IDENTIFICATION OF APPROACHES TO IMPROVE PATIENT TRUST IN HEALTH SYSTEMS: A GROUP CONCEPT MAPPING STUDY

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ABSTRACT

Background & Objective: Higher levels of institutional trust have been associated with increased health care utilization, greater adherence to treatment plans, better treatment outcomes, and improved overall health. Though numerous studies have documented the influence of institutional trust on important outcomes, there has been little attention to understanding approaches to improve patient institutional trust. This project sought to identify approaches to improve patient trust in health systems.

Methods: The project used group concept mapping (GCM) to directly engage 18 insured individuals living within the Upper Darby community with at least one visit to a primary care provider within the last two years to elicit their perspectives on ways to improve patient trust. Participants first brainstormed in a group setting to develop a list of ideas about how systems could improve trust, then each participant sorted the idea into thematic domains and rated the statements based on both importance and feasibility.

Results: Four primary domains for improving institutional trust emerged: privacy, patient-provider relationship, respect for patients, and health system guidelines. Overall, participants rated the "privacy" domain as the most feasible and important. The average overall cluster rankings varied based on age, where the aggregate importance ratings for individuals below the age of 40 rated were higher for the "respect for patients" cluster.

Conclusion: We identify four domains that are important to our population for improving patient trust of health systems, with multiple actionable items within each domain. We suggest that efforts to improve trust of health systems will be most effective if designed to directly impact these domains. Next steps involve exploring the importance of these domains across other populations and developing interventions.

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CHAPTER 1

INTRODUCTION

Over 35 years ago, Penchansky and Thomas described the multiple dimensions of healthcare access as including availability, accessibility, accommodation, affordability, and acceptability (Penchansky & Thomas, 1981). Recent national efforts, such as insurance expansions through the Affordable Care Act (ACA) and Health Resources and Services Administration funding for Health Professional Shortage Areas, have sought to decrease barriers to healthcare access for underserved populations. These programs have primarily impacted access through the domains of accessibility and affordability, leaving the other health access domains unaddressed. Studies have clearly documented that an individual's decision regarding whether and when to seek needed healthcare services can be significantly impacted by that individual's trust in the healthcare system, with lack of trust leading to poorer healthcare outcomes (Musa, Schulz, Harris, Silverman, & Thomas, 2009; Whetten et al., 2006). Thus, understanding and addressing issues of health system trust and acceptability are vital to ensure that individuals use the healthcare system to which they have been given access.

To understand the concept of trust, it is important to additionally consider distrust or mistrust. Preliminary work in this field introduced trust and mistrust as two ends of the same spectrum, however later research asserts that they are different but related concepts (Saunders & Thornhill, 2004). In their establishment of an initial trust framework, Bigley and Pearce present trust as the willingness to become vulnerable, and mistrust as the opposite of trust (Bigley & Pearce, 1998). However, other literature has begun to tease out and redefine mistrust as a construct separate from a lack of trust. Lewicki,

McAllister, and Bies describe the ability of individuals to experience concurrent trust and mistrust within the same organizational setting (Lewicki, McAllister, & Bies, 1998). Researchers have developed the "trust-mistrust-absence triangle" - a diagram to describe this new trust/mistrust perspective - with mistrust on one axis, trust on the other, and the absence of both where the axes intersect (Saunders & Thornhill, 2004).

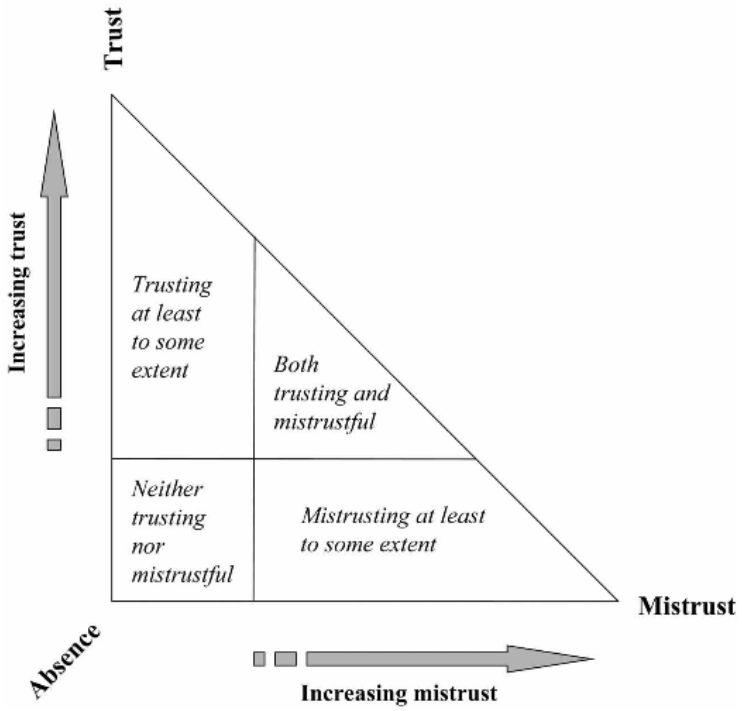


Figure 1. Trust-Mistrust-Absence Triangle

Source: Saunders, M., & Thornhill, A. (2004). Trust and mistrust in organizations: An exploration using an organizational justice framework. *European Journal of Work and Organizational Psychology*, *13*(4), 493-515.

Trust is a relational social construct existing between people or people and organizations (Gilson, 2003). Trust within healthcare exists at two distinct levels: interpersonal and institutional. Individuals may have differing trust for their doctor (interpersonal) and for the healthcare system or organization with which they identify (institutional) (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003). Interpersonal trust is

central to the development of a successful long-term relationship between an individual and his/her doctor (Hall et al., 2001). Higher levels of institutional trust have been associated with increased health care utilization, greater adherence to treatment plans, better treatment outcomes, and improved overall health (Mohseni & Lindstrom, 2007; Musa et al., 2009). Thus, there is great value in gaining a better understanding of the elements that build and impact institutional-level healthcare trust as a means of improving health outcomes of populations.

It has been suggested that health systems could implement a systematic use of robust institutional trust measures to promote the access to and quality of healthcare services (Hall et al., 2001; Ozawa & Sripad, 2013). While use of these measures would help bring focus to this important issue, evidence regarding what health systems can do to increase trust is needed for meaningful change to occur. Though numerous studies have documented the influence of institutional trust on important outcomes, there has been little attention to understanding approaches to improving institutional trust.

CHAPTER 2

REVIEW OF LITERATURE

Background

Dimensions of Trust

Initial studies investigating the role of trust on healthcare utilization sought to understand the relationship between the patient and doctor (Caterinicchio, 1979; Mechanic & Schlesinger, 1996; Tarrant, Stokes, & Baker, 2003; Thorne & Robinson, 1988). This research on interpersonal trust included development and validation of an instrument to measure patients' trust of their providers, named the Trust in Physicians Scale (TIPS) (L. A. Anderson & Dedrick, 1990; Thom, Ribisl, Stewart, & Luke, 1999). Later studies explored institutional trust, and at least 25 scales that have been developed to measure institutional trust, including the most commonly used and highly validated trust index called the Medical Mistrust Index (MMI) (Laveist, Isaac, & Williams, 2009; Ozawa & Sripad, 2013). Interpersonal and institutional trust have been found to be distinct and non-coupled entities; patients can report a high amount of trust in their personal doctor but a low trust in a health system or health plan (Boulware et al., 2003; Calnan & Sanford, 2004; Hammond et al., 2010). When comparing the MMI to TIPS, theses instruments have been found to measure distinct features of trust (Laveist et al., 2009).

With the recent shift towards developing health system accountability for defined populations with policy changes such as establishment of Accountable Care Organizations, institutional trust has become increasingly important as systems are

increasingly motivated to keep patients within their own system (Laveist et al., 2009). In spite of the increasing importance of institutional trust, a recent systematic review revealed that the assessment of institutional trust is under-represented in studies measuring trust, indicating the need for more studies to understand factors influencing institutional trust (Ozawa & Sripad, 2013). When studying institutional trust, it is important to first understand the impact of patient factors to understand how fixed characteristics influence a patient's ability to trust health care organizations.

Individual Characteristics Affecting Trust

Healthcare systems only represent one part of the relationship for institutional trust. Some patient characteristics have been found to be predictors of trust. Age has consistently been found to be positively correlated with trust (Hall et al., 2001; LaVeist, Nickerson, & Bowie, 2000; Thom et al., 1999). Past research has also found income and education to be potentially related factors, with a positive correlation between increasing income and education and increased institutional trust (LaVeist et al., 2009). Prior studies have also found race to be a statistically significant predictor of trust, with African Americans reporting the lowest level of institutional trust (Armstrong et al., 2013; Hall et al., 2001).

The impact of race on institutional trust is particularly important because studies have started to demonstrate that the differences observed in healthcare utilization by race often arise from institutional racial bias (LaVeist et al., 2000). Studies investigating the mechanism connecting medical mistrust with disparities in health outcomes by race reveal that the difference in institutional trust may be explained by perceptions of racism

(Adegbembo, Tomar, & Logan, 2006). An early study by LaVeist, Nickerson, and Bowie revealed that black cardiac patients were more likely than white patients to report institutional mistrust (LaVeist et al., 2000). Mistrust indices have revealed higher levels of medical mistrust for both interpersonal and institutional domains by minority populations (Laveist et al., 2009). Additionally, in 2009, Musa et al found that white patients have greater interpersonal medical trust whereas black patients have higher trust in informal health information from sources such as family or friends (Musa et al., 2009). In fact, some studies have suggested that adjusting for experiences of perceived racism at an institutional level completely accounts for differential patterns of patient mistrust between white and black patients, indicating the need for efforts to understand the relationship between institutional racism and institution trust (Armstrong et al., 2013; Boulware et al., 2003). Moreover, there is a meaningful opportunity to decrease health disparities by developing programs to increase institutional trust in minority groups.

Community Level Factors Affecting Trust

In addition to individual level characteristics, it is also important to consider community level factors that impact institutional trust. Minority communities are known to be unequally subjected to greater health and environmental risks from a concentrated exposure to environmental pollutants and unequal access to healthcare systems (Bullard, 1993). Examples of community level factors affecting trust include social capital and community engagement. Previous studies have found that both personal experience and community factors impact trust (Adegbembo et al., 2006). However, in their recent study of racism and institutional mistrust, Armstrong et al found that healthcare access and

residential segregation only had a minimal effect on the relationship between race and institutional mistrust (Armstrong et al., 2013).

Understanding how to define community is central to discussing the impact of community-level factors on institutional trust. Green and Mercer argue that for community-based research, the community should be defined as the population that will be affected by the research results (Green & Mercer, 2001). As such, the ACA will help define the community for this research project. The ACA requires nonprofit hospitals to survey the needs of their communities and to make the results publicly available in a report known as a Community Health Needs Assessment (CHNA). This report better connects healthcare systems to the needs of the communities that they serve, and therefore implicitly has the ability to affect institutional trust. The first round of surveys and reports occurred in 2013. The community defined in the applicable CHNA report for this project's study area will be used as the unit of community for this project.

Identified Gaps in the Literature

The existing body of literature explaining patients' trust in institutions provides a solid foundation for future work aimed at identifying ways to impact trust for various populations. A recent community-based study encourages future research to enroll patients with regular healthcare utilization and urges researchers to look into ways that healthcare organizations can increase medical trust (Laveist et al., 2009). Another recent study specifically calls for qualitative research to understand health system trust (Ozawa & Sripad, 2013). The proposed study will fill this gap in the literature by using a mixed methods participatory approach known as Group Concept Mapping to determine ways to

impact institutional trust, within a defined patient population with regular healthcare utilization practices.

Group Concept Mapping

Group concept mapping (GCM), a unique mixed methods participatory approach, has been used to perform group brainstorming for over twenty-five years (Trochim, 1989). The quality, validity, and reliability of GCM have since been systematically studied (Rosas & Kane, 2012). The modern application of GCM includes a multi-step approach, where participants generate, sort and rate a list of idea statements in response to a question stem presented at an initial group brainstorming session. These sessions can be performed directly with face-to-face interactions, indirectly with web-based platforms, or through a combination of the two. Idea statements that are generated in an initial brainstorming session are sorted and rated by participants in the second session. The sorting and rating data are then entered into computer software that generates similarity matrices and performs multidimensional scaling and hierarchical cluster analysis to create a final interactive visual display known as a cluster map (Kane & Trochim, 2007). Rating data can be combined with cluster maps to create pattern-matching displays, which compare average cluster ratings between demographic groups. In the final session, the participants evaluate, interpret and define the domains of the cluster map.

Historically, GCM methodology has been applied most frequently for program planning and evaluation. In terms of health, public health, and healthcare outcomes, GCM has been used for applications including: development of a logic model for prevention research (Anderson et al., 2006), promotion of mobility in an older adult

framework (Anderson & Egge, 2014), establishment of a pediatric palliative care provider-based model (Donnelly, Donnelly, & Grohman, 2005), and development of a geriatric acute care model (Boltz, Capezuti, & Shabbat, 2010). GCM has also been used to directly identify patient perspectives for health and healthcare issues, including the detection of barriers to mammography for a minority population (Ahmad et al., 2012) and the identification of multiple stakeholders' perspectives for older adults with vision impairment (Larizza et al., 2014). This project used GCM to directly identify patient-centered approaches that have the potential to influence patients' trust in a health system.

Project Details

Specific Aims

Our overall objective of this work is to identify approaches to improve institutional trust among a patient population. We accomplished this goal with the following specific aims:

1) To engage patients through GCM to elicit patient perspectives on ways to impact institutional trust
2) To perform an exploratory analysis to determine differences in rating information obtained within the concept mapping process by demographic groups.

Significance

Studying the factors influencing institutional trust in a sample of patients has twofold importance. First, engaging patients directly to identify approaches to improve institutional trust will better inform suggestions for how healthcare systems can improve trust. Second, this project's novel approach will directly engage a patient population that is already linked into a health system representing a population that is well-poised to provide insight into health system actions that impact institutional trust. Overall, this work may help to decrease local health disparities by identifying actions that can be developed by health systems to increase institutional trust and improve utilization of healthcare services.

CHAPTER 3

METHODS

Overview

The Community Health Needs Assessment that was published by the Mercy Fitzgerald Hospital system uncovered the need for impacting "trust in the system" within their community (Mercy Fitzgerald Hospital, 2013). Thus, we focused on a community served by this hospital system for our study population. A family medicine practice location was selected as the location for participant recruitment from the ZIP codes included in this needs assessment, with the goal of enrolling patients served by this practice to assess their trust in the system and their thoughts on improving trust. The selected clinic is approximately representative of the racial makeup of Upper Darby, PA, currently serving 63% white, 28% black, 7% Asian, and 2% Hispanic. In terms of insurance status, approximately 40% of the encounters are covered through Medicaid, 41% through commercial insurance, and 14% through Medicare.

The project used GCM to directly engage patients to identify patient-prioritized themes regarding how to improve institutional trust. Participant eligibility (outlined in Table 1) was restricted to insured individuals in an effort to reduce the impact that lack of health insurance had on reports of institutional trust, as the goal of this work was to identify modifiable system factors that may impact institutional trust. A survey was used to collect the following demographic information: age, gender, race, ethnicity, length of insurance coverage, education level, household income, and prior healthcare utilization. In addition to the demographic information, the questionnaire also collected information

about baseline factors that influence healthcare utilization, including the diagnosis of chronic diseases and accessibility or financial issues including transportation, copay requirements, and childcare concerns. Finally, the survey included the validated Medical Mistrust Index (MMI) to document the participant's level of institutional mistrust. The MMI is a 17-item scale in which participants use a 1-5 Likert-scale to indicate how much they agree (5) or disagree (1) with a statement related to medical system mistrust. Items 5 and 7-11 reflect positive health system trust statements, so they were reverse coded during analysis so that all questions coded for greater mistrust. MMI scores could therefore potentially range from 17 to 85.

Enrollment and Recruitment

A convenience sample of 18 patients was recruited and enrolled. To be considered eligible for participation, patients must have met the designated inclusion/exclusion criteria of the study, as detailed in Table 1.

Table 1: Inclusion/Exclusion Criteria

Inclusion Criteria	**Exclusion Criteria**
Adult (≥ 21 years old) Active membership in an insurance plan Visited primary care provider within the last two years Lives within Delaware County	Non-English speaking Unable to provide informed consent, including: -Prisoners -Participants with communication impairments -Other mental or physical conditions limiting cognitive function

A recruitment poster (including a brief description of inclusion/exclusion criteria, research team contact information, and a concise explanation of the research goals) was posted in the waiting room of the primary care office as well as at the entrance of a nearby community outreach center, allowing participants to self-select into the study.

Potential participants were also provided with the research team's contact information by leadership of the community outreach program. All participants were screened for eligibility by a member of the research team either in person or over the phone prior to obtaining informed consent.

Recruitment and consent were conducted under the same policies and procedures for all patients enrolled. This project was approved by Temple University and Jefferson University Institutional Review Boards (please see attached IRB approval and consent form). Informed consent was obtained in person at the first concept mapping session, before the onset of any research activities. A trained researcher informed each patient of the study's purpose, procedures, risks, and alternatives to participation, including the alternative to not participate. Potential participants were given time to read the consent form and ask questions before making their decision. Interested patients provided verbal informed consent with an IRB-approved Informed Consent with HIPAA Authorization Form. Participants were given a copy of the informed consent form. Participants who were unable or preferred to not provide informed consent were not enrolled in this study. Eighteen participants were consented and participated in study activities.

Concept Mapping Methodology

Patients were compensated with $25 per session, for a total of $75 for those who completed all three GCM sessions. The first and second sessions were conducted on the same day, with the first session lasting 90 minutes and the second session lasting 60 minutes. The third session lasted about 45 minutes and was completed on the following day. The overall GCM schedule followed a modified condensed schedule plan, with all

GCM activities occurring over the course of one weekend (Kane & Trochim, 2007). The steps of the GCM process took place over three sessions: 1) brainstorming, 2) sorting/rating, and 3) interpretation. The concept mapping process was completed as follows:

Brainstorming (Session 1)

For the first session, participants were engaged in a group setting for a structured brainstorming session. Participants were asked to generate responses to the following prompt: "Things that a health system can do to affect trust include…" The first five to ten minutes of brainstorming was written, to allow every participant time to generate individual responses. The session then opened into a group discussion in which participants voiced their ideas. Each idea statement that was generated was documented using Microsoft excel, with the spreadsheet projected onto a screen in front of the room that all participants could see. There was a lunch break at the end of session 1, during which the research team members generated a complete set of sort cards for each participant. Each sort card contained one of the idea statements from the initial brainstorming session, and thus each participant was provided with a stack of cards that contained all of the brainstormed ideas.

Sorting and Similarity Matrix Generation (Session 2)

The second session was performed in-person after the lunch break. For this session, patients were asked to sort all of the sort cards into distinct piles "in whatever way made sense to them." They were also asked to name each pile. There were three

rules for sorting: 1) there must be at least two piles, 2) you must have at least two cards per pile, 3) each card can only be put in one pile (Kane & Trochim, 2007). After patients completed the sorting session, members of the research team manually entered the idea statements into the CS Global MAX software (Concept Systems, Inc), along with the sort data from each participant. The software uses the sorting data of each participant to create binary square similarity matrix (see example in Figure 2), where a "0" represents that the two statements were not sorted together and a "1" represents that the two statements were sorted together. The individual matrices for each participant are aggregated to make a total similarity matrix, and aggregate sort data are used to create a series of visual displays.

Idea Statement Number

Idea Statement Number	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1	1	1	0	0	0	1	0	0	1	1	1	0	1	0	0
2	1	1	1	0	0	0	1	0	0	1	0	1	0	0	0
3	0	1	1	0	0	0	0	1	1	0	1	1	0	0	1
4	0	0	0	1	1	0	1	1	0	0	0	0	1	1	1
5	0	0	0	1	1	0	0	1	1	0	1	0	0	0	1
6	1	0	0	0	0	1	0	1	1	0	0	0	1	1	1
7	0	1	0	1	0	0	1	0	0	1	1	0	0	1	1
8	0	0	1	1	1	1	0	1	0	0	1	1	0	0	1
9	1	0	1	0	1	1	0	0	1	0	0	0	1	1	0
10	1	1	0	0	0	0	1	0	0	1	1	1	1	0	0
11	1	0	1	0	1	0	1	1	0	1	1	0	0	1	1
12	0	1	1	0	0	0	0	1	0	1	0	1	0	0	0
13	1	0	0	1	0	1	0	0	1	1	0	0	1	0	0
14	0	0	0	1	0	1	1	0	1	0	1	0	0	1	1
15	0	0	1	1	1	1	1	1	0	0	1	0	0	1	1

Figure 2. Example of a binary symmetric similarity matrix for 15 idea statements
Source: Kane, M., & Trochim, W. M. K. (2007). *Concept Mapping for Planning and Evaluation*. (L. Bickman & D. J. Rog, Eds.).

The first display that is generated by the software, known as a point map, is an X-Y coordinate matrix that visually displays the amount of overall similarity in the total matrix as distances between each point, where each point represents an individual idea statement. Point maps are made by the software using multidimensional scaling (MDS). Through the MDS technique, the software determines the amount of similarity between each pair of points and then graphs all of the points in a bivariate distribution. A stress index is used as the main diagnostic statistic to assess the degree to which the point map represents the sort data. Lower stress values generally indicate a better statistical fit, with a reference value of 0.285 (Kane & Trochim, 2007). The range of stress values for 95% of cases is from 0.205 to 0.365 (Kane & Trochim, 2007). Higher stress values imply that the similarity matrix (electronically produced by the software after inputting the sort data) is too complex to visually characterize with a two-dimensional point plot.

Rating and Pattern Matching (Session 2)

After sorting, patients rated all of the ideas on two scales (importance and feasibility). In this step, participants assigned a numerical value to each statement based on a 1-5 Likert-type response scale. First, the participants were asked to rate each statement based on how important they thought the statement was to impact institutional trust, with 1 = "not at all important" and 5 = "highly important." Second, the participants were asked to rate each statement based on how easy it would be for a health system to do the idea, with 1 = "not at all feasible" and 5 = "highly feasible." Paper rating information was entered into the Concept Mapping system by the research team. The information gathered by the rating step was used to determine the highest and lowest

rated clusters, to produce the rating-based pattern match displays for subgroup analysis, and to create the "go-zone" display to determine where to focus future trust-building initiatives.

The statement averages of participant subgroups were used for each cluster to create pairwise comparisons using a ladder graph, known as pattern matching displays. Pattern matching displays can be used to detect differences in the average cluster ratings between two distinct groups, two different rating criteria, or two time periods. This project used the pattern matching displays for exploratory analysis of sub-groups of the participant sample by age, gender, and race. Gender (male versus female) and race (white versus minority race) were specified in the analysis as binary variables. Age was additionally specified as a binary variable based on a median split. The Pearson product-moment correlation (r) is the main diagnostic criteria used to assess the strength of the correlation of the average cluster ratings across the two variables, with values closer to zero indicating no correlation on a scale of -1 to 1.

Clustering and Interpretation (Session 3)

The final number of clusters was determined by the research team members, based on an operational planning perspective (Kane & Trochim, 2007). Starting at the upper limit of clusters, the analyst reviewed the structure of merged statements, moving through the cluster levels until the lower bound was reached. From among those options, the analyst determined the final number of clusters based on the amount of detail needed for this research context. The final map was circulated to the patient group during the final GCM session for their evaluation and interpretation. During the final session,

participants were able to suggest moving idea statements that were on the periphery of the clusters into adjacent clusters and they were asked to determine the final cluster names.

CHAPTER 4

RESULTS

Participant Demographics

The demographic characteristics of the enrolled study sample (N=18) are presented in Table 2. Participants ranged in age from 21 to 62, with a mean age of 41 (±13.6) years. One third of participants were black, 44% were white, 11% were Asian, and 11% identified with another race. Two thirds of participants were female. Regarding education, 6% had less than a high school education, 61% had at least a high school education, and 33% had a college or postgraduate degree. The majority of participants (56) work full-time. The sample reported a range of income, with 72% having an annual household income of $25,000 - $100,000. Equal amounts (39%) of participants visited an office or clinic either once /twice or five or more times in the past year. The majority (67%) of participants reported at least one chronic disease, with the same number also reporting no difficulties with access to healthcare. The MMI scores of the participants ranged from 45 to 54, with a median score of 49.4 (± 3.1).

Table 2. Demographic Characteristics of the Sample

Variable	n	%
Age (years)		
21-30	4	22.2
31-40	6	33.3
41-50	1	5.6
51-60	6	33.3
61-62	1	5.6
Sex		
Male	6	33.3
Race		
White	8	44.4
Black	6	33.3
Asian	2	11.1

Other	2	11.1
Education		
Less than High School Degree	1	5.6
High School/GED/Some College	11	61.1
College Degree	4	22.2
Post Graduate Degree	2	11.1
Employment Status		
Working, Full-Time	10	55.6
Working, Part-Time	5	16.9
Self-Employed	1	5.6
Disabled or Retired	2	11.1
Income		
>$10,000	2	11.1
$10,000 - $24,999	1	5.6
$25,000 - $49,999	6	33.3
$50,000 - $99,999	7	38.9
$100,000 +	1	5.6
Decline to Answer	1	5.6
Office Visit Frequency		
Once or Twice	7	38.9
Three to Five Times	4	22.2
Five or More Times	7	38.9
Chronic Disease Status		
None	12	66.7
Degree of Access Issues		
None	12	66.7
One	2	11.1
Two	1	5.6
Three	3	16.6
Medical Mistrust Index Score		
45-46	4	23.5
47-48	3	17.6
49-50	2	11.8
51-52	5	29.4
53-54	3	17.6

Brainstorming Data: Idea Statements

At the end of the brainstorming (session 1), the research team refined the idea statements that had been produced to clarify the list and eliminate redundant statements. The final list included 67 idea statements (Table 3).

Table 3. Final Idea Statement List

Item #	Idea Statement
1	Be gentle with the elderly
2	Listen to family when they have concerns
3	Legalize assisted suicide
4	Simplify paperwork
5	Help patients be their own advocates
6	Offer accessibility to health system regardless of insurance
7	Clearly communicate policies with patients
8	Create guidelines for each personnel role within the health system
9	Create clear guidelines for how health systems should function
10	Make sure you see the provider you made the appointment with
11	Respond to criticism better
12	Be more careful when treating the elderly
13	Have the doctors more accessible in ER's
14	Scan medications before giving them out to prevent errors
15	Make sure nurses know what medications they are giving to patients
16	Have doctors take classes on compassion
17	Require continuing education on social skills
18	Have doctors provide options for what to do next when they don't have answers
19	Have doctors communicate better when they don't know what's going on
20	Have doctors show empathy and compassion when giving bad news
21	Help navigate the system in general
22	Help navigate the system to see specialists
23	Provide accessible interpreters
24	Prioritize patient care before insurance status
25	Post clear rules for patient visitors
26	Do not talk about colleagues in front of patients
27	Do not talk about other patients outside patients rooms
28	Have doctors communicate their expertise
29	Do not advertise medicine
30	Use actual patients when marketing for health systems
31	Have multiple sites of care for big health systems
32	Treat patients fairly
33	Treat patients as individuals
34	Treat mental pain appropriately
35	Treat mental pain differently than physical pain
36	Recognize patients by face (knowing who you actually are)
37	Call patients by name
38	Bring insurance cards or other information back to patient room as soon as possible
39	Close the curtain for patient rooms
40	Do patient registration in a private room instead of at the front desk
41	Increase privacy in the emergency room
42	Encourage patients to seek other opinions
43	Offer a choice for what pharmacy you go to

44	Pay more attention to cost when prescribing medicines (consider generics)
45	Educate doctors more about pharmacology (how medicines work)
46	Have better communication between providers in the health system
47	Offer alternative treatments for medication
48	Have better partnership between doctors and pharmacists
49	Describe medication side effects
50	Talk to patients appropriately (respectfully, regardless of age)
51	Have doctors go to more classes for bedside/chair side manner
52	Show vulnerability with patients
53	Require training in cultural competency
54	Show care for patients
55	Show humanity to patients
56	Increase interactions with parents when treating children
57	Have a good environment
58	Make sure doctors explain tests, procedures, and written instructions
59	Offer flexibility in choosing a provider
60	Be more personal with patients
61	Be more thorough with patients
62	Spend more time with patients
63	Listen to patients
64	Treat patients like people, not just a statistic
65	Not treat people like they are drug seekers
66	Offer non-judgmental testing
67	Protect personal information better

Sort Data

Multidimensional Scaling

Multidimensional scaling was used to create the two-dimensional visual display of the similarity matrix for each numbered idea statement. The resulting point map is presented in Figure 3. The distance between the numbered points on the map represent the aggregate sort data, where points with a smaller distance between them represent idea statements that were commonly sorted together. For example, many more people sorted the idea statements "43. Offer a choice for what pharmacy you go to" (*) and "44. Pay more attention to cost when prescribing medicines (consider generics)" (**) together in the same cluster as opposed to the idea statements "43. Offer a choice for what pharmacy you go to" (*) and "50. Talk to patients appropriately (respectfully, regardless of age)," (***) which were rarely sorted together. This point map produced a stress value of

0.2580. This is lower (more desirable) than the reference value of 0.285, suggesting that the map has a good overall fit between the input and the distances between the data points shown on this point map.

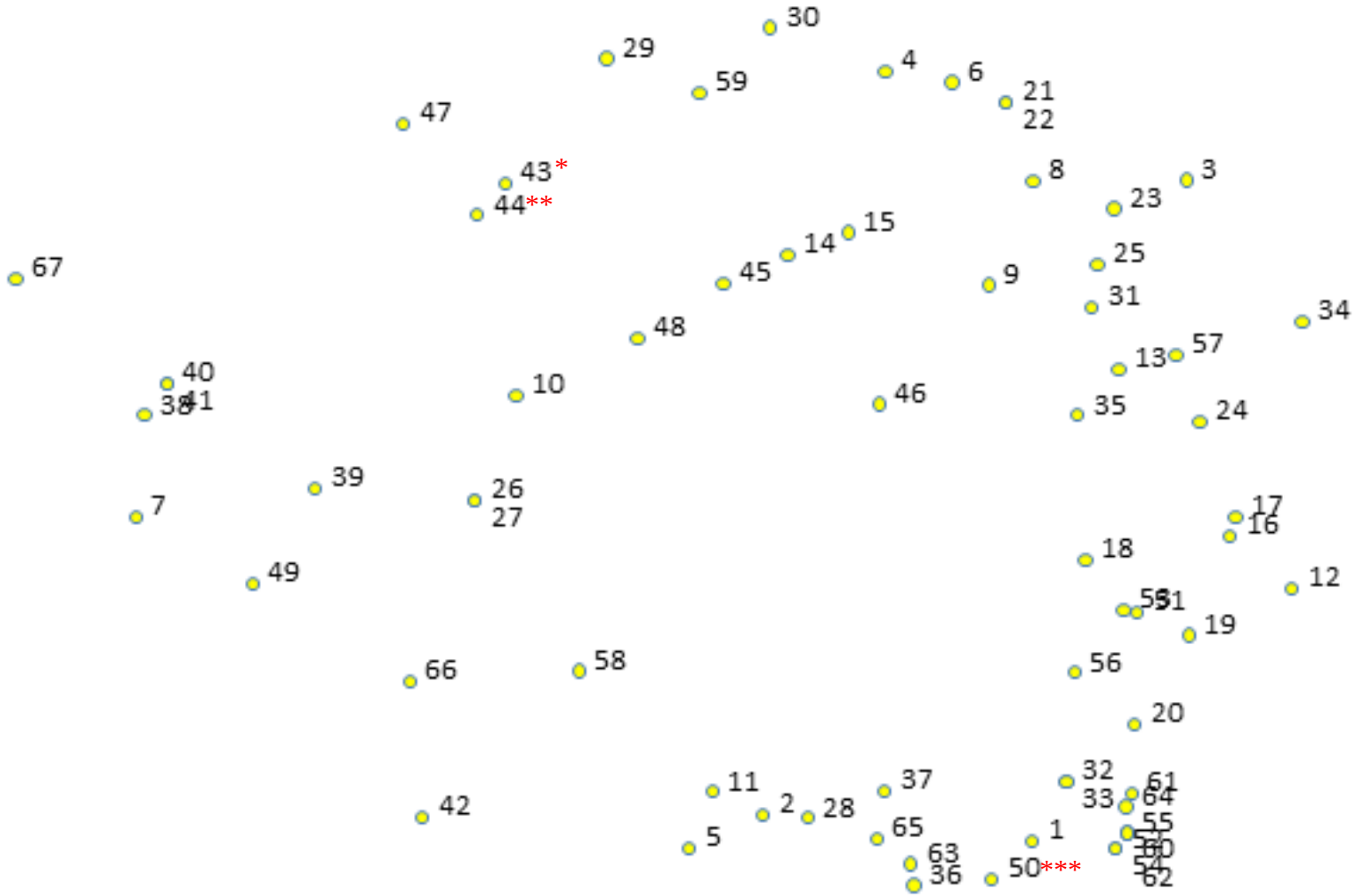


Figure 3. Point Map

Interpretation Data

Hierarchical Cluster Analysis

Hierarchical analysis methods were used to build the concept map and identify the major domains that adequately represent all of the ideas that were generated. The analyst used a divisive operational planning perspective to determine the final 4-cluster solution, where each cluster solution between 2-10 clusters was examined. The initial cluster map was produced before session 3 (interpretation session), and was then revised to reflect the input from the participants during the interpretation session. These revisions included both moving peripheral idea statements that the group agreed did not belong into adjacent clusters and generating cluster titles. The final 4-cluster solution featured 4 overall groupings of the idea statements, presented in Table 2, including the following four clusters (in size order from smallest to largest cluster): Patient Privacy, Patient-Provider Relationship, Respect for Patients, and Health System Guidelines. These 4 clusters ranged in size from 7 to 31 statements. This process yielded the final cluster map shown in Figure 4.

Table 4. Clustered Idea Statement List

Cluster Name	Item #	Idea Statement
Privacy		
	26.	Do not talk about colleagues in front of patients
	27.	Do not talk about other patients outside patients rooms
	38.	Bring insurance cards or other information back to patient room as soon as possible
	39.	Close the curtain for patient rooms
	40.	Do patient registration in a private room instead of at the front desk
	41.	Increase privacy in the emergency room
	67.	Protect personal information better
Patient-Provider Relationship		
	2.	Listen to family when they have concerns
	5.	Help patients be their own advocates
	7.	Clearly communicate policies with patients
	11.	Respond to criticism better
	28.	Have doctors communicate their expertise

	36.	Recognize patients by face (knowing who you actually are)
	37.	Call patients by name
	42.	Encourage patients to seek other opinions
	49.	Describe medication side effects
	58.	Make sure doctors explain tests, procedures, and written instructions
	63.	Listen to patients
	65.	Not treat people like they are drug seekers
	66.	Offer non-judgmental testing
Respect for Patients		
	1.	Be gentle with the elderly
	12.	Be more careful when treating the elderly
	19.	Have doctors communicate better when they don't know what's going on
	20.	Have doctors show empathy and compassion when giving bad news
	32.	Treat patients fairly
	33.	Treat patients as individuals
	50.	Talk to patients appropriately
	51.	Have doctors go to more classes for bedside/chair side manner
	52.	Show vulnerability with patients
	53.	Require training in cultural competency
	54.	Show care for patients
	55.	Show humanity to patients
	56.	Increase interactions with parents when treating children
	60.	Be more personal with patients
	61.	Be more thorough with patients
	62.	Spend more time with patients
	64.	Treat patients like people, not a statistic
Health Systems Guidelines		
	3.	Legalize assisted suicide
	4.	Simplify paperwork
	6.	Offer accessibility to health system regardless of insurance
	8.	Create guidelines for each personnel role within the health system
	9.	Create clear guidelines for how health systems should function
	10.	Make sure you see the provider you made the appointment with
	13.	Have the doctors more accessible in ER's
	14.	Scan medications before giving them out to prevent errors
	15.	Make sure nurses know what medications they are giving to patients
	16.	Have doctors take classes on compassion

17.	Require continuing education on social skills
18.	Have doctors provide options for what to do next when they don't have answers
21.	Help navigate the system in general
22.	Help navigate the system to see specialists
23.	Provide accessible interpreters
24.	Prioritize patient care before insurance status
25.	Post clear rules for patient visitors
29.	Do not advertise medicine
30.	Use actual patients when marketing for health systems
31.	Have multiple sites of care for big health systems
34.	Treat mental pain appropriately
35.	Treat mental pain differently than physical pain
43.	Offer a choice for what pharmacy you go to
44.	Pay more attention to cost when prescribing medicines (consider generics)
45.	Educate doctors more about pharmacology (how medicines work)
46.	Have better communication between providers in the health system
47.	Offer alternative treatments to medication
48.	Have better partnership between doctors and pharmacists
57.	Have a good environment
59.	Offer flexibility in choosing a provider

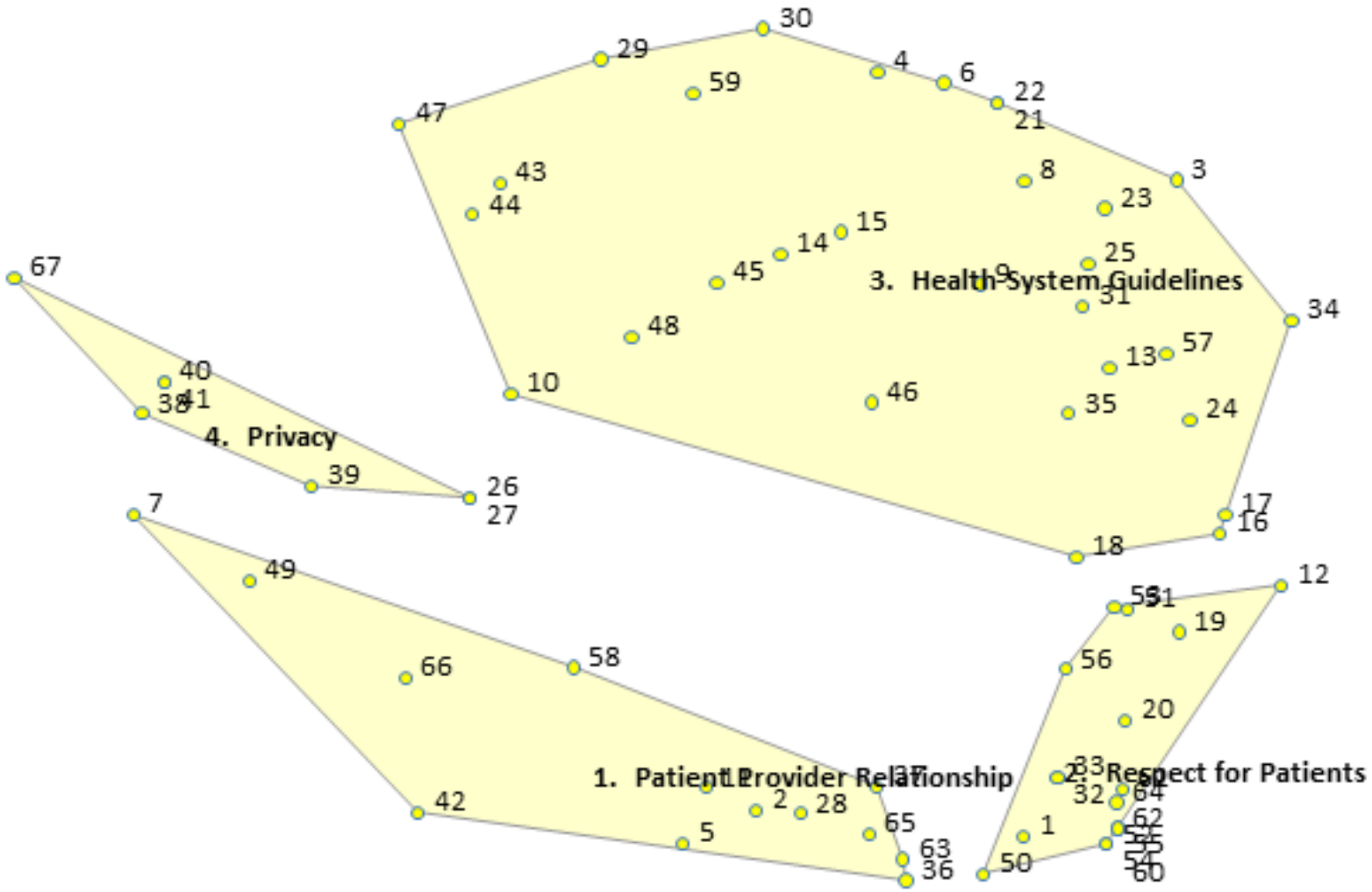


Figure 4. Final Cluster Map

Rate Data

Importance Rating Results

The aggregate average importance ratings (and standard deviation) of each idea statement for the group are presented in Table 5. The average ratings ranged from 3.15 to 5.00, with 5 indicating that an idea statement is highly important. The aggregate rating information was used to create a rating cluster map, featured in Figure 5. The map gives a visual display of the aggregate importance rating data from Table 5, with a higher number of layers indicating a higher average rating. As shown in the figure, the "Privacy" and "Respect for Patients" clusters were rated the most important, with average ratings of 4.55 (±0.32) and 4.48 (±0.46), respectively. Within the "Privacy" cluster, Idea # 27 "Do not talk about other patients outside patients rooms" was rated the highest. Idea # 32 "Treat patients fairly" was rated highest among the "Respect for patients" cluster. "Health Systems Guidelines" was the lowest rated cluster, with an average rating of 4.19 (±0.40). Within this cluster, Item # 3 "Legalize assisted suicide" was the lowest rated idea statement.

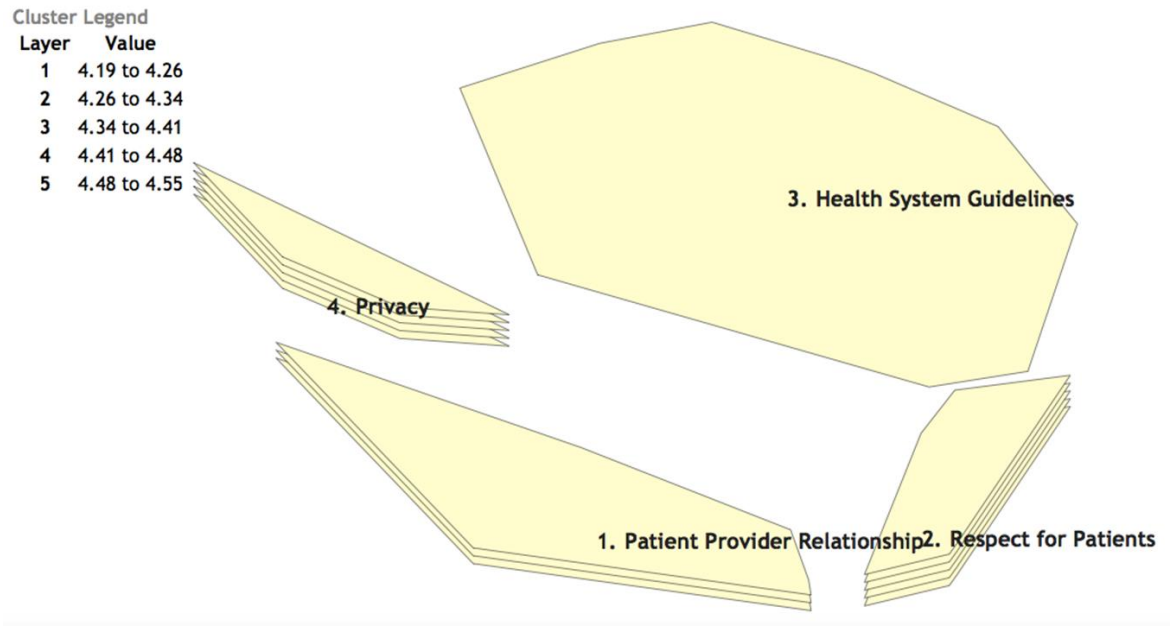


Figure 5. Importance Rating Cluster Map

Table 5. Idea Statement List with Average Importance Ratings

Cluster Name	Item #	Idea Statement	Average Importance Rating	Standard Deviation
Privacy			**4.55**	**0.32**
	26.	Do not talk about colleagues in front of patients	4.54	1.13
	27.	Do not talk about other patients outside patients rooms	4.92	0.28
	38.	Bring insurance cards or other information back to patient room as soon as possible	4.15	0.90
	39.	Close the curtain for patient rooms	4.62	0.65
	40.	Do patient registration in a private room instead of at the front desk	4.08	1.19
	41.	Increase privacy in the emergency room	4.77	0.44
	67.	Protect personal information better	4.77	0.83
Patient-Provider Relationship			**4.34**	**0.51**
	2.	Listen to family when they have concerns	4.85	0.38
	5.	Help patients be their own advocates	4.31	0.75
	7.	Clearly communicate policies with patients	4.54	0.66
	11.	Respond to criticism better	4.08	0.86
	28.	Have doctors communicate their expertise	3.46	1.51
	36.	Recognize patients by face (knowing who you actually are)	3.69	0.85
	37.	Call patients by name	4.69	0.48

42.	Encourage patients to seek other opinions	3.46	1.27
49.	Describe medication side effects	4.69	0.63
58.	Make sure doctors explain tests, procedures, and written instructions	4.62	0.65
63.	Listen to patients	4.92	0.28
65.	Not treat people like they are drug seekers	4.38	0.77
66.	Offer non-judgmental testing	4.69	0.63
Respect for Patients		**4.48**	**0.46**
1.	Be gentle with the elderly	4.46	1.13
12.	Be more careful when treating the elderly	4.54	0.88
19.	Have doctors communicate better when they don't know what's going on	4.38	0.38
20.	Have doctors show empathy and compassion when giving bad news	4.69	0.63
32.	Treat patients fairly	5.00	0.63
33.	Treat patients as individuals	4.77	0.44
50.	Talk to patients appropriately	4.77	0.44
51.	Have doctors go to more classes for bedside/chair side manner	4.23	0.93
52.	Show vulnerability with patients	3.15	1.28
53.	Require training in cultural competency	3.69	1.03
54.	Show care for patients	4.92	0.28
55.	Show humanity to patients	4.85	0.38
56.	Increase interactions with parents when treating children	4.46	0.78
60.	Be more personal with patients	4.46	0.66
61.	Be more thorough with patients	4.77	0.60
62.	Spend more time with patients	4.31	1.18
64.	Treat patients like people, not a statistic	4.69	0.63
Health Systems Guidelines		**4.19**	**0.40**
3.	Legalize assisted suicide	3.15	1.52
4.	Simplify paperwork	4.15	1.34
6.	Offer accessibility to health system regardless of insurance	4.46	0.76
8.	Create guidelines for each personnel role within the health system	4.15	1.28
9.	Create clear guidelines for how health systems should function	4.38	0.87
10.	Make sure you see the provider you made the appointment with	4.15	0.99
13.	Have the doctors more accessible in ER's	4.54	0.52
14.	Scan medications before giving them out to prevent errors	4.77	0.44
15.	Make sure nurses know what medications they are giving to patients	4.62	0.77
16.	Have doctors take classes on compassion	4.23	0.73

17.	Require continuing education on social skills	4.31	0.85
18.	Have doctors provide options for what to do next when they don't have answers	4.69	0.75
21.	Help navigate the system in general	3.92	1.19
22.	Help navigate the system to see specialists	4.08	0.76
23.	Provide accessible interpreters	4.00	1.22
24.	Prioritize patient care before insurance status	4.38	1.12
25.	Post clear rules for patient visitors	4.23	0.60
29.	Do not advertise medicine	3.46	1.45
30.	Use actual patients when marketing for health systems	3.46	1.33
31.	Have multiple sites of care for big health systems	4.15	0.80
34.	Treat mental pain appropriately	4.62	0.51
35.	Treat mental pain differently than physical pain	4.08	1.12
43.	Offer a choice for what pharmacy you go to	3.54	1.61
44.	Pay more attention to cost when prescribing medicines (consider generics)	4.08	1.19
45.	Educate doctors more about pharmacology (how medicines work)	4.38	0.65
46.	Have better communication between providers in the health system	4.46	0.88
47.	Offer alternative treatments to medication	3.69	1.18
48.	Have better partnership between doctors and pharmacists	4.38	1.19
57.	Have a good environment	4.69	0.48
59.	Offer flexibility in choosing a provider	4.54	0.78

Feasibility Rating Results

The aggregate average feasibility ratings (and standard deviation) for each idea statement are presented in Table 6, with the rating cluster map shown in Figure 6. The average rating for the idea statements range from 2.77 to 5.00, with 5 indicating that an idea was rated as highly feasible. The "Privacy" cluster was again the highest rated cluster for feasibility, with an average rating of 4.69 (±0.24). Within this cluster, Idea # 32 "Treat patients fairly" was the highest rated idea in terms of feasibility. "Health

System Guidelines" was again the lowest rated cluster, with an average rating of 3.86 (±0.41), and Item # 3 "Legalize assisted suicide" was again the lowest rated idea within this cluster.

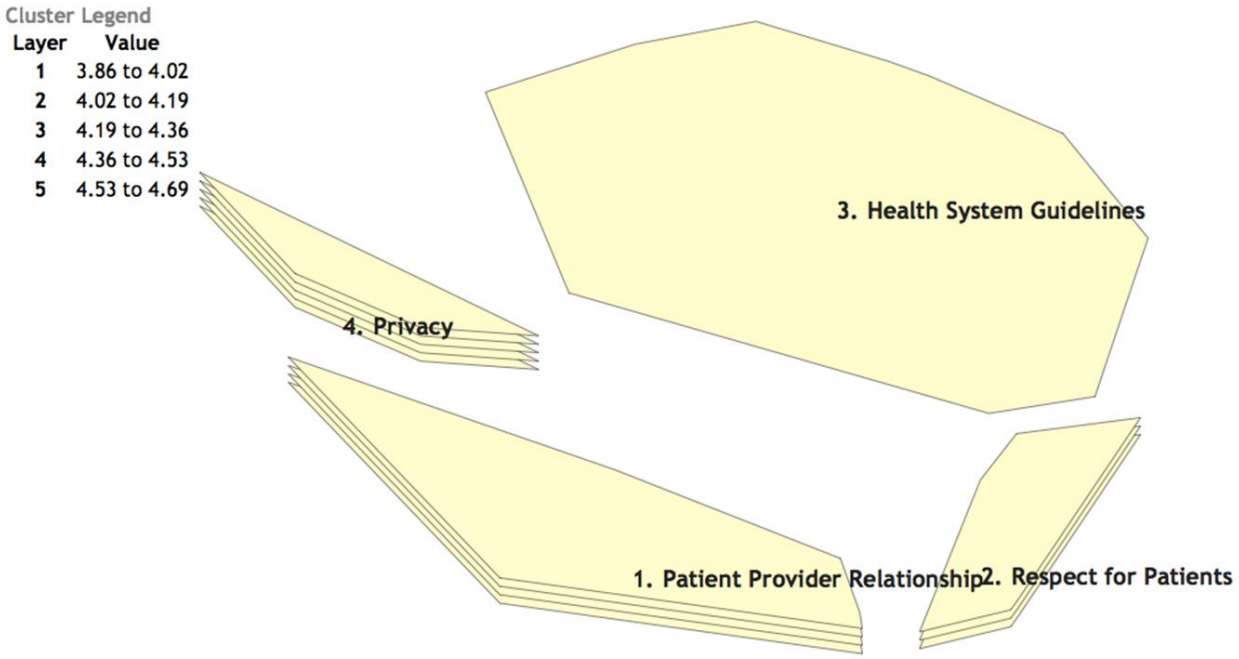


Figure 6. Feasibility Rating Cluster Map

Table 6. Idea Statement List with Average Feasibility Ratings

Cluster Name	Item #	Idea Statement	Average Feasibility Rating	Standard Deviation
Privacy			**4.69**	**0.24**
	26.	Do not talk about colleagues in front of patients	4.92	0.28
	27.	Do not talk about other patients outside patients rooms	4.85	0.38
	38.	Bring insurance cards or other information back to patient room as soon as possible	4.77	0.44
	39.	Close the curtain for patient rooms	4.92	0.28
	40.	Do patient registration in a private room instead of at the front desk	4.38	1.19
	41.	Increase privacy in the emergency room	4.38	0.87
	67.	Protect personal information better	4.62	0.65
Patient-Provider Relationship			**4.37**	**0.60**
	2.	Listen to family when they have	4.92	0.28

	concerns		
5.	Help patients be their own advocates	3.77	1.3
7.	Clearly communicate policies with patients	4.62	0.77
11.	Respond to criticism better	4.15	0.8
28.	Have doctors communicate their expertise	4.15	0.8
36.	Recognize patients by face (knowing who you actually are)	2.85	1.34
37.	Call patients by name	4.62	0.65
42.	Encourage patients to seek other opinions	4.15	1.07
49.	Describe medication side effects	4.77	0.44
58.	Make sure doctors explain tests, procedures, and written instructions	4.92	0.28
63.	Listen to patients	5.00	0
65.	Not treat people like they are drug seekers	4.08	1.12
66.	Offer non-judgmental testing	4.77	0.60
Respect for Patients		**4.29**	**0.54**
1.	Be gentle with the elderly	4.85	0.55
12.	Be more careful when treating the elderly	4.54	1.20
19.	Have doctors communicate better when they don't know what's going on	4.31	0.85
20.	Have doctors show empathy and compassion when giving bad news	4.23	1.24
32.	Treat patients fairly	5.00	0.00
33.	Treat patients as individuals	4.92	0.28
50.	Talk to patients appropriately	4.46	1.20
51.	Have doctors go to more classes for bedside/chair side manner	3.54	1.13
52.	Show vulnerability with patients	3.46	1.56
53.	Require training in cultural competency	3.23	1.3
54.	Show care for patients	4.85	0.55
55.	Show humanity to patients	4.38	1.19
56.	Increase interactions with parents when treating children	4.69	0.63
60.	Be more personal with patients	4.31	0.75
61.	Be more thorough with patients	4.00	1.08
62.	Spend more time with patients	3.69	1.11
64.	Treat patients like people, not a statistic	4.46	0.52
Health Systems Guidelines		**3.86**	**0.41**
3.	Legalize assisted suicide	2.77	1.64
4.	Simplify paperwork	3.69	1.44
6.	Offer accessibility to health system	3.31	1.44

	regardless of insurance		
8.	Create guidelines for each personnel role within the health system	4.08	1.12
9.	Create clear guidelines for how health systems should function	4.08	0.86
10.	Make sure you see the provider you made the appointment with	3.77	0.83
13.	Have the doctors more accessible in ER's	3.62	1.04
14.	Scan medications before giving them out to prevent errors	4.38	1.33
15.	Make sure nurses know what medications they are giving to patients	4.69	0.48
16.	Have doctors take classes on compassion	3.69	1.11
17.	Require continuing education on social skills	4.15	0.90
18.	Have doctors provide options for what to do next when they don't have answers	3.92	1.32
21.	Help navigate the system in general	3.69	1.18
22.	Help navigate the system to see specialists	3.77	1.17
23.	Provide accessible interpreters	3.54	1.39
24.	Prioritize patient care before insurance status	4.31	1.25
25.	Post clear rules for patient visitors	4.62	0.51
29.	Do not advertise medicine	3.54	1.61
30.	Use actual patients when marketing for health systems	3.77	1.24
31.	Have multiple sites of care for big health systems	3.54	1.13
34.	Treat mental pain appropriately	4.15	0.90
35.	Treat mental pain differently than physical pain	3.85	1.28
43.	Offer a choice for what pharmacy you go to	3.69	1.38
44.	Pay more attention to cost when prescribing medicines (consider generics)	3.38	1.45
45.	Educate doctors more about pharmacology (how medicines work)	4.00	1.15
46.	Have better communication between providers in the health system	4.08	1.32
47.	Offer alternative treatments to medication	3.92	1.12

48.	Have better partnership between doctors and pharmacists	3.62	1.19
57.	Have a good environment	4.46	0.97
59.	Offer flexibility in choosing a provider	3.62	1.39

Comparison of Importance versus Feasibility

Comparative cluster ratings for importance versus feasibility are aggregated into a common visual display known as a "go-zone" (Figure 7). Similar to an XY graph, the go zone plots each point, using the average rating data of each point to make coordinates based on Importance (Y axis) and Feasibility (X axis). This bivariate graph displays a comparison across two rating criteria: importance and feasibility. These results help guide the utilization phase by providing a framework for action to improve patient trust in health systems.

The quadrants ranged in size from 7 to 29 idea statements. The 29 statements appearing in the upper right quadrant (Quadrant 2) represent ideas that participants rated as both highly important and highly feasible, and thus represent target areas for focused efforts to build institutional trust. Consistent with the results from the rating tables in Tables 5 and 6, the three highest rated ideas in terms of both importance and feasibility were Item 32 "Treat patients fairly," Item 63 "Listen to patients," and Item 2 "Listen to family when they have concerns." Also consistent with the cluster ratings shown in Figures 5 and 6, Table 7 shows that the ideas from the highest rated cluster in terms of both importance and feasibility - "Privacy," (Items 26, 27, 38, 39, 40, 41, and 67) - are all contained within this quadrant. Overall, the ideas listed in Quadrant 2 tended to be actions that directly impact patient care, such as Item 19 "Have doctors communicate better when they don't know what's going on" or Item 64 "Treat patients like people, not just a statistic."

On the contrary, the 21 statements appearing in the lower left quadrant (Quadrant 3) represent ideas that have the lowest aggregate ratings in terms of both importance and

feasibility. The items in this quadrant represent low priority items for building institutional trust. Also consistent with the results from the rating tables, the three ideas with the lowest combined importance and feasibility rating include Item 3 “Legalize assisted suicide,” Item 36 “Recognize patients by face (knowing who you actually are),” and Item 53 “Show vulnerability with patients.” Overall, the ideas listed in Quadrant 3 were less directly related to patient care, such as Item 4 “Simplify paperwork” or Item 29 “Do not advertise medicine.”

Figure 7. "Go-Zone" Graph to Compare Importance Ratings versus Feasibility Ratings

Table 7. Go-Zone Idea Statement List

	Item #	Idea Statement
Quadrant 1: Idea statements with high average importance rating but low average feasibility rating		
	6.	Offer accessibility to health system regardless of insurance
	9.	Create clear guidelines for how health systems should function
	13.	Have the doctors more accessible in ER's
	18.	Have doctors provide options for what to do next when they don't have answers
	45.	Educate doctors more about pharmacology (how medicines work)
	46.	Have better communication between providers in the health system
	48.	Have better partnership between doctors and pharmacists
	59.	Offer flexibility in choosing a provider
	61.	Be more thorough with patients
	65.	Not treat people like they are drug seekers
Quadrant 2: Idea statements with high average importance rating and high average feasibility rating		
	1.	Be gentle with the elderly
	2.	Listen to family when they have concerns
	7.	Clearly communicate policies with patients
	12.	Be more careful when treating the elderly
	14.	Scan medications before giving them out to prevent errors
	15.	Make sure nurses know what medications they are giving to patients
	19.	Have doctors communicate better when they don't know what's going on
	20.	Have doctors show empathy and compassion when giving bad news
	24.	Prioritize patient care before insurance status
	26.	Do not talk about colleagues in front of patients
	27.	Do not talk about other patients outside patients rooms
	32.	Treat patients fairly
	33.	Treat patients as individuals
	34.	Treat mental pain appropriately
	37.	Call patients by name
	39.	Close the curtain for patient rooms
	41.	Increase privacy in the emergency room
	49.	Describe medication side effects
	50.	Talk to patients appropriately (respectfully, regardless of age)
	54.	Show care for patients

55.	Show humanity to patients
56.	Increase interactions with parents when treating children
57.	Have a good environment
58.	Make sure doctors explain tests, procedures, and written instructions
60.	Be more personal with patients
63.	Listen to patients
64.	Treat patients like people, not just a statistic
66.	Offer non-judgmental testing
67.	Protect personal information better
Quadrant 3: Idea statements with low average importance rating and low average feasibility rating	
3.	Legalize assisted suicide
4.	Simplify paperwork
5.	Help patients be their own advocates
8.	Create guidelines for each personnel role within the health system
10.	Make sure you see the provider you made the appointment with
16.	Have doctors take classes on compassion
21.	Help navigate the system in general
22.	Help navigate the system to see specialists
23.	Provide accessible interpreters
29.	Do not advertise medicine
30.	Use actual patients when marketing for health systems
31.	Have multiple sites of care for big health systems
35.	Treat mental pain differently than physical pain
36.	Recognize patients by face (knowing who you actually are)
43.	Offer a choice for what pharmacy you go to
44.	Pay more attention to cost when prescribing medicines (consider generics)
47.	Offer alternative treatments for medication
51.	Have doctors go to more classes for bedside/chair side manner
52.	Show vulnerability with patients
53.	Require training in cultural competency
62.	Spend more time with patients
Quadrant 4: Idea statements with high average importance rating but low average feasibility rating	
11.	Respond to criticism better
17.	Require continuing education on social skills
25.	Post clear rules for patient visitors
28.	Have doctors communicate their expertise
38.	Bring insurance cards or other information back to patient room as soon as possible

	40.	Do patient registration in a private room instead of at the front desk
	42.	Encourage patients to seek other opinions

Subgroup Analysis Results

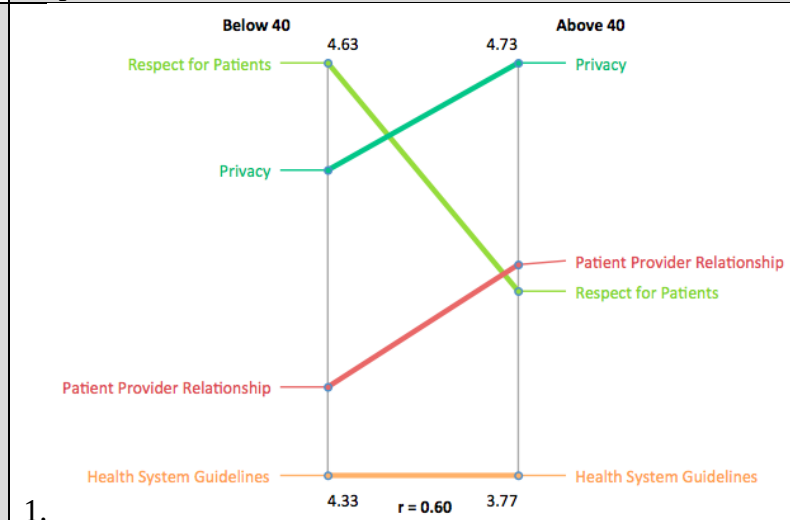
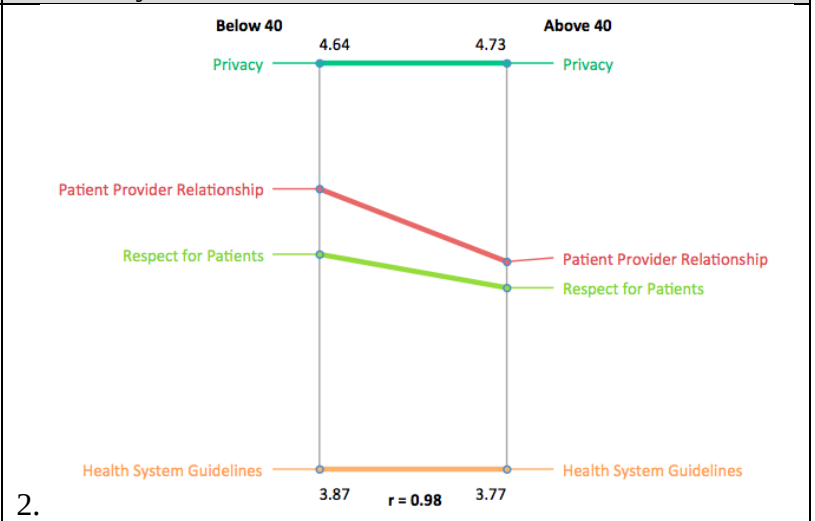
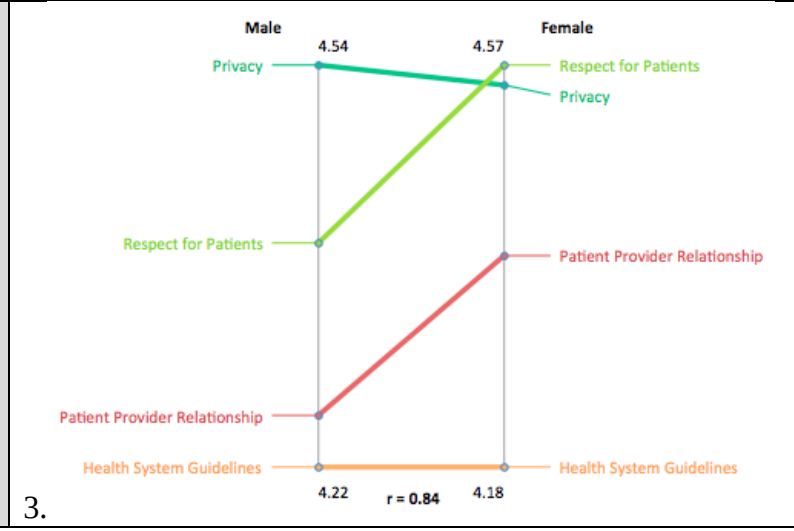
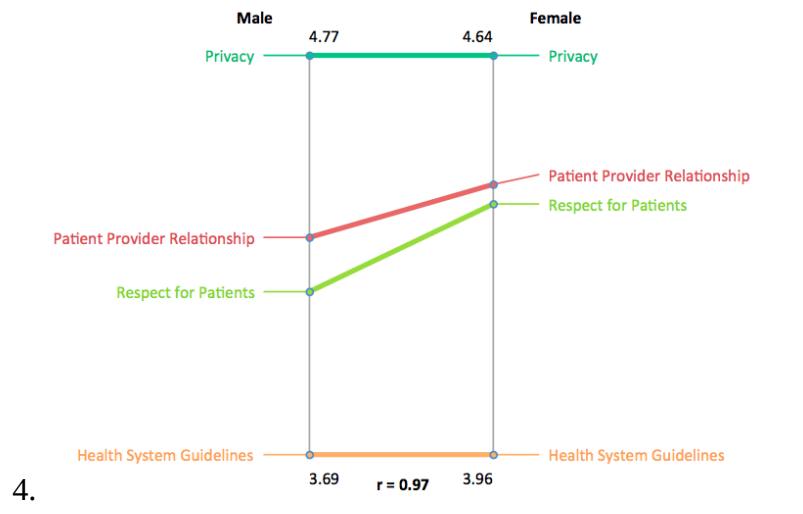
The pattern matching displays, shown in Figure 8, compare the average rating information within the 3 demographic characteristics: age, gender, and race. The panels on the left (1, 3, and 5) show the rating information in terms of importance and the panels on the right (2, 4, and 6) show the rating information in terms of feasibility. As shown in figure 6, stratification by these variables shows differences in the overall order of cluster importance ratings by age (r=0.60) and gender (r=0.84). Stratification does not produce a difference in the rank order of cluster feasibility ratings. It is important to note that the difference in average cluster ratings between the subgroups differed by less than one, so the demographic difference may not denote practical significance. It is also important to note that "group think" may influence the ratings, and may be responsible for the lack of demographic differences in the pattern matching displays. The results of each variable are described below:

Age: Panels 1 (r = 0.60) and 2 (r = 0.98) of Figure 8 show how the average cluster ratings differ based on age. The rating data was compared for all of individuals within the sample using the median (40 years) as the cutoff point. On average, when comparing individuals below and above the age of 40, those below the age of 40 assigned: a higher importance rating for "Respect for Patients"; a lower importance rating for "Patient-Provider Relationship" and "Privacy"; and a higher feasibility rating for the "Respect for Patients" and "Patient-Provider Relationship" clusters.

Gender: Panels 3 (r = 0.84) and 4 (r = 0.97) of Figure 8 show how the average cluster ratings differ based on gender. Compared to females, males tended to assign: a lower rating in terms of importance for the "Respect for Patients" and

"Patient-Provider Relationship" clusters; a slightly higher rating for the "Privacy" cluster; and a slightly lower rating in terms of feasibility for the "Respect for Patients" and "Patient-Provider Relationship" clusters.

Race: Panels 5 (r = 0.92) and 6 (r = 0.99) of Figure 8 show how the average cluster ratings differ based on race. Compared to minority participants, white participants tended to assign: a higher importance rating to "Patient-Provider Relationship"; a lower importance rating to "Respect for Patients"; and a lower feasibility rating to "Respect for Patients" and "Patient-Provider Relationship." The slight differences in the average rating values by demographic factor listed above do not produce a change in the overall cluster rankings.

	Importance	Feasibility
Age	 1.	 2.
Gender	 3.	 4.

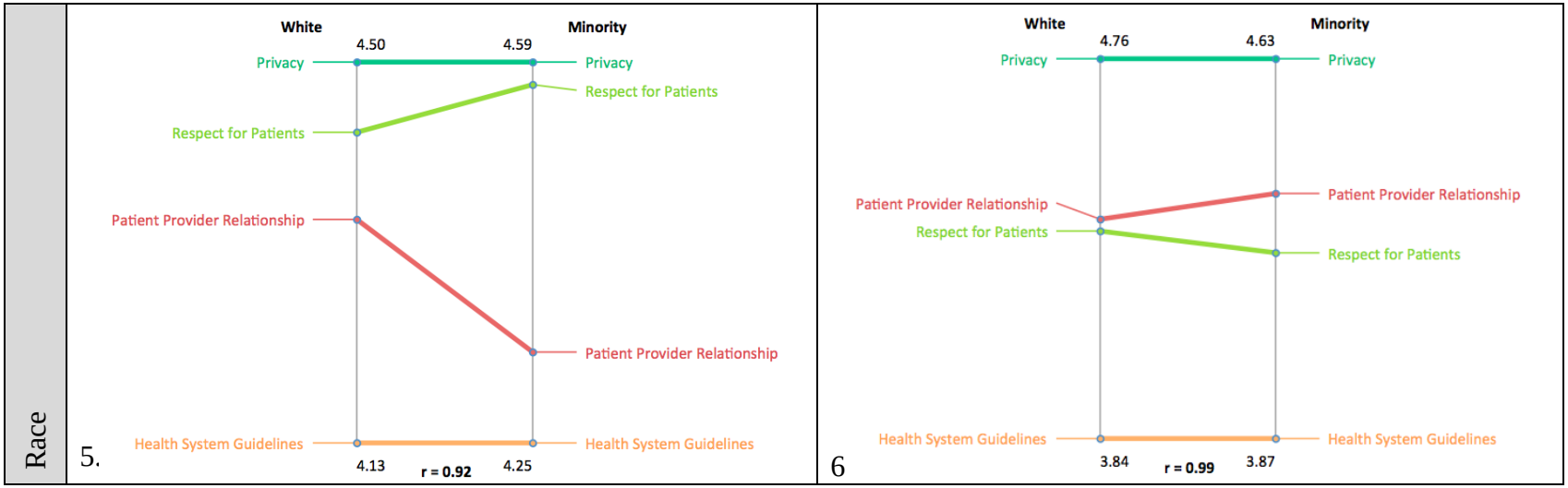


Figure 8. Comparison of Pattern Matching Displays Across Age, Gender, and Race

CHAPTER 5

DISCUSSION

Interpretation of Results

Trust is a critical factor impacting patients' decision to seek care in a timely manner. Even if services are available and affordable, patients may opt to forgo preventative services if they do not deem them the services to be acceptable. Multiple studies have already investigated the concept of trust and the ways in which mistrust serves as a barrier to healthcare utilization. Our work expands prior studies by exploring ways to improve patient trust of health systems. Specifically, this project sought to identify patient-centered approaches to improve institutional trust, as a step towards improving healthcare acceptability.

Though the use of GCM, a comprehensive list of actions and practices was generated that health systems can adopt to help build patient trust. The list of items generated by the brainstorming session ranged from broader ideas such as "Help patients be their own advocates" and "Have a good environment" to more actionable ideas such as "Close the curtain for patient rooms" and "Provide accessible interpreters." Although the prompt directed the participants to focus on health system actions, patients were often unable to separate the actions of healthcare professionals from the health systems in which they work. Thus, the list further included system-level actions such as "Have better communication between providers in the health system" as well as recommendations for individual providers, such as "Respond to criticism better."

The results of this study suggest that interventions aimed at increasing institutional trust should include initiatives that impact the following four domains: privacy, patient-provider relationship, respect for patients, and health system guidelines. To improve trust in all four of these domains, health systems must take a multi-level approach. In order to impact trust in the domains of the patient-provider relationship and

respect for patients, hospital systems should develop programs to enhance trust at the doctor or provider level. An example of how to do this would be to develop incentives to encourage doctors to improve communication in their patient interactions when they do not know the etiology of a patient's symptoms. In order to impact trust in the domain of patient privacy, hospitals should work towards building trust at the department level. For example, departmental guidelines could be set up to focus on protecting patient medical and financial information appropriate to each care setting. Finally, health systems could also impact trust at the system level to influence the domain of health system guidelines. For example, continuing education courses could be implemented to improve communication and encourage cultural competency in an effort to educate providers on the ways to make patients feel respected.

In addition to identifying general domains for improvement, this study contributes additional knowledge regarding which potential provider and health system-level changes are most important and feasible from the patient perspective. Overall, "Privacy" was consistently rated as the highest cluster both for feasibility and importance. Results from the "go-zone" graph identify additional priority areas that should be targeted from the other clusters as well. Quadrant 2 of the "go-zone" graph (which represents items that participants rated as both feasible and important) generally contained items that directly impact patient care.

Consistent with previous studies, age was identified as a potentially important factor for patient trust (Hall et al., 2001; Musa et al., 2009). The results of the pattern matching displays show differences for the overall cluster ratings based on age in terms of importance. These differences by age require further investigation in future research to better understand how and why age factors into the rating of importance.

Limitations

There are limitations to this work. Participants were selected as a convenience sample within a single community within Philadelphia. Thus, participants may not be completely representative of the broader patient population of this community (Upper Darby) and may be missing perspectives from community members that were not able to reach and recruit. Additionally the small sample size and the geographically-based population of insured patients within this single community limits the generalizability of the data to broader populations. Finally, this methodology additionally does not allow for the inference of causal links. Despite these shortcomings, this initial work contributes important insight into patient perspectives regarding approaches for improving institutional trust.

Future Research

Additional research studies are needed to continue to explore effective approaches to improving institutional trust. Companion studies could employ the same research prompt in different contextual situations to both (1) show the influence of external factors (such as neighborhood) on rating data and (2) add to the list of potential health systems actions to impact the trust that patients have in them. A companion study could also be administered within a patient group that is not well linked into the healthcare system to identify their priorities as well. Additionally, work is needed to design interventions aimed at addressing the factors identified within our study that effectively address privacy and other salient concerns.

CHAPTER 6

CONCLUSION

Plans for Use

The results from this study can be used in both planning and evaluation applications by healthcare systems. Healthcare systems may use the domains of trust identified through this work to create a tool to measure the degree of unmet need within each of these domains as a marker of where to focus initial interventions to improve trust. Additionally, this work provides a list of actionable, patient-centered interventions. The results of this study can therefore be used for program planning to improve institutional trust within the Upper Darby community. Local healthcare systems may use the information from the cluster rating maps and the "go-zone" graph to inform their future action plans.

Public Health Significance

It is essential for healthcare systems to take action to make their services more acceptable to the community they serve in order to deliver better and more patient-centered care. By implementing programs that build institutional trust, healthcare systems will promote the access to and use of the healthcare services they offer. We intend for this work to help decrease local health disparities by identifying potential health system actions to increase institutional trust and subsequently improve health outcomes through increased healthcare utilization.

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APPENDIX A

IRB APPROVAL LETTERS

TEMPLE UNIVERSITY
Research Administration

Research Integrity & Compliance
Student Faculty Center
3340 N. Broad Street, Suite 304
Philadelphia PA 19140

Institutional Review Board
Phone: (215) 707-3390
Fax: (215) 707-9100
e-mail: irb@temple.edu

Certification of Approval for a Project Involving Human Subjects

Date: 03-Jun-2016

Protocol Number:	23741
PI:	NELSON, DEBORAH B
Review Type:	EXPEDITED
Approved On:	03-Jun-2016
Approved From:	03-Jun-2016
Approved To:	02-Jun-2017
Committee:	A1
School/College:	PUBLIC HEALTH (0900)
Department:	CPH:EPIDEMIOLOGY & BIOSTATISTICS (09170)
Sponsor:	NO EXTERNAL SPONSOR
Project Title:	Identification of approaches to impact patient trust in healthcare systems: A group concept mapping study

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The IRB approved the protocol 23741.

If the study was approved under expedited or full board review, the approval period can be found above. Otherwise, the study was deemed exempt and does not have an IRB approval period.

If applicable to your study, you can access your IRB-approved, stamped consent document or consent script through eRA. **Open the Attachments tab and open the stamped documents by clicking the View icon next to each document**. The stamped documents are labeled as such.

Before an approval period ends, you must submit the Continuing Review form via the eRA module. Please note that though an item is submitted in eRA, it is not received in the IRB office until the principal investigator approves it. Consequently, please submit the Continuing Review form via the eRA module at least 60 days, and preferably 90 days, before the study's expiration date.

Note that all applicable Institutional approvals must also be secured before study implementation. These approvals include, but are not limited to, Medical Radiation Committee ("MRC"); Radiation Safety Committee ("RSC"); Institutional Biosafety Committee ("IBC"); and Temple University Survey Coordinating Committee ("TUSCC"). Please visit these Committees' websites for further information.

Finally, in conducting this research, you are obligated to submit modification requests for all changes to any study; reportable new information using the Reportable New Information form; and renewal and closure forms. For the complete list of investigator responsibilities, please see the Policies and Procedures, the Investigator Manual, and other requirements found on the Temple University IRB website: http://www.temple.edu/research/regaffairs/irb/index.html

Please contact the IRB at (215) 707-3390 if you have any questions

5/18/2016

IRB Authorization Agreement

Name of Institution or Organization Providing IRB Review (Institution A): Temple University

IRB Registration #: 00005496, 00005497 Federalwide Assurance (FWA) #: 00004964

Name of Institution Relying on the Designated IRB (Institution B): Thomas Jefferson University IRB

OHRP Federalwide Assurance (FWA) #: 00002109

The Officials signing below agree that Thomas Jefferson University may rely on the designated IRB for review and continuing oversight of its human subject research described below: (*check one*)

(___) This agreement applies to all human subject research covered by Institution B's FWA.

(X) This agreement is limited to the following specific protocol(s):

Name of Research Project: Identification of approaches to impact patient trust in healthcare systems: A group concept mapping study (TU IRB Protocol # 23741)
Name of Principal Investigator (Institution A): Deborah Nelson, PHD
Name of Principal Investigator (Institution B): Kristin Rising, MD, MS
Sponsor or Funding Agency: N/A Award Number, if any: N/A

(___) Other (*describe*):

The review and continuing oversight performed by the designated IRB will meet the human subjects protection requirements of Institution B's OHRP-approved FWA. The IRB at Institution A will follow written procedures for reporting its findings and actions to appropriate officials at Institution B. Relevant minutes of IRB meetings will be made available to Institution B upon request. Institution B remains responsible for ensuring compliance with the IRB's determinations and with the terms of its OHRP-approved Assurance. This document must be kept on file at both institutions and provided to OHRP upon request.

Signature of Signatory Official (Institution A): Michele Masucci

Date: 6/10/2016

Print Full Name: Michele Masucci, Ph.D Institutional Title: Vice President for Research

Signature of Signatory Official (Institution B): Date: 6/10/16

Print Full Name:
Walter Kraft, M.D.
Director, OHR

Kyle Conner, M.A., CIP
Associate Director, OHR

APPENDIX B

IRB APPROVED PROTOCOL

Protocol Template for Minimal Risk Studies not Regulated by FDA

1) Abstract of the study

Higher levels of institutional trust have been associated with increased health care utilization, greater adherence to treatment plans, better treatment outcomes, and improved overall health. Though numerous studies have documented the variation in individuals' institutional trust and the impact this has on important outcomes, there has been little attention to understanding approaches to impact patient institutional trust. The proposed project will use group concept mapping (GCM) to directly engage a specific population of patients with regular healthcare utilization practices and elicit their perspectives on ways to impact patient trust. This work has the potential benefit of equipping healthcare systems to better impact trust within their community.

2) Protocol Title

Identification of approaches to impact patient trust in healthcare systems: A group concept mapping study

3) Investigators & Description of Roles

Deborah Nelson, PhD; Temple University, Department of Epidemiology and Biostatistics; Principle Investigator. Dr. Nelson is the principle investigator of this project and the chair of the thesis committee for this project. She will serve in a supervisory role and will provide input into the overall study design.

Amanda Doty; Temple University, Clinical Research and Translational Medicine Program; Student Investigator. Ms. Doty will coordinate all of the research activities of the project, including recruiting/enrolling patients, overseeing the concept mapping sessions, analyzing the data, and preparing the research findings for dissemination.

Kristin Rising, MD, MS; Thomas Jefferson University, Department of Emergency Medicine; Co-Investigator. Dr. Rising is well-versed in concept mapping methodology and will serve this project in informing the data collection methods. As a clinician, Dr. Rising will additionally help guide data analysis by helping to interpret the results in the health system context.

Brendan Carr, MD, MS; Thomas Jefferson University, Department of Emergency Medicine; Co-Investigator. As a federal the director of Emergency Care Coordination Center at the US Department of Health and Human Services, Dr. Carr is uniquely poised to provide guidance on potential policy implications of the research findings. As such, Dr. Carr will help guide data analysis by helping to interpret the data in terms of possible policy recommendations.

Alexzandra Gentsch, LSW; Thomas Jefferson University, Department of Emergency Medicine; Research Assistant. Ms. Gentsch will assist during the concept mapping sessions, providing secondary support to the project coordinator when needed. Thus, she will help obtain informed consent and will be in direct contact with the participants of the concept mapping sessions.

4) Objectives

- To elicit patient perspectives on ways to impact medical trust within a specific patient population, using a novel approach
- To perform an exploratory analysis to determine trends of rating information obtained within the concept mapping process

5) Rationale and Significance

Higher levels of patient trust have been associated with increased health care utilization, greater treatment adherence, better treatment effectiveness, and improved overall health. Impacting the levels of trust in healthcare systems can be used to promote the access to and acceptability of healthcare services for the general population. Moreover, meaningful opportunity exists to decrease health disparities by focusing on initiatives that increase systems level trust by specific demographic features, to improve health outcomes for these populations.

6) Resources and Setting

The recruitment and enrollment research activities (described in detail below, in Section 8. Study Design) will occur at a primary care office and community outreach center in Upper Darby. The concept mapping sessions will be performed at the primary care office in Upper Darby, named Physical Medicine and Rehabilitation and located at 111 Long Lane, Upper Darby, PA 19081. All de-identified data analysis will occur at the two collaborating institutions- Thomas Jefferson University or Temple University.

7) Prior Approvals

An IRB Authorization Agreement will be secured with the institute that is collaborating on this project, Thomas Jefferson University. The IRB Authorization Agreement with Thomas Jefferson University will be obtained following IRB approval from Temple University.

8) Study Design

a) Recruitment Methods

A convenience sample of 35 patients will be recruited from a primary care office and community outreach program located in Upper Darby, Pennsylvania. 35 patients will be scheduled for an end target of 15-30 participants, accounting for up to a 50% no-show rate. A recruitment poster (including a brief description of inclusion/exclusion criteria, research team contact information, and a concise explanation of the research goals; see attached draft) will be hung in the waiting room of the primary care office as well as at the entrance of the community outreach center, allowing participants to self-select into the study. Potential

participants will also be provided with the research team's contact information by leadership of the community outreach program. The target recruitment number is 11-12 participants per week.

Participants will initially be screened for eligibility when they contact the research team by phone. PHI will not be collected during this initial phone call. Eligible participants who are interested in participating will be sent a confirmation letter (see attached draft) to provide information about the location and time of the group concept mapping sessions. Research personnel will obtain informed consent in person, prior to any research activities during session one of group concept mapping.

Once recruited, patients will be enrolled into the process of concept mapping. There will be 3 sessions for this study, with the following goals:
1) generation of idea statements (brainstorming) and completion of a short questionnaire
2) structuring/sorting of statements
3) interpretation of final ideas

All three sessions will occur at the primary care office recruitment site, located at 111 Long Lane, Upper Darby, PA 19082.

Patients who complete all three sessions of the concept mapping will be compensated with $75, which will be allocated as $25 per session. Patients will be remunerated with debit cards at the end of each concept mapping session.

b) Inclusion and Exclusion Criteria

To be considered eligible for participation, patients must have an active membership in an insurance plan, be aged 21 years or older, and have seen a primary care physician in the Upper Darby area within the last 2 years. Participants who do not speak English and who do not have the ability to provide informed consent (i.e. children, prisoners, individuals with communication impairments, and the decisionally impaired) will be excluded from the study.

c) Study Timelines

We expect that the participant will participate for a total of 3.5 hours. Concept mapping occurs over three sessions as follows: 1 hour for session 1 (brainstorming), 1.5 hours for session 2 (structuring of statements), and 1 hour for session 3 (interpretation).

Enrollment will be targeted at 11-12 people per week, for a period of 3 weeks. 35 patients will be scheduled for an end target of 15-30 participants, accounting for a 15-20% no-show rate.

The following table details the anticipated project timeline:

	Description of Work	Start and End Dates
Phase	**PREPARATION**	**APRIL 29th - JUNE**

1		10th
	Refine Introductory Script & Stem with Research Team	April 29th - May 2nd
	Test Modified Introductory Script & Stem with Community Representatives	May 3th - May 6th
	Finalize Introductory Script & Stem	May 28th - June 4th
	Obtain IRB Approval	May 18th
	33% Enrollment (12 participants)	May 18th - May 24th
	66% Enrollment (12 participants)	May 25th - May 31st
	100% Enrollment (11 participants)	June 1st - June 8th
	Prepare GCM Materials (Informed Consent Packets, Computers, setup software)	June 8th - June 10th
Phase 2	**GCM SESSIONS (CONDENSED SCHEDULE)**	**JUNE 11th – JUNE 12th**
	Session 1 & Upload Excel Information	June 11th
	Session 2 & Input Physical Sort Card Information	June 11th
	Prepare Cluster Map for Session 3	June 12th
	Session 3 & Finalize Final Map	June 12th
Phase 3	**DATA ANALYSIS/PRESENTATION**	**JUNE 12th – JULY 1st**
	Data Analysis	June 12th – July 1st
	Finalize Manuscript	June 12th – July 1st
	Submit Thesis	July 1st
	Present Work	July 15th

d) Study Procedures and Data Analysis

The steps of the GCM process will take place over three sessions: 1) brainstorming, 2) sorting/rating, and 3) interpretation. Informed consent will be obtained from each participant prior to beginning any formal research activities during the first GCM session. Then, participants will be convened in a group setting to participate in a structured brainstorming session. Participants will be invited to brainstorm and generate responses to a prompt such as: "Things that a healthcare system can do to impact trust include…" The first five to ten minutes of brainstorming will be written, to allow every participant time to generate individual responses. Then, the session will open into a discussion where each participant will provide their idea statements, which will be recorded using Microsoft excel. The concept mapping session will not be audiotaped, so responses from the first session cannot be identified on the individual level. The researcher will eliminate duplicate entries and upload this document into the CS Global MAX software subsequent to the session (Concept Systems, Inc). At the end of first session, participants will

fill out a brief questionnaire (see attached draft), which will collect demographic information and it will also be used to administer the Medical Mistrust Index to measure the amount of trust that the participant has in the health system. This survey will only identify the participant by study ID number.

Depending on patient preference, the second session will be preformed either in person following a short break or online using virtual forum set up via the CS Global MAX software. During the sorting process, each idea statement will be written onto a physical or virtual "sort card." Patients will be asked to sort all of the sort cards into piles by whatever means makes sense to them. Then, patients will rate all of the sorted ideas on two scales (importance and feasibility).

After patients complete this second session, members of the research team will manually enter the physical sort card information into the GCM software for use in analysis. The analysis will result in the creation of an interactive visual display, known as a cluster map. The number of clusters contained in the final cluster map is set based on the amount of detail needed. The final number of clusters will be determined by the research team members, based on an operational planning perspective (Kane, Trochim, 2007). The final map will be circulated to the patient group during the final GCM session for their evaluation and interpretation. Exploratory analysis will be performed upon the results for sub-groups of the participants.

Patients who complete all three sessions of the CM will be compensated with $75, allocated as $25 per session. The first and third sessions are anticipated to take about one hour, whereas the second is anticipated to take about one and a half hours. The overall GCM schedule will follow a modified condensed schedule plan, with all concept mapping activities occurring over a two day period (Kane and Trochim, 2007).

e) Withdrawal of Subjects

Participants may refuse to participate in this investigation or withdraw consent and quit this study without penalty and without affecting the ability to receive medical care.

Participants may quit the study and revoke permission to use and share their personal health information at any time by contacting research team, in writing, at: (Amanda Doty- 1025 Walnut St, Suite 300, Philadelphia, PA 19107). Further collection of PHI will be stopped on those who quit the study, but PHI that has already been collected may still be used.

f) Privacy & Confidentiality

All paper documents, including copies of informed consent and survey questionnaire (to collect information on age, gender, race, ethnicity, length of

insurance coverage, education level, household income, prior healthcare utilization, chronic disease diagnoses, accessibility/affordability issues, and the results of a Medical Mistrust Scale), will be collected with a unique study ID and secured in locked cabinets in a locked office. Concept mapping session data will all be processed and aggregated within the concept mapping sessions, and linkage of specific responses to individuals will not be recorded. Furthermore, this electronic data will be password-protected on network-level-access-secured computers. The demographic survey data will only be identifiable by the participant study number. All study personnel including the research assistants will be sufficiently trained in the study protocol and their duties and will maintain current HIPAA and CITI training/certification for the duration of the study.

A "HIPAA Authorization English (HRP-505)" and consent form (HRP-501) have been submitted with this application (see attached).

The entire study constitutes minimal risk to the enrolled patients. There is no expectation of any physical risk. Psychological risk and/or risk to privacy is expected to be minimal, if any, and limited to the risk of discomfort during concept mapping sessions when asked to share their opinions and personal information. It will also be mitigated by communicating frequently with enrolled patients to ensure that their continued participation is voluntary and informing them that they may opt to decline to answer any or all of the questions.

9) Risks to Subjects

The entire study constitutes minimal risk to the enrolled patients. There is no expectation of any physical risk. Psychological risk and/or risk to privacy is expected to be minimal, if any, and limited to the risk of discomfort during concept mapping sessions when asked to share their opinions and personal information. It will also be mitigated by communicating frequently with enrolled patients to ensure that their continued participation is voluntary and informing them that they may opt to decline to answer any or all of the questions.

All paper documents are secured in locked cabinets in a locked office accessible only to research personnel. The electronic data collected during the group concept mapping sessions will be password-protected on network-level-access-secured computers. PHI is only collected to the extent required by our study protocol.

There is the possible risk of loss of confidentiality. All participants will be asked to keep the contents of the concept mapping discussions confidential, however confidentiality cannot be guaranteed.

10) Potential Benefits to Subjects

There is a chance the subjects will receive no direct benefit from participating in this study, but we hope that what we learn may be helpful to future patients or society in general. Possible benefits from being in the study may include: helping others in the future by providing a better understanding of what contributes to trust in a healthcare

system. There is a chance that subjects may benefit by having the opportunity to share their perceptions and opinions.

11) Costs to Subjects

Participants will not incur any costs as a result of participating in this study.

12) Informed Consent

This research project will obtain informed consent by following all procedures and steps outlined by "INVESTIGATOR GUIDANCE: Informed Consent (HRP-802)." Informed consent will be obtained in person, prior to all research activities during session 1 of GCM. Non-English speaking patients will not be included in the study.

13) Vulnerable Populations

This project will **not** include any of the following populations:

- Adults unable to consent
- Individuals under the age of 21
- Prisoners

Pregnant women, given their unique health status, are hypothesized to have a unique perspectives on identifying methods to impact patient trust in health systems. As such, they will not be excluded from the study. Further, as the study procedures are deemed to be minimal risk, there is no additional risk expected to the fetuses.

APPENDIX C

IRB APPROVED INFORMED CONSENT

Temple IRB Approved

06/03/2016

Title of research:

Identification of approaches to impact patient trust in healthcare systems: A group concept mapping study

Investigator and Department:

Deborah Nelson, PhD; Temple University, Department of Epidemiology and Biostatistics; Principle Investigator

Amanda Doty; Temple University, Clinical Research and Translational Medicine Program; Student Investigator

Kristin Rising, MD, MS; Thomas Jefferson University, Department of Emergency Medicine; Co-Investigator

Brendan Carr, MD, MS; Thomas Jefferson University, Department of Emergency Medicine; Co-Investigator

Alexzandra Gentsch, LSW; Thomas Jefferson University, Department of Emergency Medicine; Research Assistant

Why am I being invited to take part in this research?

We invite you to take part in a research study because you are an insured patient and you have been seen by a primary care physician within the last two years.

What should I know about this research?

- Someone will explain this research to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide.

Who can I talk to about this research?

If you have questions, concerns, or complaints, or think the research has hurt you, contact the research team at **amanda.doty@temple.edu; 1025 Walnut St, Suite 300, Philadelphia PA 19107; 610-306-8848**.

This research has been reviewed and approved by an Institutional Review Board. You may talk to them at (215) 707-3390 or e-mail them at: irb@temple.edu for any of the following:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get information or provide input about this research.

Why is this research being done?

We are conducting this research study to directly engage patients to conduct focus groups and administer questionnaires to understand their perspectives on ways that health systems can impact patient trust. Mistrust of healthcare systems may prevent or delay insured patients from obtaining appropriate medical services, creating gaps in care for these patients. We will use what we learn to work to improve patient trust.

How long will I be in this research?

We expect that you will participate for a total of 3.5 hours over a two-day period. Concept mapping occurs over three sessions as follows: 1 hour for session 1 on day 1 (brainstorming focus group conversations), 1.5 hours for session 2 on day 1 (structuring of statements from focus groups), and 1 hour for session 3 on day 2 (gaining thoughts on the interpretation).

What happens if I agree to be in this research?

We would like to talk to you in a group setting, using a process called concept mapping. We will discuss your suggestions for what health systems can do to impact trust. Concept mapping is like a structured brainstorming session, in which about 15-30 people are brought together to talk about ideas related to a specific topic. There will be 3 sessions for this study, with the following goals:

1) generation of idea statements (brainstorming) and completion of a short questionnaire
2) structuring/sorting of statements
3) interpretation of final ideas

You will be given the choice to participate in step 2 after a break in person or later that day using an online program.

Is there any way being in this research could be bad for me?

The risks of participating in this research study are minimal, and include primarily a loss of confidentiality. We have measures in place to minimize this risk by keeping your information securely locked and password protected and will not report individual results linked to your name anywhere. This information will not be added to your medical record. There is also the possibility that questions will make you feel uncomfortable. If any question makes you feel uncomfortable, you don't have to answer it.

Will being in this research help me in any way?

There may be no benefit from being involved in this research, but we hope that what we learn may be helpful to future patients or society in general. However, a possible benefit from being in the study may include having the opportunity to share your perceptions and opinions.

What happens to the information collected for this research?

We will collect personal information including age, gender, race, ethnicity, length of insurance coverage, education level, household income, prior healthcare utilization, diagnosis of chronic diseases, and information about accessibility or affordability issues from a questionnaire at the first session. We will also collect information on the survey that will ask you questions about trust, known as the Medical Trust Scale.

To the extent allowed by law, we limit the viewing of your personal information, to people who have to review it. We cannot promise complete secrecy. The IRB, Temple University, Temple University Health System, Inc. and its affiliates, and other representatives of these organizations may inspect and copy your information. Personal information from the survey will be collected during this study, coded with a unique study ID, and may also be shared with the following entities of the collaborating institution: Thomas Jefferson University, Jefferson University Physicians, and Thomas Jefferson University Hospitals, Inc.

Participants may quit the study and revoke permission to use and share their personal health information at any time by contacting research team, in writing, at: (Amanda Doty- 1025 Walnut St, Suite 300, Philadelphia, PA 19107). Further collection of PHI will be stopped for those participants who quit the study, but PHI that has already been collected may still be used.

What will I be paid for taking part in this research?

If you agree to take part in this research, we will pay you for your time and effort. Patients who complete all three sessions of the concept mapping will be compensated with $75, which will be allocated as $25 for each session.

Federal tax law requires to you to report this payment as income to the Internal Revenue Service.

APPENDIX D

IRB APPROVED DEMOGRAPHICS FORM

Identification of approaches to impact patient trust in healthcare systems: A group concept mapping study

Patient Survey

1. Age: _____

2. Gender:
❑ MALE ❑ FEMALE ❑ SOMETHING ELSE: _____

3. What is your race? *(Check all that apply)*
❑ WHITE ❑ BLACK ❑ ASIAN ❑ SOMETHING ELSE

4. Are you Hispanic or Latino? ❑ YES ❑ NO

5. Health Insurance Status *(Check all that apply)*:
❑ MEDICAID
❑ MEDICARE
❑ HMO / PPO / PRIVATE
❑ VA / MILITARY
❑ OTHER: _____
❑ UNKNOWN

6. How long have you had insurance coverage?
❑ LESS THAN 1 YEAR
❑ 1-2 YEARS
❑ 2-4 YEARS
❑ MORE THAN 4 YEARS

7. What was the last grade/degree you finished in school?
❑ LESS THAN HIGH SCHOOL
❑ HIGH SCHOOL GRADUATE / GED / SOME COLLEGE
❑ COLLEGE DEGREE
❑ POSTGRADUATE DEGREE

8. What is your current employment status?
❑ WORKING FULL TIME- MAIN CURRENT JOB: _____
❑ WORKING PART TIME- MAIN CURRENT JOB: _____
❑ SELF-EMPLOYED
❑ LOOKING FOR WORK/UNEMPLOYED
❑ DISABLED
❑ RETIRED
❑ HOMEMAKER

9. What is your family's yearly household income?
❑ LESS THAN $10,000
❑ $10,000 - $24,999
❑ $25,000 - $49,999
❑ $50,000 - $99,999
❑ $100,000+
❑ UNKNOWN / DECLINE TO ANSWER

10. In the last two years, how many times did you visit a doctor, hospital, or medical clinic?
❑ NEVER ❑ ONCE OR TWICE ❑ TWO – FIVE ❑ MORE THAN FIVE

Page 1 of 3

Identification of approaches to impact patient trust in healthcare systems: A group concept mapping study

Patient Survey

10. Have you ever been diagnosed with a chronic disease?

❑ YES ❑ NO

11. Do you often have to cancel your medical appointments due to lack of transportation?

❑ YES ❑ NO

12. Have you had to cancel medical appointments because you cannot afford the cost of your co-pay?

❑ YES ❑ NO

13. Do you often have to cancel your medical appointments due to lack of childcare options?

❑ YES ❑ NO

Identification of approaches to impact patient trust in healthcare systems: A group concept mapping study

Patient Survey

Medical Mistrust Index

I would like to ask you a few questions about how you feel about healthcare organizations. When I say healthcare organizations, I am not asking about an individual doctor or nurse or any other person like that. I am asking about organizations where you might get healthcare, like a hospital or a clinic, the healthcare system in general. Please listen to the statements carefully. For each one, tell me whether you strongly disagree, disagree, agree or strongly agree.

Question	Strongly Disagree	Disagree	Agree	Strongly Agree
1. You'd better be cautious when dealing with healthcare organizations.	1	2	3	4
2. Patients have sometimes been deceived or mislead by healthcare organizations.	1	2	3	4
3. I trust that healthcare organizations will tell me if a mistake is made about my treatment.	1	2	3	4
4. Healthcare organizations often want to know more about your business than they need to know.	1	2	3	4
5. When healthcare organizations make mistakes they usually cover it up.	1	2	3	4
6. Healthcare organizations have sometimes done harmful experiments on patients without their knowledge.	1	2	3	4
7. The patient's medical needs come before other considerations at healthcare organizations.	1	2	3	4
8.Healthcare organizations are more concerned about making money than taking care of people.	1	2	3	4
9. Healthcare organizations put the patient's health first.	1	2	3	4
10. Healthcare organizations don't always keep your information totally private.	1	2	3	4
11. Patients should always follow the advice given to them at healthcare organizations.	1	2	3	4
12. I typically get a second opinion when I am told something about my health.	1	2	3	4
13. I trust that healthcare organizations check their staff's credentials to make sure they are hiring the best people.	1	2	3	4
14. They know what they are doing at healthcare organizations.	1	2	3	4
15. Sometimes I wonder if healthcare organizations really know what they are doing.	1	2	3	4
16. Mistakes are common in healthcare organizations.	1	2	3	4
17. I trust that healthcare organizations keep up with the latest medical information.	1	2	3	4

Thank you for all your time today. Your thoughts and experiences have been very helpful and we hope to use them to improve the care that healthcare systems can offer to you and others in the future.

APPENDIX E

CITI HUMAN RESEARCH COMPLETION REPORTS

COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COURSEWORK REQUIREMENTS REPORT*

* NOTE: Scores on this Requirements Report reflect quiz completions at the time all requirements for the course were met. See list below for details. See separate Transcript Report for more recent quiz scores, including those on optional (supplemental) course elements.

- **Name:** Amanda Doty (ID: 4748258)
- **Email:** amanda.doty@temple.edu
- **Institution Affiliation:** Temple University (ID: 926)
- **Phone:** 6103068848

- **Curriculum Group:** Human Research
- **Course Learner Group:** Practice Runs Training
- **Stage:** Stage 1 - Basic Course

- **Report ID:** 15670274
- **Completion Date:** 03-Apr-2015
- **Expiration Date:** 02-Apr-2016
- **Minimum Passing:** 100
- **Reported Score*:** 100

REQUIRED AND ELECTIVE MODULES ONLY	DATE COMPLETED	SCORE
Practice Runs Training (ID: 16313)	03-Apr-2015	2/2 (100%)

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

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Phone: 888-529-5929
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COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COURSEWORK TRANSCRIPT REPORT**

** NOTE: Scores on this Transcript Report reflect the most current quiz completions, including quizzes on optional (supplemental) elements of the course. See list below for details. See separate Requirements Report for the reported scores at the time all requirements for the course were met.

- **Name:** Amanda Doty (ID: 4748258)
- **Email:** amanda.doty@temple.edu
- **Institution Affiliation:** Temple University (ID: 926)
- **Phone:** 6103068848

- **Curriculum Group:** Human Research
- **Course Learner Group:** Practice Runs Training
- **Stage:** Stage 1 - Basic Course

- **Report ID:** 15670274
- **Report Date:** 11-Jul-2016
- **Current Score**:** 100

REQUIRED, ELECTIVE, AND SUPPLEMENTAL MODULES	MOST RECENT	SCORE
Practice Runs Training (ID: 16313)	15-Feb-2016	2/2 (100%)

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

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COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COURSEWORK REQUIREMENTS REPORT*

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- **Email:** amanda.doty@temple.edu
- **Institution Affiliation:** Temple University (ID: 926)
- **Phone:** 6103068848

- **Curriculum Group:** Human Research
- **Course Learner Group:** Practice Runs Training
- **Stage:** Stage 1 - Basic Course

- **Report ID:** 18243052
- **Completion Date:** 15-Feb-2016
- **Expiration Date:** 14-Feb-2017
- **Minimum Passing:** 100
- **Reported Score*:** 100

REQUIRED AND ELECTIVE MODULES ONLY	DATE COMPLETED	SCORE
Practice Runs Training (ID: 16313)	15-Feb-2016	2/2 (100%)

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COURSEWORK TRANSCRIPT REPORT**

** NOTE: Scores on this Transcript Report reflect the most current quiz completions, including quizzes on optional (supplemental) elements of the course. See list below for details. See separate Requirements Report for the reported scores at the time all requirements for the course were met.

- **Name:** Amanda Doty (ID: 4748258)
- **Email:** amanda.doty@temple.edu
- **Institution Affiliation:** Temple University (ID: 926)
- **Phone:** 6103068848

- **Curriculum Group:** Human Research
- **Course Learner Group:** Practice Runs Training
- **Stage:** Stage 1 - Basic Course

- **Report ID:** 18243062
- **Report Date:** 11-Jul-2016
- **Current Score**:** 100

REQUIRED, ELECTIVE, AND SUPPLEMENTAL MODULES	MOST RECENT	SCORE
Practice Runs Training (ID: 16313)	15-Feb-2016	2/2 (100%)

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

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COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COURSEWORK REQUIREMENTS REPORT*

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- **Name:** Amanda Doty (ID: 4748258)
- **Email:** amanda.doty@temple.edu
- **Institution Affiliation:** Temple University (ID: 926)
- **Phone:** 6103068848

- **Curriculum Group:** Human Research
- **Course Learner Group:** Social/Behavioral Research Course
- **Stage:** Stage 1 - Basic Course
- **Description:** Choose this group to satisfy CITI training requirements for investigators and staff involved primarily in Social/Behavioral Research with human subjects.

- **Report ID:** 15670271
- **Completion Date:** 03-Apr-2015
- **Expiration Date:** 02-Apr-2017
- **Minimum Passing:** 75
- **Reported Score*:** 100

REQUIRED AND ELECTIVE MODULES ONLY	DATE COMPLETED	SCORE
Temple University (ID: 1758)	03-Apr-2015	No Quiz
Belmont Report and CITI Course Introduction (ID: 1127)	20-Mar-2015	3/3 (100%)
Students in Research (ID: 1321)	03-Apr-2015	10/10 (100%)
History and Ethical Principles - SBE (ID: 490)	24-Mar-2015	5/5 (100%)
Defining Research with Human Subjects - SBE (ID: 491)	24-Mar-2015	5/5 (100%)
The Federal Regulations - SBE (ID: 502)	24-Mar-2015	5/5 (100%)
Assessing Risk - SBE (ID: 503)	24-Mar-2015	5/5 (100%)
Informed Consent - SBE (ID: 504)	24-Mar-2015	5/5 (100%)
Privacy and Confidentiality - SBE (ID: 505)	20-Mar-2015	5/5 (100%)
Research with Prisoners - SBE (ID: 506)	03-Apr-2015	5/5 (100%)
Research with Children - SBE (ID: 507)	03-Apr-2015	5/5 (100%)
Research in Public Elementary and Secondary Schools - SBE (ID: 508)	03-Apr-2015	5/5 (100%)
International Research - SBE (ID: 509)	03-Apr-2015	5/5 (100%)
Internet-Based Research - SBE (ID: 510)	03-Apr-2015	5/5 (100%)
Research and HIPAA Privacy Protections (ID: 14)	20-Mar-2015	5/5 (100%)
Vulnerable Subjects - Research Involving Workers/Employees (ID: 483)	03-Apr-2015	4/4 (100%)
Conflicts of Interest in Research Involving Human Subjects (ID: 488)	20-Mar-2015	5/5 (100%)
Unanticipated Problems and Reporting Requirements in Social and Behavioral Research (ID: 14928)	24-Mar-2015	5/5 (100%)

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

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COURSEWORK TRANSCRIPT REPORT**

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- **Email:** amanda.doty@temple.edu
- **Institution Affiliation:** Temple University (ID: 926)
- **Phone:** 6103068848

- **Curriculum Group:** Human Research
- **Course Learner Group:** Social/Behavioral Research Course
- **Stage:** Stage 1 - Basic Course
- **Description:** Choose this group to satisfy CITI training requirements for investigators and staff involved primarily in Social/Behavioral Research with human subjects.

- **Report ID:** 15670271
- **Report Date:** 11-Jul-2016
- **Current Score**:** 100

REQUIRED, ELECTIVE, AND SUPPLEMENTAL MODULES	MOST RECENT	SCORE
Students in Research (ID: 1321)	03-Apr-2015	10/10 (100%)
History and Ethical Principles - SBE (ID: 490)	24-Mar-2015	5/5 (100%)
Temple University (ID: 1758)	03-Apr-2015	No Quiz
Defining Research with Human Subjects - SBE (ID: 491)	24-Mar-2015	5/5 (100%)
Belmont Report and CITI Course Introduction (ID: 1127)	20-Mar-2015	3/3 (100%)
The Federal Regulations - SBE (ID: 502)	24-Mar-2015	5/5 (100%)
Assessing Risk - SBE (ID: 503)	24-Mar-2015	5/5 (100%)
Informed Consent - SBE (ID: 504)	24-Mar-2015	5/5 (100%)
Privacy and Confidentiality - SBE (ID: 505)	20-Mar-2015	5/5 (100%)
Research with Prisoners - SBE (ID: 506)	03-Apr-2015	5/5 (100%)
Research with Children - SBE (ID: 507)	03-Apr-2015	5/5 (100%)
Research in Public Elementary and Secondary Schools - SBE (ID: 508)	03-Apr-2015	5/5 (100%)
International Research - SBE (ID: 509)	03-Apr-2015	5/5 (100%)
Internet-Based Research - SBE (ID: 510)	03-Apr-2015	5/5 (100%)
Research and HIPAA Privacy Protections (ID: 14)	20-Mar-2015	5/5 (100%)
Vulnerable Subjects - Research Involving Workers/Employees (ID: 483)	03-Apr-2015	4/4 (100%)
Unanticipated Problems and Reporting Requirements in Social and Behavioral Research (ID: 14928)	24-Mar-2015	5/5 (100%)
Conflicts of Interest in Research Involving Human Subjects (ID: 488)	20-Mar-2015	5/5 (100%)

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COURSEWORK REQUIREMENTS REPORT*

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- **Email:** amanda.doty@temple.edu
- **Institution Affiliation:** Temple University (ID: 926)
- **Phone:** 6103068848

- **Curriculum Group:** CITI Good Clinical Practice
- **Course Learner Group:** Same as Curriculum Group
- **Stage:** Stage 1 - Basic Course

- **Report ID:** 15670272
- **Completion Date:** 30-Mar-2015
- **Expiration Date:** 29-Mar-2017
- **Minimum Passing:** 75
- **Reported Score*:** 100

REQUIRED AND ELECTIVE MODULES ONLY	DATE COMPLETED	SCORE
The CITI Good Clinical Practice Course for Clinical Trials Involving Drugs and Devices (ID: 1350)	20-Mar-2015	3/3 (100%)
Overview of New Drug Development (ID: 1351)	20-Mar-2015	5/5 (100%)
Overview of ICH GCP (ID: 1352)	20-Mar-2015	4/4 (100%)
ICH - Comparison Between ICH GCP E6 and U.S. FDA Regulations (ID: 1354)	24-Mar-2015	4/4 (100%)
Conducting Investigator-Initiated Studies According to FDA Regulations and GCP (ID: 1355)	24-Mar-2015	3/3 (100%)
Investigator Obligations in FDA-Regulated Research (ID: 1356)	24-Mar-2015	5/5 (100%)
Managing Investigational Agents According to GCP Requirements (ID: 1357)	24-Mar-2015	5/5 (100%)
Overview of U.S. FDA Regulations for Medical Devices (ID: 1358)	24-Mar-2015	3/3 (100%)
Informed Consent in Clinical Trials of Drugs, Biologics, and Devices (ID: 1359)	24-Mar-2015	4/4 (100%)
Detecting and Evaluating Adverse Events (ID: 1360)	24-Mar-2015	4/4 (100%)
Reporting Serious Adverse Events (ID: 1361)	24-Mar-2015	4/4 (100%)
Audits and Inspections of Clinical Trials (ID: 1363)	24-Mar-2015	5/5 (100%)
Monitoring of Clinical Trials by Industry Sponsors (ID: 1362)	24-Mar-2015	8/8 (100%)
Completing the CITI GCP Course (ID: 1364)	24-Mar-2015	No Quiz
Temple University (ID: 1758)	30-Mar-2015	No Quiz

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

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COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COURSEWORK TRANSCRIPT REPORT**

** NOTE: Scores on this Transcript Report reflect the most current quiz completions, including quizzes on optional (supplemental) elements of the course. See list below for details. See separate Requirements Report for the reported scores at the time all requirements for the course were met.

- **Name:** Amanda Doty (ID: 4748258)
- **Email:** amanda.doty@temple.edu
- **Institution Affiliation:** Temple University (ID: 926)
- **Phone:** 6103068848

- **Curriculum Group:** CITI Good Clinical Practice
- **Course Learner Group:** Same as Curriculum Group
- **Stage:** Stage 1 - Basic Course
- **Description:** **This ICH E6 GCP Investigator Site Training meets the Minimum Criteria for ICH GCP Investigator Site Personnel Training identified by TransCelerate BioPharma as necessary to enable mutual recognition of GCP training among trial sponsors.**

- **Report ID:** 15670272
- **Report Date:** 11-Jul-2016
- **Current Score**:** 100

REQUIRED, ELECTIVE, AND SUPPLEMENTAL MODULES	MOST RECENT	SCORE
The CITI Good Clinical Practice Course for Clinical Trials Involving Drugs and Devices (ID: 1350)	20-Mar-2015	3/3 (100%)
Overview of New Drug Development (ID: 1351)	20-Mar-2015	5/5 (100%)
Temple University (ID: 1758)	03-Apr-2015	No Quiz
Overview of ICH GCP (ID: 1352)	20-Mar-2015	4/4 (100%)
ICH - Comparison Between ICH GCP E6 and U.S. FDA Regulations (ID: 1354)	24-Mar-2015	4/4 (100%)
Conducting Investigator-Initiated Studies According to FDA Regulations and GCP (ID: 1355)	24-Mar-2015	3/3 (100%)
Investigator Obligations in FDA-Regulated Research (ID: 1356)	24-Mar-2015	5/5 (100%)
Managing Investigational Agents According to GCP Requirements (ID: 1357)	24-Mar-2015	5/5 (100%)
Overview of U.S. FDA Regulations for Medical Devices (ID: 1358)	24-Mar-2015	3/3 (100%)
Informed Consent in Clinical Trials of Drugs, Biologics, and Devices (ID: 1359)	24-Mar-2015	4/4 (100%)
Detecting and Evaluating Adverse Events (ID: 1360)	24-Mar-2015	4/4 (100%)
Reporting Serious Adverse Events (ID: 1361)	24-Mar-2015	4/4 (100%)
Audits and Inspections of Clinical Trials (ID: 1363)	24-Mar-2015	5/5 (100%)
Monitoring of Clinical Trials by Industry Sponsors (ID: 1362)	24-Mar-2015	8/8 (100%)
Completing the CITI GCP Course (ID: 1364)	15-Feb-2016	No Quiz

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

Verify at: https://www.citiprogram.org/verify/?dda0594b-573b-44ff-b50f-11c2385dfc5f

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COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COURSEWORK REQUIREMENTS REPORT*

* NOTE: Scores on this Requirements Report reflect quiz completions at the time all requirements for the course were met. See list below for details. See separate Transcript Report for more recent quiz scores, including those on optional (supplemental) course elements.

- **Name:** Amanda Doty (ID: 4748258)
- **Email:** amanda.doty@temple.edu
- **Institution Affiliation:** Temple University (ID: 926)
- **Phone:** 6103068848

- **Curriculum Group:** Responsible Conduct of Research
- **Course Learner Group:** Responsible Conduct of Research (RCR)
- **Stage:** Stage 1 - Basic Course

- **Report ID:** 15670273
- **Completion Date:** 03-Apr-2015
- **Expiration Date:** 02-Apr-2017
- **Minimum Passing:** 80
- **Reported Score*:** 100

REQUIRED AND ELECTIVE MODULES ONLY	DATE COMPLETED	SCORE
Responsible Conduct of Research (RCR) Course Introduction (ID: 1522)	20-Mar-2015	No Quiz
Research Misconduct (RCR-Basic) (ID: 16604)	20-Mar-2015	5/5 (100%)
Data Management (RCR-Basic) (ID: 16600)	20-Mar-2015	5/5 (100%)
Authorship (RCR-Basic) (ID: 16597)	20-Mar-2015	5/5 (100%)
Peer Review (RCR-Basic) (ID: 16603)	20-Mar-2015	5/5 (100%)
Mentoring (RCR-Basic) (ID: 16602)	20-Mar-2015	5/5 (100%)
Conflicts of Interest (RCR-Basic) (ID: 16599)	20-Mar-2015	5/5 (100%)
CoI Case Study The Case of the Promising New Technology (RCR-Humanities) (ID: 1456)	03-Apr-2015	4/4 (100%)
Collaborative Research (RCR-Basic) (ID: 16598)	20-Mar-2015	5/5 (100%)
Temple University (ID: 1758)	03-Apr-2015	No Quiz

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid independent Learner.

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COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COURSEWORK TRANSCRIPT REPORT**

** NOTE: Scores on this Transcript Report reflect the most current quiz completions, including quizzes on optional (supplemental) elements of the course. See list below for details. See separate Requirements Report for the reported scores at the time all requirements for the course were met.

- **Name:** Amanda Doty (ID: 4748258)
- **Email:** amanda.doty@temple.edu
- **Institution Affiliation:** Temple University (ID: 926)
- **Phone:** 6103068848

- **Curriculum Group:** Responsible Conduct of Research
- **Course Learner Group:** Responsible Conduct of Research (RCR)
- **Stage:** Stage 1 - Basic Course

- **Report ID:** 15670273
- **Report Date:** 11-Jul-2016
- **Current Score**:** 100

REQUIRED, ELECTIVE, AND SUPPLEMENTAL MODULES	MOST RECENT	SCORE
Responsible Conduct of Research (RCR) Course Introduction (ID: 1522)	20-Mar-2015	No Quiz
Authorship (RCR-Basic) (ID: 16597)	20-Mar-2015	5/5 (100%)
Temple University (ID: 1758)	03-Apr-2015	No Quiz
Collaborative Research (RCR-Basic) (ID: 16598)	20-Mar-2015	5/5 (100%)
Conflicts of Interest (RCR-Basic) (ID: 16599)	20-Mar-2015	5/5 (100%)
CoI Case Study The Case of the Promising New Technology (RCR-Humanities) (ID: 1456)	03-Apr-2015	4/4 (100%)
Data Management (RCR-Basic) (ID: 16600)	20-Mar-2015	5/5 (100%)
Mentoring (RCR-Basic) (ID: 16602)	20-Mar-2015	5/5 (100%)
Peer Review (RCR-Basic) (ID: 16603)	20-Mar-2015	5/5 (100%)
Research Misconduct (RCR-Basic) (ID: 16604)	20-Mar-2015	5/5 (100%)
Responsible Conduct of Research (RCR) Course Conclusion (ID: 1043)	20-Mar-2015	No Quiz

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- **Name:** Amanda Doty (ID: 4748258)
- **Email:** amanda.doty@temple.edu
- **Institution Affiliation:** Temple University (ID: 926)
- **Phone:** 6103068648

- **Curriculum Group:** Human Research
- **Course Learner Group:** Biomedical Research
- **Stage:** Stage 1 - Basic Course

- **Report ID:** 15670270
- **Completion Date:** 03-Apr-2015
- **Expiration Date:** 02-Apr-2017
- **Minimum Passing:** 75
- **Reported Score*:** 100

REQUIRED AND ELECTIVE MODULES ONLY	DATE COMPLETED	SCORE
Temple University (ID: 1758)	03-Apr-2015	No Quiz
Avoiding Group Harms - U.S. Research Perspectives (ID: 14080)	20-Mar-2015	3/3 (100%)
Populations in Research Requiring Additional Considerations and/or Protections (ID: 16680)	20-Mar-2015	5/5 (100%)
Belmont Report and CITI Course Introduction (ID: 1127)	20-Mar-2015	3/3 (100%)
History and Ethics of Human Subjects Research (ID: 498)	20-Mar-2015	7/7 (100%)
Basic Institutional Review Board (IRB) Regulations and Review Process (ID: 2)	03-Apr-2015	5/5 (100%)
Informed Consent (ID: 3)	03-Apr-2015	5/5 (100%)
Social and Behavioral Research (SBR) for Biomedical Researchers (ID: 4)	03-Apr-2015	4/4 (100%)
Records-Based Research (ID: 5)	20-Mar-2015	2/2 (100%)
Genetic Research in Human Populations (ID: 6)	03-Apr-2015	2/2 (100%)
Vulnerable Subjects - Research Involving Prisoners (ID: 8)	03-Apr-2015	4/4 (100%)
Vulnerable Subjects - Research Involving Children (ID: 9)	03-Apr-2015	3/3 (100%)
Vulnerable Subjects - Research Involving Pregnant Women, Human Fetuses, and Neonates (ID: 10)	03-Apr-2015	3/3 (100%)
International Studies (ID: 971)	03-Apr-2015	3/3 (100%)
FDA-Regulated Research (ID: 12)	03-Apr-2015	5/5 (100%)
Research and HIPAA Privacy Protections (ID: 14)	20-Mar-2015	5/5 (100%)
Vulnerable Subjects - Research Involving Workers/Employees (ID: 483)	03-Apr-2015	4/4 (100%)
Conflicts of Interest in Research Involving Human Subjects (ID: 488)	20-Mar-2015	5/5 (100%)

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- **Course Learner Group:** Biomedical Research
- **Stage:** Stage 1 - Basic Course

- **Report ID:** 15670270
- **Report Date:** 11-Jul-2016
- **Current Score**:** 100

REQUIRED, ELECTIVE, AND SUPPLEMENTAL MODULES	MOST RECENT	SCORE
History and Ethics of Human Subjects Research (ID: 498)	20-Mar-2015	7/7 (100%)
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