Supplementary Online Content


eAppendix 1. Initial Discussion Guide Groups 1-7
eAppendix 2. Discussion Guide 2
eAppendix 3. Group Sizes and Structure

This supplementary material has been provided by the authors to give readers additional information about their work.
eAppendix 1. Initial Discussion Guide Groups 1-7.

Not all modules were used in every group.

**InfoSAGE Interview Guide**

The focus groups will be professionally moderated.

**I. Introduction and warm up – 10 min:**
- Purpose and agenda
- Audiotaping information
- Introductions and ground rules

**II. Information-seeking**
"We are interested in understanding how you look for information, specifically health information."

- Health domains
  - General senior health issues
    "Think through a recent health question you just had. How did you find information to help you address it?"
  - Specific illnesses / health concerns
    "Tell us about the topics of greatest importance to you today regarding your health."
  - Legal/social issues
    "What questions have you had about legal planning related to health? Where would you look for that information?"
    Examples: advanced directives, living will, health care proxy

- Utility of different resources
  "Tell us how you look for information."
  Prompts: how do you use the following resources? What was the experience like?
  - Internet
  - Peers/friends/word of mouth
  - Children
  - Other people (doctors, social workers)
  - What tools are most useful? Least useful?
  "Tell us about something you were looking for but had a hard time finding."
  "Tell us about a search for medical information that went really well."

- Trustworthiness of information
  "Tell us how you decide what information to believe."
  Role of peers and personal testimonials, Internet, books, your doctor
Internet
If people used the Internet:
How easy is it for you to use the Internet?
What was the experience like?
What is hard? What is easy?
If people did not:
Why not? What barriers exist?

III. Health Care Communication
Communication
In your life, who are important types of people to communicate with about your health? Who would you want to be aware of your health updates?
How does your family communicate among themselves?
How are family members included in discussions the patient has with their clinicians?
What barriers to communication between patients and their providers exist, and why does the group think they are constructed?

Privacy and Control of Personal Health Information
Who do you want to control your information? How do you decide when that should change? When might you give control to someone else?

Specific questions/prompts about communication:
Specialists versus primary care doctors
Children, children-in-law
Visiting nurses
Physical therapy, other providers
Spiritual support – priests, rabbis, imams, etc.

IV. Tools for Communication
For elders living independently, we are interested in tools they might use to help them communicate with family members and health care providers and possibly delay moving out of their homes.
How do you feel about using technology in this way, for example, fall sensors? Medication reminders and alerts? Sensors monitoring activity?
What do you see as benefits of such technology? What are possible downsides? What might make you more or less inclined to use such tools?
Incorporation into daily life
Privacy concerns
Home versus assisted living:
What are the challenges to staying at home? What help do you need and how have you found it? Examples: Driving, maintenance, show shoveling, groceries, getting to doctors appointments, meals on wheels, getting meds, communicating with doctor, cooking, cleaning, home health aides, how to sell a house, avoiding reverse mortgages and other scams.
If they decide to give up living at home, how do they find out about options?

V. Caregiver Needs
For family members and caregivers, we would like to understand:
- What support services do you use or need to take care of the elder? How do you find them and how would they like to be able to find them? How do they find daycare, respite care, home care aides, insurance coverage?
- How do you manage communication with health care team, clarity of health goals, and understanding of medications?
- How do you find residential options when care giving becomes too much? Where would they get information?
- How does the family unit coordinate care needs, appointment accompaniment delegation?
- How does the family provide updates back to care team?
- Caregiver isolation and caregiver social network – what are the issues and how do you resolve them?
- What services are available/used for caregivers to take care of themselves?
- For caregivers of seniors now living in assisted living, how are your communication needs different than when the senior was living at home? How connected are they with family?

VI. Privacy
The group has discussed privacy as a theme throughout; we want to make sure that specific areas are addressed if not already covered:
- PHR notifications
- Communication from providers and others
- Handing off rights
- Choosing between siblings
- End of life decisions

VII. Closing:
Participants will be asked if they have any additional comments or questions. They will then be asked to provide a brief evaluation of the focus group interview experience.
eAppendix 2. Discussion Guide 2

Iteration focusing on control of information and privacy for groups 8-10

Group Introduction
- Researchers learning how people use and share information related to their health and well being
- We have learned from prior groups… families are very important, want to help with medical care and 'logistics,' would like access to information
- Purpose of this group is to learn more about wishes and preferences for sharing information among people who may be involved in your life.
- Backdrop: Online Community focused on you and people who help you

Personal Introductions and Framing
- Please tell us a little bit about yourself, and who may be involved in helping you out (such as friends or family)
- Please tell us about your experience with using the Internet for your health
  - Personal Health Records? Are families involved?
  - If you have a personal health record, is someone else able to access your account? If so, why do you share, and how did you decide who to share with?

Health & Medical Information
- With whom do you want to share medical information? (medication lists, medical problems)
  - Prompt: Family, caregivers, aides?
- How much do you share? (all of it, just some of it, different amounts for different people)
  - Prompt: How do you decide with whom to share, and how much? why?
  - Prompt: Are Sensitive topics different? Antidepressants? Bladder Control?
- Should your medical information all be treated in the same way? That is, anyone having access to it would have access to all of it. Or, should we make an option that would allow you to restrict access to some information? What kinds of things would you consider sensitive?
  - Mental health diagnosis or medications
  - Bladder control problems
  - Reference to sexual function, use of Viagra or other medications
  - Others?
- How did you come to this decision?
How would you want to control information? Who could access your information?
- Prompt: Any care giver? Any official clinician? Only people you designate?
- How do you think about sharing health information with nursing assistants, aides, therapists? Sharing with your residence? Sharing with social workers?
- If you had sensors or monitors that could track your health, who would you want to be able to see that information?
- Prompt: family, clinicians?
- Prompt: privacy concerns
- What other concerns do you have about sharing your medical information?

Well-Being or Social Information
- Who (types of people) do you share information about how you are getting along, what needs you may have, what errands you may need to run, needs for rides, etc

- How much do you share with others about how you are doing? (nonmedical)
  - [or how much would you want to share]
  - How about ‘what’ you are doing each day?
- How would you want to control information? Who could access your information?

- Who could invite others to view your information and share in your care coordination?

Shared Decision-Making
- If you became sick, who would you like to manage your information and decisions?
- How do you transfer this responsibility? How do you share it? How do you take back control?
- What would make you more comfortable handing off decisions to others?
- Control, Access, Granularity vs. Simplicity
- How would you like to control who can see your health information?
- How much control should you set? individual items vs. global permissions?
- Are there people who you would like involved in health but not home life, or vice versa?
  - “Levels of Trust” : care organizer, close family, other family, clinicians, friends, neighbors
- If your families used a system to share information amongst your family members and other important people in your lives, how much say would you want in what information is shared or discussed?
Resources (Non-Personal Information)
- For community resources, who should be able to contribute?
- Who should monitor the site: content, chat rooms? (or should no one monitor, and residents simply eject people they decide they don’t want in their network)
- How do you feel about people on the network writing about local medical resources, like commenting on particular doctors?
### eAppendix 3. Group Sizes and Structure

Elders and caregivers participated in one of ten groups.

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