

Introducing end-of-life group discussions in the primary care setting: Preliminary findings on patient engagement and satisfaction

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Introduction

Patients have expressed an interest in learning more about end-of-life care, including exploring their own feelings and values around death and dying. However, in a California survey, only 23% of people reported having put their end-of-life wishes in writing and only 7% reported having had a doctor ask about their wishes for medical treatment at the end of their lives.

This project, supported by the 2013-2014 Harvard Medical School Innovation Fellows Program, explores the capacity of the primary care physician to initiate end-of-life planning among non-terminally ill patients age 65 and older through a structured peer group discussion.

Objectives

- Provide a safe space where patients and their loved ones can explore their preferences, values and goals related to end-of-life care
- Educate patients about end-of-life care planning and options
- Increase proportion of patients who have a signed health care proxy on file
- Expand end-of-life conversations outside of the small group discussion
- Help discussion participants recognize core values about end-of-life care
- Empower patients to take an active role in their health care

Methods

This is a pilot study using multiple semi-structured questionnaires in a prospective fashion. The questionnaires include knowledge surveys on end-of-life care, satisfaction survey and patient activation surveys. Patient activation and involvement in his/her own care was assessed using a validated questionnaire PAM (Patient Activation Measure). A total of 50 patients were recruited, and 39 were shortlisted and randomly assigned to control (n=19) and treatment group (n=20). The treatment group participated in group discussions on end-of-life care with a team consisting of the primary care physician, a medical resident, a nursing student, and a premedical student.

Surveys and
Questionnaires

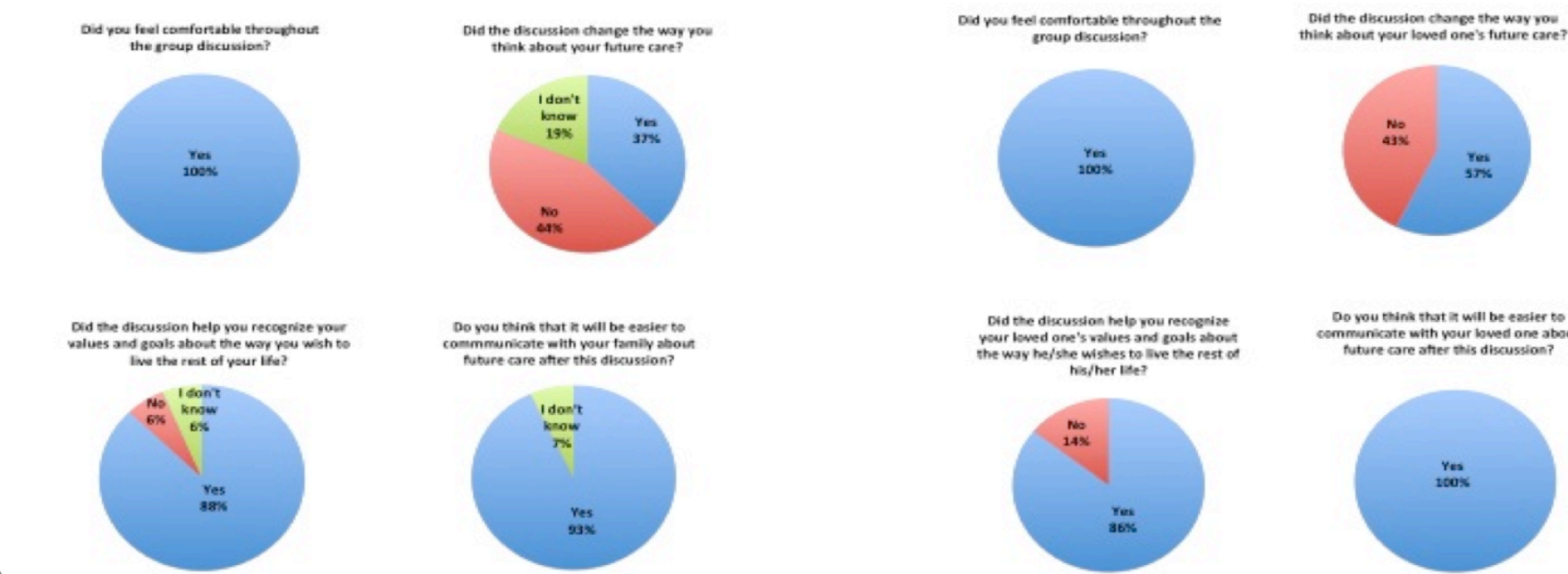
View Our Interactive
Discussion Module

Results

Our study included 15 treatment patients, 7 family members, and 11 control patients. We held four group discussions.

- 100% of patients and family members reported feeling comfortable throughout the group discussion (n=22)
- 73% of treatment patients showed increased knowledge about end-of-life care planning issues, compared to 27% of control patients (n=26)
- The proportion of study patients with a health care proxy on file increased 40%, compared to a 0% increase among control patients (n=26)
- On average, participants reported sharing their discussion experience with four people outside of the study (n=15)
- 86% of patients and family members reported that the group discussion helped them recognize values and goals about end-of-life care (n=22)
- The PAM scores increased slightly from 68.6 to 69.1 in the treatment group and 63.5 to 66.3 in the control group (n=26). The majority of the participants in the treatment and control group entered the study at a PAM level 3 or 4 (93% of treatment patients and 91% of control patients)

View Data



Conclusions

- Patients are comfortable discussing end-of-life care planning in a small group setting with their primary care physicians
- Peer group discussions are an effective method for educating patients about end-of-life care planning
- Patients are more likely to fill out health care proxy forms if they have participated in a peer group discussion
- Patients and family members feel more comfortable having end-of-life care discussions with their loved ones after peer group discussions
- Peer group discussions helped patients identify core values regarding end-of-life care
- Patients who agreed to participate in the study had high activation levels, which may reflect their willingness to engage in a discussion about an uncomfortable topic

References

1. Steinhauer KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. Ann Intern Med. 2000; 13(10): 825-832.
2. Lake Research Partners and the Coalition for Compassionate Care of California. (February, 2012) Final Chapter: Californians’ Attitudes and Experiences with Death and Dying. Retrieved at <http://www.chcf.org/publications/2012/02/final-chapter-death-dying#ixzz365ceRwwl>

Surveys and Questionnaires (click on a survey for an enlarged version)

Surveys and Questionnaires for Data Collection

Baseline Questionnaire

1. Which of the following statements best describes your current situation (please select one statement):

☐ I have thought about what I would like if I become terminally ill, and have talked about it with my family.

☐ I have thought about it briefly but have not discussed it with my family.

☐ I do not like to think about it, and discussing it makes me feel uncomfortable.

2. Please select one of the following:

☐ I know what a Health Care Proxy is, and I have one.

☐ I know what a Health Care Proxy is, but I do not have one.

☐ I do not know what a Health Care Proxy is.

3. Please select one of the following:

☐ I know what an Advance Directive is, and I have one.

☐ I know what an Advance Directive is, but I do not have one.

☐ I do not know what an Advance Directive is.

4. Please select one of the following:

☐ I understand what services hospice and palliative care provide.

☐ I know the basics of hospice and palliative care, but would like to learn more.

☐ I do not understand hospice and palliative care.


5. Please select one of the following:

☐ I have a clear understanding of my values and goals around end-of-life care.

☐ I am somewhat aware of my values and goals around end-of-life care.

☐ I have not yet thought about my values and goals around end-of-life care.

Baseline Questionnaire


Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and not just what you think others want you to say.

If the statement does not apply to you, circle N/A.

1. When all is said and done, I am the person who is responsible for taking care of my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2. Taking an active role in my own health care is the most important thing that affects my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3. I am confident I can help prevent or reduce problems associated with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4. I know what each of my prescribed medications do.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6. I am confident that I can tell a doctor concerns I have even when he or she does not ask.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7. I am confident that I can follow through on medical treatments I may need to do at home.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8. I understand my health problems and what causes them.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9. I know what treatments are available for my health problems.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
11. I know how to prevent problems with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
12. I am confident I can figure out solutions when new problems arise with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

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PAM Questionnaire

Satisfaction/Experience Questionnaire - Participant

1. Did you feel comfortable throughout the group discussion?

☐ Yes ☐ No ☐ I don't know

2. Did the discussion change the way you think about your future care?

☐ Yes ☐ No ☐ I don't know

3. Did the discussion help you recognize your values and goals about the way you wish to live the rest of your life?

☐ Yes ☐ No ☐ I don't know

4. Do you think that it will be easier to communicate with your family about future care after this discussion?

☐ Yes ☐ No ☐ I don't know

5. Do you think that having this conversation in a group is better than having it one-on-one with your physician?

☐ Yes ☐ No ☐ I don't know

6. Do you have any suggestions for future conversations about this topic?

Thank you for your time and participation!

Satisfaction Survey-Participant

Satisfaction/Experience Questionnaire - Family Member

1. Did you feel comfortable throughout the group discussion?

☐ Yes ☐ No ☐ I don't know

2. Did the discussion change the way you think about your loved one's future care?

☐ Yes ☐ No ☐ I don't know

3. Did the discussion help you recognize your loved one's values and goals about the way he/she wishes to live the rest of his/her life?

☐ Yes ☐ No ☐ I don't know

4. Do you think that it will be easier to communicate with your loved one about future care after this discussion?

☐ Yes ☐ No ☐ I don't know

5. Do you think that having this conversation in a group is better than having it one-on-one with a physician?

☐ Yes ☐ No ☐ I don't know

6. Do you have any suggestions for future conversations about this topic?

Thank you for your time and participation!

Satisfaction Survey-Family Member



Discussion Resources

A Review: Having the Conversation

Resources for Future Planning


- ❖ **Prepare For Your Care:**
<https://www.prepareforyourcare.org>
- ❖ **The Conversation Project:**
<http://theconversationproject.org>
- ❖ **The Conversation Project Starter Kit:**
<http://theconversationproject.org/starter-kit/intro/>
- ❖ **Health Care Proxy Form:** <http://molst-ma.org/sites/molst-ma.org/files/MA-Health-Care-Proxy-Form.pdf>
- ❖ **MOLST:** <http://molst-ma.org>
- ❖ **Advanced Directive/Comfort Care/DNR:**
<http://www.mass.gov/eohhs/docs/dph/emergency-services/comfort-care-form.pdf>
- ❖ **If you have questions about options regarding facilities or assisted living in the future, please contact Dr. Bloch who will refer you to a Case Manager.**

Important Reminders

Today we discussed values and goals around your future health care plans. These are by no means set in stone, and they can change at any point in time. If you feel that your goals for your care have changed, please consult with Dr. Bloch who will support you through the process.

If you have not already completed your Health Care Proxy and Advanced Directive forms, please do so at your convenience and return them to Dr. Bloch's office. Both of these forms are important in identifying goals for your future health care.

We encourage you to continue this conversation at home with family members and loved ones. The more you make your wishes known, the more likely they will be expressed and respected.



Resource List

Thinking about Values (Adapted from The Conversation Project)

1) I want my doctors to do what they think is best. 1 2 3 4 5 I want to have a say in every decision.

2) I want all care possible to prolong my life, including tubes and wires. 1 2 3 4 5 Being comfortable and pain-free is more important than prolonging life.

3) I wouldn't mind spending my last days in a hospital. 1 2 3 4 5 I want to spend my last days at home.

4) I wouldn't mind being in a nursing facility. 1 2 3 4 5 Independence is very important to me.

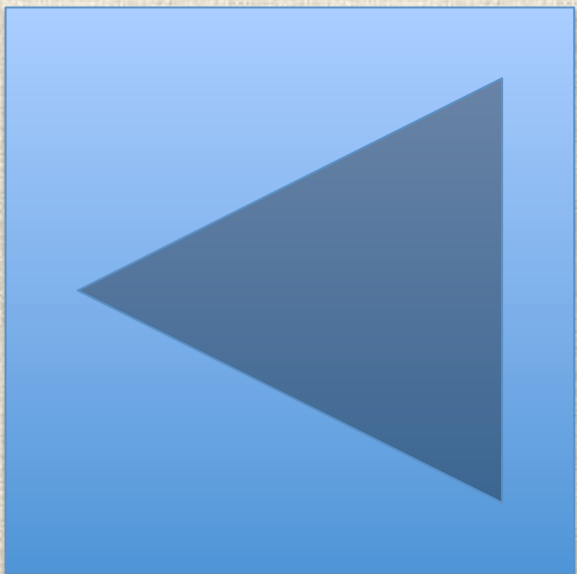

5) My loved ones should do exactly what I've said. 1 2 3 4 5 My loved ones should do what brings them peace.

If I can no longer recognize my loved ones and be aware of my surroundings...

6) I would still like all possible care. 1 2 3 4 5 I wouldn't want to prolong my life.

Values Survey

See results from this survey



Baseline Questionnaire

1. Which of the following statements best describes your current situation (please select one statement):

- ☐ I have thought about what I would like if I become terminally ill, and have talked about it with my family.
- ☐ I have thought about it briefly but have not discussed it with my family.
- ☐ I do not like to think about it, and discussing it makes me feel uncomfortable.

2. Please select one of the following:

- ☐ I know what a Health Care Proxy is, and I have one.
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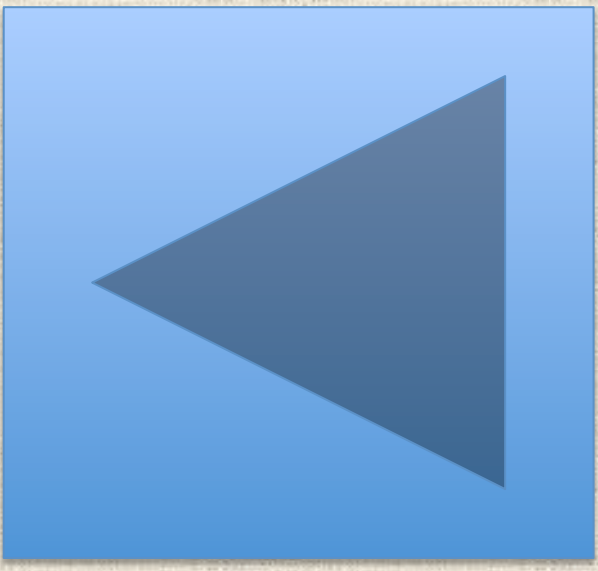
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- ☐ I understand what services hospice and palliative care provide.
- ☐ I know the basics of hospice and palliative care, but would like to learn more.
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5. Please select one of the following:

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- ☐ I am somewhat aware of my values and goals around end-of-life care.
- ☐ I have not yet thought about my values and goals around end-of-life care.

See results from this survey

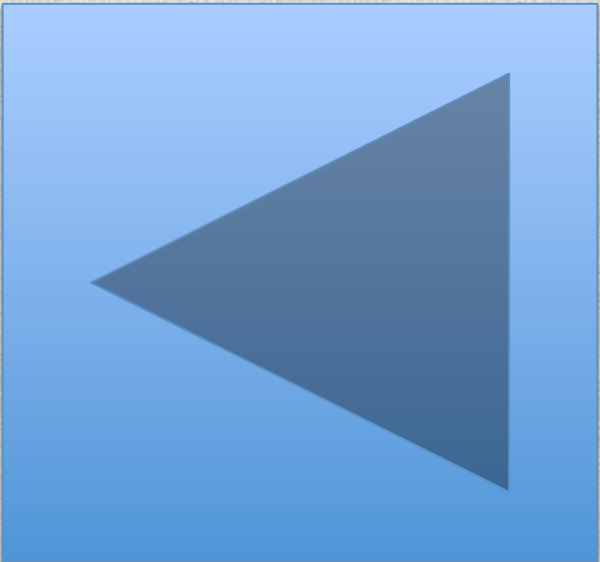


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2.	Taking an active role in my own health care is the most important thing that affects my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3.	I am confident I can help prevent or reduce problems associated with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
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Thinking about Values (Adapted from The Conversation Project)

- 1)

I want my doctors to do what they think is best

1

2

3

4

5

I want to have a say in every decision
- 2)

I want all care possible to prolong my life, including tubes and wires

1

2

3

4

5

Being comfortable and pain-free is more important than prolonging life
- 3)

I wouldn't mind spending my last days in a hospital

1

2

3

4

5

I want to spend my last days at home
- 4)

I wouldn't mind being in a nursing facility

1

2

3

4

5

Independence is very important to me
- 5)

My loved ones should do exactly what I've said

1

2

3

4

5

My loved ones should do what brings them peace

If I can no longer recognize my loved ones and be aware of my surroundings...

- 6)

I would still like all possible care

1

2

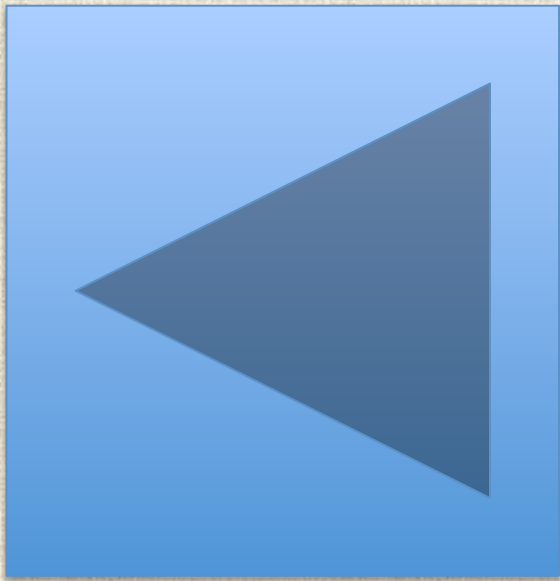
3

4

5

I wouldn't want to prolong my life

See results from this survey



Satisfaction/Experience Questionnaire - Participant

1. Did you feel comfortable throughout the group discussion?

- ☐ Yes ☐ No ☐ I don't know

2. Did the discussion change the way you think about your future care?

- ☐ Yes ☐ No ☐ I don't know

3. Did the discussion help you recognize your values and goals about the way you wish to live the rest of your life?

- ☐ Yes ☐ No ☐ I don't know

4. Do you think that it will be easier to communicate with your family about future care after this discussion?

- ☐ Yes ☐ No ☐ I don't know

5. Do you have any suggestions for future conversations about this topic?

Thank you for your time and participation!

Satisfaction/Experience Questionnaire - Family Member

1. Did you feel comfortable throughout the group discussion?

- ☐ Yes ☐ No ☐ I don't know

2. Did the discussion change the way you think about your loved one's future care?

- ☐ Yes ☐ No ☐ I don't know

3. Did the discussion help you recognize your loved one's values and goals about the way he/she wishes to live the rest of his/her life?

- ☐ Yes ☐ No ☐ I don't know

4. Do you think that it will be easier to communicate with your loved one about future care after this discussion?

- ☐ Yes ☐ No ☐ I don't know

5. Do you have any suggestions for future conversations about this topic?

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❖ **Health Care Proxy Form:** <http://molst-ma.org/sites/molst-ma.org/files/MA-Health-Care-Proxy-Form.pdf>

❖ **MOLST:** <http://molst-ma.org>

❖ **Advanced Directive/Comfort Care/DNR:**

<http://www.mass.gov/eohhs/docs/dph/emergency-services/comfort-care-form.pdf>

❖ **If you have questions about options regarding facilities or assisted living in the future, please contact Dr. Bloch who will refer you to a Case Manager.**

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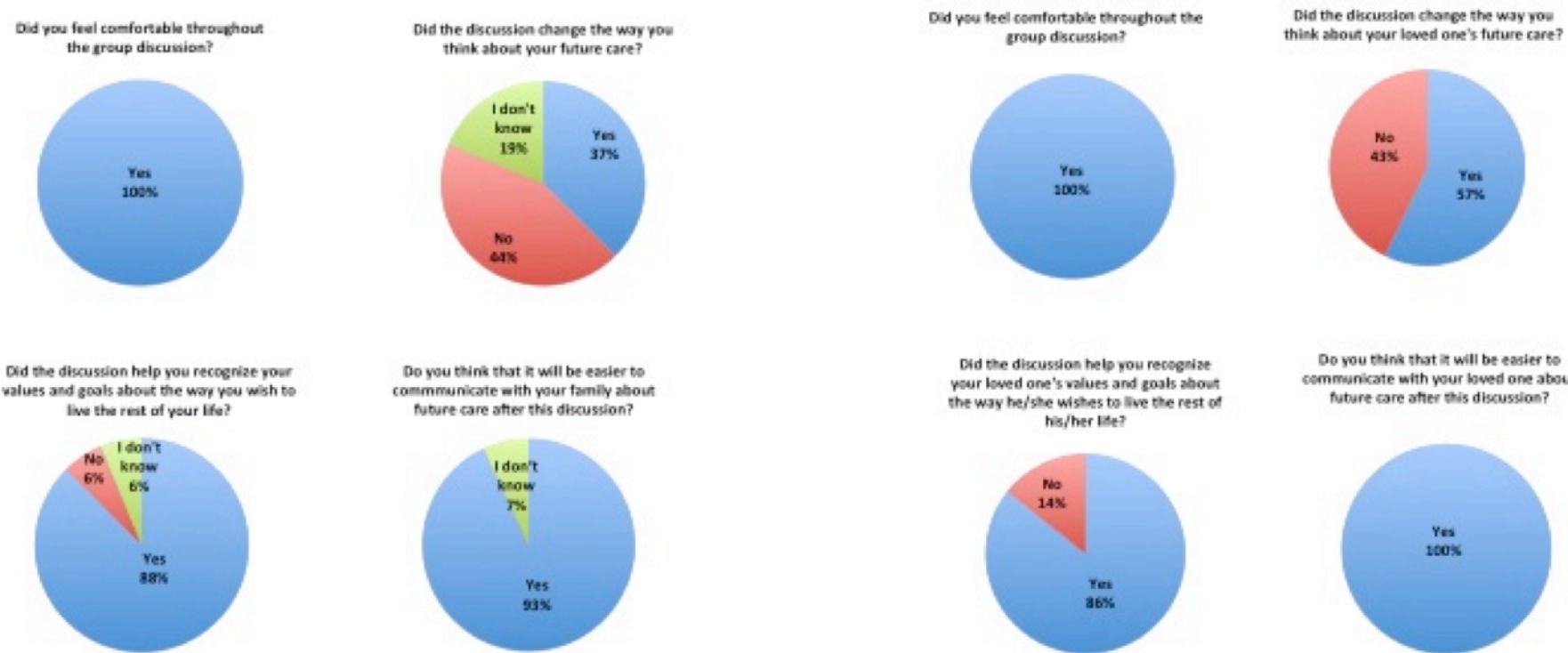
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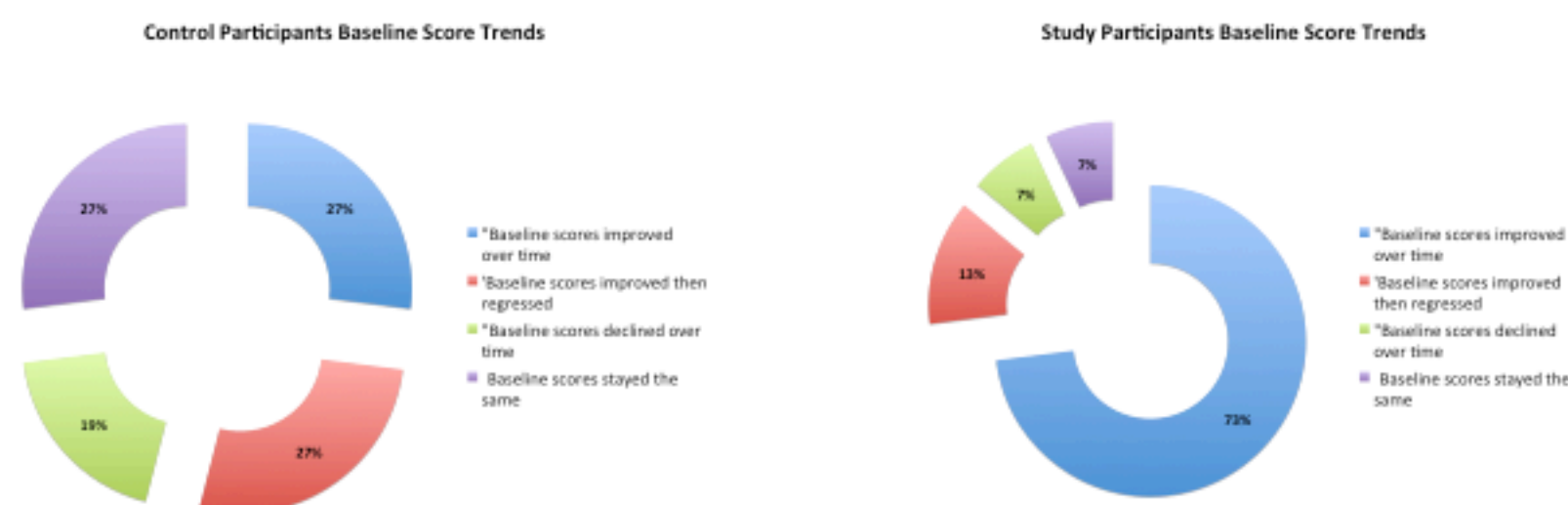


Results (click on each group for more detail)

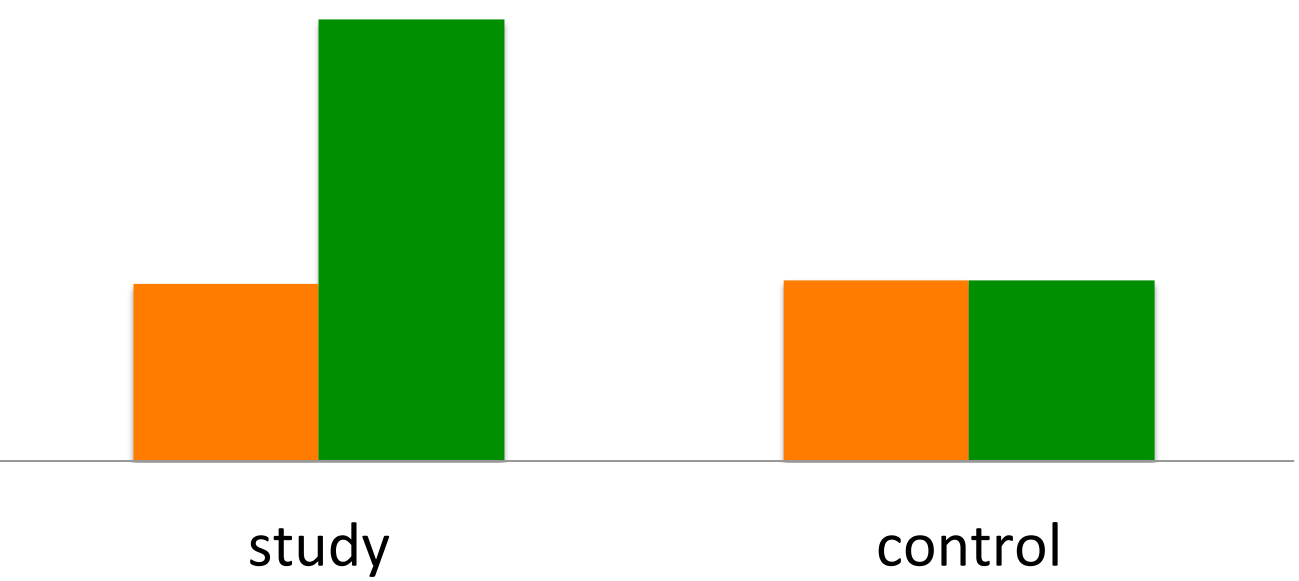
Patient and Family Member Satisfaction Surveys



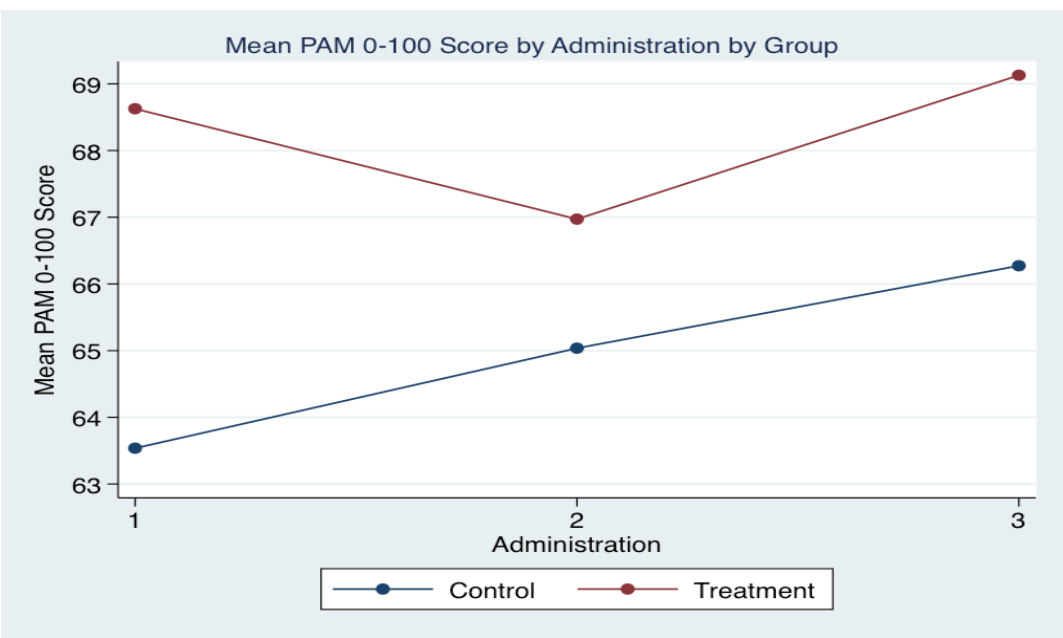
Treatment and Study Baseline Survey Trends



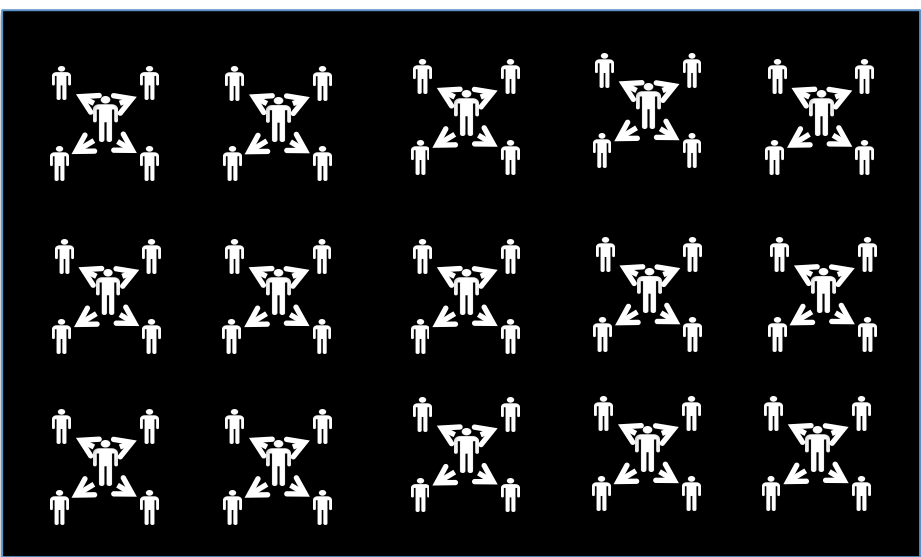
% of Participants with Health Care Proxy on File



Patient Activation Measure Results



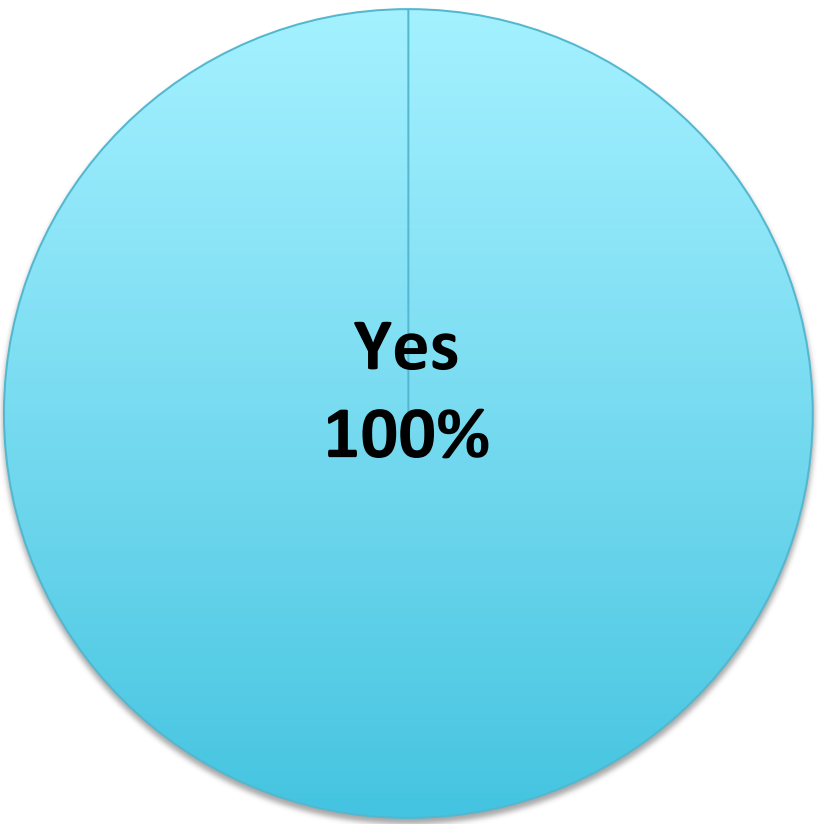
Expanding the Conversation



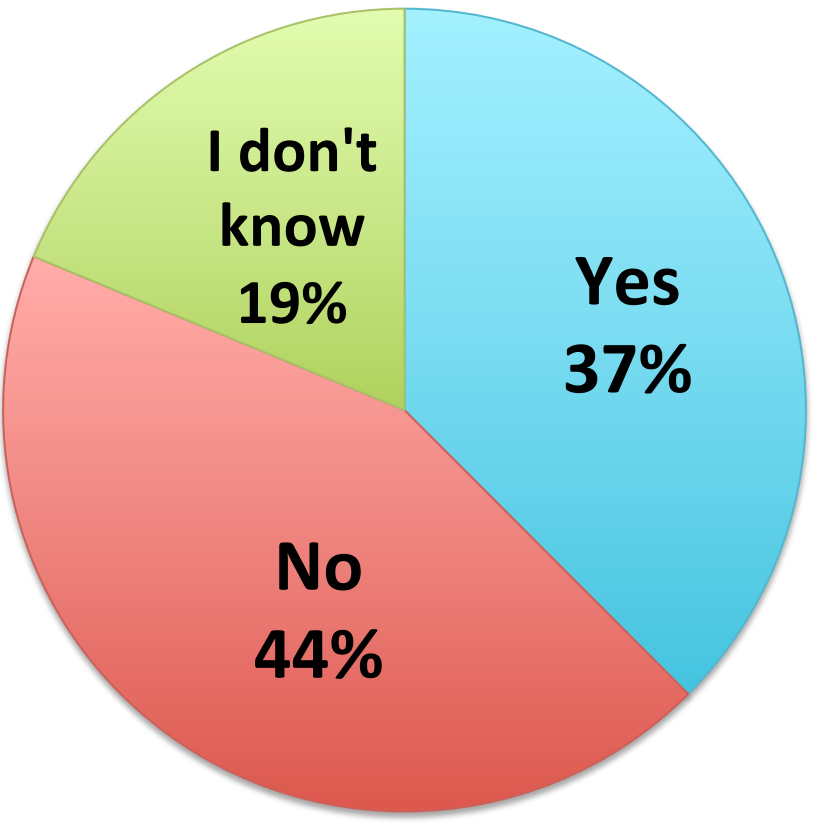
Results from Satisfaction Questionnaire

Patient Feedback

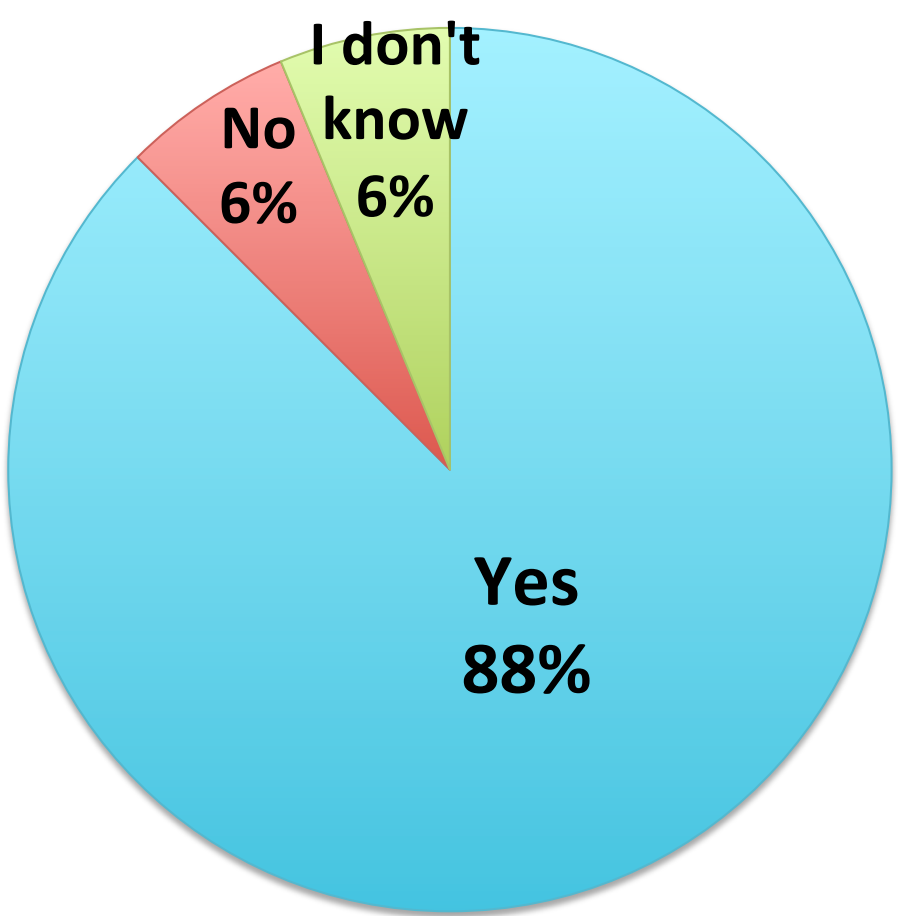
Did you feel comfortable throughout the group discussion?



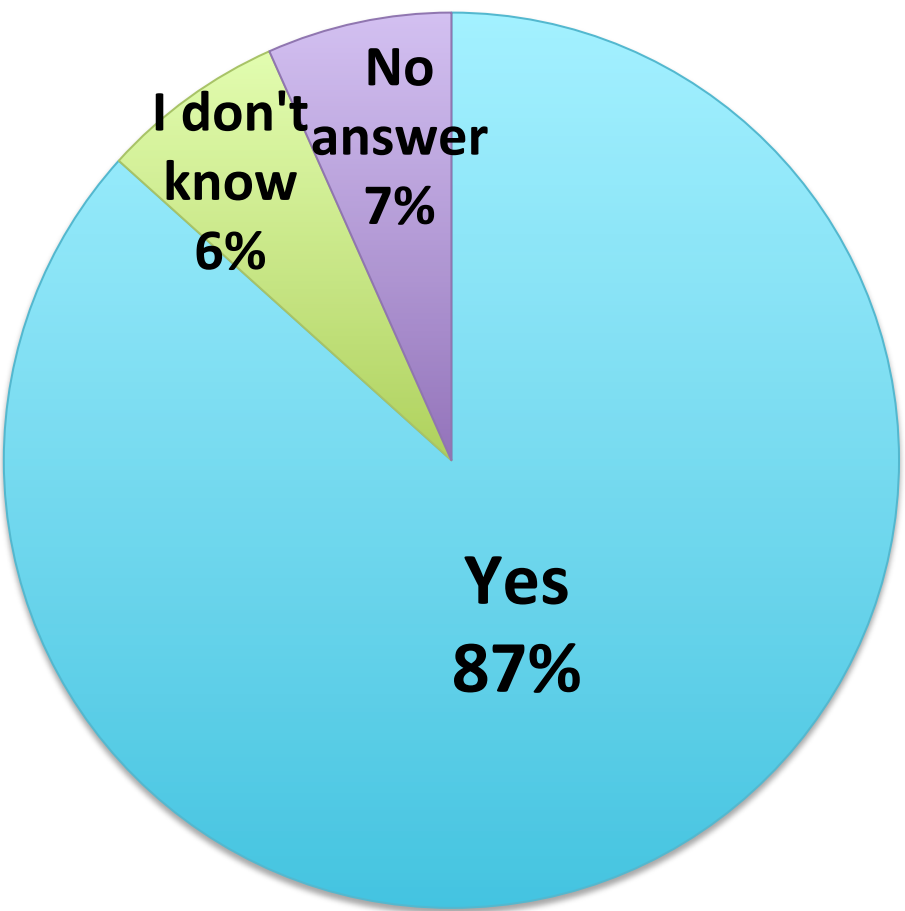
Did the discussion change the way you think about your future care?



Did the discussion help you recognize your values and goals about the way you wish to live the rest of your life?

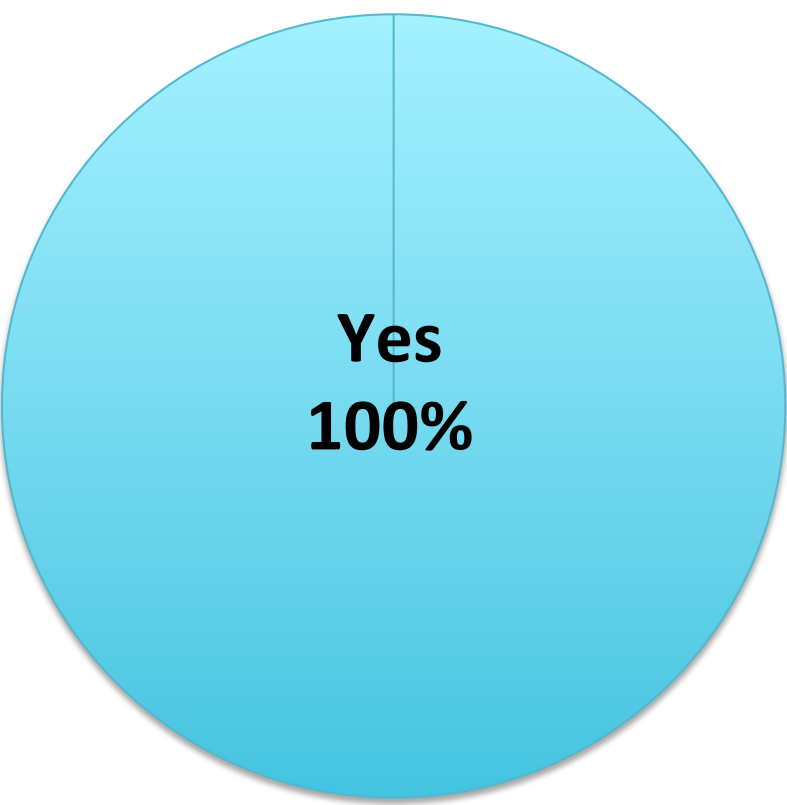


Do you think that it will be easier to communicate with your family about future care after this discussion?

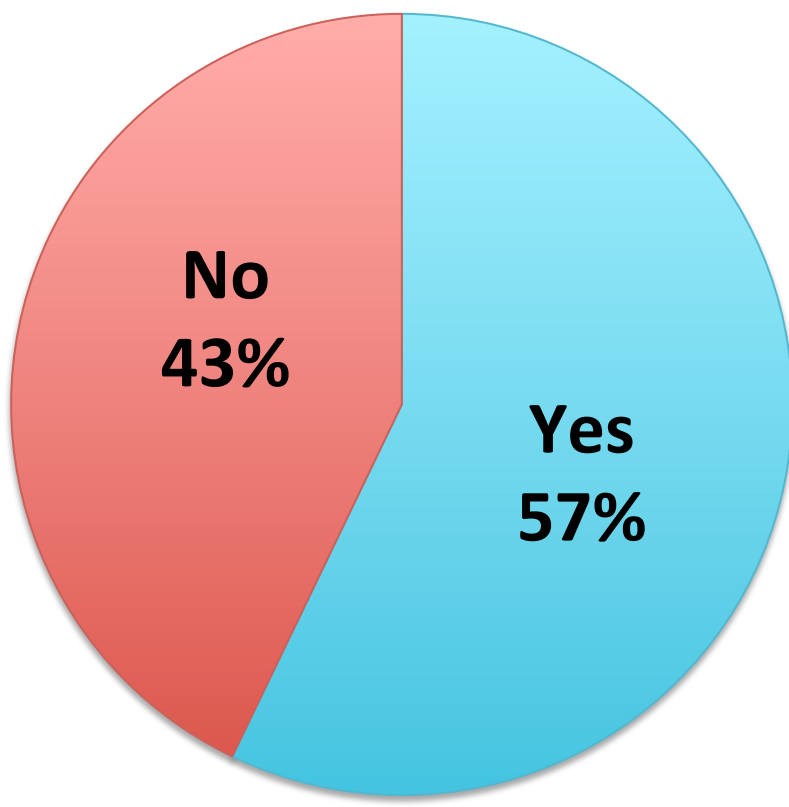


Family Member Feedback

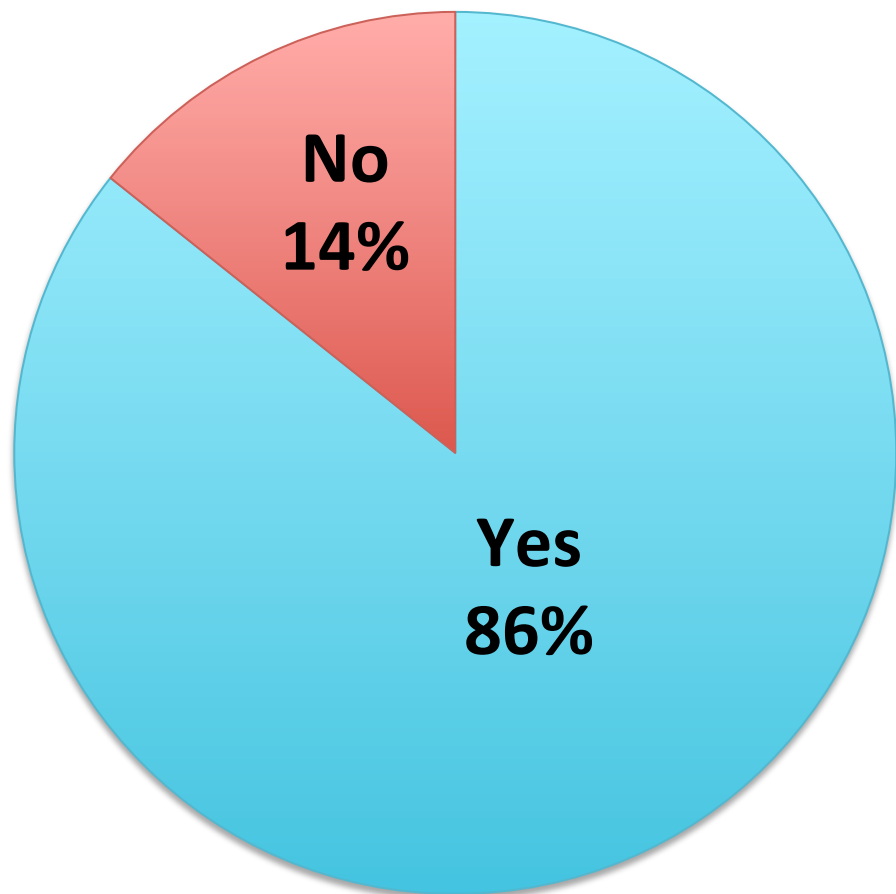
Did you feel comfortable throughout the group discussion?



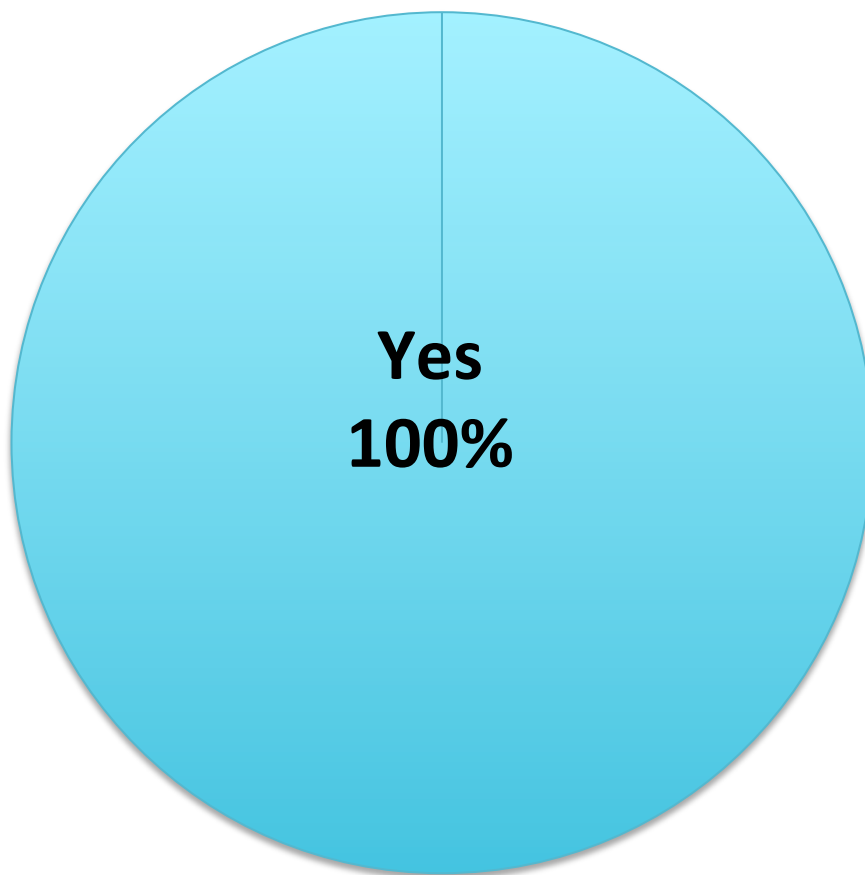
Did the discussion change the way you think about your loved one's future care?



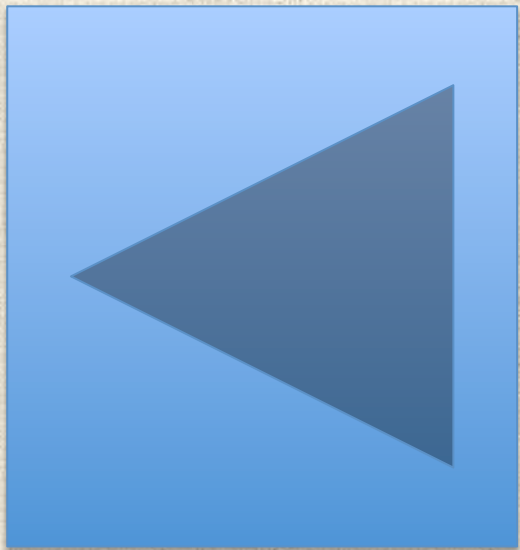
Did the discussion help you recognize your loved one's values and goals about the way he/she wishes to live the rest of his/her life?



Do you think that it will be easier to communicate with your loved one about future care after this discussion?

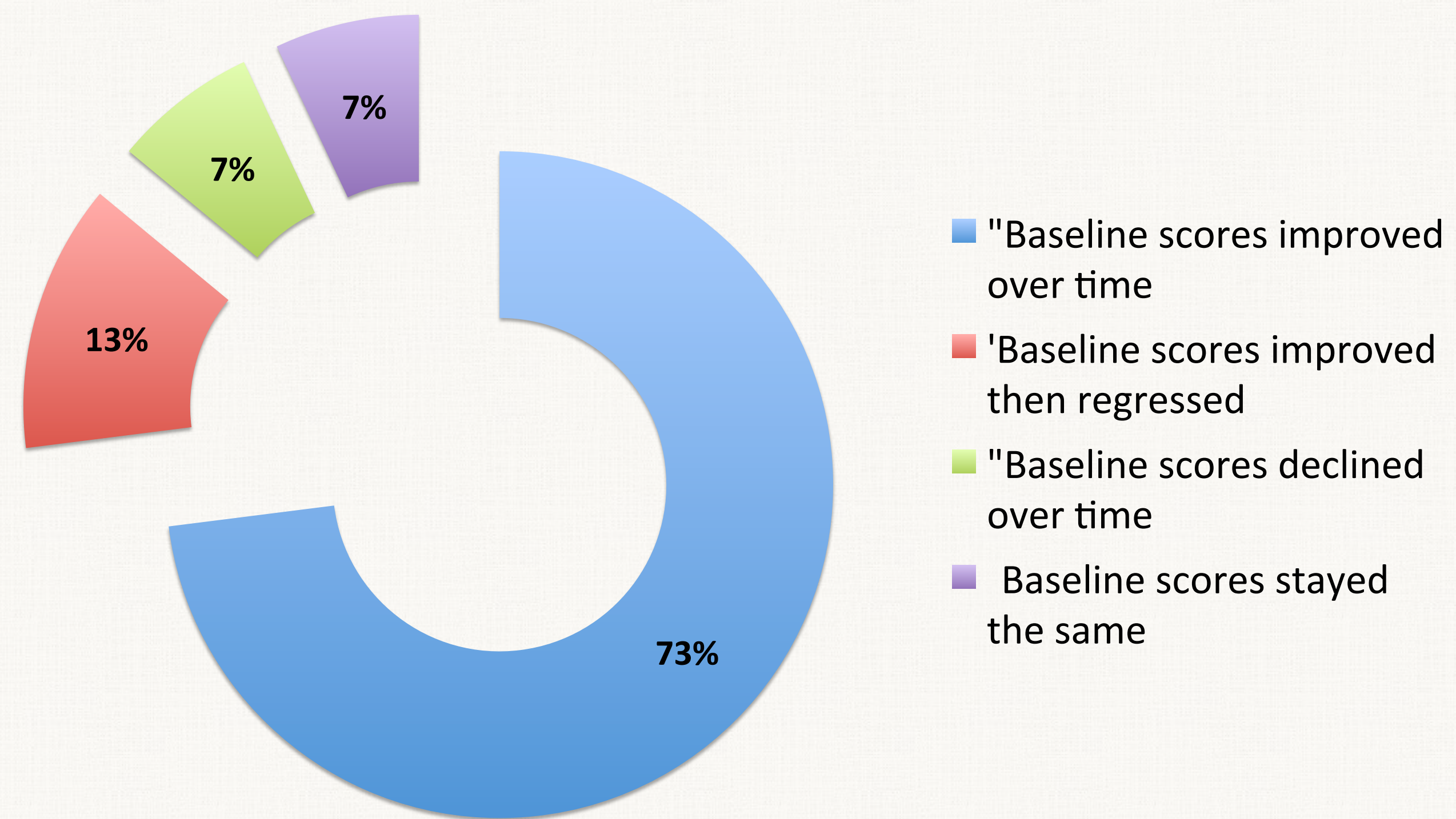


View Satisfaction Questionnaire

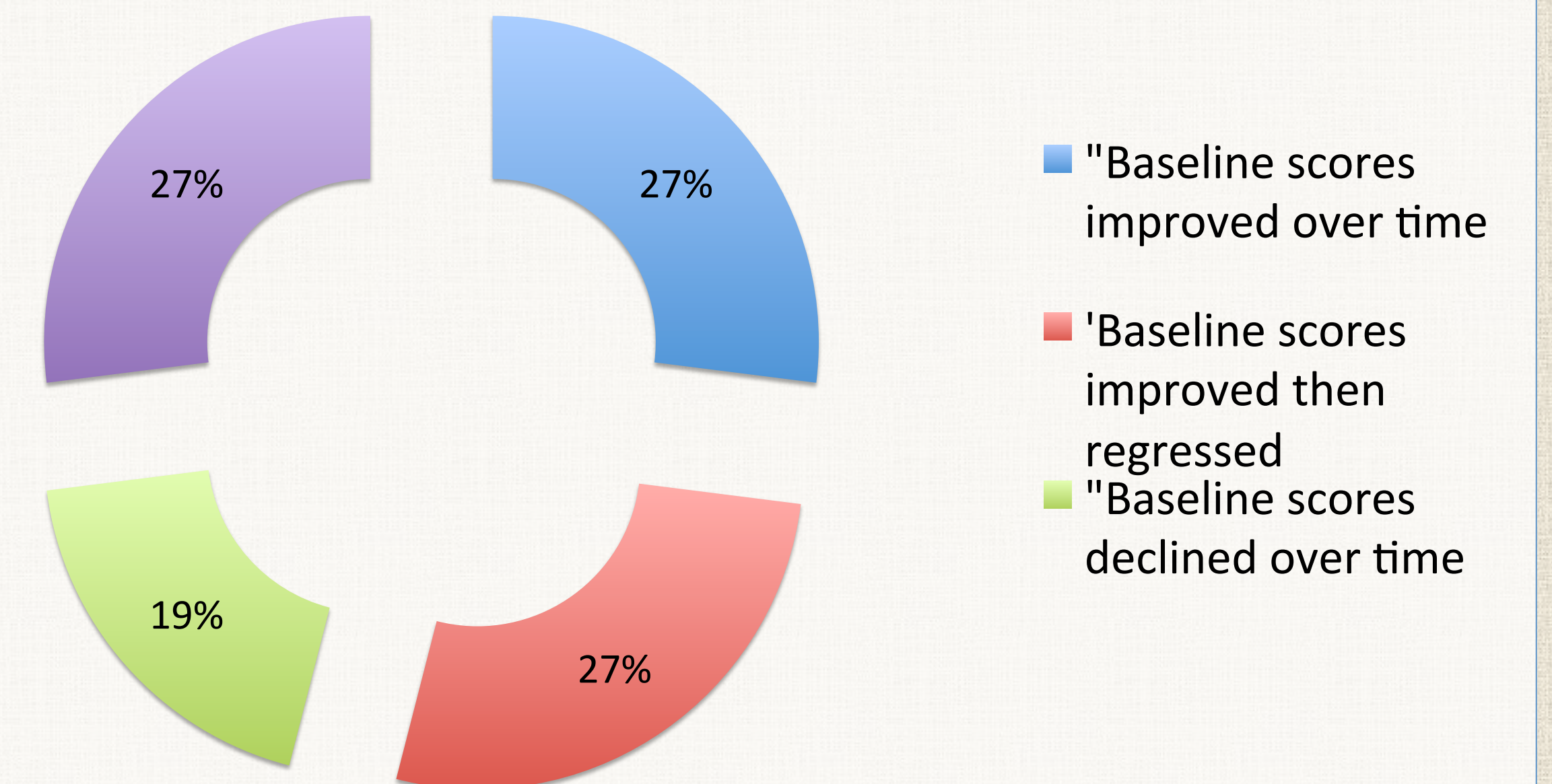


Results from Baseline Questionnaire

Treatment Participants Baseline Score Trends



Control Participants Baseline Score Trends

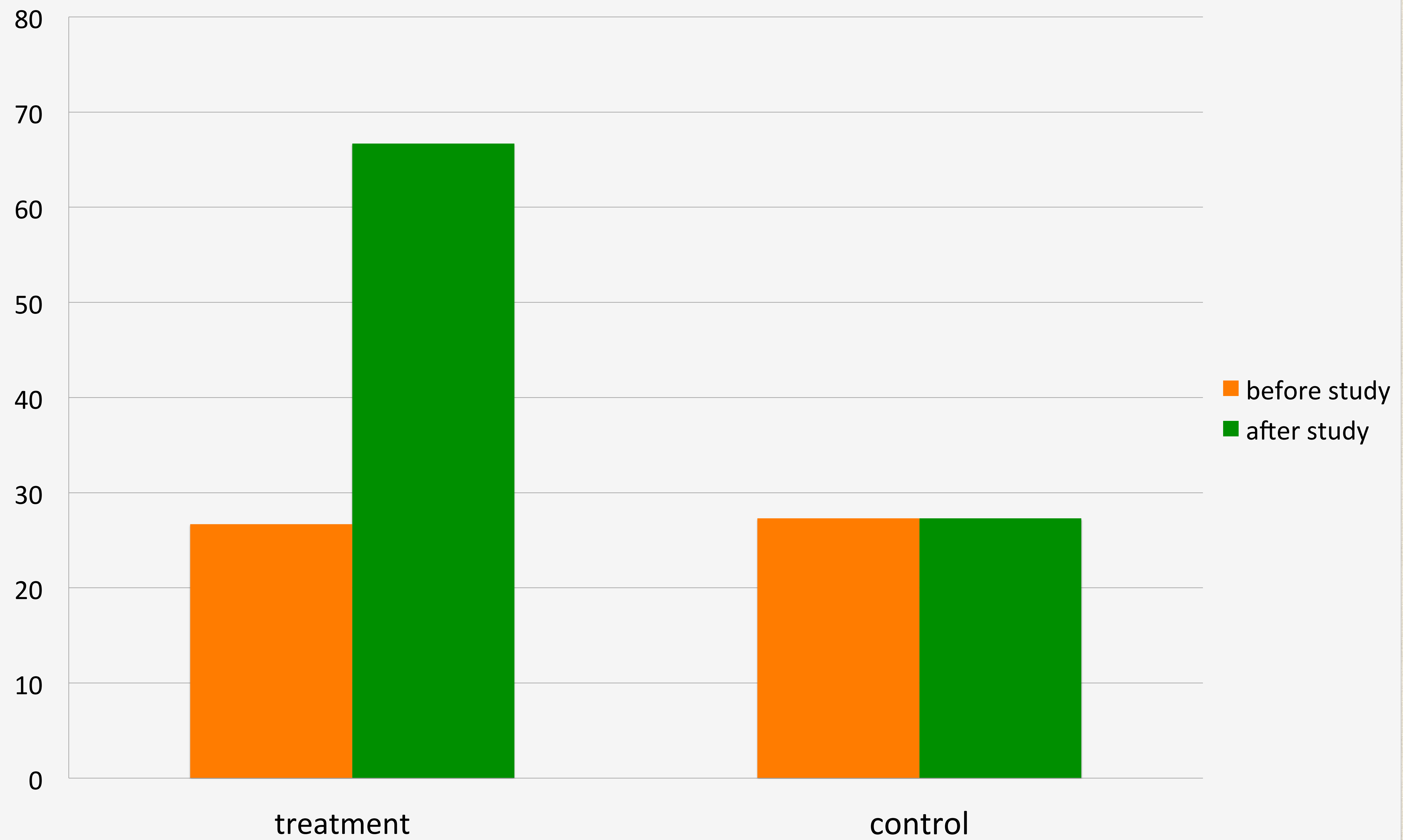


View Baseline
Questionnaire

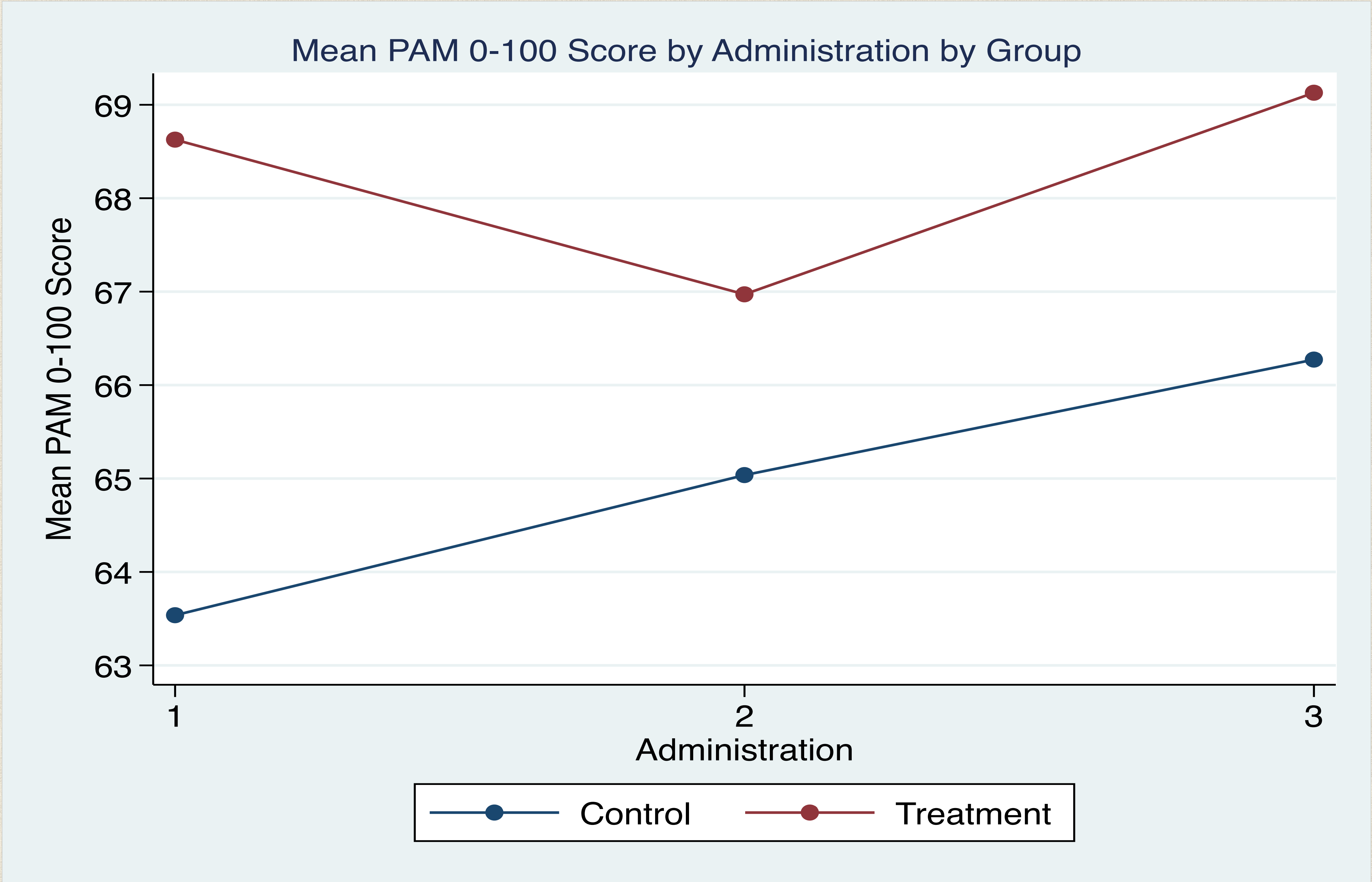




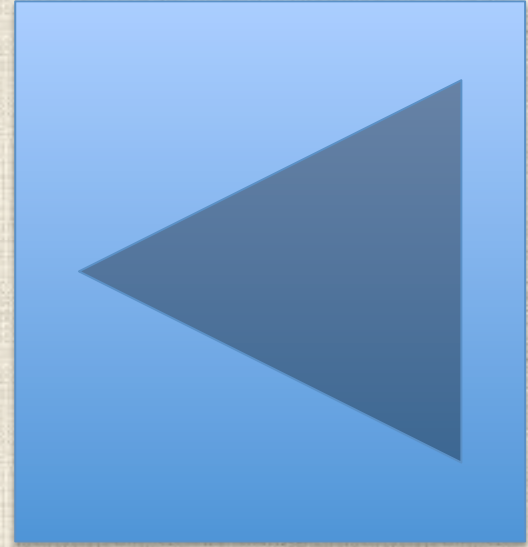
% of Participants with Health Care Proxy on File



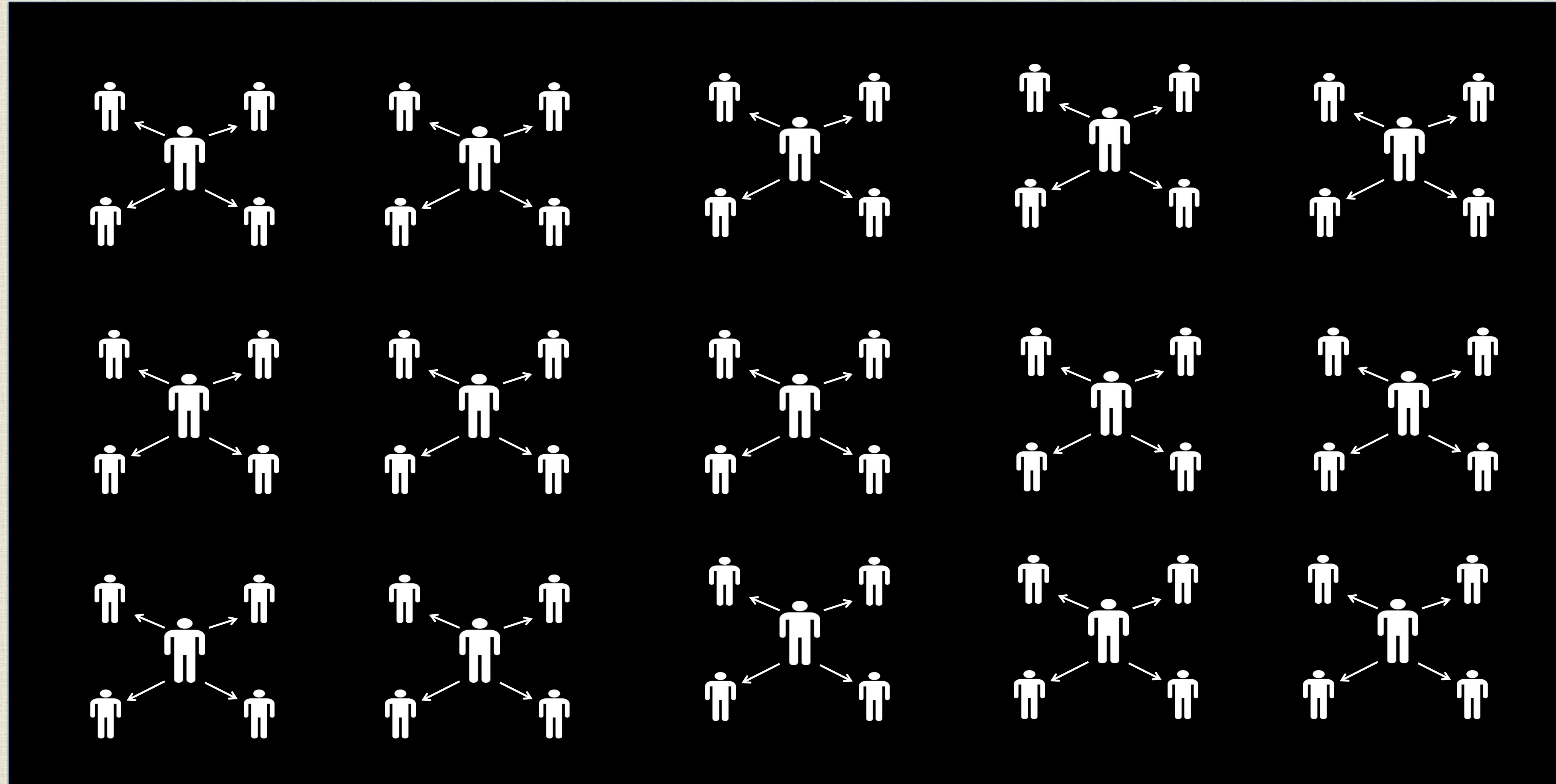
Patient Activation Measure (PAM) Results



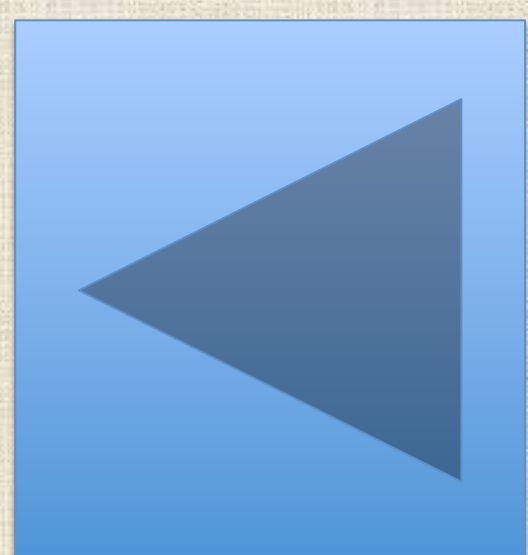
[View Patient Activation Measure](#)



We asked patients, “How many people have you spoken to about the group discussion?”



On average, each patient spoke to four people about their experience in the group discussion.



**View module slides with
narration and video**

**View module slides only
(no narration or video)**



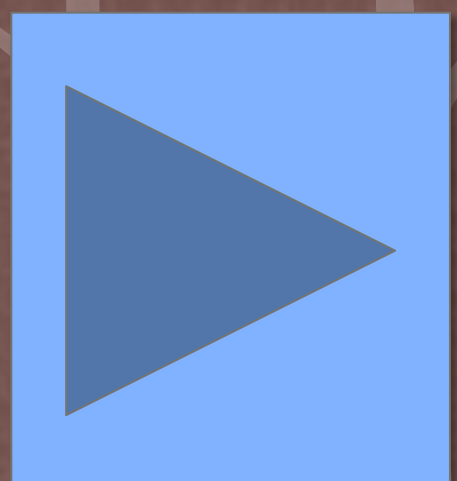
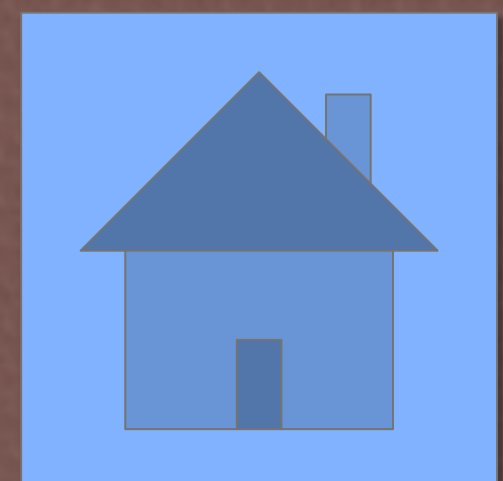
THE CONVERSATION

Dr. Nathalie Bloch

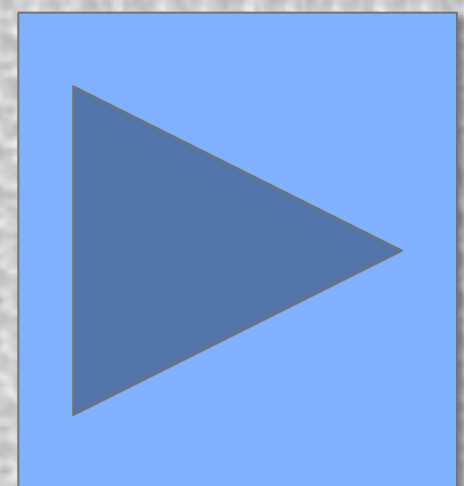
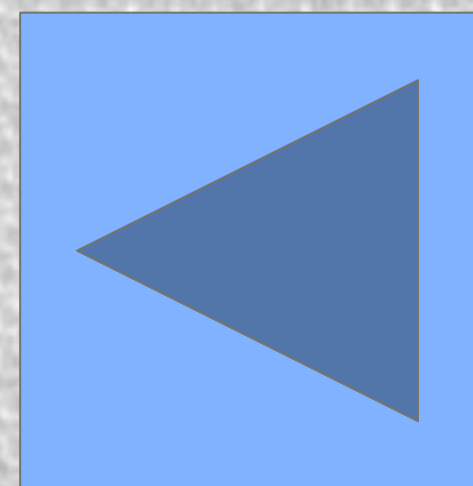
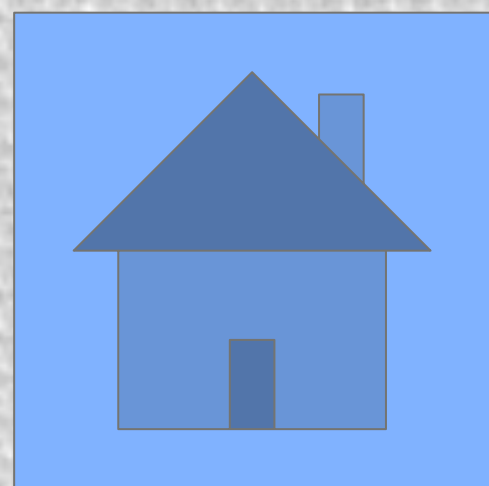
Dr. Aftab Iqbal

Alyse Krantz

Abigail Frydryk



Discussion Set-Up



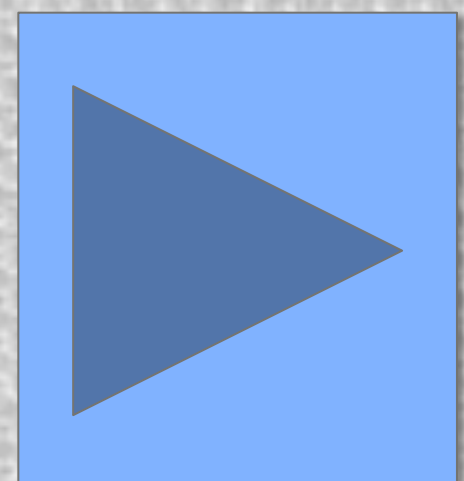
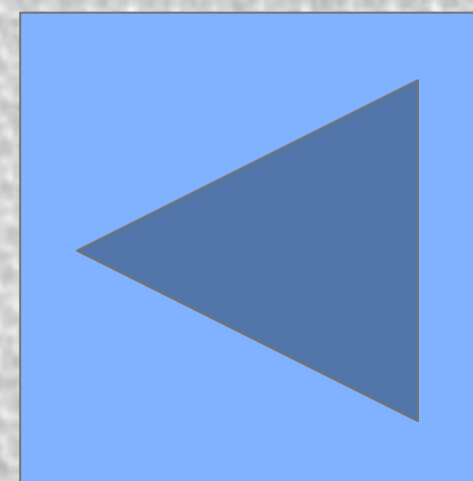
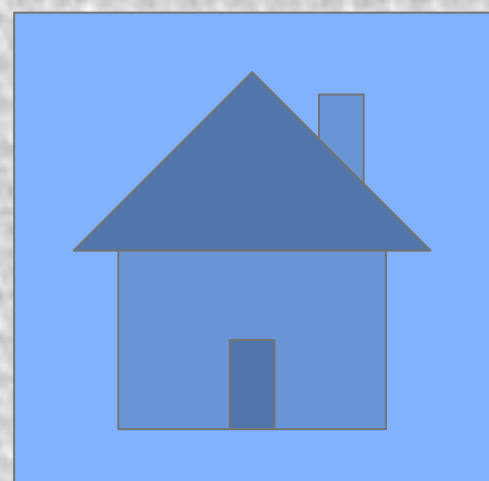
Team Member Introduction



Nathalie Bloch MD MPA:

Primary Care Physician and an Internist.

An asst. medical director and a board member at MACIPA and a fellow for Innovation at the Harvard Medical School. Moved to Boston in 2003- finished here her residency at Mount Auburn Hospital and completed a master degree in public administration at the Harvard Kennedy School.

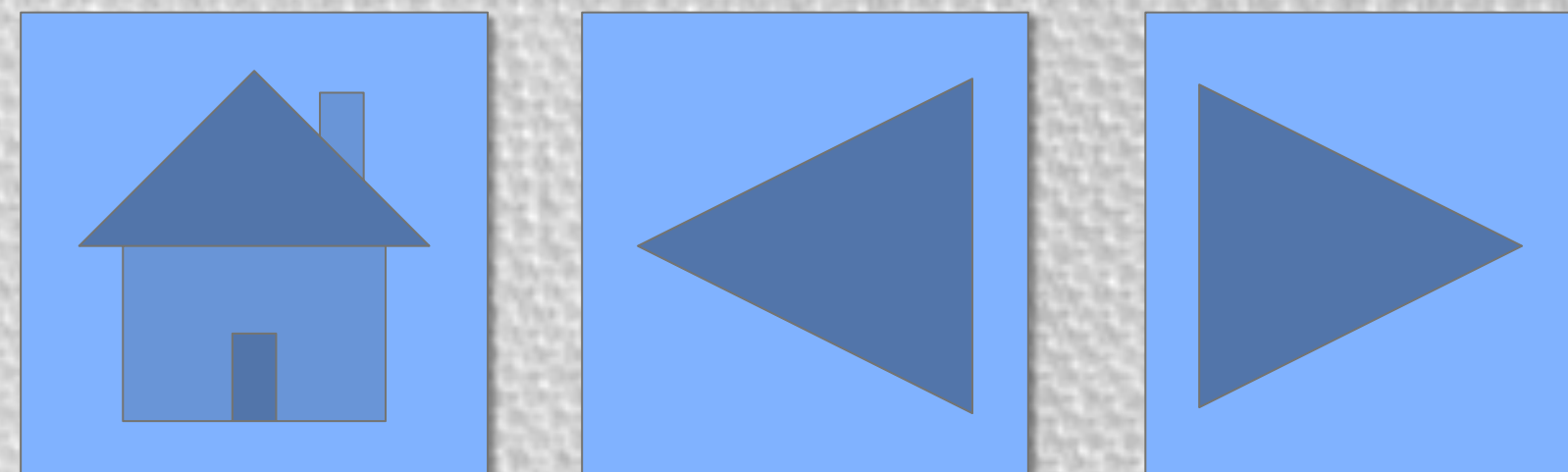


Team Member Introduction



Aftab Iqbal MD MPH:

Aftab Iqbal is a third year internal medicine resident at Mount Auburn Hospital with a passion for access to primary care, healthcare delivery mechanisms, global health and geriatrics. Aftab got his medical degree from Rawalpindi Medical College, Pakistan ('08) and went on to complete a masters degree in epidemiology as a Fulbright scholar at the Harvard School of Public Health ('10). He has served as an Associate Director at a healthcare startup, Naya Jeevan, which works on providing micro-health insurance to people who earn less than 200 dollars/month in Pakistan.

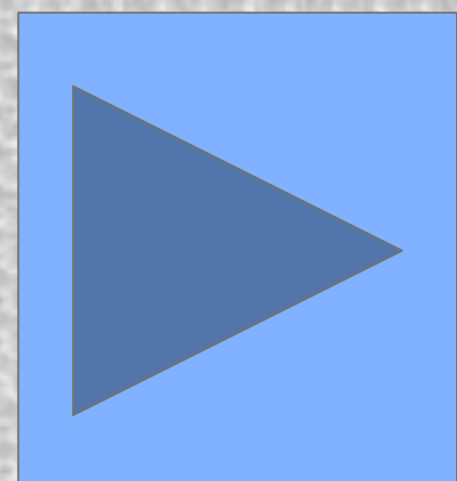
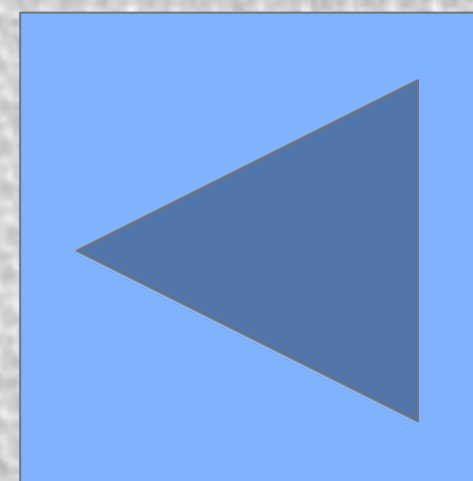
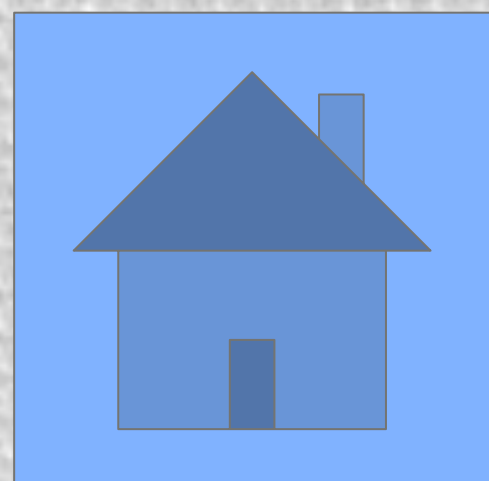


Team Member Introduction



Alyse Krantz BA MS:

Alyse Krantz is a pre-medical student at the Harvard Extension School. Before pursuing medicine, Alyse taught elementary school in New York City and Bogotá, Colombia. She holds a B.A. from the University of California at Santa Cruz and an M.S. from Brooklyn College. Alyse hopes to practice family medicine in underserved/immigrant communities.

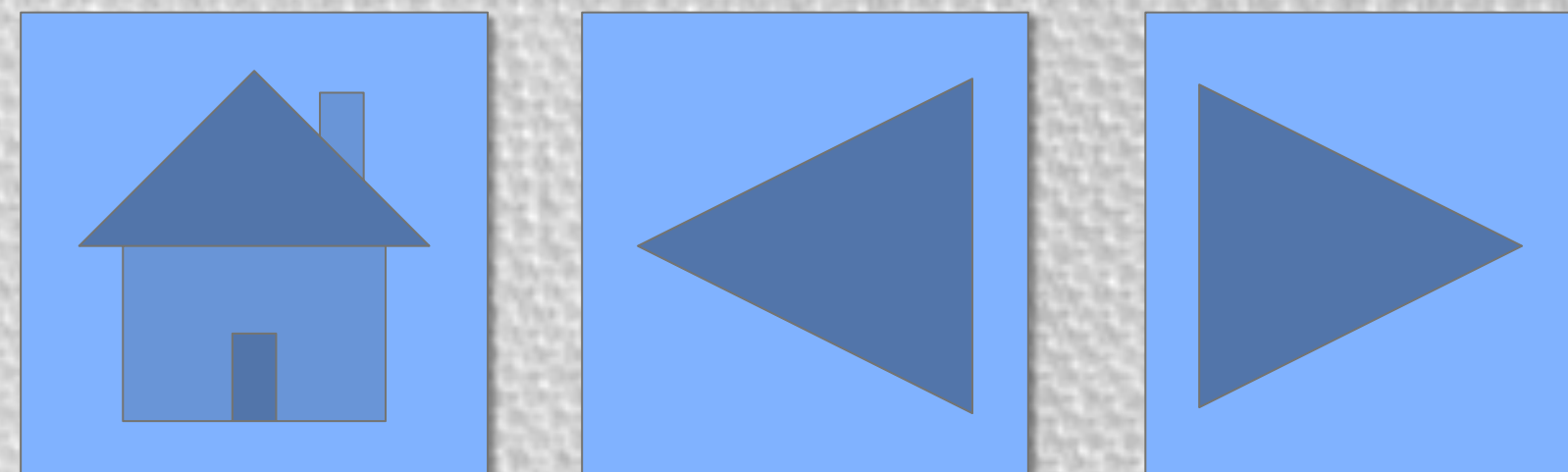


Team Member Introduction



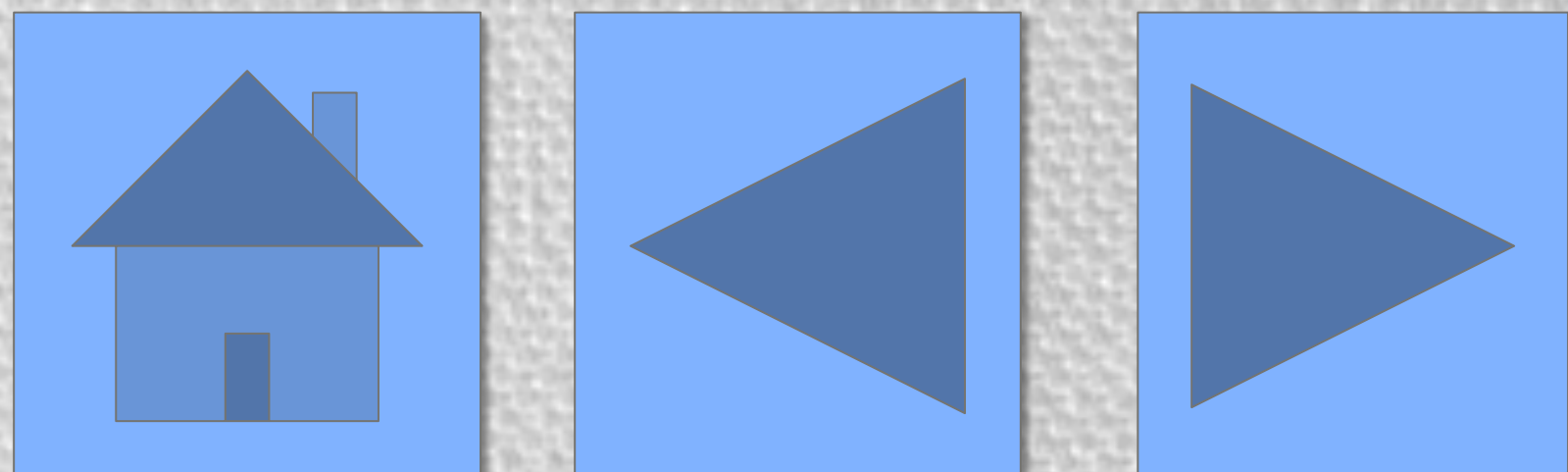
Abby Frydryk BS:

Abby Frydryk is an acute care nurse practitioner student at the MGH Institute of Health Professions. She completed her undergraduate degree at Indiana University and received a B.S. in Public Health. Her interests lie in internal medicine and geriatrics.

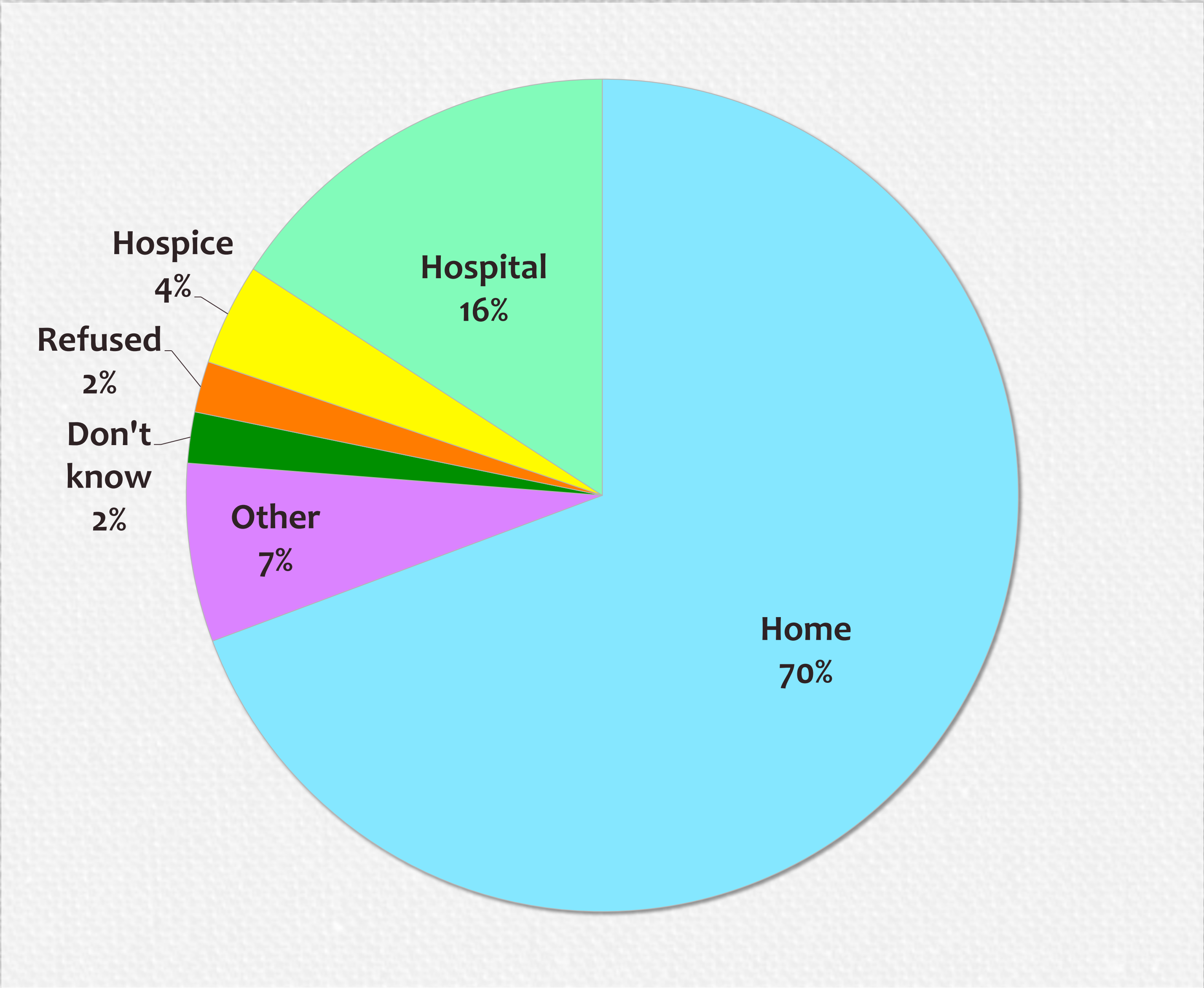


Introduction

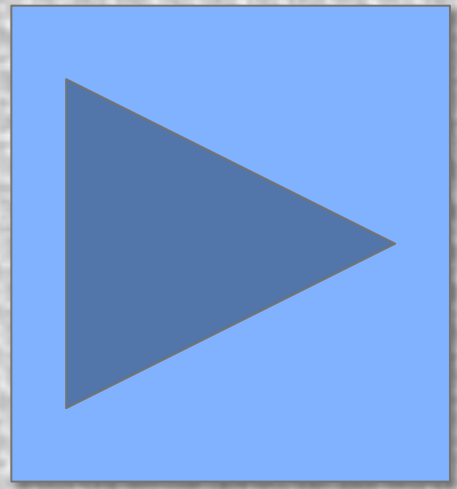
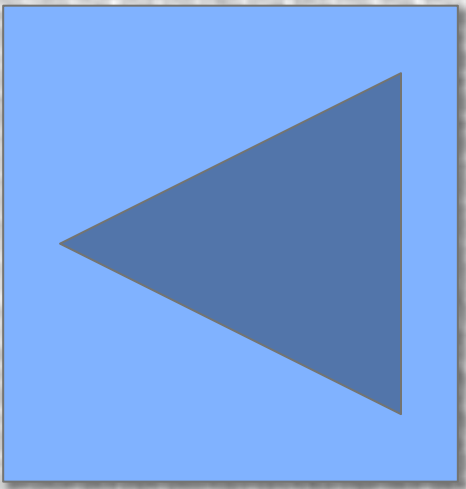
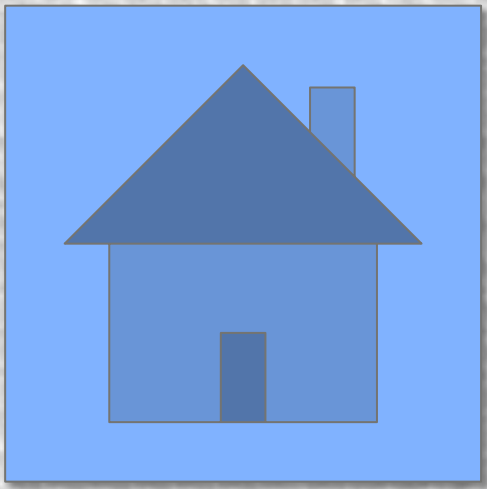
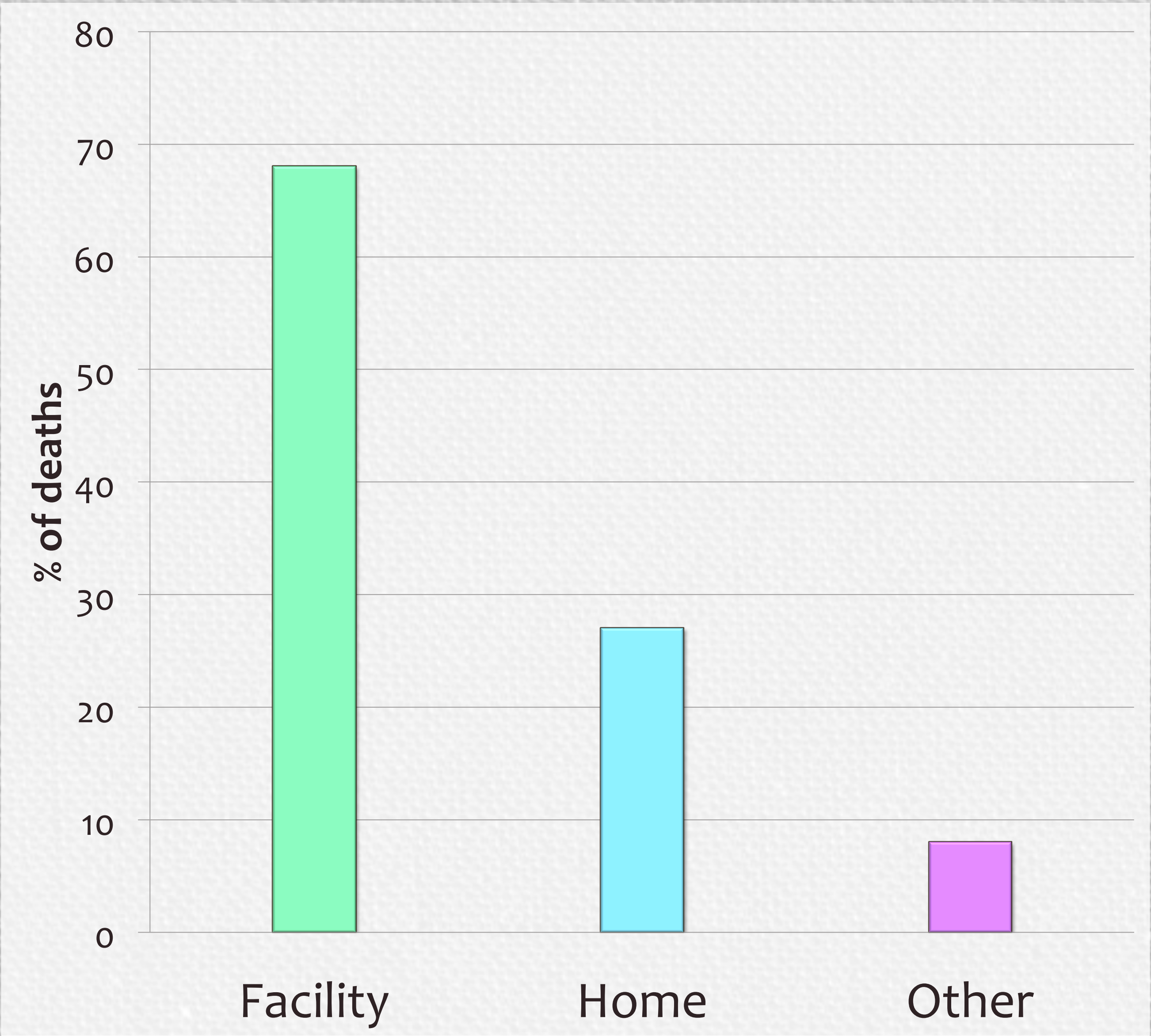
- Individual and family member introduction
 - Study purpose
 - Confidentiality
- Questions before we begin?



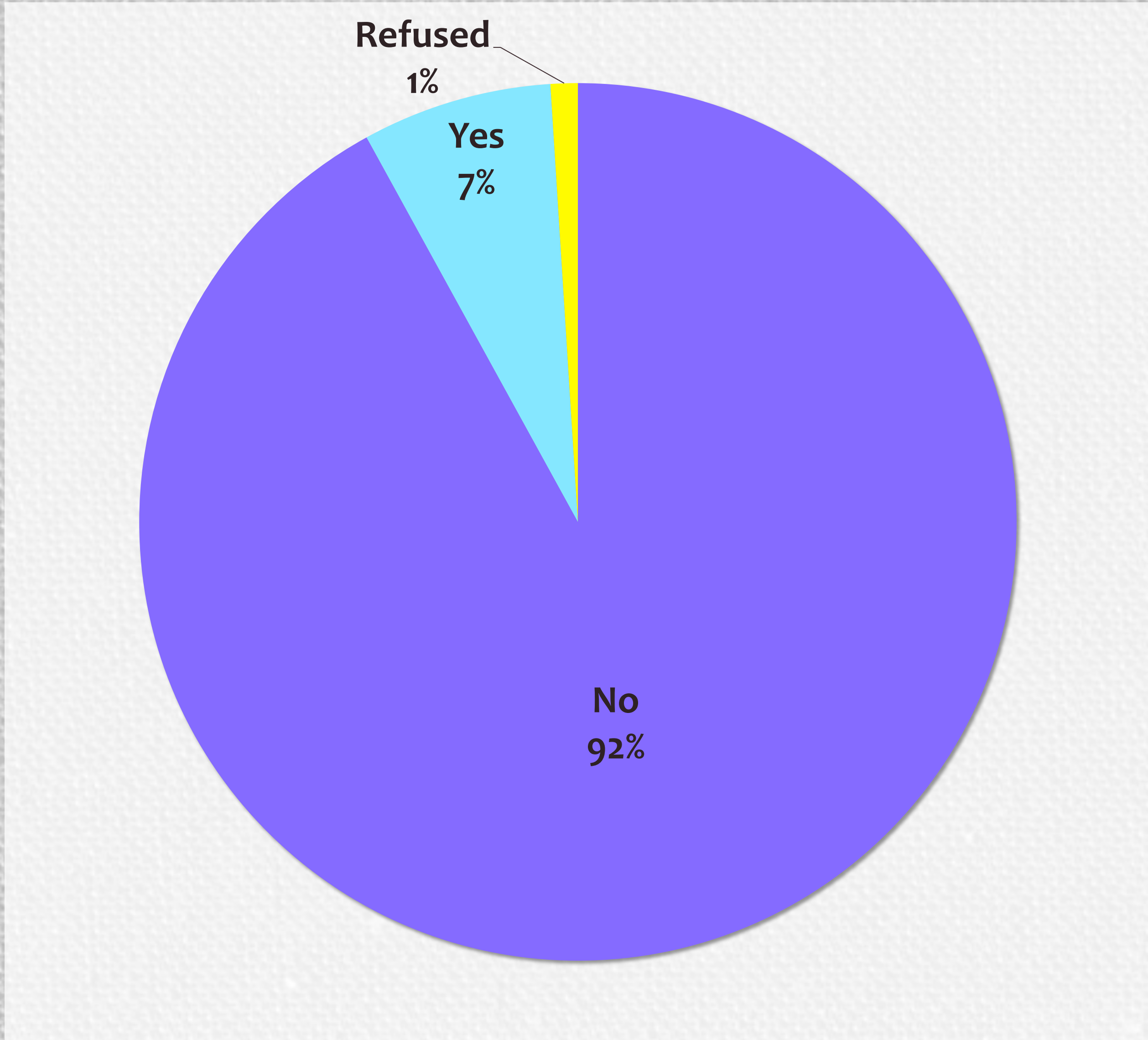
Preferred Location of Death



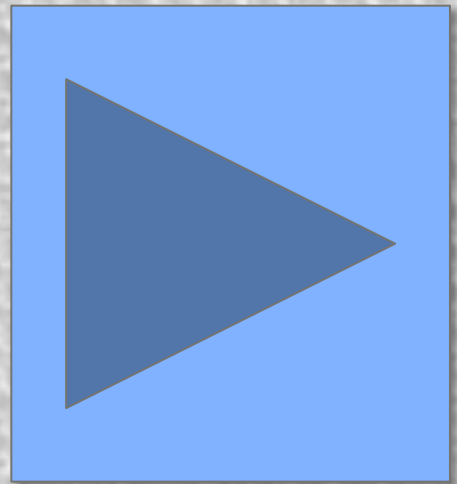
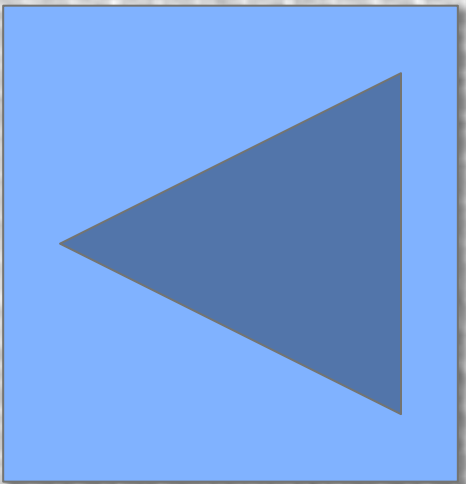
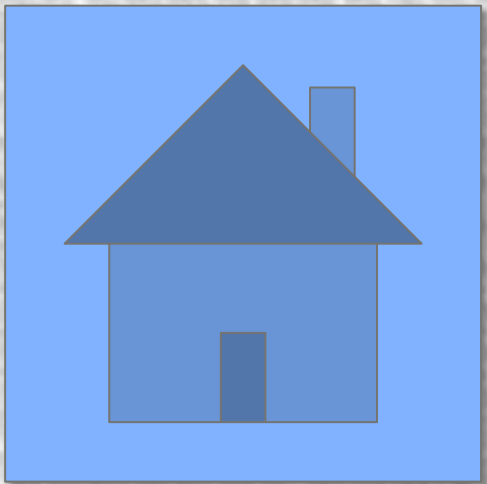
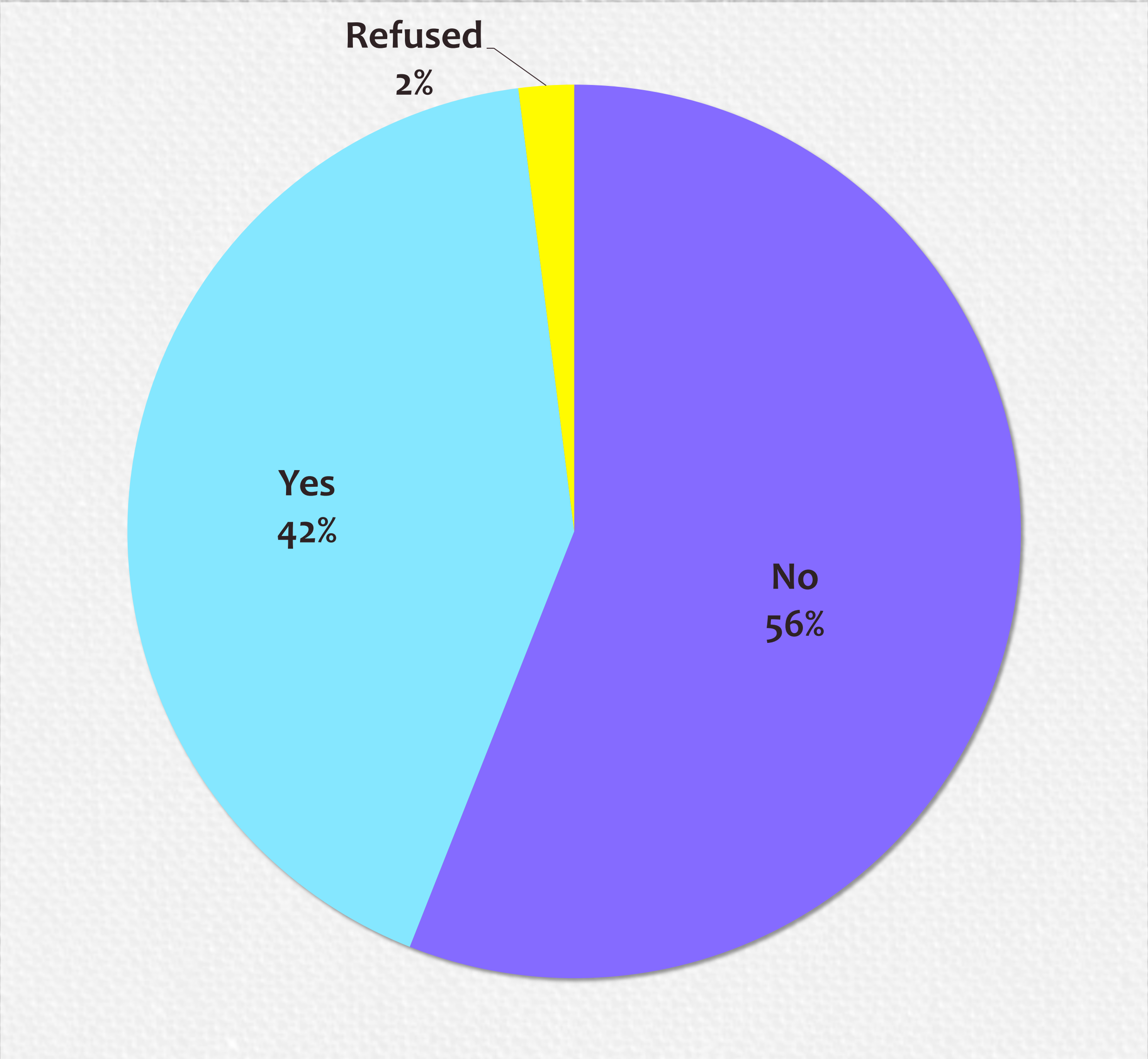
Actual Location of Death



Discussed End-of-Life Wishes with a Doctor



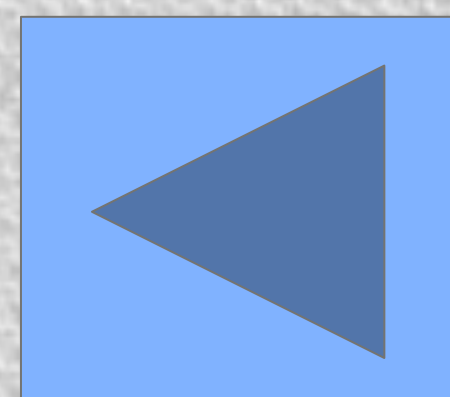
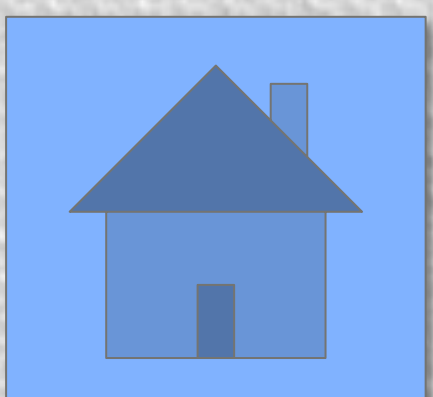
Discussed End-of-Life Wishes with a Loved One



Video



Responses?



<http://abcnews.go.com/WNT/video/conversation-familys-private-decision-17438081?tab=9482930§ion=1206853&playlist=17438316>

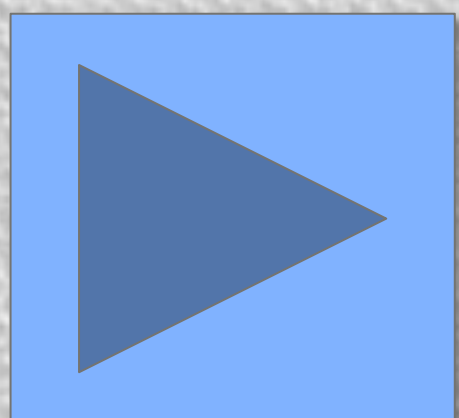
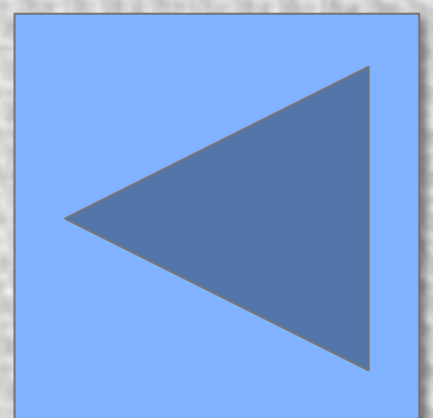
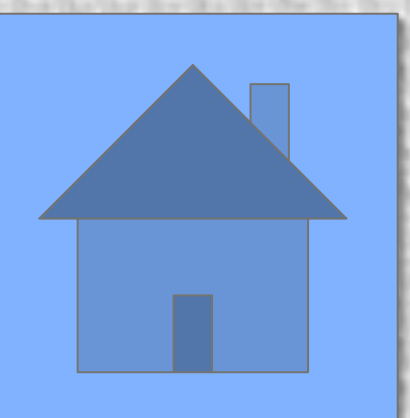
“I want mine to be...”

“I want mine to be... surrounded by loved ones and alert enough to acknowledge the special presence of those in my home with me”.

“I want mine to be at home... relaxed and planned out (as much as it can be) so that folks can focus on laughing and healing”.

“I want mine to be...put off as long as possible. I would like to be pain-free and receive all possible care until the very end”.

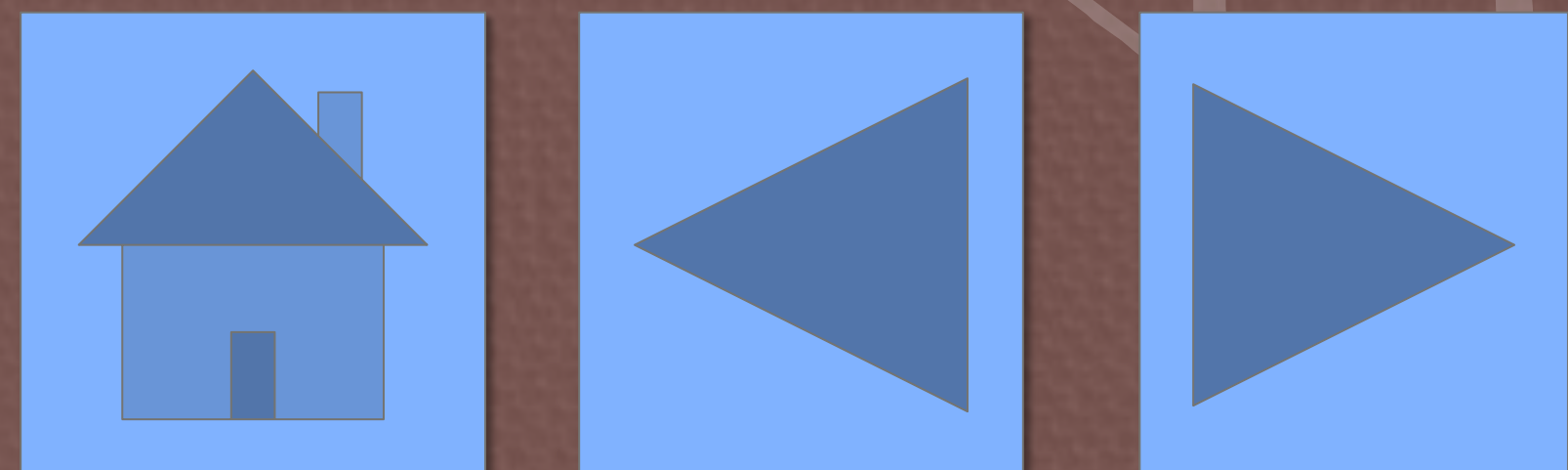
“I want mine to be...in a facility, with great nurses providing comfort care”.



Values Questionnaire

A questionnaire to help you explore your feelings, values, and goals around future care.

- Please complete the Values Questionnaire with a family member
- Discussion
- Personal experiences



Thinking about Values (Adapted from The Conversation Project)

1) I want my doctors to do what they think is best

12345

I want to have a say in every decision

2) I want all care possible to prolong my life, including tubes and wires

12345

Being comfortable and pain-free is more important than prolonging life

3) I wouldn't mind spending my last days in a hospital

12345

I want to spend my last days at home

4) I wouldn't mind being in a nursing facility

12345

Independence is very important to me

5) My loved ones should do exactly what I've said

12345

My loved ones should do what brings them peace

If I can no longer recognize my loved ones and be aware of my surroundings...

6) I would still like all possible care

12345

I wouldn't want to prolong my life

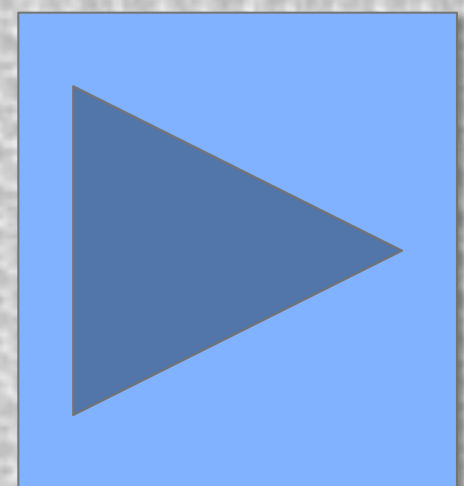
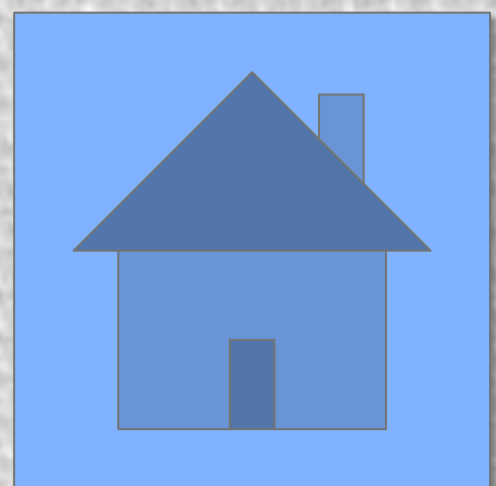


Advance Directive

Advance directives are legal documents that allow you to spell out your decisions about end-of-life ahead of time.

Today we will discuss two types of **advance directives**:

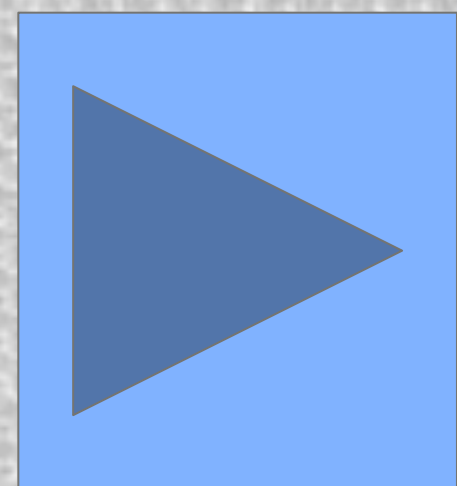
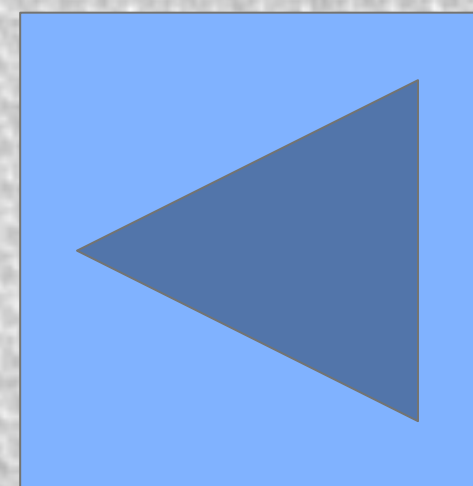
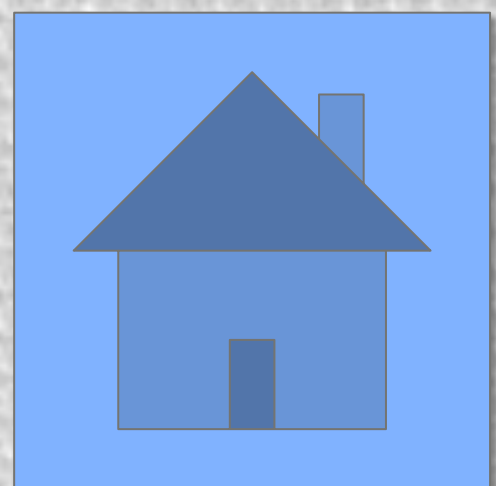
1. Health Care Proxy Form
2. Do Not Resuscitate/ Do Not Intubate



Health Care Proxy Form

The form identifies your health care agent (often called a “proxy”), the person you trust to act on your behalf if you are unable to make health care decisions or communicate your wishes.

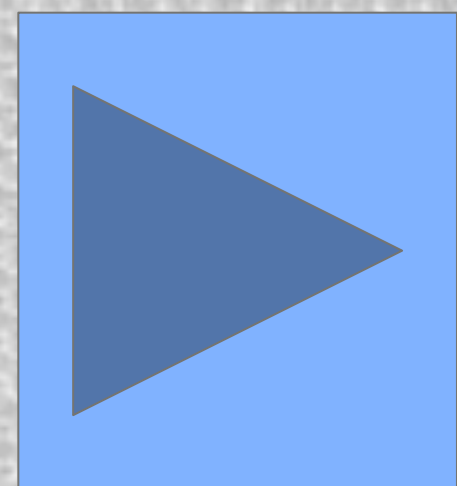
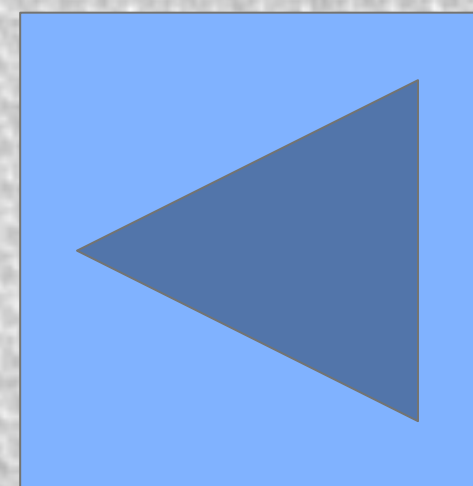
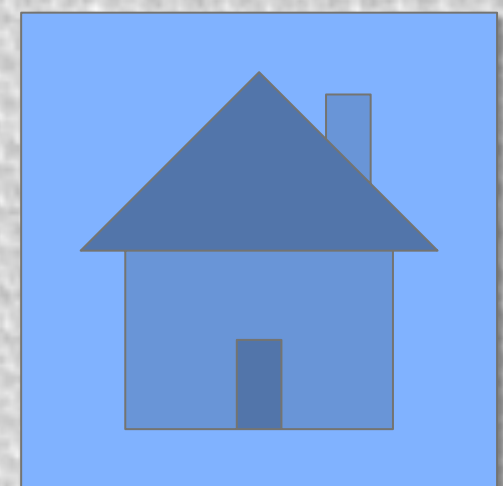
This is probably the most important document to sign.



Choosing a Health Care Proxy

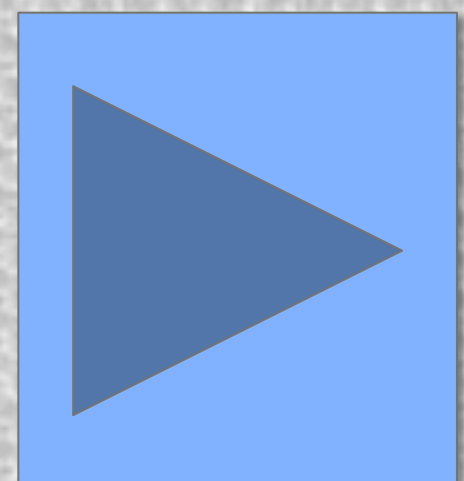
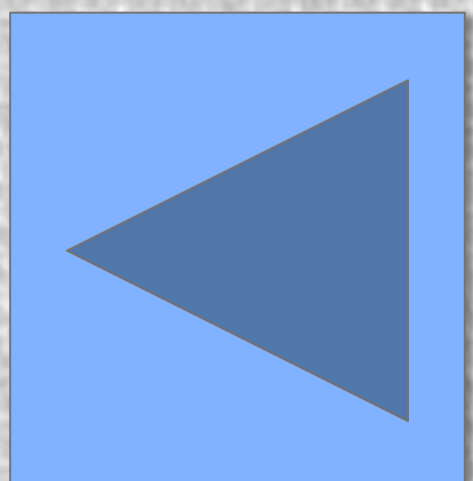
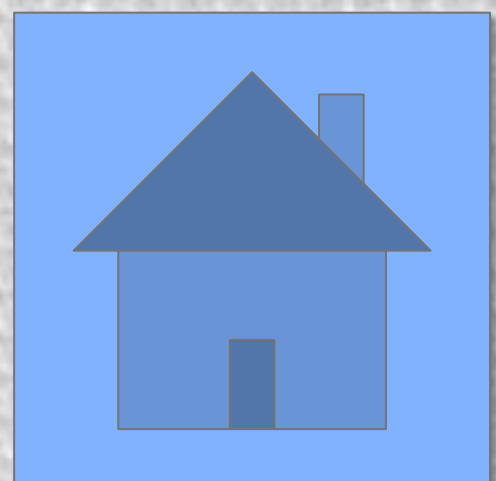
Your Health Care Proxy should be someone who:

- You trust to honor and respect your wishes
- Is comfortable with carrying out difficult decisions
- Someone you feel comfortable sharing health information with



DNR/DNI

Do Not Resuscitate/Intubate orders are medical orders signed by a physician that instruct health care providers not to attempt cardio-pulmonary resuscitation (CPR) or intubation in the event of cardiac and respiratory arrest

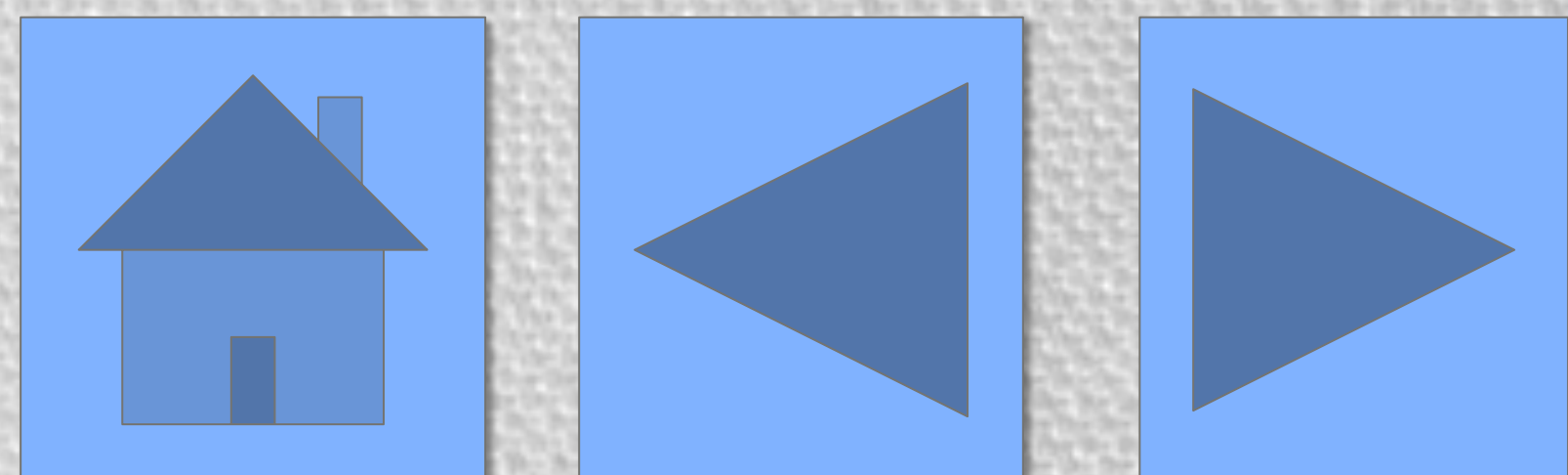


CPR

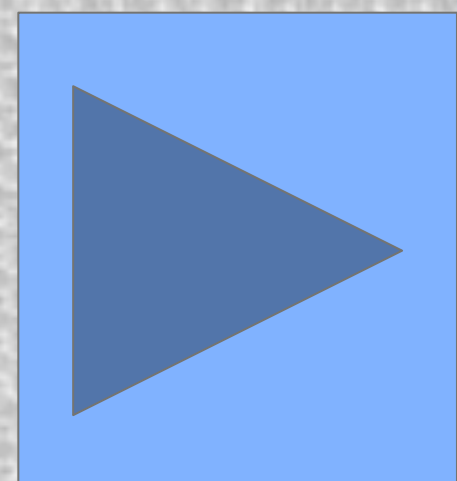
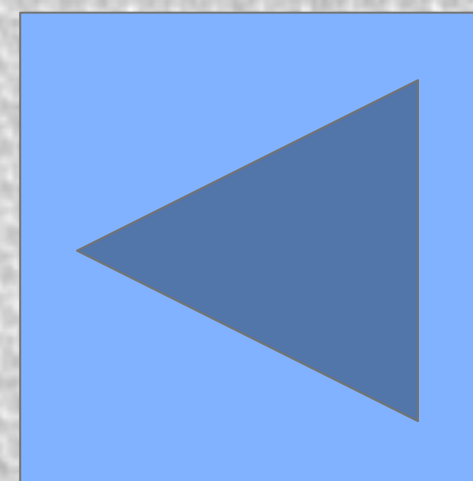
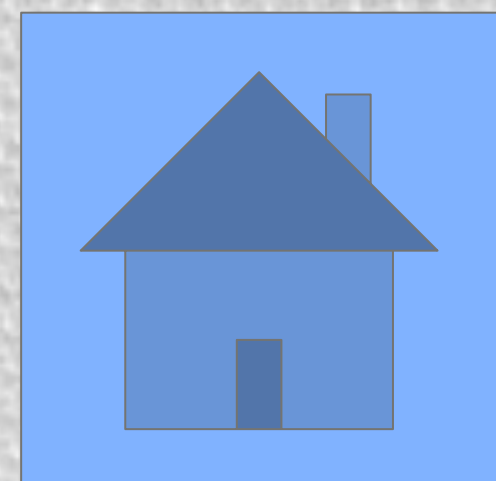
Cardiopulmonary resuscitation (CPR)

is a set of medical procedures that attempt to restart the heartbeat and breathing of a person who has no heartbeat and has stopped breathing.

CPR can be life-saving in certain cases for otherwise healthy people but is much less effective when a person has a serious chronic illness.

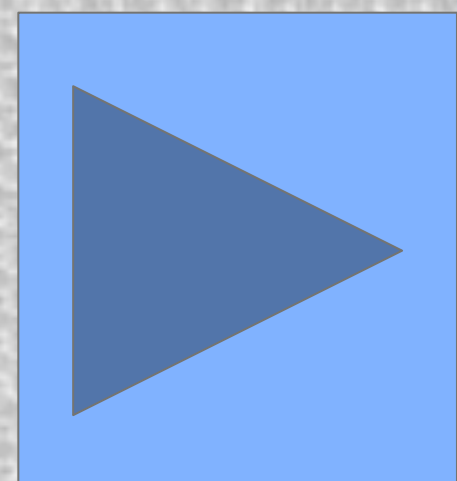
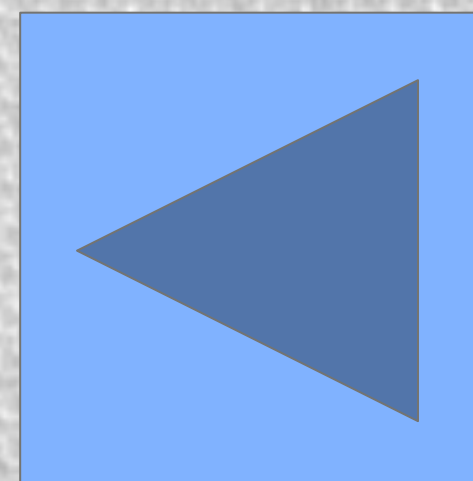
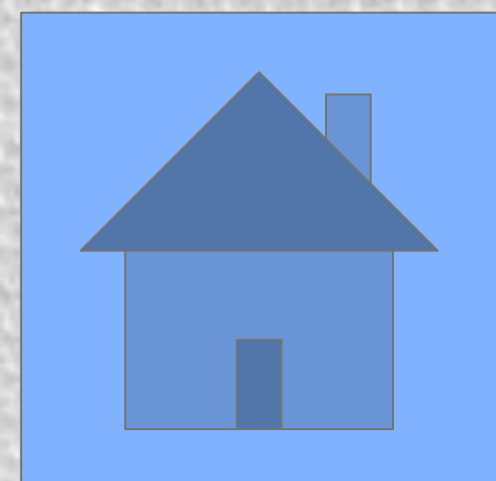


Cardiopulmonary Resuscitation (CPR)



Intubation & Mechanical Ventilation

Intubation and mechanical ventilation is the use of a tube and a machine to help get air into and out of your lungs.



Additional Resources for Planning

Your Conversation Starter Kit

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

We know that no guide and no single conversation can cover all the decisions that you and your family may face. What a conversation can do is provide a shared understanding of what matters most to you and your loved ones. This can make it easier to make decisions when the time comes.



Created by The Conversation Project and the Institute for Healthcare Improvement

A Review: Having the Conversation

Resources for Future Planning

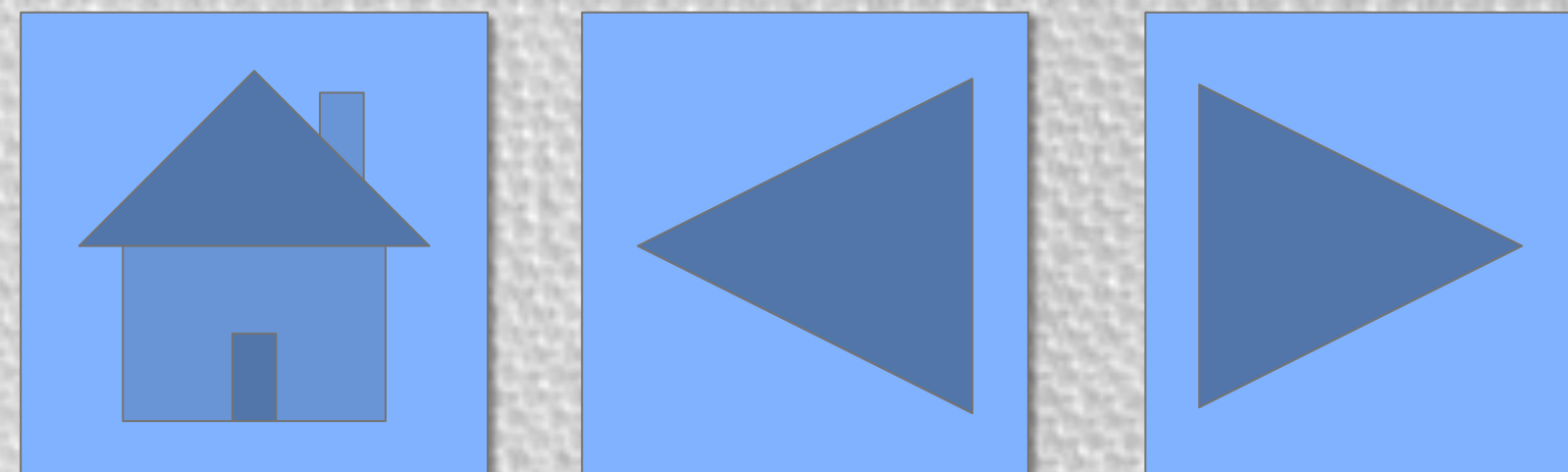
- ❖ **Prepare For Your Care:**
<https://www.prepareforyourcare.org>
- ❖ **The Conversation Project:**
<http://theconversationproject.org>
- ❖ **The Conversation Project Starter Kit:**
<http://theconversationproject.org/starter-kit/intro/>
- ❖ **Health Care Proxy Form:** <http://molst-ma.org/sites/molst-ma.org/files/MA-Health-Care-Proxy-Form.pdf>
- ❖ **MOLST:** <http://molst-ma.org>
- ❖ **Advanced Directive/Comfort Care/DNR:**
<http://www.mass.gov/eohhs/docs/dph/emergency-services/comfort-care-form.pdf>
- ❖ **If you have questions about options regarding facilities or assisted living in the future, please contact Dr. Bloch who will refer you to a Case Manager.**

Important Reminders

Today we discussed values and goals around your future health care plans. These are by no means set in stone, and they can change at any point in time. If you feel that your goals for your care have changed, please consult with Dr. Bloch who will support you through the process.

If you have not already completed your Health Care Proxy and Advanced Directive forms, please do so at your convenience and return them to Dr. Bloch's office. Both of these forms are important in identifying goals for your future health care.

We encourage you to continue this conversation at home with family members and loved ones. The more you make your wishes known, the more likely they will be expressed and respected.



Closing

- Thank you for your time
- Reiterate confidentiality
 - Planning is ongoing
 - Satisfaction survey

Thank you for your participation!

