

# The Silent Majority: Limited Health Literacy Participants Missing from Market Research

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Market researchers are used to asking questions. It is their job to query and probe “to gather information about markets or customers” (McQuarrie, 2016), but how adept are they at turning those questions inward? Have health care-related market researchers synthesized what is currently known about health literacy to inform their study designs or their participant recruitment goals?

Traditional recruitment into market research studies begins with a determination of participant eligibility. This is based on a multitude of shared characteristics and demographics, but health literacy status is often not a consideration. This may be a serious oversight with far-reaching ramifications because a participant’s “capacity to obtain, process, [act upon,] and understand basic health information and services needed to make appropriate health decisions” (Nielsen-Bohlman, Panzer, & Kindig, 2004) is governed by health literacy.

Consider how market research is supposed to work (Figure 1). For example, qualitative studies seek to secure representative samples of target audiences because it is widely believed that trends identified in the smaller group may apply to the larger population. Failure to take health literacy status into account during recruitment ignores the

single greatest trait that influences consent, comprehension, and compliance (Brown and Bussel, 2011; DeWalt & Pignone, 2005; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Donovan-Kicken et al., 2012; Russell, Mullan, & Billington, 2015). What’s more, an examination of health literacy levels among adults in the United States coupled with the levels of those typically recruited into market research may reveal a major flaw in current health care related market research recruitment rationales.

A brief review of the history of market research and health literacy may illuminate the point at which we now find ourselves—the juncture where the two meet.

## LOOKING BACK TO LOOK FORWARD

Health literacy as a field of inquiry is still young, comparable to an adolescent. In contrast, market research as a business practice is a still-active senior citizen, well-established but hardly obsolete. Some have noted that “Even the Children of Israel sent interviewers out to sample the market and produce of Canaan” (Lockley, 1950).

In the U.S., the tools of market research were in use as early as 1824, when *The Pennsylvanian* newspaper in Harrisburg, PA, featured a report of a straw vote “without

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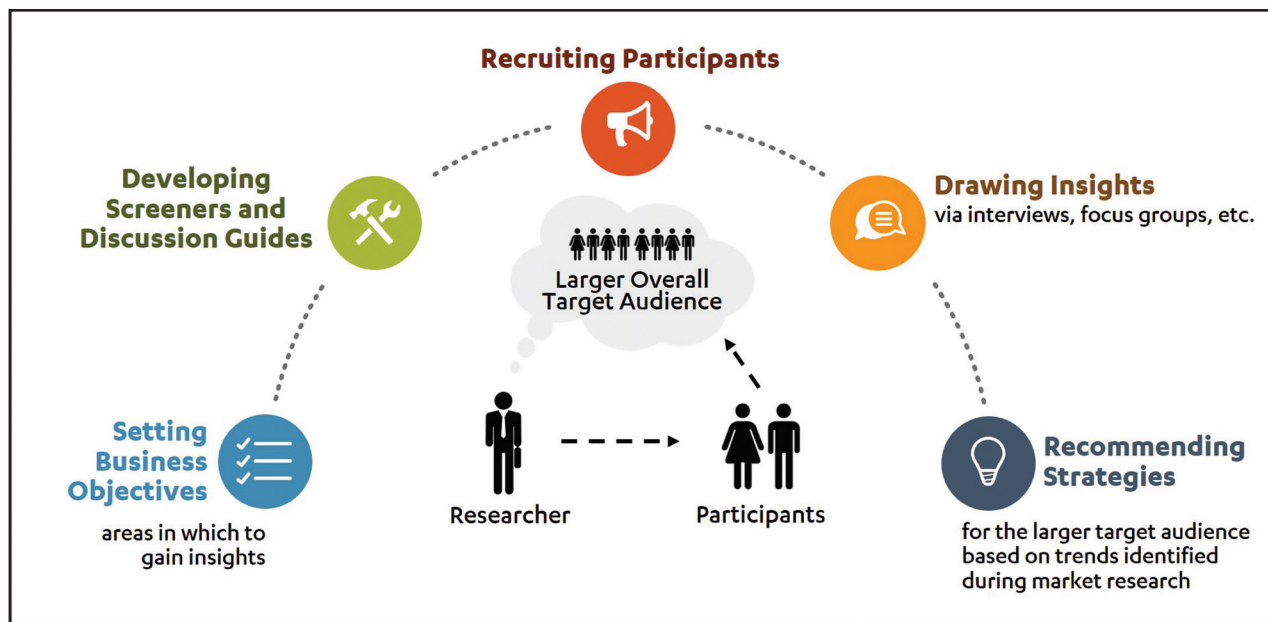


Figure 1. How market research is “supposed” to work.

Discrimination of Parties” (Gleim & Conrad, 1824). Market research, as an established field of business within the U.S., can be traced back to the first few decades of the 1900s (Lockley, 1950; Persuadable Research Corporation, 2016). Does its long history as a business practice, however, mean that practitioners have been properly recruiting participants into market research? With an increasing awareness of health literacy, we may have to consider the possibility that most of us involved in health care related market research have been going about it the wrong way. Understanding the journey that the concept of health literacy has taken will explain why this is so.

Health literacy first appeared as a fully articulated concept in the literature in 1974 (Simonds, 1974). Its onset as a first-generation idea placed it in orbit around the notion of health education and the need to develop minimum standards for health literacy in the classroom. It was not, however, until about two decades later that health literacy was fully embraced as a viable concept, taking root in two related but distinct spheres: clinical care and public health (Baker, Parker, Williams, Clark, & Nurss 1997; Council of Chief State School Officers, 1998; Williams et al., 1995).

Undertaking the following two-step exercise will help inform our thinking about the role that health literacy currently plays or should play in health care related market research: (1) divide the general population into two camps—limited health literacy and health literacy proficiency; and (2) consider sample size and the presumed

value of market research respondents as representatives of a greater whole.

Several studies tell us that only about 12% of U.S. adults present with above basic health literacy (Goodman & Finnegan, 2013; Kirsch, Jungeblut, Jenkins, & Kolstad, 2002; Kutner, Greenburg, Jin, & Paulsen, 2006). That means that most U.S. adults (about 88%) possess basic or below-basic health literacy.

As previously stated, extrapolating information about a representative sample and inferring facts about the larger population is what market research is all about. The premise is that any trends and patterns of perceptions identified in the audience sampling will generally apply to the larger group that the respondents represent.

It is here, at the intersection where health literacy and market research meet, that we get the opportunity to test whether one can “teach an old dog a new trick.” The point at issue is whether traditional health care related market research recruitment results in a true representative sampling of a target market.

## HEALTH LITERACY AND MARKET RESEARCH: A TRUANT TEAM

Because our review of health literacy levels among U.S. adults reveals that most Americans have only basic or below-basic health literacy, one would expect to see that reality reflected in the makeup of market research participants; however, that seldom is the case.

Most producers of patient materials ignore the health literacy question altogether when they test their collateral with consumers (King et al., 2006). Health literacy level assessments with participants are, accordingly, rarely done. Therefore, an attempt to quantify the average breakdown of health literacy levels generally represented in market research is difficult; however, there are some exceptions.

Merck & Co., Inc. (Kenilworth, NJ) has been at the forefront of this movement, spearheading a new approach to test patient labeling with a diverse demographic including people across health literacy levels. They made a concerted effort to purposefully seek out participants with limited health literacy by expanding beyond typical facility lists and engaging in novel recruitment strategies. After all their efforts, they identified an average of 30% of people with lower health literacy among all participants across testing for six patient-labeling documents (Courtade & Myers, 2016).

One may be surprised that the representation was not higher (i.e., closer to the 88% basic and below-basic health literacy level in the general population) considering the extra care and effort taken to recruit participants with lower health literacy.

It may simply be that people who present with high proficiency in health literacy are more willing than those with lower health literacy to participate in research. Logically it makes sense that this could be the case, as participation could reveal uncomfortable or embarrassing health literacy challenges among lower-proficiency participants. The link between feeling ashamed of one's limited health literacy and attempts to hide one's limited health literacy are well documented (Parikh, Parker, Nurss, Baker, & Williams, 1996). This aligns with the position of many recruitment firms that participants with limited health literacy constitute "hard-to-recruit" audience targets.

In practical terms, this means that the audience sample in health care related market research for certain studies may not always be an accurate representation of the larger population. As the value of insights gleaned from market research is directly proportional to our ability to infer universal trends, such a significant misrepresentation of the target audience for select studies may provide misleading or incomplete understandings. Unfortunately, health literacy is not considered in most market research design even though it should be front and center for many types of research projects. Even among studies where health literacy status clearly plays a prominent role (e.g., medication labeling research), recruitment screeners infrequently set quotas for participants with limited health literacy.

This line of inquiry about inclusion of participants with limited health literacy in market research begets other questions. One of these questions is how we define health literacy.

## THE EVOLUTION OF HEALTH LITERACY CONCEPTUALIZATION

Earlier we characterized the current stage of health literacy as adolescence. Much like any other adolescent, health literacy has already adopted and discarded various labels and stages in its quest for self-identity (**Figure 2**).

In 1999, the Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs of the American Medical Association described it as "the constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment," including "the ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials."

This characterized health literacy as a set of individual capacities that allow a person to acquire and use new information. These capacities were presented as relatively stable over time, although concessions were made that competency may improve with educational programs or decline with aging or pathologic processes that impair cognitive function.

During the 1990s, measurement of health literacy focused purely on patient deficits, which had the potential of stigmatizing people with lower health literacy and giving the appearance of patient blaming. The trend over the past several years, however, has been to correct conceptual errors and neglected contexts. The move has been away from that singular focus on the patient to a greater acceptance of patient-physician collaboration/responsibility (Rudd, 2015).

If one believes that any definition of health literacy must include at its core the ability to function in the health care environment, then one may find merit in relatively recent developments in describing health literacy. One argument that is gaining a lot of traction is the notion that health literacy depends upon characteristics of both the individual and health care system. From this perspective, health literacy is a dynamic state of a person during a health care encounter (Paasche-Orlow & Wolf, 2007; Rudd, Renzulli, Pereira, & Daltroy 2005; Baker, 2006). To clarify, a person's health literacy level may vary depending upon several constantly shifting variables (e.g., the medical problem being treated, the patient's experience with that problem, the health care provider interacting with the patient, the health care system providing the care).

Simply said, context matters. This means that a person's health literacy skills may be somewhat malleable and can

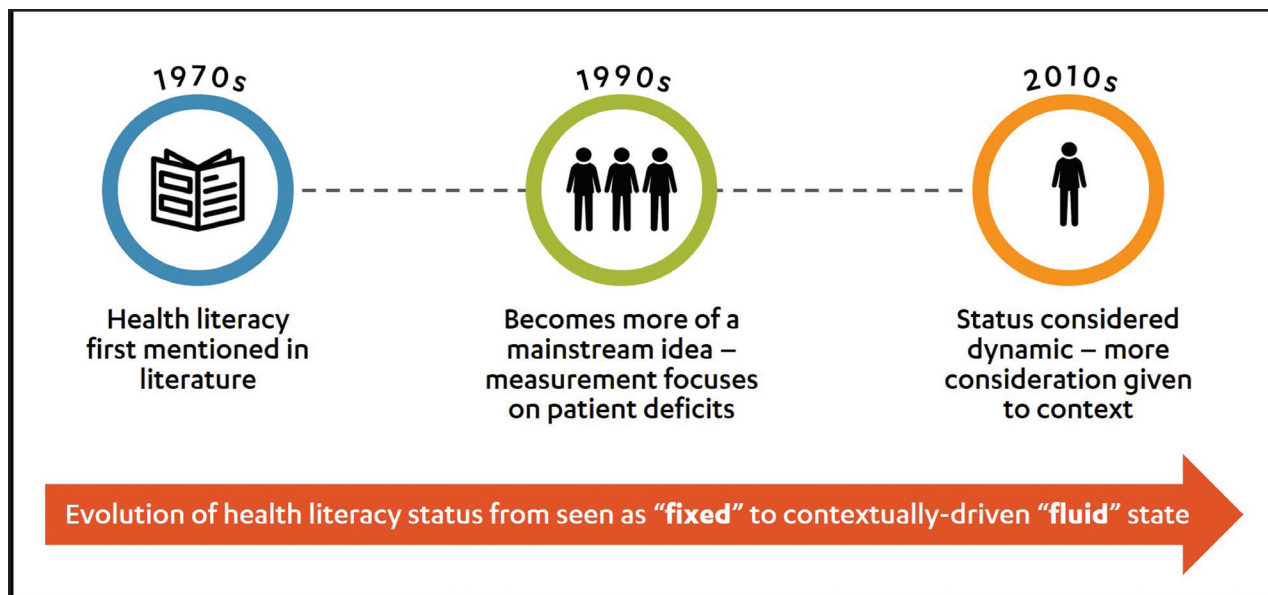


Figure 2. The evolving view of health literacy status.

change from moment to moment. How does this new understanding of health literacy affect health care related market research? If one accepts this article’s proposition that participants at different health literacy levels should be actively and intentionally recruited more frequently into market research to reflect the larger population more accurately, then one must consider what health literacy as a fluid state means. Can a participant have below-basic health literacy when dealing with one medical condition, but above-basic health literacy with another condition? How would this affect health literacy assessment and market research recruitment?

There is no gold standard in recruitment techniques of market research participants with limited health literacy. Many questions have yet to be asked, let alone answered (e.g., how do we more efficiently and swiftly recruit limited health literacy participants into pertinent studies? In which studies would a greater consideration of health literacy status and intentional inclusion of participants with lower literacy be most beneficial?). Clearly, our understanding of health literacy is still evolving; however, market researchers who know enough to stay at the forefront and explore these issues will have an advantage over those who proceed with business as usual.

### CONCLUDING THOUGHTS

Including participants at all levels of health literacy in pharmaceutical market research may seem obvious, but in practice it is seldom done. Moreover, it is a recommendation that few market researchers have even heard. For those who work in the health literacy space day-in and day-out, this

may seem absurd until one recalls a concept often used in the industry to describe the mindset of some health care communicators—the curse of knowledge. This concept is used to describe a cognitive bias in which the communicator who is well versed on a certain subject assumes that those with whom he or she communicates shares that base of knowledge. Accordingly, this seemingly simple idea may be novel for many market research recruiters.

Recognizing the need to recruit participants of limited health literacy into research is the first of three steps that can be undertaken to prevent business as usual (Figure 3). The second step is figuring out how to do it. This task is harder than it may seem. Because routine recruitment sources typically do not include many people with limited health literacy from whom to draw, recruiters must go deeper in their study enrollment efforts.

Studies over the years have revealed that certain populations are at greater risk for lower overall general health literacy than others. Less education, lower income, minority status, English as a second language, and age older than 65 years are all traits that have been linked to greater instances of limited health literacy (Goodman & Finnegan, 2013; Kirsch et al., 2002; Kutner et al., 2006). Using a proxy for health literacy status based on these demographic criteria selections, therefore, is a good initial foray in targeting recruits with lower health literacy (Amresh, Ash, Gazamararian, Wolf, & Paasche-Orlow, 2008). How best, though, to reach these potential participants when they are largely missing from recruiter databases? Outreach initiatives at community-based organizations like adult learning centers, community health clinics, senior centers,



Figure 3. A health-literate prescription for market researchers.

residential communities for those age 55 years and older, and social service organizations can be solid resources for pharmaceutical market research recruiters.

The third step market researchers should do to is to authenticate that potential participants reflect the health literacy diversity needs of their study. Automating repetitive processes is a great way to enhance efficiencies, but it generally does not make sense for pharmaceutical market research recruitment. Just consider the daughter who functions as the caregiver for her elderly mother with cervical cancer. The daughter may exhibit reasonably high health literacy when it comes to that condition because she has so much experience caring for her mother. That does not necessarily mean, however, that the daughter will show the same high level of health literacy when it comes to a different medical condition, such as hypertension.

There are a myriad of tools available for validating health literacy status but, as stated earlier, there is no gold standard. Rather than search for a one-size-fits-all validation solution, one can consider the context and select the right tool. The contextually driven fluidity found in health literacy scenarios like the one above means that a standard, regimented recruitment approach may be a bad idea. Fortunately, we do not have to guess at the caregiver's potential disparate health literacy levels between cervical cancer and hypertension; we can simply administer the Cervical Cancer Literacy Assessment Tool for a study dealing with that condition, and the High Blood Pressure Health Literacy Scale for a study dealing with hypertension.

Likewise, if a study is designed to engage a specific skill, we should consider that skill when selecting our health

literacy assessment. Often, we will be able to match the test we administer with the specific context. For example, if we are conducting research into dosing instructions, we may be particularly interested in participants' health literacy as it relates to their ability to manipulate and comprehend numbers. Health literacy status as measured by the Newest Vital Sign (which is based on a nutrition label from an ice cream container) directly corresponds to participants' numeracy skills, so this may be an ideal tool choice for health literacy measurement for such a study.

There are not ailment-specific health literacy validation tools for every conceivable condition, or ones that cover every potential dimension of health literacy (e.g., prose, numeracy, interactional), but there are enough available to warrant a customized approach when possible. A good place to start may be visiting the Health Literacy Tool Shed (<https://healthliteracy.bu.edu/all>), which is an online database that features information on 134 (and counting) health literacy measures.

The key takeaways for market researchers are to recognize, strategize, and customize: (1) recognize the problem, which is that patients with limited health literacy tend not to be included in market research and, therefore, there is an overrepresentation of higher health literacy participants in research, which isn't reflective of actual real-world conditions; (2) strategize to develop a solution to recruitment obstacles by relying more on grassroots outreach than on recruitment databases; and (3) customize the validation process to account for the context, ensuring that participants' health literacy levels are matched with the particular condition being studied.

If this strategy is used, the reported insights and recommended strategies will be based on the most accurate representation of patient consumers as possible. In this way, the industry can course-correct and ensure a high level of confidence in the integrity of their study designs.

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