

Original Article

Stakeholders' Perceptions and Information Needs Regarding Research Medical Donation



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Abstract

Context. Research Medical Donation (RMD), which entails collecting human tissue within hours after death, benefits cancer research but data are limited regarding barriers institutions face accruing patients to RMD programs.

Objectives. The objective of this study was to generate stakeholder perspectives to best inform the complex RMD process, which includes communicating with patients and their proxies and procuring tissue in a timely manner, all the while respecting end-of-life care sensitivities.

Methods. We explored perceived core needs and challenges of RMD by engaging stakeholders (cancer clinicians, patients, and their caregivers) in eight teleconference focus groups. Breast, pancreatic, and lung cancer clinicians comprised two groups. Each cancer separately had two groups for patients and their caregivers combined. Qualitative analysis of focus group transcripts included identifying and reaching group consensus on transcript themes and establishing agreement on consensus templates to identify primary common and divergent themes.

Results. A total of 45 people (13 clinicians, 24 patients, eight caregivers) participated in the groups. The themes identified were as follows: 1) clinicians and patients had limited previous knowledge about RMD; 2) RMD was perceived to mainly benefit research; 3) logistical and privacy questions arose; 4) introducing RMD was deemed sensitive, with patient-specific timing; 5) rare and/or virulent cancers appeared associated with willingness to participate in RMD.

Conclusion. Patients, families, and cancer clinicians have generally low knowledge of RMD but, upon learning about it, deem it valuable for scientific advancement (particularly for rare and virulent cancers), necessary to be carried out with individualized sensitivity to end-of-life issues, and through training programs with involved clinical staff. *J Pain Symptom Manage* 2019;58:792–804. © 2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Autopsy, stakeholders, perceptions, knowledge, focus groups, medical donation

Introduction

Despite recent therapeutic improvements, many cancers are still associated with a poor prognosis. Therefore, a better understanding of the molecular underpinnings of cancer and its treatment effects is imperative. Research Medical Donation (RMD), the process of collecting human tissue within approximately two to six hours¹ after death, has been recognized to have benefits in tissue analysis,^{2–5} including the ability to sample both normal

and cancer tissues, to obtain relatively large samples, and to allow comparison of not only the primary cancer site to metastases but also pretreatment archived tissue to post-treatment tissue. The literature has begun to describe challenges faced in developing RMD programs^{6,7} but is limited, primarily by focusing on lung cancer at a single center. That same center more recently published additional data⁸ on the perspectives of patients with lung cancer actually enrolled in the RMD

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process, with the main themes that patients wanted to contribute to cancer research and ensure their family received information about the use of their bodily tissues.

At Memorial Sloan Kettering Cancer Center (MSK), we started an RMD program in 2015, which is now under the auspices of a formal MSK Pathology core facility, and a protocol outlining the process of obtaining tissue for cancer research. Despite this foundation, program leadership recognized a need for iterative and formative evaluation of key issues surrounding RMD was needed in a breadth of areas, including the following: stakeholder knowledge, acceptance, and impressions about how to optimize RMD; logistic concerns related to RMD; and the sensitive nature of communication about making such arrangements at the end of life. We also sensed that perspectives of stakeholders from different disease types may vary. For instance, we observed some understandable degree of hesitancy toward the prospect of RMD from patients, families, and clinicians in our breast cancer group, given the relatively large number of therapies available for this cancer, and the relatively young age at which patients are treated. Anecdotal reports from our thoracic oncologists, however, suggested that RMD acceptance appears to be higher among individuals affected by cancers with poorer prognoses, such as lung cancer.

To further investigate these issues, we convened focus groups of relevant stakeholders (clinicians, patients, and caregivers) to assess knowledge and opinions about the RMD process, including how to improve it. We hypothesized that RMD awareness and knowledge would be minimal across stakeholder groups and that improvements needed would center on the sensitive nature of end-of-life communication. In addition, we believed different cancers would carry their own unique need profiles around RMD, with poorer prognosis and rarer cancers being associated with a greater perceived appropriateness for RMD.

Methods

The MSK Institutional Review and Privacy Boards determined this study to be of minimal risk to participants.

Study Design

All focus groups were held via teleconference calls. The study team organized and conducted focus groups with clinicians (medical oncologists and medical oncology nurses) and separately, with patients. In addition, patients were invited to have a close family member or informal caregiver participate in their focus group session. Focus groups were conducted according to established methodological guidelines and

led by a qualitative methods specialist in MSK's Department of Psychiatry and Behavioral Sciences.⁹ We conducted a total of eight focus groups. For optimal scientific rigor, there were two focus groups with clinicians, each aimed to have approximately six to eight participants. Therefore, seven to 10 participants were invited, as participant no-shows are known to be common. Similarly, we held two patient/caregiver focus groups for each disease type under study. We recruited MSK patients actively receiving follow-up or treatment for one of three distinct cancer types (of any stage): breast, pancreatic, and lung. We choose these cancers because 1) breast and lung cancers are commonly diagnosed cancers, which both makes recruitment easier for these cancers and may impact stakeholders' impressions about RMD; 2) pancreatic cancer is much rarer than breast and lung cancers, is associated with treatment options of relatively modest effectiveness, and was the focus of the prior RMD program of study coinvestigator Dr. Christine Iacobuzio-Donahue at Johns Hopkins; and 3) lung cancer is common and associated with poor prognoses, although it has a relatively larger number of molecularly targeted treatment options.

Focus Group Recruitment and Conduct

A recruitment letter with an addressed and stamped opt-out card was mailed to patients whose medical oncology clinicians identified as potentially feeling sufficiently well to participate in the study. If no opt-out card was received by the study team, staff telephoned patients to offer two different dates on which each focus group was to be held. Clinicians (medical oncologists and medical oncology nurses) received a recruitment invitation by e-mail and could similarly opt out. Verbal consent was obtained over the telephone from all patients and caregivers who agreed to participate before the scheduled focus group dates. Clinicians agreeing to participate provided written consent by e-mail, or verbally. Agreement to participate was confirmed both at scheduling and the beginning of each focus group session. Both clinicians and patients/caregivers participated in one 90-minute teleconference focus group. Study team members facilitated the group together in person in an MSK meeting space. Patients/caregivers received \$25 as an incentive for their participation. The focus groups were led by a team member (E. S.) with qualitative methods expertise and a social/health psychologist (J. G. H.). These team members facilitated each group using a semistructured focus group guide (see [Appendix](#)) examining key topics established by the entire study team, including previous knowledge about RMD, perceived benefits of RMD, areas of concern about RMD, and communication needs for discussing RMD. Stakeholder impressions on each topic were explored using a mixture of closed- and

open-ended questions with subsidiary probes to follow-up on participant responses. For participants to have a basic knowledge of the RMD topic from which the ensuing discussions could be built, each focus group session began with a brief definition and description of RMD. All focus groups were audio-recorded for transcription and subsequent data analysis.

Data Analysis

Analysis of the focus group transcripts was guided by an inductive thematic content analysis approach^{10–13} and involved several phases of both independent and collaborative analyses across a multidisciplinary coding team (J. G. H., E. S., D. R., K. L., M. G., and E. K.). First, each team member reviewed each transcript independently and recorded their observations about key themes in an analysis template, along with illustrative quotations supporting each key theme. After these independent analyses, the coding team met to reach consensus regarding the primary themes for that transcript. A consensus template was generated describing the team's views about key themes from each transcript, along with supporting illustrative quotations. This process continued until all transcripts were both independently and collaboratively reviewed and analyzed. The themes identified included both established themes (i.e., themes based on the existing, limited literature^{6,7,14} and our team's observations) and inductive themes that emerged during analysis of the transcripts. Inductive themes included stakeholder views regarding RMD in relation to aspects of individual cancer type treatment availability, prognosis, and commonness. The final analysis phase included each team member independently reviewing the consensus templates and generating opinions about the primary themes observed across all transcripts. The team then met to reach consensus regarding the identification and description of these key convergent and divergent themes, which included organization of subthemes within the overarching themes identified.

Results

Study Participants

Of the 37 clinicians invited to participate, 30 wanted to (but 13 could not due to scheduling conflicts), three did not respond, and four declined. Of the 47 patients invited to participate, 17 could not due to scheduling conflicts or health issues, and eight declined. In total, 45 people (13 clinicians, 24 patients, and eight caregivers) participated in the focus groups, from 2017 to 2018. Table 1 shows demographics of the two focus groups for clinicians, which included medical oncologists as well as medical oncology nurses, all with varying genders, race/ethnicity, and cancer type expertise. Table 2 shows

Table 1

Demographics of Clinician Focus Group Participants

Demographic	Group 1 (n = 7)	Group 2 (n = 6)
Age (mean age in yrs, range)	39 (32–55)	32 (28–39)
Not reported	1 (14%)	2 (33%)
Gender		
Male	3 (43%)	1 (17%)
Female	4 (57%)	5 (83%)
Race/ethnicity		
White/Caucasian	3 (43%)	4 (67%)
Asian	3 (43%)	0 (0%)
Not reported	1 (14%)	2 (33%)
Clinician type		
Oncologist	5 (71%)	3 (50%)
Nurse	2 (29%)	3 (50%)
Specialty		
Pancreatic	3 (43%)	4 (67%)
Lung	1 (14%)	1 (17%)
Breast	3 (43%)	1 (17%)
Time in practice, yrs		
<15	5 (71%)	4 (67%)
15–24	2 (29%)	0 (0%)
25+	0 (0%)	2 (33%)
Percent of clinical time		
<25	2 (29%)	3 (50%)
26–50	4 (57%)	3 (50%)
51+	1 (14%)	0 (0%)

demographics of the patient and caregivers participating in the six additional focus groups (two per cancer type: pancreatic, lung, and breast). Mean ages were slightly lower for the patients with breast cancer (56 years) than the pancreatic (68 years) and lung cancer (72 years) patients. Patients with breast cancer also had a greater number of years since their cancer diagnosis compared with patients with pancreatic and lung cancers. Caregiver relationships to the patients included spouse, sibling, and friend.

Qualitative Analyses

Saturation was reached over iterative rounds of thematic content analysis, as was consensus among the coding team. Tables 3 and 4 show the themes that emerged (commonalities and differences per topic area, respectively) from analysis of the focus group transcripts, as well as exemplar participant quotes. The findings identified from data analysis included the following themes:

Clinicians and Patients Generally Had Limited to No Previous Knowledge About RMD. Although a few clinicians had some basic awareness of MSK's recent RMD implementation, there was generally limited knowledge across all stakeholders, such as one patient with pancreatic cancer noting "Up until a week ago, I knew nothing about this." Logistical questions and worries about family comfort level with RMD were expressed, such as one patient commenting "I just don't want to make anything more difficult for [my family]," immediately arose in response to initial exploratory questions about RMD. There was also generally little

Table 2
Demographics of Patient and Caregiver Focus Group Participants

Demographic	Pancreatic (n = 10)	Lung (n = 9)	Breast (n = 13)
Patients			
No. of patients	6 (60%)	7 (78%)	11 (85%)
Focus Group 1	3 (30%)	4 (44%)	4 (36%)
Focus Group 2	3 (30%)	3 (43%)	7 (64%)
Age (mean age in yrs, range)	68 (60–77)	72 (59–83)	56 (36–73)
Gender			
Male	3 (50%)	1 (14%)	0 (0%)
Female	3 (50%)	6 (86%)	11 (100%)
Race/ethnicity			
White/Caucasian	5 (83%)	7 (100%)	10 (91%)
Black/African American	1 (17%)	0 (0%)	1 (9%)
Education			
High school	2 (33%)	0 (0%)	0 (0%)
Some college	1 (17%)	0 (0%)	0 (0%)
College	1 (17%)	3 (43%)	3 (27%)
Postgraduate	1 (17%)	1 (14%)	3 (27%)
Not reported	1 (17%)	3 (43%)	5 (45%)
Marital status			
Married	4 (67%)	5 (71%)	5 (45%)
Single	1 (17%)	1 (14%)	6 (55%)
Divorced	1 (17%)	0 (0%)	0 (0%)
Widowed	0 (0%)	1 (14%)	0 (0%)
Religion			
Roman Catholic	1 (17%)	2 (29%)	2 (18%)
Jewish	1 (17%)	3 (43%)	4 (36%)
Other Christian	1 (17%)	1 (14%)	1 (9%)
None	2 (33%)	0 (0%)	3 (27%)
Not reported	1 (17%)	1 (14%)	1 (9%)
Time since diagnosis, yrs			
<1	3 (50%)	1 (14%)	0 (0%)
1–2	3 (50%)	4 (57%)	0 (0%)
3–4	0 (0%)	1 (14%)	3 (27%)
5–6	0 (0%)	0 (0%)	2 (18%)
7–8	0 (0%)	0 (0%)	2 (18%)
9+	0 (0%)	1 (14%)	4 (36%)
Caregivers			
No. of caregivers	4 (40%)	2 (22%)	2 (15%)
Focus group 1	2 (50%)	2 (100%)	1 (50%)
Focus group 2	2 (50%)	0 (0%)	1 (50%)
Gender			
Male	3 (75%)	1 (50%)	1 (50%)
Female	1 (25%)	1 (50%)	1 (50%)
Relationship to patient			
Spouse	3 (75%)	2 (100%)	1 (50%)
Sibling	0 (0%)	0 (0%)	1 (50%)
Friend	1 (25%)	0 (0%)	0 (0%)

understanding of the amount of tissue required for an RMD collection.

RMD Was Seen to Mainly Benefit Research, Not Patients or Families Directly. Clinicians believed RMD was a crucial tool in helping address the unknowns of cancer pathogenesis to better inform and advance treatments. One clinician commented “there’s so much we can do with the DNA.” A commonly recurring benefit voiced by participants was the potential for RMD to help advance treatment for future generations, especially for hereditary cancers. Most participants did not view RMD as an act of altruism but rather as a social contract of “paying forward” or simply “something that should be done.” There was division among participants regarding if RMD would lead

to a positive emotional benefit for patient and caregiver quality of life. Participants believed that while RMD participation may bring some comfort to patients and caregivers, such effects would be minor. Some believed that this benefit would occur only long after the patient died. Patients with breast cancer were the most resistant to framing RMD as altruistic, noting that there is high research saturation among this cancer type and they are frequently asked to participate and donate their time and bodily tissues while living. Nonetheless, one patient with breast cancer in particular believed RMD “would provide some comfort ... that you’ve done something good ... to help research and help the lives of others,” illustrating the dual potential for participation to indirectly benefit patients and families.

Concerns About RMD Existed. Several logistical and privacy questions and concerns about RMD arose, particularly among patients and caregivers. These included questions about how RMD would be coordinated without complicating funeral arrangements, as well as religious concerns, expressed by one patient who worried that the time taken by RMD would prevent a religious custom of being “buried very quickly” after death. Some privacy concerns arose with one participant wondering, “what’s happening [with the bodily tissue]? Am I anonymous?” Regarding potential ethical concerns, lung and pancreatic cancer patient/caregiver participants generally expressed trust that MSK would handle their bodily tissue responsibly. However, breast cancer patient/caregiver comments illustrated a concern over consent and transparency. Patients with breast cancer also voiced that a report for the family detailing RMD findings should be generated routinely as a condition of RMD procedure.

Importance of Sensitive and Individualized Communication. Owing to the knowledge gap and concerns about potential problems with RMD, participants universally voiced that introducing RMD to patients is a sensitive endeavor, with the ideal timing to begin a conversation regarding RMD being specific to each individual patient and their circumstance. One clinician noted that it is “hard knowing when the right time is” and that the “end-of-life topic is hard to approach at any point in time ... it creates a lot of anxiety for the patient.” Speaking to the delicate nature of communicating about the end of life, a patient noted “I think some training needs to happen so that people who maybe get into something with a patient and realize it’s not going well ... because I’ve had that happen too ... like people who just don’t know how to deal with emotion at all.” Patients also spoke to the need for ongoing communication (instead of a one-time discussion) about RMD, and about how written materials, or even more interactive aids (e.g., testimonials from other patients or past caregivers), could help in the process. No clear consensus emerged regarding who should initiate discussions about RMD. Patients with breast cancer most strongly believed that discussions about RMD might negatively impact their relationship with their oncologist, worrying that the clinician might view them as “just a donor body.” Clinician concerns arose about mediating family conflicts and wanting to respect the wishes of all parties involved.

Cancer Type Did Not Universally Impact Perceptions of RMD, but Other Cancer Factors May. Participants did not believe that the specific type of cancer (such as pancreatic, lung, or breast) per se would influence people’s attitudes about RMD, including the desire to

participate. However, other cancer patient factors, such as “cultural groups, certain racial groups, or certain socioeconomic levels,” as one patient commented, might. Through maximizing the cultural diversity of participation in RMD, it was believed “the research will be stronger,” the same patient continued. In addition, although the specific cancer type was not seen as a major motivating factor for patients to consider RMD, the perceived seriousness and/or rarity of any cancer were relevant to RMD acceptability. For instance, in the pancreatic cancer group, participants agreed that a diagnosis of such a serious and relatively rare cancer may inspire people to consider RMD.

Discussion

There is an increasing focus on issues pertinent to serious illness and death as the medical landscape becomes more technologically sophisticated. However, this study showed that patients, families, and cancer clinicians currently have generally low knowledge of RMD. Upon learning about it, these stakeholders view RMD as a valuable program for scientific advancement and necessary to be carried out with individualized sensitivity to end-of-life issues, as well as through training programs with involved clinical staff. We also found that specific cancer factors (e.g., rarity, severity) seem to influence attitudes about RMD, including the desire to participate in an RMD program. Our data therefore demonstrate unmet needs that must be addressed, such as through communication skills training (including fostering clinician awareness about the potential impact different cancer- and patient-related factors may play) and optimizing logistics of complex biomedical research at the end of life.

This study benefited from a rigorous qualitative research methodology and included specialists with expertise and experience in relevant areas of psycho-oncology. Adhering to established standards in focus group planning (including how to best ensure saturation in qualitative assessments¹⁵) and conduct, as well as qualitative analysis of focus group data strengthened the study. The stakeholder samples included different clinician disciplines (oncologists and nurses) as well as patients and caregivers. The samples were representative and demographically heterogeneous. Our use of numerous groups per stakeholder type enabled us to achieve thematic saturation in the data collected.

Our findings corroborate and advance the existing literature on RMD. Research has begun to describe challenges some institutions face in developing RMD programs^{6,7} and has focused on lung cancer. Our study was particularly unique in including not only

Table 3
Focus Group Topics and Emergent Themes

Topic Area	Emergent Theme	Illustrative Quote
Previous Knowledge about Research Medical Donation (RMD)	Limited previous knowledge about RMD or how much tissue would be used.	<p>“Up until a week ago I knew nothing about this. I’m kind of guessing it’s in this context it means turning over probably the parts of your body affected by the disease that Sloan Kettering is looking at.” (Patient, Pancreatic Cancer)</p> <p>“I know that there is an existing protocol to do warm autopsies. Beyond that I’d say my knowledge is fairly limited ...” (Clinician, Breast Cancer)</p> <p>“I heard about it generally when people talk about donating their bodies to science [...] just like they would study people who have Alzheimer’s and pass away. They would want to study their brain ...” (Patient, Lung Cancer)</p>
	Other types of donation (e.g., organ donation) used as a reference point for understanding RMD.	<p>“I haven’t really thought about it too much. I think that medical students when they’re in school use cadavers to learn about anatomy and to practice their skills. And those cadavers have to come from somewhere. And many years ago, a lot of them came from institutions that would have had people with no relatives in them. And then now I guess they come through the organ donation process, not too sure about that.” (Patient, Pancreatic Cancer)</p>
	Worries about family comfort and logistical questions emerged as immediate concerns at first mention of RMD.	<p>“I think that no matter what it’s going to be hard for my family, but perhaps if they understand this is something I want, then they’ll support that. I just don’t want to make anything more difficult for them.” (Patient, Breast Cancer)</p> <p>“Well it would concern me if, you know, I was leaving this as a black box for my loved ones who are cared—you know who are in bereavement or whatever when I’m dead if they have this on their heads and they don’t understand what to do, I would be concerned if the process was complex and put a burden on them during that time.” (Patient, Pancreatic Cancer)</p>
Perceived benefits of RMD	The potential to further cancer research seen as the main benefit of RMD.	<p>“So, I think the most important part is that the tissue is always the issue. We don’t have enough, so in a, in the autopsy collection harvest that’s made, tissue samples of known permutations and then the discovery [of] all mechanisms from a distance [...] There’s also so much we can do with the DNA that they’re doing right now.” (Clinician, Lung Cancer)</p> <p>“The benefits are obviously not for the patient. Now, it’s for the future of patients. Obviously, they take the tissue after the patient has passed away, so it’s not going to do that person any good but down the road the more tissue I would assume that the research people have to work with, the better the chance of improving the treatment process for future people who come down with a disease.” (Caregiver, Pancreatic Cancer)</p>
	Division in belief that there is a positive emotional benefit to RMD for patients and caregivers.	<p>“I think there’s some, I don’t know if you want to call it psychological, or some benefit to the patient and their family to show you’ve done everything you could to you know, to help research and help the lives of others. It would provide some comfort, I think or showing you’ve, you’ve done something good, you know, some value.” (Patient, Breast Cancer)</p> <p>“I don’t think it’ll affect my family. Family’s going to be grieving and the fact that you know, some of my cancerous tissues are being sent over some place, I don’t think will give them any comfort. I know that if I had like an organ to give to save somebody’s life, I think that they would get a comfort that my, if my heart or heart or whatever is beating in somebody else, that would definitely give them comfort. I don’t think having my cancerous body part will help them at all.” (Patient, Lung Cancer)</p>
Concerns about RMD	Logistics of RMD, especially how RMD impacts funeral planning	<p>“And then also, let’s say it happens up here [loved one passes away out of state], and the body has to go down to Sloan Kettering or maybe over in</p>

(Continued)

Table 3
Continued

Topic Area	Emergent Theme	Illustrative Quote
Sensitivity to cultural and religious practices, especially timing of burial		<p>Westchester; the thing is, then who transports the body to Westchester, and then who gets the body to the burial place, and who's responsible financially for these things?" (Caregiver, Lung Cancer)</p> <p>"I'd want to know more, [because] my body would be—it could be open casket. I would want to know more about how invasive the procedure would be [...] I hate to be really specific here, but this is a very serious conversation. So, I die eventually, and am I wheeled down to the morgue, and you take tissue out, and then the body goes to the funeral home? Is that what happens?" (Patient, Breast Cancer)</p> <p>"It would seem to me that there are certain religions where the person has to be buried within 24 hours. So how does that work with your research plans? Does that give anybody any time to do anything? That's one question I would have." (Patient, Breast Cancer)</p> <p>"[I]n my religion you're supposed to be buried very quickly so I don't know how this program works but somebody mentioned about your body lying there for months, that just wouldn't work for me." (Patient, Pancreatic Cancer)</p>
Ethical concerns over how their tissue would be used and shared		<p>"I just had a general concern I think societally, there should be some kind of assurance as to what this tissue is being used for. And we're kind of thinking, yeah, it's being used for medical research by people at Sloan and we know people at Sloan and they're good people and we trust them implicitly [...] but my general concern is how is the tissue being used and is it being kept confidential and what are—what are the limits on how it's distributed?" (Patient, Pancreatic Cancer)</p> <p>"Are we going to be like, is our tissue going to end up like Henrietta Lacks, going all around the world? [...] And that's one of the things about this. Those people had no clue that their mother's cells were all over the world in a petri dish. So, to me, there's some concerns along those lines. Well, what's happening? Am I anonymous?" (Patient, Breast Cancer)</p>
Communication about RMD	Timing of communication about RMD should be sensitive and patient specific	<p>"I think it's definitely hard knowing when the right time is, because it's all patient based and it kind of depends on their personality and your relationship with them [...] the end-of-life topic is a hard topic to approach at any point in time, I think, and it creates a lot of anxiety for a patient." (Clinician, Breast Cancer)</p> <p>"I would suppose that [discussion is] very individual, but I would suppose at a point when you resigned to the fact that you're not going to last forever. And, I guess, that varies from one person to the next." (Patient, Breast Cancer)</p>
Specific trainings should be available to help clinicians communicate about RMD in a sensitive way.		<p>"I think it would be great if there is some, like, kind of some go to, I don't like scripting at all, but just because it's such a sensitive topic that we're going in to, just some phrases that we could use, and we're in a highly sensitive situation like this, just like, as a go to [...] like, for example if a family member was very upset by the fact that we're bringing up, just some things to kind of diffuse it or phrases that we could use to kind of help convey how important it is. I think we all know, but just some good language." (Clinician, Breast Cancer)</p>

Written materials to supplement discussions about RMD, such as testimonials, are important for acceptability.		<p><i>“I think some training needs to happen so that people who maybe get into something with a patient and realize that it’s not going well, that they know how to handle it without backing out of the room, because I’ve had that happen too earlier in journey in life, like people who just don’t know how to deal with emotion at all.”</i> (Patient, Breast Cancer)</p> <p><i>“I would you know, any time I get information from my doctor, what they usually do is they give me information and they a lot of times give me some written information [...] And then I think about it and I discuss it with my husband. He comes with me to the appointments. And then afterward we come back and ask all the questions that we thought about afterward. So, it’s sort of like ... I assume would be like an ongoing conversation.”</i> (Patient, Lung Cancer)</p> <p><i>“I think what you [other participant] just said, testimonials, I think there’s power in a person with cancer speaking about their choice to do this. And that, it’s an option and that, that other people should consider.”</i> (Patient, Breast Cancer)</p>
Influence of unique cancer factors on perceptions of RMD	RMD donations across cancer types would increase tissue diversity, advancing cancer research.	<p><i>“To the extent there are, you know stories that—of the ways that this has helped people and those are communicated then I think maybe that would enhance the impact. So if I’m—if I know that I’m dying in the near future, the idea that I’m giving some tissue that might potentially help somebody, some day, I think it’s comforting and it makes me feel good and it contributes to a good mental attitude. I think the effect of that probably could be enhanced if we knew how it had helped other people in the past or specific examples of it.”</i> (Patient, Pancreatic Cancer)</p> <p><i>“Much of it expands the pool of who’s covered in research, so I think a lot of issues with a lot of research is that it tends to be very much a certain cultural groups, certain racial groups and certain socio-economic levels. So, if this is something where sensitivities can be taken to account and it can expand the, the overall pool of people involved, I think it’ll be, the result of research will be stronger because of the diversity in the availability of tissue.”</i> (Patient, Breast Cancer)</p>
The “seriousness” of cancer was a potential motivator for RMD participation.	The “seriousness” of cancer was a potential motivator for RMD participation.	<p><i>“I do have a particularly virulent form of cancer that’s been highly resistant to many forms of treatment and whose prognosis is still pretty dire. And so that is one reason I would think it’s important in my case, because there is a lot more to be learned in this particular branch [...] There are all these new therapies that are being tried. And they’re all very new. And because of that, we are important, because we’re at the beginning. And they can learn from us and move on.”</i> (Patient, Lung Cancer)</p>
Other emergent themes	Previous experiences with participating in MSK research (or being approached to participate) influences RMD acceptability. Participants with positive experiences participating in clinical research had more trust in the hospital’s ability to handle their tissue responsibly.	<p><i>“I’m both a family member—my wife has been living with cancer for ten years—and also a patient as well. And the benefit [of research] is that it gives you hope [...] I would not be concerned about it. After all, it’s my wishes, and if [this hospital] wants to take a piece of tissue for research, they’re more than welcome to do so [...] And I’m actually in a clinical trial right now. So hopefully, what’s going on in this clinical trial may help me, but also may help future people because of the clinical trial and the findings that they develop.”</i> (Caregiver, Lung Cancer)</p> <p><i>“I can’t believe that I was as young as I was and came in and was still trying to get my head around the fact that I had breast cancer and was going to have chemotherapy and I didn’t even know what else was going to come. But in that same day, someone was asking me to have an invasive breast, a, brain scan with contrast, and by the way, more than one. Would I consider doing this for helping, I’m like what? What? What? and I was standing there by myself like, who allowed this to happen?”</i> (Patient, Breast Cancer)</p>

Table 4
Focus Group Topics and Divergent Themes

Topic Area	Divergent Theme	Reference Quote
Previous knowledge about Research Medical Donation (RMD)	A few clinicians had some awareness of previous efforts to implement an RMD program at the hospital	<i>"I have been heavily involved with a medical donation program. I think it does great things to help breast cancer patients and I probably approach other patients to consent to the medical donation program."</i> (Clinician, Breast Cancer)
Perceived benefits of RMD	In the breast and pancreatic cancer focus groups, some participants mentioned that RMD may help them find "meaning" in suffering.	<i>"If I'm out there doing this crap, I hope some good comes out of it [...] it comes back to my feeling of like, you know, if I can do this, at least hopefully my leaving tissues behind will bring something good out of it, you know. Kind of the final, final 'screw you' to cancer."</i> (Patient, Breast Cancer) <i>"It just means that it's not for nothing that we suffer through this [...] If somebody learns something from it that's a positive."</i> (Caregiver, Pancreatic Cancer)
	In both pancreatic cancer focus groups, participants felt altruism was the main benefit of RMD.	<i>"It seems to me it gives your whole life an additional perspective to what normally [happens] when people die, that it's over. Now you have another thing to provide for other people, by donating your organs or your tissues or whatever. So, I think it's a very positive experience."</i> (Caregiver, Pancreatic Cancer)
	In both breast cancer focus groups, participants were the most resistant to framing RMD as "giving back."	<i>"I think the idea that it's a 'give-back' doesn't work because I don't think they [the patients] have any more to give back than what they've been through. But the idea that they can help others is extremely impressive and can be motivational."</i> (Caregiver, Breast Cancer) <i>"I tend to think that many of us may feel that having cancer is not a great thing. Some of us may feel we get a raw deal here, so why do we want to give back?"</i> (Patient, Breast Cancer)
Concerns about RMD	Participants in both lung cancer focus groups asked why RMD cannot take place while they are alive, freeing family from the burden of coordinating RMD procedures after their passing.	<i>"I don't understand why this has to be after someone dies that you do this. When they do biopsies all the time [...] So, you don't—it doesn't make sense to you why they can't just take a biopsy before the patient has passed? Why isn't that studied for research? Why do you have to wait until someone passes away to do it? [...] I don't think my family would be happy about it."</i> (Patient, Lung Cancer)
	Participants in the pancreatic cancer focus groups were less concerned with condition of the body after donation than those in the lung and breast cancer focus groups.	<i>"It sounds to me, what I'm guessing, is that when you're talking about this, you're taking a small amount of tissue probably from a tumor, maybe from other places in the body, maybe from lymph cells, I don't know."</i> (Patient, Pancreatic Cancer) <i>"I guess from my standpoint, I'm not super religious. And don't have these concerns and it's not a factor in my life. I mean I don't know, I mean I can't speak for the general population and what types of people or what religious might, you know, have an issue with this."</i> (Caregiver, Pancreatic Cancer)
	Participants in the lung and pancreatic cancer focus groups generally trusted the hospital to handle their tissue responsibly, while those in the breast cancer focus groups expressed deep concern over consent and transparency.	<i>"I guess I was just maybe being—maybe being naïve. I don't know. But just kind of implicitly trusting that it would be used appropriately and confidentially or whatever so it hasn't been a—it hasn't been a major concern on my mind ..."</i> (Caregiver, Pancreatic Cancer) <i>"Well I have to tell you the truth. You're asking me deep and meaningful questions and I don't mean to harp on it, but all of it makes me go back to that red flag. It's like we're leaving a legacy and they're not even writing a report on it. I can't get off that, it sounds so dismissive like 'yep we're just collecting these samples and</i>

	<p>Participants in both the breast and pancreatic cancer focus groups felt generating a report for the family was meaningful and ethical.</p>	<p><i>we're going to do what we want.' I do think it's a big deal and I think the, the, the institution of [the hospital] needs to treat it as such and be willing to be more transparent about it."</i> (Patient, Breast Cancer)</p>
Communication about RMD	<p>Participants in the breast cancer focus groups felt the strongest that discussions of RMD could negatively impact their relationship with their oncologist; worried that provider would view them as just a "donor body" and that might change their care.</p>	<p><i>"I just, I think that one of the things that you [other patient] brought up is that some sort of report or that you'd like to have that information about what, what they took, what they intend to do with it um, and that, and like and a thank you. An acknowledgment."</i> (Patient, Breast Cancer)</p>
	<p>Clinicians felt that RMD can be a challenging discussion specifically because it brings up notions of end of life and potential treatment failure.</p>	<p><i>"When you mentioned the topic, you mentioned that there wouldn't be a report generated as in an autopsy. I'm assuming then again, for example, again, I have to go back to my personal [example], my daughter. Nothing would be generated that could actually benefit her personally, and it's a bit of a concern [...] I know it's private, but I would like to know if the family would be able to receive some specific information that would be beneficial to the family."</i> (Patient, Pancreatic Cancer)</p>
	<p>Clinicians expressed specific concerns about patients feeling like a "means to an end" in RMD discussions. Some clinicians worried about having enough time to have a sensitive discussion about RMD with patients.</p>	<p><i>"Well, I originally thought that the oncologist is probably the one to be able to say what is the right time to bring it up, but I don't think he should bring it up. I think that it would impact my feelings about my treatment. [...] Right off the bat, I would be somewhat offended. Then I would think, well, he's bringing it up because I don't have much longer to live. He is more interested in my tissue than in me as a person. And I happen to love my oncologist. I just don't think the doctor is, that's his role. His role is to treat you and not to think past that."</i> (Patient, Breast Cancer)</p>
Influence of unique cancer factors on perceptions of RMD	<p>Participants in the pancreatic cancer focus groups and clinicians agreed that a diagnosis of pancreatic cancer may inspire people to consider signing up for RMD.</p>	<p><i>"So, I mean, it's an uncomfortable thing to bring up. I mean, I don't know. At least for me. I think there's a, there's always some awkwardness about talking about death with somebody who's dying and, bringing this element into it just feels to me a little bit even more uncomfortable. I mean, we try to, it's so much, so concrete. You can, when you can talk about death with people, you can continue to talk about it as a, sort of, theoretical thing even up to that point where they lose consciousness. But, once you start doing this kind of planning, it, it feels very robust."</i> (Clinician, Breast Cancer)</p>
		<p><i>"I also think here at [this hospital] we have to be very sensitive to some of the external perceptions of the institution and when our, when our motto is 'more science, less fear' I think we have to make sure that particularly patients who have not gotten what they wanted out of the treatment, i.e. survival, don't wind up perceiving that they're being used for institutional goals not consistent with their own, right. We have to have a value alignment here ... you don't want them to feel like they're being treated as a science experiment."</i> (Clinician)</p>
		<p><i>"There is never enough time to discuss even the more basic things. So, to add this to the mix probably would, kind of, [negatively] impact the clinician in bringing it up."</i> (Clinician)</p>
		<p><i>"And I would say that because it's such a tough cancer to treat, it only enhances the desire to participate [...] we keep reading about breakthroughs and very rarely is pancreatic cancer listed as one of the cancers it helps. But it—but it's not never [listed], so it's not hopeless. But it's just a tough one and so ... the more and better research they can spend the sooner we'll get to a cure."</i> (Caregiver, Pancreatic Cancer)</p>

(Continued)

Table 4
Continued

Topic Area	Divergent Theme	Reference Quote
	<p>Participants in the lung cancer focus groups hoped that research on their tissue would help reduce stigma against their group.</p>	<p>“So, usually pancreatic cancer patients consider themselves underserved, it’s one of the rarest, but they believe the cancer is not very [researched], there’s not so much, I think, going on and it’s still one of the deadliest diseases with short life expectancy.” (Clinicians)</p> <p>“I think it [my cancer type] is quite relevant because it’s like everybody says, they don’t ... you know they have all these breast cancer [events] and all these cancers and when it comes to lung cancer, people usually don’t sympathize because quote, ‘most people who get it, smoke.’ And so, therefore, there is not that, there is a stigma attached to lung cancer. So, I think doing any research or any help we can get in doing research will really help a lot. I myself know that I worked near 9/11 and was there that day and was there for many months afterward and that is supposedly what had triggered both my cancers. But, it was environmental, even though I wasn’t smoking, but it was environmental. And so, I think, though, any type of research especially from you know, for lung cancer would be very important, even though there is a stigma attached to the lung cancer.” (Patient, Lung Cancer)</p>

lung cancer but also pancreatic and breast cancers to examine if different cancer-related factors brought unique challenges to RMD. Although our data are hypothesis-generating and thereby necessitate further study, it seems patients and caregivers affected by relatively rarer and/or more serious cancers, like pancreatic and lung (vs. breast), were more willing to participate in RMD, and many stated this was motivated by a desire to garner information that could help future patients with these serious illnesses. In addition, the relative commonness and more indolent nature of breast cancer seemed to lead those patients to feel they had less time to participate in additional research like this and that such participation might negatively influence the opinions and/or treatment offered by their oncologists. Like prior studies, ours also identified fundamental barriers relating to provider knowledge of RMD and the sensitive communication needed to ensure patients and their loved ones are adequately informed about the nature and intent of RMD. Studies on family members’ experiences of autopsy¹⁶ (which is distinct from, but shares some aspects with, RMD) indicate room for improvement in how clinicians discuss it (e.g., regarding religious, logistical, and emotional factors) and that communication skills training^{11,12} to improve interactions between clinicians and families is imperative. Other autopsy programs exist in cancer patients (one such Australian program is for people who have died of breast, melanoma, ovarian, and prostate cancer, and like ours, recognizes the end-of-life sensitivities at hand, including with how funeral customs must be facilitated),¹⁷ in patients with nonmalignant diseases such as neurodegenerative disorders,¹⁸ and even for individuals who die without cancer,¹⁹ to study human genetic variations in normal (nondiseased) tissue specimens. Like ours, these programs entail ongoing learnings and must regularly address complexities both logistical and psychosocial in nature.

Our study had limitations, including that although we surveyed various relevant stakeholders, all were working or treated at one specialty cancer center. Such specialized institutions, however, are where specialized RMD programs exist. In addition, unlike a recent qualitative study of patients with lung cancer and their families and clinicians,⁸ none of the patients in our focus groups were actually enrolled in RMD (although one patient participated in RMD in the weeks before he died, many months after his involvement in our study). In addition, while holding focus groups over the telephone mitigated the logistical hurdles inherent to scheduling several people from different places to convene at the same time, it prevented us from assessing and responding to participants’ nonverbal cues. The literature, however, suggests that employing telephone instead of

in-person focus groups does not generate fewer, or inferior, data.²⁰ Moreover, participants may have been comforted by the greater degree of anonymity provided by telephone focus group methodology. A final potential limitation is that we did not record cancer stage or treatment specifics of patients in the focus groups as part of the baseline demographic data.

These results supported our hypothesis that knowledge about RMD is generally low across stakeholder groups and that such a topic must be approached with cultural and interpersonal sensitivity, ideally supported by communication training initiatives. In addition, and through direct RMD program experience, study team members have observed that some patients and families have both strong wishes to participate in RMD (sometimes seeking out researchers, as others have published¹) and deep gratitude for programs that fulfill their wishes. However, greater RMD participation is needed to expedite scientific discoveries. Our data support the previously limited literature that such participation is likely to be accepted by families.²¹ Nonetheless, as such programs grow in scale, more research into the practices and effects of RMD will be necessary. This necessity also applies to tissue donation that occurs when patients are living, such as is increasingly occurring with research biopsies in oncology clinical trials.²²

In conclusion, knowledge about RMD continues to be limited in general, and patients, caregivers, and clinicians all believe that as with any topic about advancing sickness and death, RMD must be approached with sensitivity to the myriad issues often involved therein. Communication skills training can and should be applied to clinical teams that want to create or build their programs in RMD to best advance the science of medical care while meeting the psychosocial needs of participating patients and their loved ones.

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Appendix A

Clinician Focus Group Guide

I. Welcome & Introduction (one minute):

- Welcome! My name is Elyse Shuk and we want to thank you so much for coming to participate in this discussion today. We realize that you all have busy lives and schedules, so we appreciate you taking the time to meet with us today and participate in this research project. Before we begin, I'd like to go over the topics we are covering today and provide some guidelines for our discussion.

II. Overview/Purpose of Focus Group (two minutes):

- As you know, we are here today to get your thoughts and opinions about research medical donation, which entails the process of obtaining human tissue from cancer patients after their death for the purpose of analyzing such tissue to advance medical knowledge regarding cancer development and treatments.
- We will discuss several topics today, including your knowledge about research medical donation, concerns you may have regarding the process, your views regarding how to best communicate about the option of research medical donation with your patients and their families, and the possible influence that a patient's cancer type may have on clinician communication regarding research medical donation with patients.

III. Focus Group Guidelines and Introductions (10 minutes):

- Now I will review some guidelines for our discussion. Remember, we are interested in learning your thoughts and opinions, so anything you share will be very informative for us.
- I will be asking the questions, but we would like you all to take part in the discussion. Our goal is for all of you to share what you think, so please feel free to **speak directly to each other** and discuss your opinions with each other.
- There are **no right or wrong answers** to the questions that I will ask. Again, we want to hear what you think about the topics. Please **feel comfortable to share different opinions from others**.
- We realize that you may never have thought of many of the things that I'll be asking you about today, so please **feel free to take the time you need to think** about the questions and how you would like to respond.
- I would like to hear from everyone today, so if I haven't heard from you in a while, **I may invite you to share their thoughts**.
- Given that we have a lot of material to cover in a short period, **I may need to interrupt the conversation so I can move to the next topic**. If this occurs, please don't feel that we aren't interested in your opinion.
- Since we are audio recording the conversation, if you could **speak clearly**, we would greatly appreciate it.
- A member of our study team, __ (insert name) __, will also be taking notes during our discussion.
- All information that you share today will be **kept strictly confidential**. We will not include your names in any study documents.
- Thanks again! We will **start the audio recording now**.
- First we would like all of us to **introduce ourselves**. So, we will go around the group and if you could each state your first name only, and take 30 seconds to share something that you like to do in your spare time. I will start. I volunteer as a ceramics studio assistant outside of work.

V. Discussion (65 minutes):

The first topic that we will discuss today is what you may currently know about research medical donation.

Topic 1: Knowledge About Research Medical Donation (10 minutes)

- 1) What do you presently know about research medical donation?@
- 2) What would you like to know or understand better about research medical donation if you were to discuss this option with patients and their families?
Probe: What would be the most important information needs regarding research medical donation and its process that you would have?

Now we would like to share with you some information regarding research medical donation and the process it entails. Research medical donation is an option for patients who want to donate tissue samples to cancer research after they pass away. While the patient is living, we make prearrangements to collect tissues. Then, when the patient passes away, we collect tissues. The tissues are collected through a surgical process that is not as thorough as an autopsy, and no report is generated for the patient's medical record or family. Afterward, the family proceeds with cremation or funeral (including open-casket) services. Cancer researchers use the donated samples in research, both in exploring why a particular cancer may have responded to treatment, and trying to better characterize the biomedical make-up of cancers in general for future patients. There is no cost to the patient or family to participate. Here at MSK, research medical donation is coordinated through the MSK Medical Donation

Program. Next we would like to learn your perspectives regarding any concerns that you may have about research medical donation and the process that it entails.

Topic 2: Concerns About Research Medical Donation (20 minutes)

- 1) What concerns do you associate with research medical donation?
- 2) In your role as a clinician, what practical concerns do you have about research medical donation?
 Probe: What concerns, if any, do you have regarding the process of arranging transportation to receive the bodies of patients after their death?
 Probe: What concerns, if any, do you have regarding any costs that patients may believe they would incur if they participated in MSK's Medical Donation Program?
 Probe: What concerns, if any, do you have regarding coordinating the timing to allow for research medical donation following a patient's death?
- 3) In your role as a clinician, what do you think the emotional impacts of research medical donation could be?
 Probe: How do you think you would personally feel if you were placed in the position of introducing and explaining research medical donation to a patient and their family?
 Probe: What specific emotional concerns, if any, do you think you would have when discussing the option of research medical donation with a patient and their family (e.g., risk of upsetting family members, discomfort with discussing death and dying issues, feeling unfamiliar with the topic and issues involved)?
- 4) In your role as a clinician, what ethical concerns do you have about research medical donation?
 Probe: What concerns do you think you may have related to a patient's decision-making process when considering participation in research medical donation (e.g., the potential need to negotiate differing levels of interest in research medical donation between patients and family members)?
 Probe: In your role as a clinician, what challenges do you believe you might encounter related to the process of obtaining patient consent to take part in research medical donation?
 Probe: To what extent do you feel that you may be placed in a position to pressure a patient to take part in research medical donation?

Now we would like to ask you questions regarding the processes of communicating about research medical donation with patients and their family members.

Topic 3: Communication about Research Medical Donation (20 minutes)

- 1) What, if any, prior experiences have you had with communicating about research medical donation with patients and their families?
 Probe: Please describe how the process of communication regarding research medical donation went for you.
 Probe: At what point during the patient's clinical course of care and treatment did you discuss research medical donation with the patient and his/her family members?
 Probe: What, if anything, made the process of communicating about the option of research medical donation with patients and their families challenging for you? What were the most prominent communication challenges that you experienced?
 Probe: What specifically could have improved the communication experience?
- 2) What do you perceive to be the central challenges in discussing research medical donation with patients and families?
 Probe: When do you feel would be the best time to discuss research medical donation with patients and families?
 Probe: How do you feel you would manage to find the time to have discussions about research medical donation with patients given the time pressures associated with your clinical responsibilities?
- 3) What do you think would help you to feel more comfortable, confident, or skilled in discussing research medical donation with patients and families?

Now we'd like to briefly describe an NIH-funded Communication Skills training program offered here at MSK. This training program involves a combination of both didactic training regarding how to communicate effectively with patients in support of their needs, as well as simulated sessions with professional actors playing the roles of patients to enable clinicians to put their communication skills into practice in a variety of clinical scenarios.

- 4) If you were to participate in a half-day MSK-sponsored Communication Skills training program solely about MSK's Medical Donation Program, what information would you specifically want to learn in the training program?
 Probe: What skills would you find most valuable in gaining?
 Probe: Are there certain communication scenarios you would find most beneficial to explore? If so, what scenarios specifically come to mind?

Finally, we would like to explore your perspectives as to whether and how you feel the specific type of cancer that a patient has been diagnosed with may play a role in shaping how you may discuss the option of research medical donation with patients and their families.

*Topic 4: Influence of Unique Cancer Factors on Processes of Communication regarding Research Medical Donation
(15 minutes)*

- 1) How do you feel that a patient's unique cancer diagnosis might influence how you would discuss research medical donation with them?
Probe: To what extent do you think that patients with different types of cancer would have different information needs?
Probe: If so, what information needs do you think would be most relevant in the lung cancer context? The pancreatic cancer context? The breast cancer context?
 - 2) To what extent do you think that there are unique challenges for communicating about research medical donation in the lung cancer context, or the pancreatic cancer context, or the breast cancer context?
Probe: If so, what do you feel are the different communication challenges based on cancer type? (Example follow-up probes: patient age at diagnosis, treatment availability, commonness of cancer, prognosis, role of lifestyle factors in etiology, state of scientific knowledge regarding cancer etiology)
 - 3) To what extent do you think that there are unique benefits or motivations for patients regarding research medical donation that you may emphasize when communicating about research medical donation in the lung cancer context, or the pancreatic cancer context, or the breast cancer context?
Probe: If so, what do you feel are the different benefits or motivations for patients based on cancer type? (Example follow-up probes: patient age at diagnosis, treatment availability, commonness of cancer, prognosis, role of lifestyle factors in etiology, state of scientific knowledge regarding cancer etiology)
- VI. Conclusion (five minutes):

Okay, we've covered all the issues that I wanted to discuss. Before we finish, I want to give you the opportunity to reflect on our discussion and share anything that you think is relevant to your perspectives on research medical donation or the process of communicating about this option with patients and families that did not come up during the conversation.

Again, thank you very much for your honesty and willingness to participate in this discussion! We have learned a lot today, and your opinions will help us to best develop an MSK-sponsored Communication Skills training program for clinicians to discuss the option of research medical donation with their patients. If you'd like, please feel free to stay a bit if you have any questions about our research, or have any other comments that you would like to share.

Thanks again!

Appendix B

Patient and Caregiver Focus Group Guide

- I. Welcome & Introduction (one minute):
 - Welcome! My name is Elyse Shuk and we want to thank you so much for coming to participate in this discussion today. We realize that you all have busy lives and schedules, so we appreciate you taking the time to meet with us today and participate in this research project. Before we begin, I'd like to go over the topics we are covering today and provide some guidelines for our discussion.
- II. Overview/Purpose of Focus Group (two minutes):
 - As you know, we are here today to get your thoughts and opinions about research medical donation, which entails the process of obtaining human tissue from cancer patients after their death for the purpose of analyzing such tissue to advance medical knowledge regarding cancer development and treatments.
 - We will discuss several topics today, including your knowledge about research medical donation, benefits that you may associate with research medical donation, concerns you may have regarding research medical donation, your views regarding what would make research medical donation an acceptable option for you as patients and caregivers, and your thoughts regarding how a patient's unique cancer type may influence attitudes regarding research medical donation.
- III. Focus Group Guidelines and Introductions (10 minutes):
 - Now I will review some guidelines for our discussion. Remember, we are interested in learning your thoughts and opinions, so anything you share will be very informative for us.
 - I will be asking the questions, but we would like you all to take part in the discussion. Our goal is for all of you to share what you think, so please feel free to **speak directly to each other** and discuss your opinions with each other.
 - There are **no right or wrong answers** to the questions that I will ask. Again, we want to hear what you think about the topics. Please **feel comfortable to share different opinions from others**.
 - We realize that you may never have thought of many of the things that I'll be asking you about today, so please **feel free to take the time you need to think** about the questions and how you would like to respond.

- I would like to hear from everyone today, so if I haven't heard from you in a while, **I may invite you to share their thoughts.**
- Given that we have a lot of material to cover in a short period, **I may need to interrupt the conversation so I can move to the next topic.** If this occurs, please don't feel that we aren't interested in your opinion.
- Since we are audio recording the conversation, if you could **speak clearly and try to speak one at a time**, we would greatly appreciate it.
- A member of our study team, __ (insert name) __, will also be taking notes during our discussion.
- All information that you share today will be **kept strictly confidential.** We will not include your names in any study documents.
- Finally, if any of you become emotionally distressed as a result of considering and commenting on the issues we are discussing today, please let us know once the discussion has ended and we can inform you of MSK resources in the social work and psychiatry departments that you may consult in the event you would like emotional support.
- Thanks again! We will **start the audio recording now.**
- First we would like all of us to **introduce ourselves.** So, we will go around the group and if you could each state your first name only, and take 30 seconds to share something that you like to do in your spare time. I will start. I volunteer as a ceramics studio assistant outside of work.

IV. Discussion (70 minutes)

The first topic that we will discuss today is what you may currently know about research medical donation.

Topic 1: Knowledge about Research Medical Donation (10 minutes)

- 1) What does the term research medical donation mean to you?
 Probe: What do you think this process involves?
 Probe: Where have you heard about research medical donation?

Now we would like to share with you some information regarding research medical donation and the process it entails. Research medical donation is an option for patients who want to donate tissue samples to cancer research after they pass away. While the patient is living, we make prearrangements to collect tissues. Then, when the patient passes away, we collect tissues. The tissues are collected through a surgical process that is not as thorough as an autopsy, and no report is generated for the patient's medical record or family. Afterward, the family proceeds with cremation or funeral (including open-casket) services. Cancer researchers use the donated samples in research. There is no cost to the patient or family to participate.

- 2) If you were considering participating in research medical donation, what are the most important needs for information regarding research medical donation and its process that you would have?
 Probe: What questions would you have?

Next we would like to learn your views regarding what you perceive to be benefits from participating in research medical donation.

Topic 2: Benefits of Research Medical Donation (15 minutes)

- 1) What benefits do you associate with research medical donation?
 Probe: What benefits do you think exist for patients?
 Probe: What benefits do you think exist for families?
 Probe: What benefits do you think exist for doctors?
 Probe: What benefits do you think exist for medical science?
- 2) Some patients have described the ability to "give back" or make an altruistic gift as a benefit of research medical donation. What do you think about this perspective?
 Probe: How do you think participating in research medical donation as a way to "give back" could influence a patient's quality of life (at the end of their life)?
 Probe: How do you think a patient's participation in research medical donation could influence family members' bereavement?
- 3) Some patients have also described how participating in research medical donation can allow them to leave a legacy. What do you think about this perspective?
 Probe: How do you think participating in research medical donation as a way for a patient to leave a legacy could influence a patient's quality of life (at the end of their life)?
 Probe: How do you think this could influence family members' bereavement?

Now we would like to learn your perspectives regarding any concerns that you may have regarding research medical donation and the process that it entails.

Topic 3: Concerns About Research Medical Donation (20 minutes)

- 1) What concerns do you associate with research medical donation?
 Probe: What concerns do you think exist for patients?
 Probe: What concerns do you think exist for families?
 Probe: What concerns do you think exist for a patient's medical team?
- 2) What practical concerns do you have about research medical donation?
 Probe: What concerns, if any, do you have regarding the process of transporting the patient after their death?
 Probe: What concerns, if any, do you have related to financial costs that you believe may be associated with participating in a research medical donation program?
 Probe: What concerns, if any, do you have regarding how a patient's participation in a research medical donation program may impact funeral planning and logistics?
- 3) What do you think the emotional impacts of research medical donation could be on patients and their family members?
 Probe: What conflicts, if any, related to decision making regarding a patient's interest in research medical donation might exist in the family, or between the patient and the family?
- 4) What cultural or religious concerns do you have about research medical donation?
 Probe: What concerns, if any, do you have related to needs for timing of a patient's burial and associated ability to participate in research medical donation?
 Probe: What concerns, if any, do you have related to preserving the sanctity of the body?
- 5) What ethical concerns do you have about research medical donation?
 Probe: What worries, if any, might you have regarding how a medical donation will be used?
 Probe: What concerns, if any, might you have regarding privacy of a patient's medical information?

Next we would like to discuss what you feel would make research medical donation an acceptable choice for you, the information you would like to receive to become educated about the option, and how you believe a discussion about research medical donation with a patient's oncologist may affect the patient's relationship with his or her doctor.

Topic 4: Acceptability of Research Medical Donation (15 minutes)

- 1) What could make research medical donation an acceptable choice to you, as both patients and caregivers?
- 2) What information would you want to receive to learn more about research medical donation if you were considering it as an option?
 Probe: Which health care provider(s) would you want to receive this information from?
 Probe: As a patient, when would be an acceptable time in your treatment to receive this information?
 Probe: As patients and caregivers, how would you like a health care provider to introduce the option of research medical donation to you?
- 3) How do you think a discussion about research medical donation could affect the relationship between an oncologist and their patient?
 Probe: How might this discussion affect the relationship between an oncologist and a patient's family or caregiver?

Finally, we would like to explore your views regarding the potential role that a patient's unique cancer type may play in influencing perceptions and attitudes regarding research medical donation.

Topic 5: Influence of Unique Cancer Factors on Perceptions of Research Medical Donation (10 minutes)

- 1) For patients like you with your type of cancer and for their caregivers, how do you feel that the diagnosis of _____ cancer (*moderator to speak to the appropriate cancer diagnosis—lung, breast, or pancreatic—per participant subsample*) may influence beliefs and attitudes regarding research medical donation? (Example follow-up probes: patient age at diagnosis, treatment availability, commonness of cancer, prognosis, role of lifestyle factors in etiology, state of scientific knowledge regarding cancer etiology)
- 2) How do you feel that your level of interest in research medical donation may be influenced by characteristics associated with the type of cancer that you have been affected by? (Example follow-up probes: patient age at diagnosis, treatment availability, commonness of cancer, prognosis, role of lifestyle factors in etiology, state of scientific knowledge regarding cancer etiology)

V. Conclusion (five minutes)

Okay, we've covered all the issues that I wanted to discuss. Before we finish, I want to give you the opportunity to reflect on our discussion and share anything that you think is relevant to your views regarding research medical donation that did not come up during the conversation.

Again, thank you very much for your honesty and willingness to participate in this discussion! We have learned a lot today, and your opinions will help us learn how to best instruct clinicians as to how to appropriately communicate about research medical donation with patients and their families. If you'd like, please feel free to stay a bit if you have any questions about our research, would like information about MSK resources in social work and psychiatry that you could consult for emotional support, or have any other comments that you would like to share.

Thanks again!