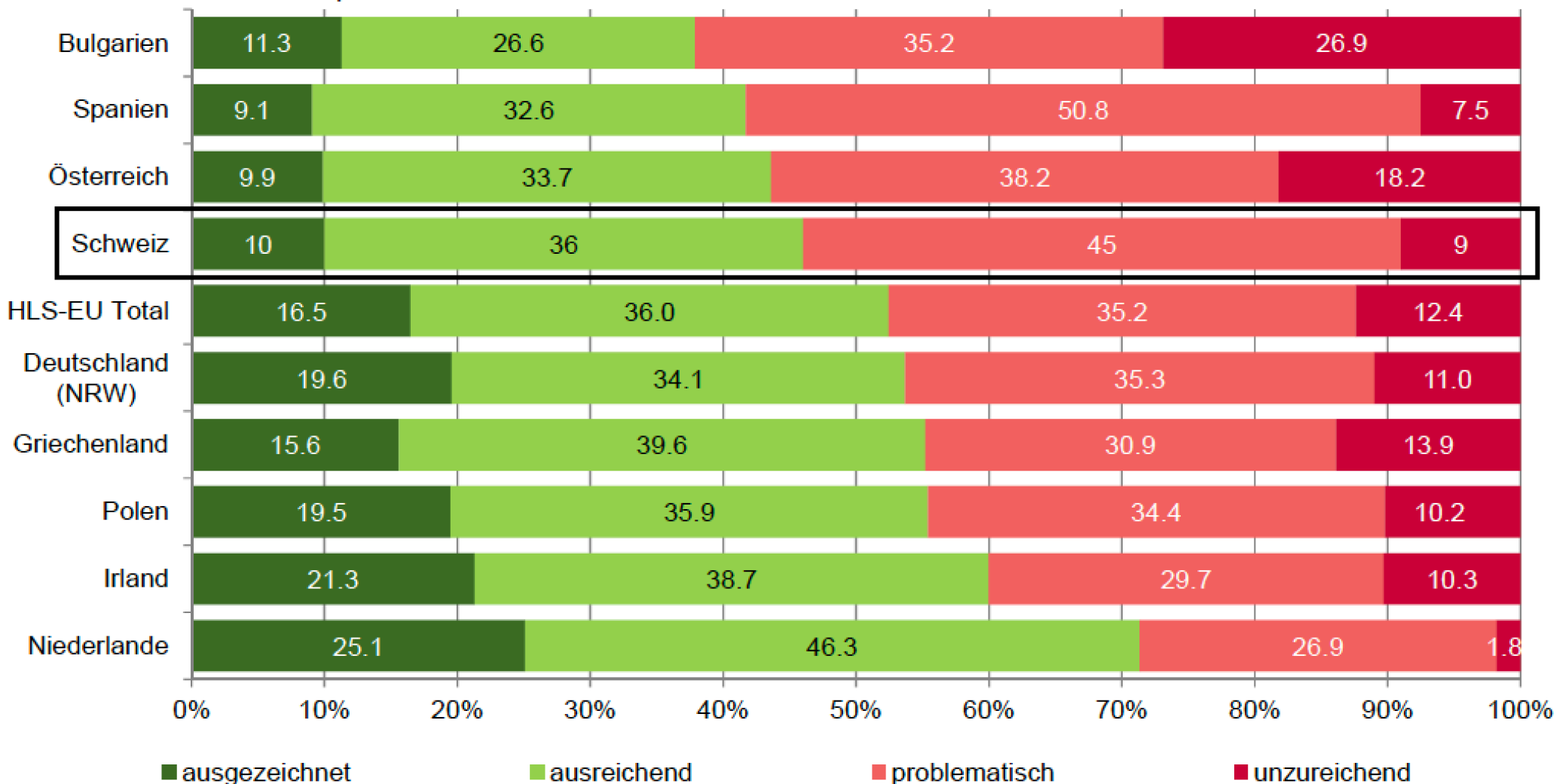
Journée scientifique «Renforcer la littératie en santé:
Pourquoi? Comment?»

Lausanne 23 September 2019

Peter J. Schulz

Health Literacy in Switzerland compared to other countries

in % EinwohnerInnen in Europa



- “Compared to other European countries, Switzerland has major problems when it comes to understanding of information in the domain of disease prevention”;
- “Particularly with respect to vaccination, Swiss citizen show greater problems with understanding (50% very difficult or difficult) compared to other European countries”

HLS-EU: 46 items, 4-point scale

3 items measuring vaccination literacy:

- “On a scale from very easy to very difficult, how easy would you say it is to: find information about vaccinations (...) that you should have?” (Q1.19)
- “On a scale from very easy to very difficult, how easy would you say it is to: understand why you need vaccinations?” (Q1.22)
- “On a scale from very easy to very difficult, how easy would you say it is to: judge which vaccinations you may need?” (Q1.26)

HLS-EU 3 items measuring vaccination literacy

Objective Vaccination knowledge (Zingg & Siegrist, 9 items,
 $\alpha = .811$)

Representative Survey in Switzerland, Spring 2018, N = 1713

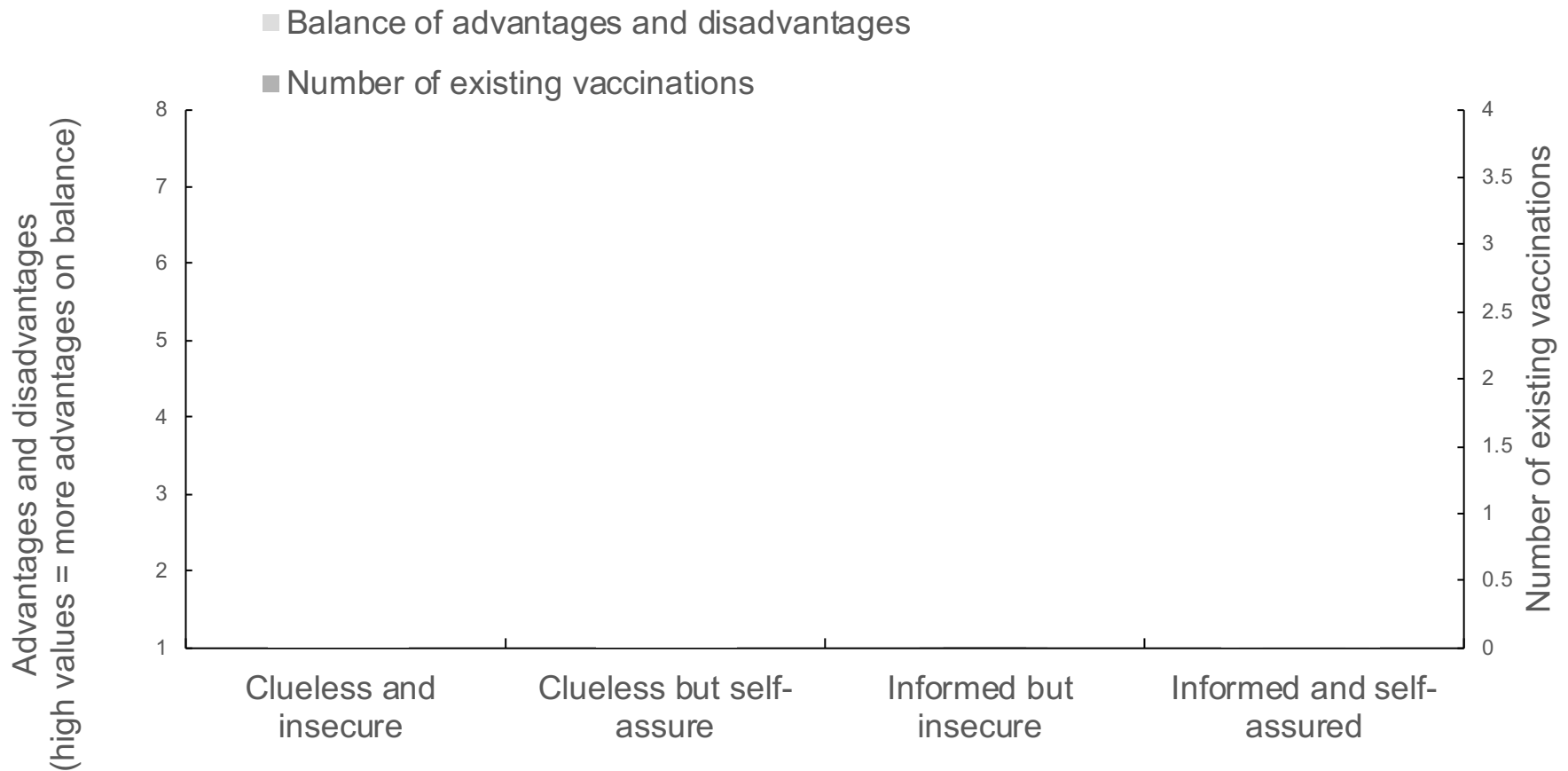
Institute of Communication & Health (in collaboration with
BAG)

How reliable are HL measures?

		Objective vaccination knowledge		Total
		Low	High	
Subjective vaccination literacy (HLS-EU)	Low			
	High			
	Total	N = 723 (45%)	N = 884 (55%)	N = 1607 (100%)

How reliable are HL measures?

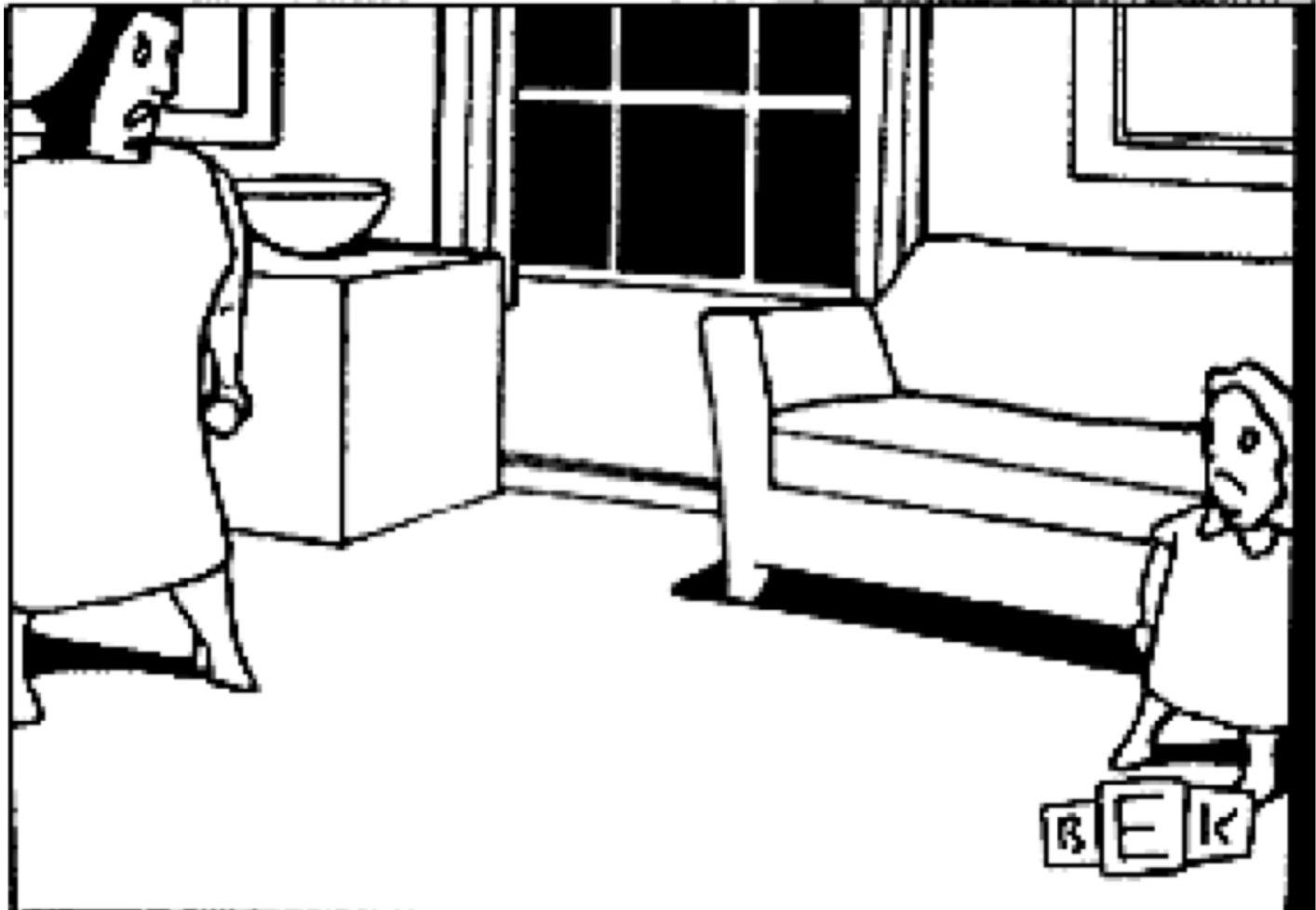
Figure: Knowledge types, existing vaccinations and perceived consequences of vaccinations



And the bigger picture...

In the broader context of task performance, numerous research programs have examined the impact of ignorance (cf. review Dunning 2011).

- ❖ The “unknown unknowns” – respondents may be unaware of their lack of competence in a specific area;
 - ❖ Subjects who perform poorly on a test (lack expertise) have little sense of their lack and overestimate their performance both in absolute terms and relative to others (Kruger & Dunning, 1999)
 - ❖ A possible reason for this overestimation: Subjects may believe they know more than they do—drawing on intuitive “knowledge” or general impressions to derive an answer
- ❖ In the context of health:
 - ❖ subjective measures of health literacy could be mistaken or distorted by intuitions and could lead to judgmental errors.
 - ❖ having found information on the Internet, the patient could feel “expert”



“Someday, you’ll act like you understand.”

So, what about disentangling Health Literacy and empowerment?

Health Literacy, Empowerment, and Patient Behavior

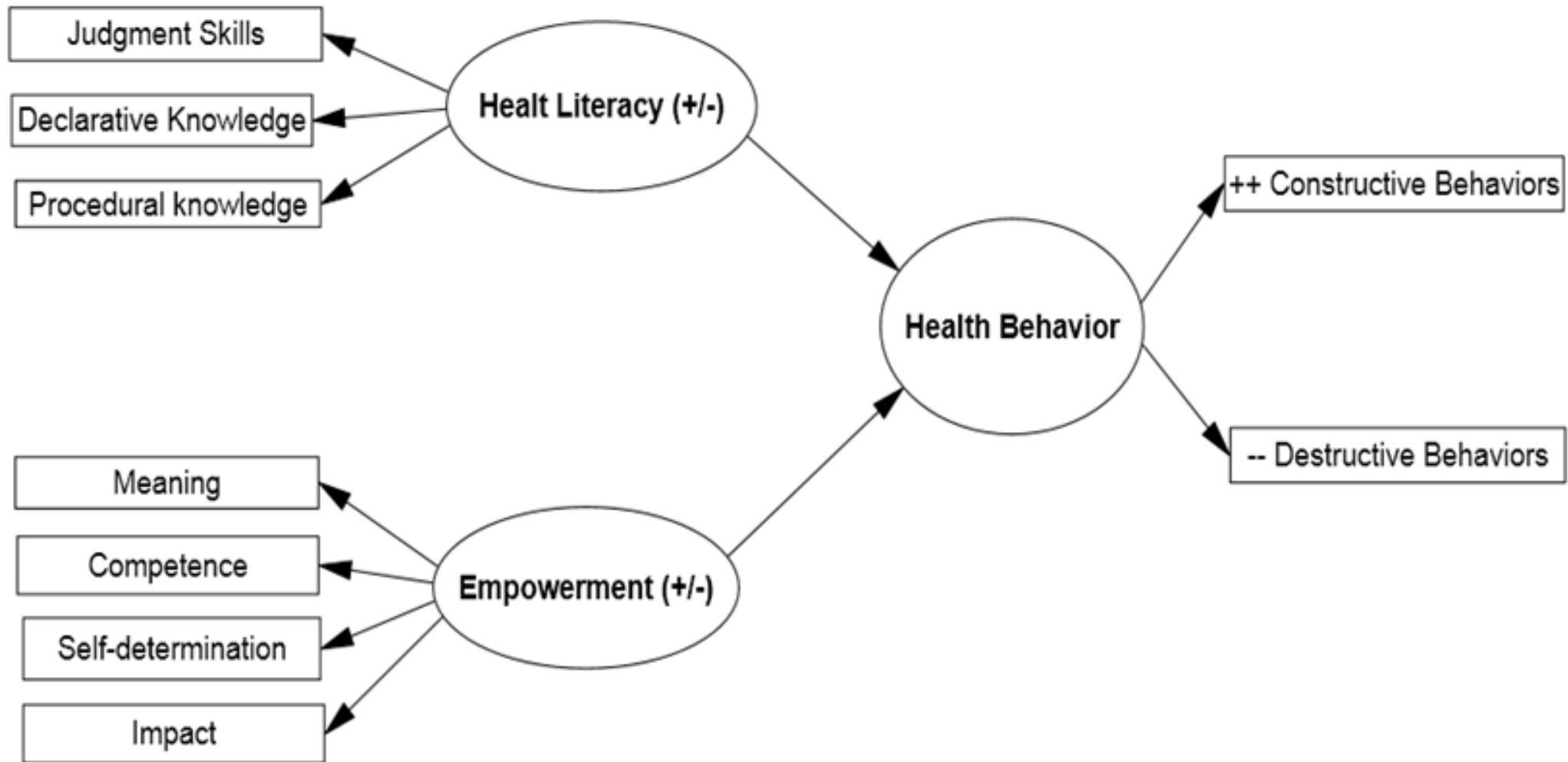
		Psychological Empowerment	
		Low	High
Health Literacy	Low	High-needs Patient	Dangerous Self-manager
	High	Needlessly Dependent Patient	Effective Self-manager

Dimensions of patients' empowerment

- **Meaningfulness:** relevance of managing one's disease
- **Competence:** sense of competence to manage one's disease
- **Self-determination:** sense of autonomy to manage one's disease
- **Impact:** sense of control over the outcome of disease management

(Based on Thomas & Velthouse, 1990; Spreitzer, 1995)

Health Empowerment Model (Schulz & Nakamoto, 2013)

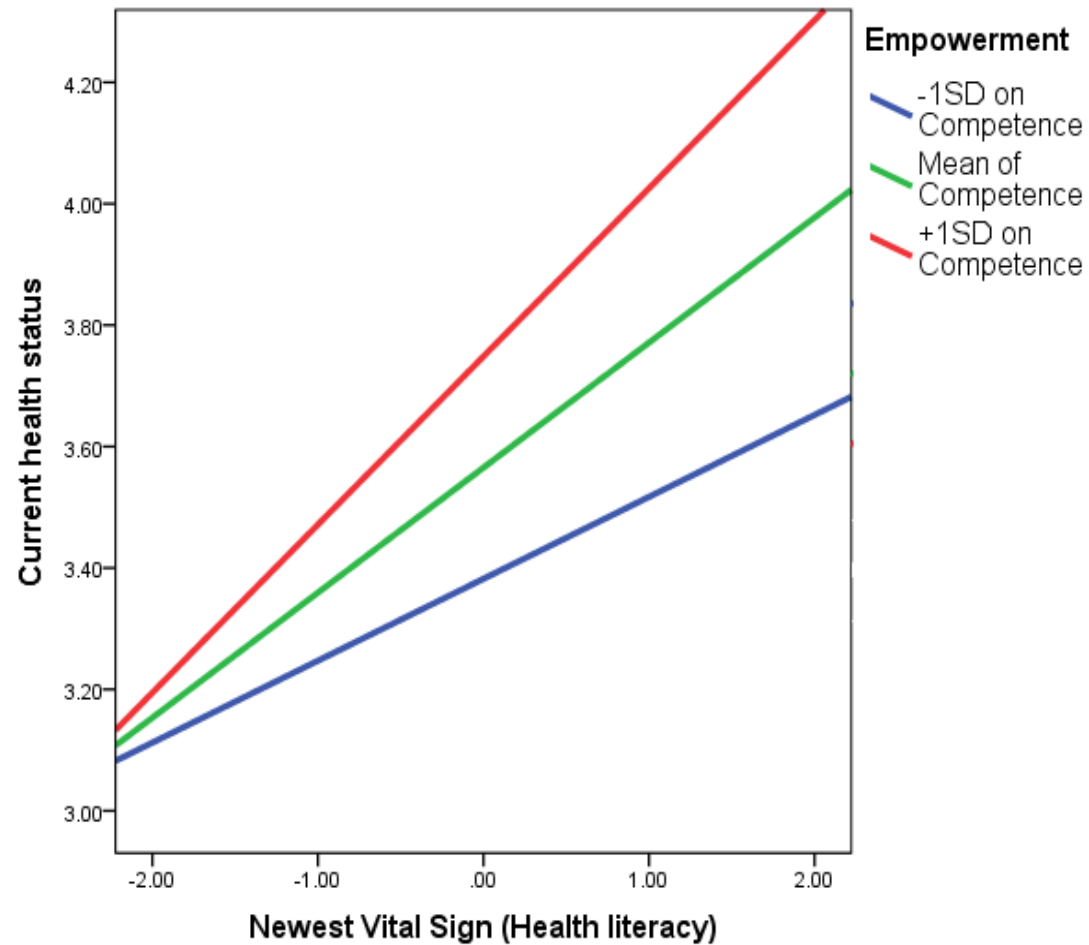


Health Literacy, Empowerment, and Patient Behavior

		Psychological Empowerment	
		Low	High
Health Literacy	Low	High-needs Patient	Dangerous Self-manager
	High	Needlessly Dependent Patient	Effective Self-manager

- ❖ Nice idea, but does it work?
- ❖ Study with patients in hospitals in Hungary (2015)
 - ❖ N = 302,
 - ❖ Measures: HL : NVS and S-TOFHLA; empowerment: Health empowerment scale (Camerini & Schulz, 2012); DV: respondents' current health status;
- ❖ Results:
 - ❖ Participants with high level of health literacy and concurrent empowerment reported the best health status;
 - ❖ By contrast, patients reporting low health literacy and empowerment reported the worst health status;
- ❖ The data thus provide empirical evidence for the independence of the concepts and for their interaction in predicting health status.

Health Empowerment Model



Health Literacy – Measurement



How do we measure “the capacity to obtain, process, and understand basic health information”

Watch your HL measures...

Word Recognition Tests (Performance-based)

WRAT-R (Jastak & Wilkinson, 1993)	Wide Range Achievement Test-Revised	Reading, spelling, arithmetic
REALM (Davis et al., 1993)	Rapid Estimate of Adult Literacy in Medicine	List of medical words
MART (Hanson-Divers, 1997)	The Medical Terminology Achievement Reading Test	Reading in actual medicine bottles

Comprehension & Numeracy Tests (Performance-based)

TOFHLA (Parker et al., 1995)	Test of Functional Health Literacy in Adults	Reading and numeracy comprehension
NVS (Weiss et al., 2005)	Newest Vital Sign	Reading and numeracy comprehension

Self-Report Measurements (Perceived-Based)

BHLS (Chew et al., 2008)	Brief Health Literacy Screen	Reading, interpreting, understanding
FCCHL (Ishikawa, Takeuchi, & Yano, 2008)	Functional, Communicative & Critical Health Literacy	Obtaining, understanding

Table 2. Areas Under the Receiver Operating Characteristic Curve and 95% CI for the Health Literacy Screening Questions (N=1,796)

Screening Questions	S-TOFHLA		REALM	
	Health Literacy		Health Literacy	
	Inadequate	Inadequate or Marginal	Inadequate	Inadequate or Marginal
	(N=123)	(N=255)	(N=75)	(N=381)
How confident are you filling out forms by yourself? ("Confident with Forms")	0.74 (0.69–0.79)	0.72 (0.69–0.76)	0.84 (0.79–0.89)	0.71 (0.68–0.74)
How often do you have someone help you read hospital materials? ("Help Read")	0.67 (0.62–0.72)	0.63 (0.59–0.66)	0.72 (0.67–0.79)	0.62 (0.60–0.65)
How often do you have problems learning about your medical condition because of difficulty reading hospital materials? ("Problems Reading")	0.66 (0.61 – 0.71)	0.63 (0.61–0.67)	0.72 (0.65–0.78)	0.63 (0.60–0.66)

BHL measure

	Hungary (N = 302)	Italy (N = 218)	Lebanon (N = 230)	Switzerland (N = 1146)	Turkey (N = 167)
BHLS 1: How confident are you filling out forms by yourself? (Confident with Forms)	-0.31***	-0.08	-0.25***	-0.13***	-0.27***
BHLS 2: How often do you have someone help you read hospital materials? (Help Read)	-0.21***	-0.14*	0.36***	0.14***	-0.24**
BHLS 3: How often do you have problems learning about your medical condition because of difficulty reading written information? (Problems Reading)	-0.19**	-0.24***	-0.17**	-0.15***	-0.17***

The BHLS items as a quick assessment of health literacy are not related with the performance-based S-TOFHLA:

- (a) within each country the two measures did not sufficiently correlate with each other
- (b) the BHLS are not able to single out individuals with inadequate or marginal health literacy

Mantwill et al. 2018

Measuring Health Literacy (S-TOFHLA)

Your doctor has sent you to have a _____ X-ray.

- a. stomach
- b. diabetes
- c. stitches
- d. germs

You must have an _____ stomach when you come for _____.

- | | |
|-----------|--------|
| a. asthma | a. is. |
| b. empty | b. am. |
| c. incest | c. if. |
| d. anemia | d. it. |

The X-ray will _____ from 1 to 3 _____ to do.

- | | |
|---------|-----------|
| a. take | a. beds |
| b. view | b. brains |
| c. talk | c. hours |
| d. look | d. diets |

S-TOFHLA:

36 cloze items and 4
numeracy items

time to administer: 12
minutes

Why does Health Literacy Matter?

Health Outcomes/Services

- ❑ General health status
- ❑ Hospitalization & Rehospitalization
- ❑ Emergency department use
- ❑ Asthma Control
- ❑ COPD
- ❑ Depression
- ❑ Diabetes control*
- ❑ HIV control*
- ❑ Prostate cancer stage
- ❑ Mammography*
- ❑ Pap smear
- ❑ Pneumococcal immunization
- ❑ Influenza immunization
- ❑ STD screening
- ❑ Cost
- ❑ Mortality

Behaviors

- ❑ Substance abuse*
- ❑ Breastfeeding
- ❑ Behavioral problems
- ❑ Adherence to medication*
- ❑ Smoking*
- ❑ Consent Process
- ❑ End-of-life decision making

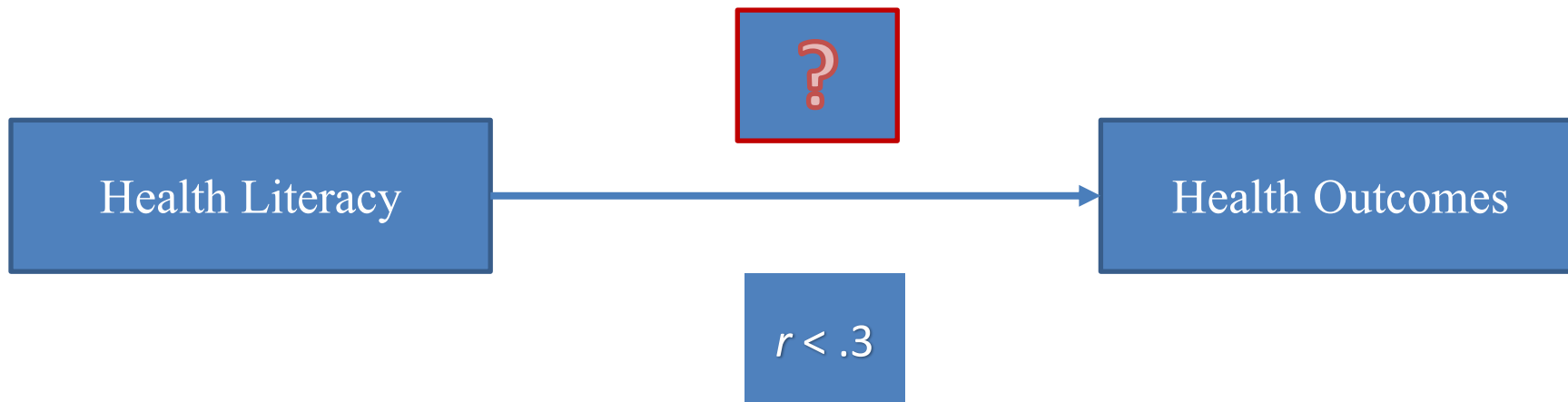
Knowledge

- ❑ Birth control
- ❑ Pap screening
- ❑ Emergency department instructions
- ❑ Asthma
- ❑ Hypertension
- ❑ Diabetes
- ❑ And many more...

How does Health Literacy influence patient outcomes?



How does Health Literacy influence patient outcomes?



The case of diabetes management



Correlation between HL and glycemic control

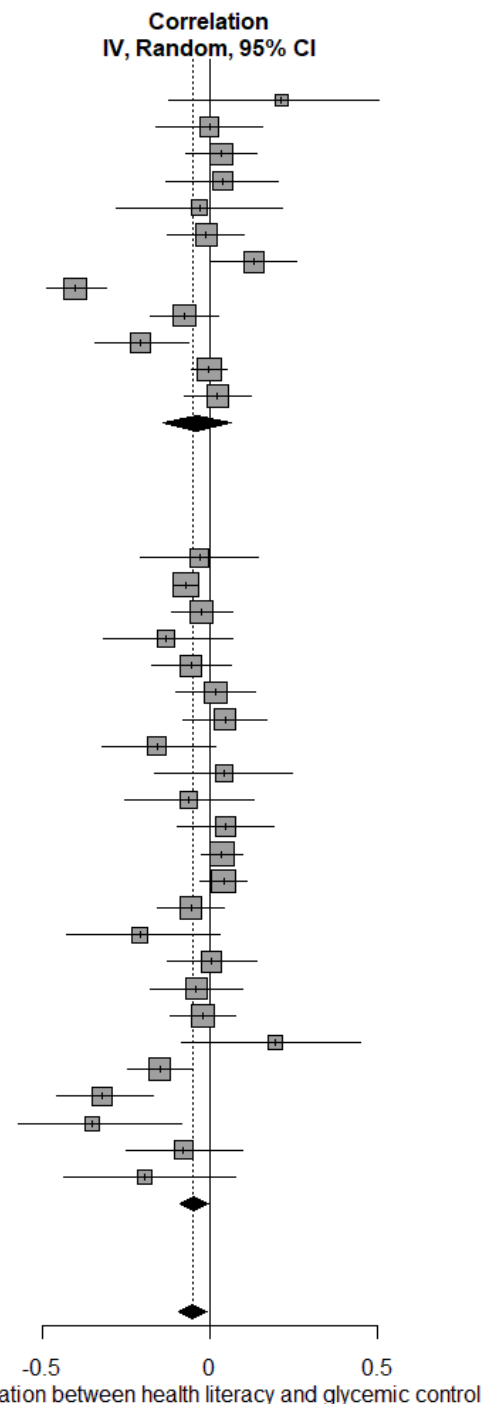
Study or Subgroup	Total	Weight	Correlation IV, Random, 95% CI
Al Sayah 2014	36	1.1%	0.214 [-0.123; 0.507]
Al Sayah 2015	154	2.6%	0.000 [-0.158; 0.158]
Al Sayah 2015 (2)	342	3.3%	0.035 [-0.071; 0.140]
Ishikawa 2008	138	2.5%	0.040 [-0.128; 0.206]
Lai 2013	63	1.6%	-0.030 [-0.276; 0.219]
Lee 2016	295	3.2%	-0.010 [-0.124; 0.104]
Maneze 2016	224	3.0%	0.133 [0.002; 0.259]
Niknami 2018	347	3.4%	-0.400 [-0.485; -0.308]
Radwan 2018	369	3.4%	-0.074 [-0.175; 0.028]
Woodard 2014	183	2.8%	-0.207 [-0.341; -0.064]
Yamashita 2011	1318	4.0%	-0.001 [-0.055; 0.053]
Zuercher 2017	381	3.4%	0.025 [-0.076; 0.125]
Total (95% CI)	3850	34.3%	-0.037 [-0.138; 0.065]

Heterogeneity: $\tau^2 = 0.0206$; $\chi^2 = 71.93$, $df = 11$ ($P < 0.001$); $I^2 = 85\%$
 Test for overall effect: $t_{11} = -0.80$ ($P = 0.439$)

Performance based			
Bains 2011	125	2.4%	-0.030 [-0.205; 0.146]
Brega 2012	2594	4.2%	-0.070 [-0.108; -0.032]
Chen 2014	467	3.6%	-0.022 [-0.113; 0.068]
Coccaro 2016	100	2.1%	-0.129 [-0.317; 0.069]
DeWalt 2007	268	3.1%	-0.054 [-0.173; 0.066]
Ferguson 2015	278	3.2%	0.019 [-0.099; 0.136]
Gerber 2005	244	3.1%	0.047 [-0.079; 0.172]
Gordilho-Souza 2014	129	2.4%	-0.156 [-0.320; 0.017]
Kim 2004	92	2.0%	0.043 [-0.163; 0.246]
Mancuso 2010	102	2.1%	-0.063 [-0.254; 0.133]
Mayberry 2014	183	2.8%	0.049 [-0.097; 0.192]
Morris 2006	1002	3.9%	0.037 [-0.025; 0.098]
Morris 2013	751	3.8%	0.042 [-0.029; 0.114]
Osborn 2010	383	3.4%	-0.055 [-0.155; 0.045]
Powell 2007	68	1.7%	-0.207 [-0.425; 0.033]
Rothman 2004	217	2.9%	0.007 [-0.126; 0.140]
Saeed 2018	204	2.9%	-0.039 [-0.175; 0.099]
Schillinger 2002	408	3.5%	-0.020 [-0.117; 0.077]
Schillinger 2003	51	1.4%	0.198 [-0.082; 0.449]
Schillinger 2006	395	3.4%	-0.148 [-0.243; -0.050]
Tang 2007	149	2.6%	-0.320 [-0.457; -0.168]
Thabit 2009	51	1.4%	-0.350 [-0.571; -0.082]
White 2013	127	2.4%	-0.077 [-0.248; 0.099]
Williams 1998	55	1.5%	-0.192 [-0.435; 0.077]
Total (95% CI)	8443	65.7%	-0.046 [-0.088; -0.004]

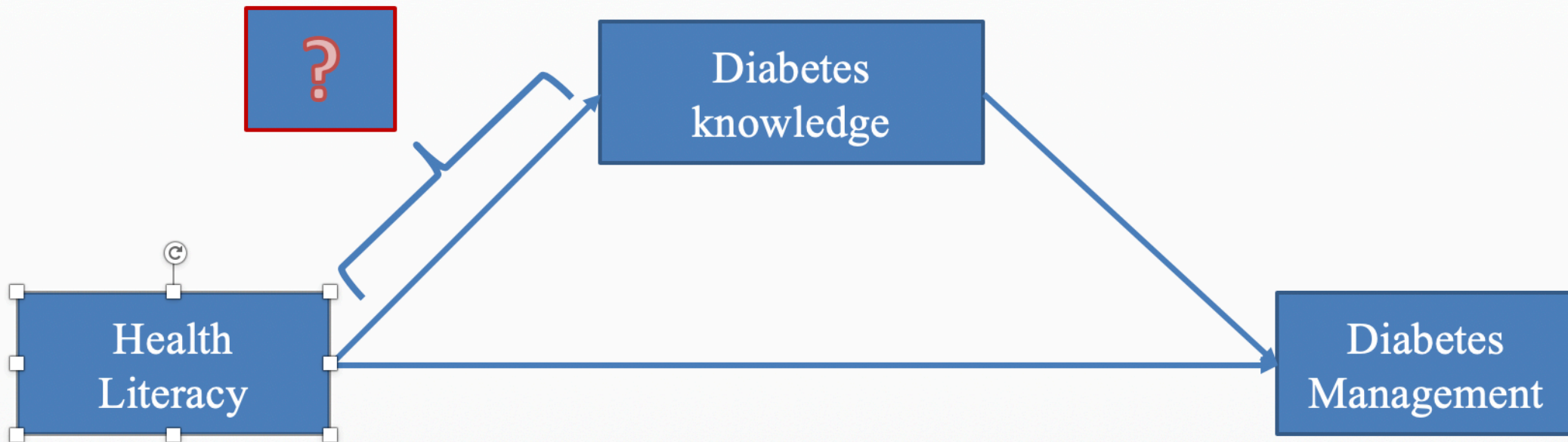
Heterogeneity: $\tau^2 = 0.0036$; $\chi^2 = 49.88$, $df = 23$ ($P < 0.001$); $I^2 = 54\%$
 Test for overall effect: $t_{11} = -2.25$ ($P = 0.034$)

Total (95% CI) **12293** **100.0%** **-0.048 [-0.091; -0.006]**
 Heterogeneity: $\tau^2 = 0.0098$; $\chi^2 = 121.81$, $df = 35$ ($P < 0.001$); $I^2 = 71\%$
 Test for overall effect: $t_{35} = -2.30$ ($P = 0.027$)
 Test for subgroup differences: $\chi^2 = 0.03$, $df = 1$ ($P = 0.858$)



Marciano L, Camerini AL, Schulz PJ (2018).
 The role of health literacy in diabetes
 knowledge, self-care, and glycemic control: a
 meta-analysis. *Journal of General Internal
 Medicine*, (accepted Dec 2018).

The case of diabetes management



Correlation between HL & diabetes knowledge

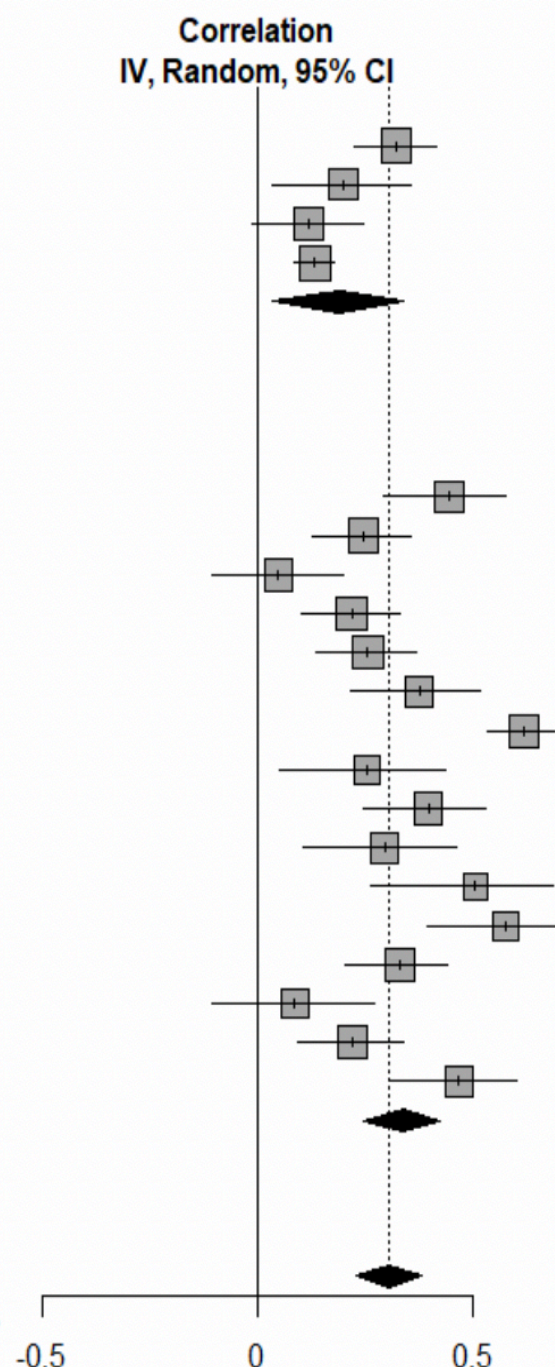
Study or Subgroup	Total	Weight	Correlation IV, Random, 95% CI
Self-report			
Al Sayah 2015 (2)	342	5.7%	0.323 [0.224; 0.415]
Ishikawa 2008	138	4.9%	0.200 [0.034; 0.355]
Maneze 2016	224	5.4%	0.120 [-0.011; 0.247]
van der Heide 2014	1714	6.2%	0.134 [0.087; 0.180]
Total (95% CI)	2418	22.1%	0.193 [0.036; 0.341]
Heterogeneity: $\tau^2 = 0.0075$; $\chi^2 = 12$, $df = 3$ ($P = 0.007$); $I^2 = 75\%$			
Test for overall effect: $t_3 = 3.90$ ($P = 0.030$)			

Performance based

Study or Subgroup	Total	Weight	Correlation IV, Random, 95% CI
Bains 2011	125	4.8%	0.446 [0.293; 0.576]
DeWalt 2007	268	5.5%	0.246 [0.130; 0.356]
Eyüboğlu 2016	167	5.1%	0.050 [-0.103; 0.200]
Gazmararian 2018	266	5.5%	0.220 [0.102; 0.332]
Gerber 2005	244	5.4%	0.258 [0.136; 0.371]
Gordilho-Souza 2014	129	4.8%	0.378 [0.219; 0.517]
Jeppesen 2011	240	5.4%	0.618 [0.533; 0.691]
Kim 2004	92	4.4%	0.255 [0.053; 0.437]
Leung 2013	137	4.9%	0.398 [0.247; 0.530]
Mancuso 2010	102	4.5%	0.296 [0.108; 0.464]
McClearly-Jones 2011	50	3.5%	0.506 [0.265; 0.687]
Powell 2007	68	4.0%	0.578 [0.394; 0.718]
Rothman 2005	217	5.3%	0.330 [0.206; 0.444]
Swavely 2013	106	4.6%	0.088 [-0.105; 0.274]
Wallace 2009	230	5.4%	0.222 [0.095; 0.341]
Williams 1998	114	4.7%	0.469 [0.312; 0.601]
Total (95% CI)	2555	77.9%	0.339 [0.247; 0.424]
Heterogeneity: $\tau^2 = 0.0279$; $\chi^2 = 81.35$, $df = 15$ ($P < 0.001$); $I^2 = 82\%$			
Test for overall effect: $t_3 = 7.47$ ($P < 0.001$)			

Total (95% CI)	4973	100.0%	0.308 [0.228; 0.383]
Heterogeneity: $\tau^2 = 0.0262$; $\chi^2 = 129.77$, $df = 19$ ($P < 0.001$); $I^2 = 85\%$			
Test for overall effect: $t_{19} = 7.78$ ($P < 0.001$)			

Test for subgroup differences: $\chi^2 = 5.19$, $df = 1$ ($P = 0.023$) Correlation between health literacy and diabetes knowledge



- ❖ A meta-analysis based on 61 studies on HL & Diabetes (N = 18905)
- ❖ Higher levels of health literacy are significantly associated with better diabetes knowledge (n = 20, $r = 0.308$, $p < 0.001$).
- ❖ Health Literacy and Diabetes Self-Care: only partly are higher levels of HL associated with more frequent self-care activities
 - ❖ self-report health literacy measures, the overall association with self-care activities is significant and positive (n = 6, $r = 0.095$, $p = 0.045$);
 - ❖ no such association was found for studies with performance-based tests.
- ❖ Higher levels of health literacy are associated with lower levels of Glycemic Control (HbA1C) (n = 36, $r = -0.048$, $p = 0.027$).

- Does facilitating reading material really help people with low levels of health literacy?
- Need of longitudinal studies: how does the learning curve of people with low and high HL levels increase?

Thank you

