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## Moving Public Health Learners to the Skeptical Edge with Information Creation as a Process

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## CHAPTER 7

# Moving Public Health Learners to the Skeptical Edge with Information Creation as a Process

Xan Goodman

### Introduction

During the twentieth century, the discipline of public health benefitted from many notable achievements, including the discovery and application of antibiotics to treat infection, the development of a vaccine that allowed for the eradication of smallpox, and a vaccine for polio.<sup>1</sup> In this chapter, I will focus on two other notable public health cases of the twentieth century, as related to public health information creation. These cases hinge on a proposed threshold concept: social determinants of health (SDOH). Social determinants of health describe factors that influence population health behaviors and health outcomes. Poverty, socioeconomic status, stress, one's built environment—that is, whether a person's neighborhood has sidewalks or bike lanes—and one's race or ethnicity are all SDOHs. Even access to healthy food is a social determinant that affects the health status and health outcomes of populations. The Healthy People 2020 Initiative and World Health Organization have outlined more social factors that influence health.<sup>2</sup> This chapter explores SDOH as a threshold concept through the lens of the cases of Henrietta Lacks and the Tuskegee Experiment, as well as the information literacy threshold concept Information Creation as a Process.<sup>3</sup>

An understanding of social determinants of health is essential to students of public health, as these students will enter careers in epidemiology, environmental health, health promotion, and health care, where they will grapple with questions of how SDOH impact populations. Students will work as epidemiologists, community health workers, infectious disease experts, food inspectors, environmental health specialists, public health officers, professors, and sexual health educators, among many other careers. Students will encounter essential questions, such as: Is health care a human right? Additionally, public health dilemmas abound and are evident in multiple contexts, from viral disease outbreaks such as Zika to debates in the United States about universal healthcare coverage.<sup>4</sup> The aim of focusing on Henrietta Lacks and the Tuskegee Syphilis Study is to explore two well-known public health cases with library instruction that encourages students to adopt a new lens through which they view information and a skeptical approach to information creation in public health. At the same time, students will be encouraged to critically think about SDOH and information creation using instructor-selected reading materials and information sources, so they can apply what they learn. In this chapter, I propose lessons aimed at undergraduate students. Public health undergraduate students are poised to become contributors to policy, guidelines, and evidence-based research, and grasping these threshold concepts will be critical to their ability to positively affect the communities they will serve.

I am a liaison librarian at the University of Nevada, Las Vegas (UNLV) Libraries, where I support the Schools of Allied Health, Community Health Sciences, and Nursing. In my role, I work with professors and course coordinators to integrate library instruction into the curriculum. UNLV is located in Las Vegas, a city community with complex public health challenges. The city has a built environment, for example, that results in an excessively high number of pedestrian fatalities.<sup>5</sup> There is a paucity of fresh food grocers, and sixteen Las Vegas census tracts are designated as food deserts.<sup>6</sup> Systematic issues conspire to create an environment with low-quality public education, and low graduation rates that mostly affect lower socioeconomic populations.<sup>7</sup> These are just a few examples of the many public health challenges that our students will encounter as professionals.

## **The social determinants of health as a threshold concept**

A threshold concept represents a foundational disciplinary concept a student will ideally grasp to achieve mastery in a discipline. As defined by Meyer and Land, threshold concepts have five primary characteristics, that they are: troublesome, bounded, transformative, integrative, and irreversible.<sup>8</sup> SDOH

as a concept embodies these five characteristics. Students newly introduced to SDOH might experience feelings of discomfort, disbelief, and even anger about the SDOH. Students will necessarily struggle when introduced to this concept as their current ideas about health and health outcomes are upended. SDOH as a framework for understanding public health is troublesome, bounded, transformative, integrative, and irreversible. It is important to note that I found no existing research on what students tend to believe before being exposed to SDOH. Thus, I provide examples of direct classroom experience and assignment responses in this chapter.

SDOH are often troublesome when students first encounter the idea that factors such as low socioeconomic status or access to a built environment might affect health. Students will sometimes express doubt and exhibit an affective response of discomfort with this new knowledge. Besides discomfort, troublesome new knowledge might also represent a point in the learning process where a student gets stuck<sup>9</sup>—for example, when students are initially unable to grasp how the zip code of populations might determine incidence of disease or be strong predictors of mortality. The troublesome nature of SDOHs might present in the classroom from students who exhibit strong emotional responses. I experienced this directly in class discussions about health as a human right; students expressed that they did not “buy” the idea that health is a human right and were noticeably emotional in their discussion. Some did not want to pay for the health care of others and asked, *Why should I have to pay for someone else?* Others talked about personal responsibility and how people might be less responsible for their health if universal health care were available.<sup>10</sup> Some students were more nuanced and expressed that there is simply not enough money available to provide access to health care for all, so those who are unable to afford care might need to go without or find other options. As students grapple with understanding the significance of SDOH, they are discomforted by the potential ramifications of this idea.

A student who encounters troublesome knowledge is said to be in the space of liminality. The liminal space is one where a student thinks, where they mull over a new concept, sometimes tossing it aside, retreating, and returning to again pick it up. When first encountering SDOH, students might retreat from these concepts because they are troubling, slightly unbelievable, and difficult to grasp. To cross the liminal space and integrate new knowledge about SDOH, a student needs to experience a transformation in their thinking. Transformative thinking in a discipline represents a change in how a discipline is approached. To become a successful public health practitioner students need to integrate knowledge about the SDOH into their thinking. Integrative refers to a student adopting the ways of a discipline. They simply begin to think, for example, like an epidemiologist or a public health officer. Once new disciplinary knowledge is adopted, it is described as irrevers-

ible; once learned it cannot be unlearned.<sup>11</sup> Bounded refers to the knowledge boundaries of a discipline. The SDOH is a threshold concept that bounds the practice of public health; it is foundational to understanding how to do the discipline.

SDOH move a healthcare practitioner to examine the systems and structures that affect health outcomes. As an example, Dr. Adewale Troutman is an allopathic medical doctor who also has a graduate degree in public health. Dr. Troutman served as past president of the American Public Health Association and Director of Public Health in Louisville, Kentucky.<sup>12</sup> Dr. Troutman's work to map disease in Louisville, Kentucky, is grounded in the threshold concept of SDOH. Dr. Troutman examined why populations in particular zip code regions had higher incidences of mortality and rates of disease. His epidemiological exploration of population health and the role of health inequities led to a citywide initiative in Louisville to improve the health of communities.<sup>13</sup> A physician trained in public health will have an awareness of health disparities and health inequities and will approach the practice of medicine differently. Doctors often treat the individuals instead of focusing on disease prevention and populations.<sup>14</sup> Among physicians who have earned a degree in public health, their practice of health care often seems to have been affected by an understanding of the SDOH. Fineberg expressed this well: "A physician who appreciates the role and potential for public health interventions... has a deeper understanding of the conditions that preserve health, of the primacy of disease prevention, and of the interfaces between personal and medical care and community health protection," and Dr. Troutman's work provides one example.<sup>15</sup>

## Information Creation as a Process

Policy, evidence-based papers, guidelines, and research are all forms of public health-related information created by different processes. Information Creation as a Process is one of six frames outlined in the Association of College and Research Libraries' (ACRL) *Framework for Information Literacy for Higher Education* (Framework). I will use this frame to explore how a librarian and a faculty member might partner to combine an information literacy threshold concept with a discipline-specific threshold concept to motivate students to question critically, take a skeptical approach to information, and apply what they learn to question the public health information they encounter. The Framework suggests that "experts look to the underlying processes of creation as well as the final product to critically evaluate the usefulness of the information."<sup>16</sup> Undergraduate students are novice learners who are encountering disciplinary content for the first time, and they will not move

to expert level in one course. However, Information Creation as a Process can be introduced along with SDOH in a scaffolded manner to build this skill. In the Introduction to Public Health Course at UNLV, students read texts such as *Silent Spring* and *The Immortal Life of Henrietta Lacks*, in addition to other works. In librarian-designed lessons, students will be encouraged to delve deeper into the original medical data at the heart of the Henrietta Lacks case, so they will consider the processes that went into their creation. A potential collaboration between a faculty member and librarian can be established to allow students to explore the frame Information Creation as a Process through a skeptical approach to information, critically thinking about SDOH.

## Public Health Education Standards

Undergraduate public health education is guided by standards established by the Council on Education for Public Health (CEPH). CEPH requires an institution offering a bachelor's degree in public health to offer a general education curriculum that addresses the following areas: scientific knowledge, including the biological and life sciences and concepts of health and disease; foundations of social and behavioral sciences; basic statistics; and the humanities and the arts. CEPH also describes foundational domains a student should acquire. Specific domains relevant to information literacy instruction include:

- The basic concepts, methods, and tools of public health data collection, use, and analysis, and why evidence-based approaches are an essential part of public health practice
- The socioeconomic, behavioral, biological, environmental, and other factors that impact human health and contribute to health disparities
- Basic concepts of legal, ethical, economic, and regulatory dimensions of health care and public health policy and the roles, influences, and responsibilities of the different agencies and branches of government<sup>17</sup>

CEPH has also issued two broad competency areas for undergraduate learners: “the ability to communicate public health information, in both oral and written forms, through a variety of media and to a diverse audiences” and “the ability to locate, use, evaluate, and synthesize public health information.”<sup>18</sup> Students are also required to have an opportunity to engage in experiential activities and additional co-curricular experiences that expose students to life-long learning opportunities and other meaningful experiences, such as networking, professionalism, teamwork, and leadership.

## University context

Within the health sciences programs at UNLV, the curriculum is intended to be scaffolded programmatically to provide an education, whereby concepts are introduced, enhanced, and reinforced. Thus, a first-year student who has indicated an interest in the health sciences will be enrolled in the first-year health sciences seminar course, HSC100. In the second-year seminar, PBH 205 students are introduced to public health and learn about SDOH. These undergraduate students are novice learners who are encountering disciplinary content for the first time. In PBH 205, they are required to read the *Immortal Life of Henrietta Lacks*. In PBH 330, students examine SDOH and their importance regarding global health. In their capstone course, PBH 495, students are required to complete either an independent research project or a project with a community partner. As a result of this requirement, students often select Las Vegas agencies that serve clientele who are affected by SDOH, and SDOH might feature prominently in any final project.

The following table identifies the core sequence of first-year, second-year, milestone, and capstone classes for the Bachelor of Science in Public Health as mapped to the frame Information Creation as a Process, SDOH, and CEPH foundational domains. As a liaison librarian, I have worked with each of the following courses in varying capacities: HSC 100, PBH 205, and PBH 330. I have developed the curriculum map below to use as a tool to pitch library instruction sessions modeled on the frame Information Creation as a Process to public health instructors; the courses included in this map do not represent all of the opportunities to introduce Public Health Education Standards in the curriculum. Table 7.1 includes other suggestions for mapping the SDOH to the frame Information Creation as a Process. In this chapter, the suggested lessons are for the second-year seminar course, PBH 205.

## Henrietta Lacks

The story of Henrietta Lacks raises questions about Information Creation as a Process. Hers is the remarkable account of an African-American woman with a sixth-grade education unknowingly providing cells to science, making Henrietta and her cells immortal.<sup>19</sup> Her cells were described as immortal because they could be grown in laboratories and used in medical research practically in perpetuity.<sup>20</sup> Henrietta was treated at the renowned Johns Hopkins Hospital in the 1950s, at the time one of the only hospitals in Baltimore that would treat black patients.<sup>21</sup> Henrietta's race and socioeconomic status constrained her options to access health care, one of the key SDOH. At Johns Hopkins, she received treatment, but doctors initially misdiagnosed Henri-

**Table 7.1. UNLV Bachelor of Science in Public Health Program**

UNLV Course	ACRL Frame Information Creation as a Process	Knowledge Practice	Disposition	SDOH	CEPH Bachelor's Degree Foundational Domains
First-Year Seminar HSC 100 Inquiry and Issues in the Health Sciences	Introduced	Recognize that information may be perceived differently based on the format in which it is packaged.	Accept that the creation of information may begin initially through communicating in a range of formats or modes.	Not introduced	General education course for health sciences. No specific public health content is covered.
Second-Year Seminar PBH 205 Introduction to Public Health	Introduced and connected to SDOH	<p>Articulate the capabilities and constraints of the information developed through various creation processes. (Introduced)</p> <p>Develop their own creation processes, along with an understanding that their choices impact the purposes for which the information product will be used and the message it conveys. (Introduced)</p>	<p>Are inclined to seek out characteristics of information products that indicate the underlying creation process.</p>	Introduced	<p>The socioeconomic, behavioral, biological, environmental and other factors that impact human health and contribute to health disparities (Introduced)</p> <p>Basic concepts of legal, ethical, economic and regulatory dimensions of health care and public policy and the roles, influences, and responsibilities of the different agencies and branches of government (Introduced)</p>



<b>Table 7.1. UNLV Bachelor of Science in Public Health Program</b>					
<b>UNLV Course</b>	<b>ACRL Frame Information Creation as a Process</b>	<b>Knowledge Practice</b>	<b>Disposition</b>	<b>SDOH</b>	<b>CEPH Bachelor's Degree Foundational Domains</b>
Milestone Course PBH 330 Global Health	Reinforced	Monitor the value that is placed upon different types of information products in varying contexts. (Introduced)  Articulate the capabilities and constraints of the information developed through various creation processes. (Reinforced)	Are inclined to seek out characteristics of information products that indicate the underlying creation process.	Reinforced	The socioeconomic, behavioral, biological, environmental and other factors that impact human health and contribute to health disparities (Reinforced)  Basic concepts of legal, ethical, economic and regulatory dimensions of health care and public policy and the roles, influences, and responsibilities of the different agencies and branches of government (Reinforced)

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<b>UNLV Course</b>	<b>ACRL Frame Information Creation as a Process</b>	<b>Knowledge Practice</b>	<b>Disposition</b>	<b>SDOH</b>	<b>CEPH Bachelor's Degree Foundational Domains</b>
Capstone Course PBH 495 Public Health	Enhanced	Develop their own creation processes, along with an understanding that their choices impact the purposes for which the information product will be used and the message it conveys. (Reinforced)  Articulate the capabilities and constraints of the information developed through various creation processes. (Enhanced)	At this stage, students are creating their own capstone information product in the form of a research paper or report about their community partnership. Here, students should have acquired culminating skills.	Enhanced	The socioeconomic, behavioral, biological, environmental and other factors that impact human health and contribute to health disparities (Enhanced)  Basic concepts of legal, ethical, economic and regulatory dimensions of health care and public policy and the roles, influences, and responsibilities of the different agencies and branches of government (Enhanced)

etta's cancer, and she died within six months. In the process, physicians acquired a sample of her tissue during the diagnostic process and more tissue during a cancer surgery. The tissue taken during Mrs. Lacks's surgery was done so without her consent. After her death, it appears that physicians deceived her husband into allowing an autopsy to take even more tissue samples from her body. Doctors at Johns Hopkins were experimenting with growing cancer cells in a laboratory environment, and they needed cells. Henrietta's cells were taken, cultured, and shipped to researchers around the United States and the world. Within less than a year of her death, a tissue culture enterprise had been established to sell Henrietta's cells to researchers for a profit.<sup>22</sup> The cells are still sold today for hundreds of dollars per vial.<sup>23</sup>

Henrietta's case embodies a common outcome that can result from SDOH, such as socioeconomic status or access to care—that because certain populations lack control over their options for the care, they may be coerced or unknowingly used as human subjects. Subjects might have little understanding of scientific research and are thus vulnerable targets for plunder and exploitation. For example, Henrietta's family was contacted in the early 1970s for blood tests, and in the 1980s parts of Henrietta's medical records were published without knowledge or consent from her family.<sup>24</sup>

The frame Information Creation as a Process encourages students who study this case to question the circumstances that allowed doctors to take tissue samples from an unsuspecting patient and cultivate them, even if they were helpful to science. Students are encouraged to question the information creation process for the source of this medical data. As with many human subjects, Henrietta's identity was unknown to researchers using the cells; the cell line developed from her tissue was merely referred to as HeLa cells, based on the first two letters of her first and last name.<sup>25</sup>

## Tuskegee experiment

Sexually transmitted infections (STIs) are a stubborn public health dilemma. Students with interest in sexual health promotion, epidemiology, or local public health departments will become familiar with reporting structures for STIs and the extensive efforts to treat these infectious diseases, which have a high cost socially and within the healthcare system. The problem of STIs and their high cost for communities has been longstanding, which leads to the case of the Tuskegee Experiment, also known as the Tuskegee Syphilis Study and the Tuskegee Study of Untreated Syphilis in the Negro Male. It is a foundational public health study supported by the United States National Public Health Services in the mid-twentieth century.<sup>26</sup> This experiment provides an entry point for public health undergraduates to scrutinize the multiple roles

of public health officials and thereby develop skepticism and critical thinking about the sources of public health knowledge.

The Tuskegee Experiment began in Macon County, Alabama in 1932 and ended in 1972. The study involved approximately 600 male subjects, of whom two-thirds had syphilis while one-third were a control group who did not have syphilis.<sup>27</sup> None of the subjects enrolled in the experiment were informed that they were part of a study; instead, they received false prognoses and were denied therapeutic care for syphilis. The men did receive some routine medical care that included “free physical examinations, free rides to and from the clinics, hot meals on examination days, [and] free treatment for minor ailments...”<sup>28</sup> but were explicitly denied care for syphilis. All of the participants had social factors that influenced their health outcomes. Most participants in the Tuskegee Experiment were from farming communities in rural Alabama, many were uneducated, and all subjects were African-American. Their socioeconomic status varied, but most were poor. Over the course of forty years, the men had medical tests, and some were only told they had “bad blood.”<sup>29</sup> In the initial stages of the study, there was no known treatment for syphilis; however, even after the discovery of penicillin as a treatment, it was withheld from the men for over twenty years of the study.<sup>30</sup> The experiment was to watch men die from the effects of syphilis.

The environment of rural Macon County, Alabama from the 1930s to 1970s might be difficult for one to grasp. Students and readers might wonder why the subjects did not seek treatment for their disease outside of the county. The truth is that some did try. However, subjects enrolled in the study were outed to healthcare practitioners in the region as being a part of the Tuskegee Experiment; even if treatment was sought, subjects were denied.<sup>31</sup> The complexity of the Tuskegee Experiment is a fertile ground in which to explore the frame Information Creation as a Process. A focus on this case in Introduction to Public Health is aimed at encouraging students to question the foundations of public health practice with STIs. Even though the Tuskegee Experiment ended in the 1970s, there are other examples of studies that followed the progression of disease in patients without treating them, such as the Guatemala Syphilis Study and the New Zealand study of women with cervical cancer.<sup>32</sup>

## Library instruction

In PBH 205, the second-year seminar, students are required to write reflection papers related to weekly readings. They answer the following questions: *What was the main point of the reading? What information did you find surprising and why? After reading the chapters, do you see the world differently? How?*

*Why? How do you personally feel about what you read?* These questions give students a chance to reflect on SDOH and to explore personal growth.

Librarians can partner with faculty to reinforce this trajectory of learning and create integrated library instruction sessions focused on the Tuskegee Experiment and HeLa cells as types of information to encourage students to view SDOH and the information creation process critically. The learning outcomes include a change in student thinking about SDOH and information creation and the development of healthy skepticism toward public health information.

In a one-shot lesson, these outcomes might be difficult to assess, but the librarian could do so later in the semester, if given access to student reflection papers. Ideally, I will integrate multiple library instruction sessions rather than a one-shot lesson. Students are already reading and reflecting about Henrietta Lacks, so the suggestion to add additional lessons on the SDOH and Information Creation as a Process seems feasible, given my prior instruction in public health courses.

**Lesson one.** Students will create a visual map of the SDOH to show relationships between the healthcare environments at the time of each case and how the SDOH influenced the introduction of Henrietta Lacks and the Tuskegee men into a system where they were used to create information without their permission. Students will question how African-American bodies were used to benefit others, and explore SDOH including socioeconomic status, racial, and health equity. The HeLa and Tuskegee cases each provide a useful opportunity to raise questions about data collection, including from whom and for use by whom the data was collected. A visual map could show the lack of options to equitable and quality care. It could include a decision-making tree that visually represents how Henrietta Lacks's cells were cultured and later commoditized for use globally in laboratories. Harms experienced by the Tuskegee men as a result of non-therapeutic treatment or harms suffered by the Lacks family due to Henrietta's unknowing contribution to science could also be mapped. Regarding the information creation process, students could be guided to question the validity of the researcher's sampling methods in targeting people without full access to care.

**Lesson two.** Next, students can explore the ethics of each case and informed consent, as they struggle with how to articulate the unique constraints that led to the development and subsequent use of men in the Tuskegee Experiment and the collection of Henrietta's cells. The frame Information Creation as a Process and its knowledge practices could be used to encourage students to critically question study design, subject enrollment, and SDOH as factors that influenced the health outcomes of the Tuskegee Experiment subjects and the collection of Henrietta's cells.

Students could complete a pre-reading assignment about informed consent to learn about guidelines for the treatment of human subjects. One possi-

ble source would be the Belmont Report,<sup>33</sup> which establishes ethical treatment of human subjects as outlined in the National Research Service Award Act of 1974.<sup>34</sup> Students can explore ethics of current and emerging public health information creation processes and compare the cases of Henrietta Lacks or the Tuskegee Experiment with the aim of promoting students' development of a skeptical, critical approach to Information Creation as a Process.

**Lesson three.** Lastly, students can examine the role of health professionals more closely in the development of information. For the Tuskegee Experiment, students could watch the documentary *Deadly Deception* in order to practice developing informed skepticism and critical questioning about the frame Information Creation as a Process. Foundational questions might center on the role of the Public Health Service in designing the Tuskegee Experiment, the role of public health officials in Alabama in continuing the deception, and the role of government and institutions of higher education such as the Tuskegee Institute as creators of information. This line of questioning also aligns with the frame Authority is Constructed and Contextual, but in focusing on Information Creation as a Process, students can interrogate the very sources of public health information—in this case, black men and the data taken from them while tracking the progression of the disease. A similar lesson can be designed using the HeLa cells, highlighting the plunder of the body of a black woman as an information source that was used in scholarly outputs, cures, commerce, and other research.

## Conclusion

Information Creation as a Process in the Henrietta Lacks case and the Tuskegee Experiment link to how SDOH affect health outcomes. In each of these cases, poverty, lack of other healthcare options, socioeconomic status, race, health inequity, and health disparity all flowed together to produce bias in how information was created. Because of the nature of health information, students often do not even think about the information creation process, how the information came to be, and the importance of data to a population. Students might identify with the poverty of the subjects in each case or the struggle to find quality health care as a consumer. As such, there is a potential to connect the SDOH with their experiences and the stories of Henrietta Lacks and the men of the Tuskegee Experiment to move students to question information creation critically.

In Las Vegas, students live in a healthcare environment that is replete with health inequities and inequality, so much so that in 2016, UNLV and the University of Nevada, Reno hosted a conference to address health inequality,<sup>35</sup> and the UNLV student body has some characteristics outlined in the

SDOH. As of this writing, UNLV is the second most diverse campus in the United States, and many are first-generation college students who come from resource-limited backgrounds.<sup>36</sup>

When exposed to SDOH and Information Creation as a Process, students can begin to experience those characteristics of threshold concepts and start the journey to think differently about how the SDOH affect populations. They can be transformed through their exploration of stories about information creation and the use of populations with characteristics described by SDOH. Additionally, these are also communities that future students will serve in their careers. The lessons I proposed in this chapter are designed to encourage students to question critically, to interrogate how information is created with a skeptical lens, and to examine the use of humans as sources in the information creation process. I anticipate that students will experience the SDOH as a threshold concept and have their worldview transformed with regards to public health.

Henrietta Lacks's case is not merely about cancer cells. Her case represents an example of the intersection between SDOH and information creation. The use of human subjects in the Tuskegee Experiment, too, is not just about syphilis; it is about the confluence of SDOH in the production of information. Learning the language of SDOH and connecting this to Information Creation as a Process will be transformational for students once grasped. Students can begin to understand a foundational concept in public health and have the language with which to grapple with the types of information used in their careers. Equipping students with knowledge about SDOH will help them question research data collection, ethics of research, and the problematic nature of using vulnerable populations to advance public health. These cases occurred in the mid-twentieth century, but in the twenty-first century, pressing realities of unequal access to care still affect the poor and communities of color in the United States. These issues remain far-reaching and relevant to students at UNLV and across the nation.

## Notes

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