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Facts and Fears in Public Reporting: Patients' Information Needs and Priorities When Selecting a Hospital for Cancer Care

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Abstract

Objective: Public reporting on providers' care quality has potential to empower patients to make evidence-based decisions. Yet patients seldom consult resources like provider report cards in part because they perceive the information as irrelevant. To inform more effective public reporting, we investigated patients' information priorities when selecting a hospital for cancer treatment. We hypothesized patients would be most interested in data on clinical outcomes.

Methods: An experienced moderator led a series of focus groups using a semi-structured discussion guide. Separate sessions were held with patients aged 18–54 and over 54 in Philadelphia, PA, Phoenix, AZ, and Indianapolis, IN, in 2017. All 38 participants had received treatment for cancer within the last two years and had a choice of hospitals.

Results: In selecting hospitals for cancer treatment, many participants reported that they considered factors such as reputation, quality of the facilities, and experiences of other patients. For most, however, decisions were guided by trusted advisors, with the majority agreeing that a physician's opinion would sway them to disregard objective data about hospital quality. Nonetheless, nearly all expressed interest in having comparative data. Participants varied in selecting from a hypothetical list, "the top three things you would want to know when choosing a hospital for cancer care." The most commonly preferred items were overall care quality, timeliness, and patient satisfaction. Contrary to our hypothesis, many preferred to avoid viewing comparative clinical outcomes, particularly survival.

Conclusions: Patients' information preferences are diverse. More, fear or other emotional responses might deter patients from viewing outcomes data such as survival. Additional research should explore optimal ways to help patients incorporate comparative data on the components of quality they value into decision-making.

Public reporting is a vital tool for improving healthcare.(1) In addition to prodding providers to improve, comparative, freely available data on providers' performance quality can empower patients to make evidence-based decisions about where to seek care.(2–9) Patients express strong interest in having access to information about providers' care quality.(10–15) To meet this demand, "report cards" have proliferated.(16–18)

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Yet the record shows that patients seldom consult these resources.(14, 19) Exploring this disconnect, researchers have pinpointed problems in dissemination and communication, including low public awareness of report cards and flaws in how information is conveyed.(2, 4, 14, 20, 21) But a more fundamental obstacle – one concerning the data themselves – must also be addressed: Many patients perceive the information in report cards as irrelevant.(22–24) Understanding patients' perspectives and information priorities can inform more effective public reporting.

Cancer care is an opportune area for exploring these issues. First, there is expanding interest in public reporting in oncology through initiatives like the Prospective Payment System-Exempt Cancer Hospital Quality Reporting Program.(25, 26) Second, cancer patients face complex considerations, as treatment commonly includes both inpatient and outpatient care and often extends long-term. Third, the decision of where to seek care can have profound consequences for cancer patients, as there is wide variation in practices, outcomes, and costs of cancer care across the U.S.(27–30) Thus, research is urgently needed to identify cancer patients' information needs when making these complex and critical choices. Lessons learned can inform public reporting in other areas, including those where care is complex or long-term (e.g. serious or chronic conditions).

We therefore sought to explore patients' information needs and priorities when choosing a hospital for cancer treatment. We used qualitative methods to examine the range of patients' views and experiences, exploring in depth such crucial questions as: Do patients value quality data as a tool to inform their choices? When patients select a hospital for cancer care, which quality data are relevant to them, and why? We hypothesized that patients would be most interested in clinical outcomes data (e.g. survival, complications), as these address vital, short- and long-term patient experiences.(7, 15, 31)

Methods

We conducted a series of focus groups to investigate patients' information needs when selecting a hospital for cancer care. From June to August 2017, one author (SC) with extensive expertise organizing focus groups on healthcare issues moderated six 90-minute groups, following detailed discussion guides developed and pilot rested by the research team (Appendix A). Additional authors and contributors (ALS, EF, AK, AY) attended to take notes and solicit participants' feedback on the findings.

Recruitment was conducted in partnership with Cancer Support Community (CSC), a national non-profit organization serving people impacted by cancer. CSC used consecutive methods to recruit participants online or by telephone from local membership databases. The recruitment invitation identified the study's purpose as exploring "patients' experiences choosing a hospital for cancer treatment." Eligible participants were primary or coequal decision-makers for their healthcare, had received cancer treatment at a hospital within the previous two years, and had a choice of hospitals for treatment. Participants were excluded if any household member worked in healthcare or related industries. Memorial Sloan Kettering Cancer Center's institutional review board determined the study to be exempt. Sessions were audiotaped and transcribed. Our methods are reported according to the Consolidated Criteria for Reporting Qualitative Research guidelines (Appendix B).(32)

Separate sessions were held with patients aged 18–54 and 55 and older in Philadelphia, PA, Phoenix, AZ, and Indianapolis, IN. Sites were selected because they had a diverse patient population and several hospital choices for cancer care. Groups ranged in size from 5 to 7, tending toward the small range of the typical suggested group size, to elicit a sense of all participants' views given the personal relevance of the topic.(33) Thirty-eight individuals participated, with a mean age of 55 years. Seventy-nine percent were female. Nearly three quarters (74%) were white, and 5% were Hispanic. Participants had been diagnosed with a variety of cancers (Table 1). Participants had early and advanced stage cancer, with both primary and recurrent disease.

Sessions opened with participants independently completing a short questionnaire asking: 1) whether the quality of cancer care varies across hospitals, and 2) whether the decision of which hospital to use is important for cancer patients (Table 2). After sharing their responses, participants described their experiences choosing a hospital for cancer care and how they would advise a friend making this decision. The moderator probed participants' interest in data comparing hospitals' cancer care quality and asked what they would do if data contradicted advice from a trusted physician. Participants viewed a list of ten hypothetical measures of hospitals' cancer care quality (Table 3). The list was comprehensive across major domains of cancer care quality,(7, 34) with additional measures for "overall quality" and "patient satisfaction," as research documents strong patient interest in summary and peer opinion data.(10, 35, 36) Participants independently ranked the three most important items on the list and discussed their selections. Data saturation was achieved through a standard protocol of six sessions(33, 37) in which similar themes arose repeatedly.(38, 39) The authors assessed each session before conducting the next to enable exploration of emergent concepts.

Four authors (SC, ALS, EF, DL) reviewed the transcripts to identify major themes and draft a codebook. Two transcripts were manually coded to refine and finalize the codebook (Appendix C). Two authors (EF and DL) then independently coded all transcripts, using QDA Miner software,(40) for the presence of common themes (e.g. views of hospital quality, important factors when selecting hospitals). There was high inter-rater reliability (Percent agreement = 97%; Kappa = 0.95). Coding differences were resolved through consensus with a third party (SC) participating as needed.

Results

Assessing hospital quality

The vast majority of participants (33/38) agreed that cancer care is "better at some hospitals, worse at others." All rated the decision of which hospital to choose as somewhat or very important (Table 2). They drew from experience to emphasize the magnitude of this decision:

> The first [hospital I chose] didn't take the extra step and the second one did, and it changed my prognosis significantly…It's really important to look around at what's out there.
>
> It's life and death…Everybody here's had cancer, so we understand that.

Participants had contemplated a wide range of factors when selecting a hospital, including *reputation and rankings*:

> [The hospital I chose] has the reputation of being one of the best.
>
> I've used US News…you look at all these rankings.

Some were concerned about *cleanliness and infection control*:

> I knew who had MRSA…I knew who had Ebola patients.
>
> There's [3 hospitals]. And I said, okay, let's pick the cleaner one.

Patient experience was also important:

> How is the staff, how professional are they? How do they treat their patients overall?
>
> A machine that doesn't buzz through the night…[If I need] something during the night, do I have to wait ten minutes or can I get it done in five minutes?

Many had sought a hospital *specializing in cancer care*:

> I just went looking for a cancer center.
>
> I looked for one that specialized in prostate cancer.

A few mentioned hospitals' *treatment outcomes*.

> We researched survival rates.
>
> We did some research...They have the best cure rates in the world.

People over data

For many participants, however, the selection process was guided less by facts and figures than by people and relationships. *Friends, family, and other patients* were valued sources of guidance:

> A lot of my friends and family…are on [Facebook], and so I put a little blurb out there and [got advice].
>
> I go to a church [with] 5,000 members. I asked people there who were survivors.

Participants also had relied on clinicians' recommendations. *Trust in physicians* was a common theme:

> I have no idea why [my doctor]…sent me there. I didn't ask her, because I just do what she tells me to do. And I trust.
>
> The surgeon that I went to, I trusted so, so much, and if she would have said, "I want to do it at a different hospital," that's what would have been done.

Most said they would follow their physician's recommendation even if data showed that another hospital offered higher-quality care:

> I would trust the doctor more than the [data].
>
> Your doctor invests in your care for so long…Why would you not listen to what he's saying over [data] that you really don't know how true it is?

Interest in comparable data

Nonetheless, nearly all participants expressed interest in having access to a website comparing hospitals' cancer care quality. They urgently wanted robust data:

> Give me some hard facts, give me some numbers.
>
> I want definitive, objective information.

But again, they wanted the website to include a "human" element to guide and assure them:

> [I would want a] chat box to ease your mind at that moment, you have a question and there's a nurse, chat with a nurse right there, something like that.
>
> If you could make a website that would give me a hug. [laughter]

Information priorities

Participants considered ten hypothetical measures of cancer care quality (Table 3), independently selecting "the three most important facts to know when choosing a hospital for cancer care." Participants varied widely in what they prioritized. The most commonly selected item was **overall quality of cancer care**, with a large majority (27/38) including this in their top three:

> Really it's the overall quality [that matters]. You can't pick it down to small things.
>
> You [want] a hospital [to] accommodate everything you might want.

How quickly patients get the cancer care they need was the second most popular item, selected by half (19/38) of participants. They recounted the urgent need for treatment to proceed quickly:

> You want care as quickly as you can get it, so that you know what's going on and you're able to have all those questions answered.
>
> When I went to the second hospital I [received] treatment right away…I felt like I had a better quality of life. I felt like something was happening…It made a big difference.

Nearly half (15/38) selected **how satisfied patients are with the hospital's cancer care**:

> [This] just sums up the whole rest of the list.
>
> I think a lot of these [other measures] draw into that.

About a third (14/38) prioritized **whether the hospital minimizes treatment inconveniences for patients**:

> [At my hospital] I've seen four doctors in the same day. [At my previous hospital], it took me two days to see two separate doctors, and I scheduled it two months in advance.

> [My hospital] schedules all their appointments in one day…so [patients] don't have to keep taking time off or finding someone to keep their children or find a way to get there.

Others, however, were willing to trade convenience for better care:

> [Convenience] was less important than [the hospital] doing everything that could be done to keep me alive.

> [I chose] a cancer specialist hospital...it's something like 40 minutes in good traffic. But it was worth it to me.

A third (13/38) selected **how often patients experience complications from cancer treatments**:

> Complications says something about care. If you have a high number of complications, something's wrong.

> How many people died from MRSA or…had their left breast taken by accident? You just want to know…do they make a lot of mistakes?

About a fifth (8/38) prioritized the **number of cancer patients treated at the hospital**:

> That to me indicates how much they know or how much experience maybe they've gained with what they're doing.

> I wanted [a hospital] that had done this a lot…not one that just had five or six cases in the last year or something like that.

> Some, however, disputed volume's relevance to individual patients: It doesn't make any difference. It's about me. [laughs]

> I can be the only one and I'm okay with that.

Fewer than a fifth (7/38) prioritized **how common it is for patients to be alive four years after cancer surgery**:

> Number one for me is how common it is for patients to be alive. The other [items on the list] hardly even matter to me.

> I think that's kind of important for most of us.

Many, however, were visibly unsettled by this item. They believed such disturbing information was best avoided:

> I love data, [but] I can't stand…seeing survival rates because that just upsets me.

> I do better living in the moment and following the instructions I have and feeling good with the doctor and the hospital.

Some went on to deny that survival data were relevant to individual patients:

> I don't care to know [that data]. That patient's cancer is different than my cancer.

> Everybody is different, it's individual. So I don't know how you could make decisions based strictly on that [data].

Unprompted, they also disputed the accuracy of survival rates:

> The second that data is put out, it's already five to ten years old.

> You can have five different people, one who is diagnosed super, super early, one who was diagnosed super, super late, one who [gets] a lumpectomy, one a mastectomy, one with reconstruction, you know, all these different things. And to lump [them together] in survival rate…tells you so little…It's apples to oranges.

Participants also diverged in their views of **how well the hospital follows recommended guidelines for cancer care**. Some (6/38) valued it highly:

> You want them to be up to date on the most advanced practices and…doing what they need to do.

Yet others interpreted guideline adherence in negative terms:

> Not following them sometimes is a plus…I want places ready to do something experimental if it might help.

> I do not want my doctor just to check off the list, "I gave you this, I gave you that" … I hope [my doctor] looks at me individually and says, "My experience and what I read says that we can do this, even if it steps outside the guidelines, let's do it."

A few (4/38) prioritized **whether all patients are treated equally**:

> I want to go to a place where they say, "These are all my patients, we treat them all the same and we treat them all well."

> Always number one to me, in every area, [is] whether I'm going to get the same treatment [being] an African American.

Most, however, were taken aback by this item. They agreed that equity was important but doubted that patients were ever treated unequally:

> I personally did not know of anybody that didn't get the treatment they needed.

> Everyone seems to be treated equally.

Least popular was **how often patients with terminal disease receive the hospice services they need.** Only one participant ranked this measure as a top-three priority. A few others agreed this information is important:

> I didn't put it in my top three, but it is important to me…to give dignity to your dying process and to keep you comfortable.

> That's important to know about, because death is a part of cancer.

Most, however, said hospice data were irrelevant to them:

> If I’m looking for a hospital to get me well, I’m not going to be thinking about hospice.
>
> You’re not going to be looking at what their hospice care is. You are going to be concentrating on how are you going to stay alive.

As with survival rates, many said hospice data were disturbing and should be avoided:

> Can’t even think about it at this point. Forward-thinking, not even thinking about hospice.
>
> It would just take away all that cancer patients need to live. We need to be strong and positive.

Discussion

Our study sheds light on the information that patients would value in report cards and other public reporting efforts to promote evidence-based decision-making. To the question of whether patients value quality data as a tool to inform their choices, most participants in our focus groups answered “Yes”: Nearly all wanted access to robust data on hospitals’ quality of cancer care, and many described their own attempts to research and compare providers.

Our study also explored the question of which quality data are relevant to patients and why. Most participants in our focus groups attached great importance to summary and patient experience measures -- findings consistent with previous research in other healthcare domains.(10, 35, 36, 41) Beyond these items, however, their information priorities varied widely. Some highly valued guideline adherence, for instance, while others dismissed it as “cookbook medicine.” Similarly, some participants prioritized volume of patients treated and equated it with experience, while others interpreted this measure as reducing patients to “just a number.” This diversity in participants’ expressed priorities is also consistent with findings from the decisionmaking literature.(41–45)

More, participants’ information priorities often reflected their specific experiences, needs and concerns. For example, while the majority of white participants viewed equity as a non-issue, some African-American participants prioritized equitable care. This finding speaks to the extensive literature on race-related attitudes and experiences among patients, where medical mistrust among African Americans emerges as a signal effect of racism.(46–48)

While no dimensions of quality presented in this study were universally rejected as unimportant, contrary to our hypothesis, few participants prioritized having access to comparative data on clinical outcomes. Their stated information priorities thus diverged from those of healthcare professionals, policy makers, researchers, and quality improvement experts, for whom outcomes – particularly survival rates -- are often paramount.

Notably, most participants disfavored viewing hospitals’ survival data and, similarly, hospice data, not because they saw the information as unimportant but because it was too emotionally disturbing. Many vividly recounted fearing for their lives and avoiding information touching mortality. When confronted with it in our study, they denied its accuracy or relevance to their individual situations. No other measures prompted such reactions. This finding is consistent with the literature on the psychology of decision-making, in which patients' choices are modeled as multi-dimensional, involving both cognition and emotion.(49, 50) It also concords with research on the emotional and social dimensions of serious, chronic, or stigmatized health conditions, which may powerfully affect patients' cognition and behavior.(51–56)

So how might public reporting efforts better help patients make evidence-based decisions, thereby improving their care outcomes? Our findings, though suggestive and exploratory, underscore the pivotal role of referring physicians. Consistent with other research,(57–60) participants in our study often depended on their physicians, trusting their advice even in the face of data that would support a different choice. Thus, public reporting efforts might benefit from engaging clinicians to consult the data and advise patients accordingly.(51, 61) However, this task will present its own challenges that may require further study.(14, 62, 63)

More, in guiding patients to select hospitals with better outcomes, public reporting must present emotionally charged data in a way that is engaging rather than upsetting. To this end, public reporting could draw lessons from choice architecture, in which "good default settings" minimize unwanted effects of emotion on decision-making without restricting choice. (64–66) For example, choice architecture might entail hospital report cards using default star ratings, sorting defaults, or other strategies to give greater visual prominence to providers with better survival outcomes. Softening potentially upsetting data in these or other ways could increase the likelihood of patients engaging with public reporting resources.

Furthermore, translating patients' expressed priorities into user-friendly performance reports is crucial. Research demonstrates that effective presentation of performance data is vital to enabling patients to digest the information and incorporate it into their decision-making. (67, 68) To this end, public reporting must clearly define and present a range of quality measures that patients value, such as overall quality of care, timeliness of treatment, and patient satisfaction, and enable users to focus on the information that matters most to them.(22–24) Presentation is particularly crucial when measures conflict (e.g. if timeliness is inconsistent with patient satisfaction) and are more difficult to reconcile.(67)

Our study has some limitations. First, as with any focus group study, the findings are intended not to quantify or generalize but to elicit the range and dynamics of patients' views. Second, findings reflect expressed views rather than observed behavior. Future work should assess how patients would incorporate comparative quality data into their real-world decision-making.(10) Third, drawing from a population of cancer patients means the perspectives we captured are retrospective. Patients without prior cancer experience might have different views and priorities. More, patients who participate in support communities like CSC may be different from less active patients.

Our findings highlight the challenge of empowering patients to make decisions informed by data, particularly when crucial evidence may be deeply disturbing. Additional research should explore how best to address these potent forces. Nonetheless, nearly all participants in our study understood that the quality of cancer care varies across hospitals, and they were enthusiastic about having access to comparative performance data. Public reporting that addresses patients' priorities and concerns – including those around emotionally charged data --could help to overcome a key barrier to patient engagement.

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Appendix A.: Discussion Guide

1. Introduction (2 Minutes)

- Welcome, everyone. My name is Susan, and thank you for coming today.
- We will be talking today about how patients choose a hospital for cancer treatment.
- I am joined today by [names]. We are an independent research team from Memorial Sloan Kettering Cancer Center and have no vested interest in anything we will be discussing. The goal of this research is to help other patients facing this decision. Your open and honest opinions are what we are looking for. No right or wrong answers.
- You will receive your $50 gift card immediately after the session
- We are recording today's conversation to help me remember what we talk about. [names] are here to help me take notes and stay on track with time.
- Everything we talk about will be kept confidential and anonymous.
- Similarly, I'm asking you all to keep today's conversation confidential. To respect everyone's privacy, what is said in here should not be discussed outside of this session.
- Please keep in mind that we want everyone to have a chance to speak. In a focus group, it is important to hear everyone's opinions.
- Also, your participation is voluntary. You can stop participating at any time.
- Please turn off your cell phones so our conversation isn't interrupted.
- Finally, please turn your name cards towards me. Write your names on there if you haven't already.
- Ok, let's get started by going around the room and introducing ourselves. Please tell us your first name and where you live.

2. Beliefs/knowledge about hospital quality/variation (10 minutes)

- **a.** Now I’d like everyone to look at the first 2 questions on the piece of paper you all should have. Take a moment to read both questions, and then mark down your answers. Let me know if you need a pen or anything else.
- **b.** So let’s talk about these 2 questions together. First let’s discuss the quality of cancer care at hospitals. What do you all think: Are there differences among hospitals, or hospitals all about the same in the quality of cancer care that they provide?
    - **i.** Probe for thinking and experiences – why?
    - **ii.** Anyone feel similarly to X? Anyone have a different view?
    - **iii.** Go around and make sure everyone participates
- **c.** So now let’s talk about the second question: For cancer patients, how important is the decision of which hospital to use?
    - **i.** Probe – why is it important/not?
    - **ii.** Anyone feel similarly to X? Anyone have a different view?
    - **iii.** Go around and make sure everyone participates

3. Selecting a hospital – experiences, considerations, use of data (15–20 min)

- **a.** Now let’s talk about how you came to be treated at a particular hospital. In selecting a hospital, what information did you or your doctor consider?
    - **i.** Open discussion – make sure everyone weighs in
    - **ii.** Probe as needed:
        - **1.** **What do you mean by this** [reputation, etc.]?
        - **2.** **What information did your doctor use** to give you the recommendation?
    - **iii.** How about other things that we haven’t mentioned? Was there anything else that you or your doctor considered in selecting a hospital?
- **b.** Did you or your doctor seriously consider other hospitals, besides the one you used?
    - **i.** If yes, why?
    - **ii.** If no, why not?
- **c.** When choosing a hospital, did any of you or your physicians look for information comparing different hospitals?
    - **i.** If no: why not?

- **ii.** If yes: what did you or your doctor look for? Why?
    - **1.** What did you find?
    - **2.** Was the information useful? Why or why not?

4. Useful information for patients (60 minutes)

- **a.** Now imagine you were helping a good friend choose a hospital for cancer care. Let's say your friend has a choice of several hospitals, all in their insurance network and all conveniently located. What would you advise your friend to think about when deciding which hospital to use?
    - **i.** Probe as needed:
        - **1.** What information would be important for your friend to know?
        - **2.** What do you mean by this…
        - **3.** What else should your friend think about when picking a hospital?
- **b.** Now I'd like you to imagine if there was a website with information about the quality of cancer care at different hospitals: If you were selecting a hospital for cancer care, would you use this website?
    - **i.** Why or why not?
    - **ii.** Go around and make sure everyone participates
- **c.** Now let's say this website showed you all kinds of facts about these hospitals – information like the things listed under #3, on the other side of that questionnaire you all have. [Show list on screen and – read aloud] I'd like you think about which of these facts would be most important to know about.
    - **i.** So take some time to think, and then mark the top 3 things that you would want to know when choosing a hospital for their cancer care. Write a 1 on the line next to the most important thing, then a 2 for the second most important, and 3 for third most important. I'll give you a minute or 2, please take your time.
    - **ii.** Does anyone need more time? Great - now let's go around the room and share what we wrote down.
    - **iii.** Discuss any remaining items – what about this? Is this important to know about? **Do hospitals vary on these issues?**
- **d.** Now I'd like to show you a website called Hospital Compare [show the website]. This website rates the quality of care at different hospitals. There is no detail about cancer care specifically, but there is a lot of other information.
    - **i.** Has anyone heard of or looked at Hospital Compare before?

        1. [show of hands]
        2. If yes, did you or your doctor look at these ratings when you chose a hospital for cancer care?

    ii. So let's look at this website together. Say you live in Chicago and want to look at hospitals in your area – so you put Chicago in the search bar [search Chicago, IL]. What you get is a list of different hospitals, with star ratings and other information for each.

        1. What do you think about this information?

    iii. This website also lets you compare hospitals – I'll show you how that works: Let's say we want to learn more about Mercy and Rush hospitals – we'll add them to our compare list and then hit the Compare button. [Select Mercy and Rush, hit Compare]. So here's what we see for Mercy and Rush.

        1. What do you think about this information?
        2. What draws your eye? Is there anything you want to click on? [let them free explore]
        3. What do you like about what you see here, and why?
        4. What do you not like, and why?
        5. What here is useful to patients in selecting a hospital for cancer care?
        6. Is there anything missing here that would be helpful for cancer patients to know?

    iv. Now let's look more closely at these 2 hospitals. [click Readmissions – 30-day readmissions - COPD]. So here, we see a couple different things:

        1. First, we see that Rush has an overall rating of 4 stars, and Mercy has 2 stars.
        2. Second, we see information about the death rates for patients with an illness called chronic obstructive pulmonary disease, or COPD. We see here that the death rate for patients at Rush is similar to the national average. The death rate at Mercy is better than average.
            a. What do you think about this information?
            b. Which is more important to know – the star rating or the death rate information?
            c. If you were a patient with this condition, which hospital would you choose, and why?

            - **i.** For those who chose Rush - what if the death rate at Rush was worse than the national average - would that change your thinking?
            - **ii.** Go around, make sure everyone participates

    - **3.** Ok, so now you all have an idea of which hospital you'd use, based on the information on this website. But what if your doctor recommended the other hospital, not the one you chose? What would you do in that situation, and why?
        - **a.** Go around and make sure everyone participates

5. Other Comments/thoughts (5 min)

- **a.** [Allison will read summary of key points] Does this seem like a fair summary of our conversation today? Anything you'd add or change?
- **b.** Is there anything else you can tell me that we have not had a chance to cover? What else would be helpful for patients to know when choosing a hospital for cancer treatment?
- **c.** Do you have any other advice for patients trying to choose a hospital?
- **d.** Ok great – that's all we have for you today. Thanks so much for participating in our study. **Please just leave the papers you were working on so I can collect them**. And feel free to grab some food on your way out. Thanks again, everyone!

Appendix B:: COREQ checklist for Chimonas, Patients' interest in comparable information on hospitals' quality of cancer care

Number and Item	Guide questions/description	Reported
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Methods
2. Credentials	What were the researcher's credentials? e.g., PhD, MD	Title Page
3. Occupation	What was their occupation at the time of the study?	Title Page
4. Gender	Was the researcher male or female?	N/A
5. Experience and training	What experience or training did the researcher have?	Title page, methods
6. Relationship established	Was a relationship established prior to study commencement?	Methods
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g., personal goals, reasons for doing the research	Methods
8. Interviewer characteristics	What characteristics were reported about the interviewer/ facilitator? e.g., bias, assumptions, reasons and interests in the research topic	Methods
9. Methodological orientation and theory	What methodological orientation was stated to underpin the study? e.g., grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Methods

Number and Item	Guide questions/description	Reported
10. Sampling	How were participants selected? e.g., purposive, convenience, consecutive, snowball	Methods
11. Method of approach	How were participants approached? e.g., face-to face, telephone, mail, e-mail	Methods
12. Sample size	How many participants were in the study?	Results
13. Non-participation	How many people refused to participate or dropped out? Reasons?	N/A
14. Setting of data collection	Where was the data collected? e.g., home, clinic, workplace.	Methods
15. Presence of nonparticipants	Was anyone else present besides the participants and researchers?	Methods
16. Description of sample	What are the important characteristics of the sample? e.g., demographic data, date	Results, Table
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Methods
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Methods
20. Field notes	Were field notes made during and/or after the interview or focus group?	Methods
21. Duration	What was the duration of the interviews or focus group?	Methods
22. Data saturation	Was data saturation discussed?	Methods
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
24. Number of data coders	How many data coders coded the data?	Methods
25. Description of the coding tree	Did authors provide a description of the coding tree?	Methods
26. Derivation of themes	Were themes identified in advance or derived from the data?	Methods
27. Software	What software, if applicable, was used to manage the data?	Methods
28. Participant checking	Did participants provide feedback on the findings?	Methods
29. Quotations presented	Were participant quotations presented to illustrate the themes/ findings? Was each quotation identified? e.g., participant number	Results
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Results, Discussion
31. Clarity of major themes	Were major themes clearly presented in the findings?	Results, Discussion
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Results, Discussion

Appendix C.: Codebook

- **I.** Patient attitudes
    - **A.** Quality of cancer care at hospitals
        - **1.** Varies
        - **2.** Does not vary
    - **B.** Choice of hospitals

        1. Is somewhat or very important
        2. Is not important
    - **C.** Considered different hospitals for their treatment
    - **D.** Would want/use a website with comparable information
        1. Want some personalized or human element (re: chat function on website)
        2. Want to know where the information is coming from/if it is reliable
        3. Would not want/use a website with comparable information

- **II.** Information patients considered, or would advise a friend to consider, when selecting a hospital
    - **A.** Sought information on the quality of care at hospital(s)
        1. Did not seek information/avoided information
    - **B.** Chose a surgeon/physician, and followed them regardless of hospital affiliation (selected a treating physician)
    - **C.** Followed their (referring) doctor's advice (talked to their doctor about options for care, re: referrals)/ Followed health professional's advice/ second opinion
    - **D.** Sought/followed advice from friends, family, or other patients
    - **E.** Any other factors mentioned (Note: make a list of these, and see if any come up multiple times)
        1. Structure: e.g., staffing, teaching hospital, availability of resources in one place, specialization, cleanliness, environment, appearance, EMR, technology, volume, experience re: physician/staff
        2. Process: e.g., clinician-to-clinician communication, clinician-to-patient communication, what is being done to the patient, the treatments received, comforting the patient, patient experience in a hospital
        3. Outcomes: e.g., what happens to the patient, patient mortality, complications of care, symptom management, infections
        4. Reputation: e.g., reputation, best/worst hospital/top rated
        5. Other: e.g., non-hospital factors, location, insurance coverage, out of pocket expenses
    - **F.** Hesitant to provide concrete advice to another patient; Stressed the individual experience

            1. Advocate for self
            2. Suggested asking questions and provided general guidance, but not specific about what questions to ask/slow down
            3. Right thing is different for everyone – my experience may not mean anything for you
        G. Patient comfort level- subjective as opposed to structure or process

III. Patients' views of 10 measures of hospital quality

- **A.** Overall summary measure
- **B.** Timeliness
    - **1.** Urgency to make decision quickly/time pressure
- **C.** Patient satisfaction /patient testimonials
- **D.** Treatment inconveniences
- **E.** Complications
- **F.** Volume
- **G.** Survival/mortality
    - **1.** Scared, upset by this information - Did not even want to think about death, only treatment
    - **2.** Denied this was relevant – I'm not a statistic, everyone is different
- **H.** Follow guidelines
    - **1.** Saw guidelines as a negative
- **I.** Equity
    - **1.** Questioned whether unequal treatment was an issue
- **J.** Hospice services
    - **1.** Scared or upset by this information, did not want to think about it

IV. Hospital Compare exercise

- **A.** Star rating more influential than death rate information
- **B.** Death rate information more influential than star rating
- **C.** Neither star rating nor death rate – would do more research, would not make a decision yet
- **D.** Trust in doctor's recommendation overrides website data
    - **1.** Did not know how their doctors made their recommendations/ want more information/would ask doctor why

2. Said doctors recommend within their health system, or based on physician relationships

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Table 1

Characteristics of Focus Group Participants[1]

Characteristics	All (N=38)	Ages 18–54 (N=18)	Ages 55+ (N=20)
Mean (median) Age	55(55)	44 (45)	64 (66)
No. (%) Male	8 (21)	2 (11)	6 (30)
No. (%) Hispanic	2 (5)	2 (11)	0 (0)
No. (%) by Race			
White	28 (74)	15 (83)	13 (65)
Black	9 (24)	2 (11)	7 (35)
American Indian or Alaska Native	1 (3)	1 (6)	0 (0)
No. (%) by job status			
Retired	15 (39)	1 (6)	14 (70)
Employed	13 (34)	10 (56)	3 (15)
Unemployed	6 (16)	4 (22)	2 (10)
Other	4 (11)	3 (17)	1 (5)

[1] Participants had been treated for the following cancers: Brain, breast, colorectal, esophagus, liver, lung, melanoma, multiple myeloma, non-Hodgkin’s lymphoma, ovarian, pancreatic, prostate, soft tissue sarcoma, renal, thyroid, and uterine.

Table 2

Participants' Views of Hospitals' Cancer Care

In general, the quality of cancer care is:	**No. (%)**
About the same at all hospitals	5 (13)
Better at some hospitals, worse at others	33 (87)
For cancer patients, how important is the decision of which hospital to use?	
Not important	0 (0)
Somewhat important	3 (8)
Very important	35 (92)

Table 3

Participants' Preferences for Information on Hospitals' Cancer Care Quality

What are the three (3) most important facts to know when choosing a hospital for cancer care? Please write "1" for the most important, "2" for the second most important, and "3" for the third most important.	**1 No. (%)**	**2 No. (%)**	**3 No. (%)**	**Top 3 No. (%)**
Overall quality of cancer care	17 (45)	4 (11)	6 (16)	27 (71)
How quickly patients get cancer care	8 (21)	5 (13)	6 (16)	19 (50)
How satisfied patients are with cancer care	3 (8)	8 (21)	4 (11)	15 (39)
Whether the hospital minimizes inconveniences	0 (0)	6 (16)	8 (21)	14 (37)
How often patients experience complications	1 (3)	6 (16)	6 (16)	13 (34)
Number of cancer patients treated at the hospital	2 (5)	2 (5)	4 (11)	8 (21)
How common it is for patients to be alive four years after surgery	5 (13)	1 (3)	1 (3)	7 (18)
How well the hospital follows recommended guidelines	0 (0)	5 (13)	1 (3)	6 (16)
Whether all patients are treated equally	2 (5)	1 (3)	1 (3)	4 (11)
How often patients with terminal disease receive hospice services	0 (0)	0 (0)	1 (3)	1 (3)