Hi <name>,

Thank you for your interest in the study. We need to recruit particular demographics for the study; to ensure you meet our requirements, could I ask you to briefly answer these questions? Once I hear back, I will let you know how to proceed.

- Please identify the chronic illness the family is coping/has coped with.
- When was the illness diagnosed?
- Which city do you live in?
- Where does the patient live?
- Where do your family members live?
- Do you share or receive any health information related to the patient?
- What is your relationship to the patient?

Data is kept completely anonymous and this is explained in our consent form; please review this document closely before agreeing to participate in the study: http://clab.iat.sfu.ca/health. Also note that the diary study is optional and we will only be asking certain individuals.

If you have questions or concerns please feel free to contact me at carolyn_pang@sfu.ca.

Warm regards,
Carolyn

Italics are instructions to the interviewer. Non-italicized text is a sample of what you can say. Don't be afraid to read this script the first several times until you remember it. You can simply say, "To make sure I don't forget anything, I am just going to read my script to you." People always say, "Sure, no problem."

Introduce yourself and tell them about the study.

My name is Carolyn, and I will be conducting the study with you and will answer your questions.

We are investigating how family members who live in different households try to maintain an awareness of patients' changing health conditions while providing social support from a distance. Our interest is in how you communicate with family members, which tools you use and how you feel after each conversation. We are also interested in understanding the type of health information you share or receive within your social networks.

For your participation in the study, you receive $30.

Tell them about the study method.

The study will involve a **semi-structured interview** where I will ask you questions about your household, your family, the illness, and communication tools. I will also get you to answer a questionnaire.

Tell them about data collection.

I'm going to be collecting data using a variety of methods. I'll take handwritten notes and also audio-record the interview, if that is fine with you. Also, if it is okay, I'd like to take pictures of some sketches I'll ask you to make, and any calendars you use.

Let them know it's okay to quit if they are uncomfortable about anything you ask.

While I don't foresee any issues, if you should feel uncomfortable at any time, you are free to quit the study without repercussions. Just let me know.

Give them the consent form.

IN PERSON
I now need you to read over this consent form, a copy of which is given to you, and let me know if you have any questions. The form mostly details what I have just told you. Once you have read it, you can sign the back.

VIDEO CONFERENCE
Have you had a chance to review the online informed consent form I sent you the link to? Thank you.

Give them the $30 and have them sign the receipt.

IN PERSON
So I don't forget later on, I'm going to pay you now and have you sign this receipt. The receipt allows us to get reimbursed for the money.

Start the study.

Alright, we are all set to start the study. I'm going to turn on the audio recorder at this time.

Section 1: Family and social map (demonstrate social groups)

1. Please draw a picture or map that shows how you are connected with all the people who you communicate with about <patient>'s condition. Try starting by writing your name down and drawing a circle for you. Then draw some other people. You can draw them anywhere, but think about where you place them in relation to yourself.
    a. Tell me about your drawing, who are these people and why did you draw the map the way you did?

    b. Confirm number of people in the group.

    c. How many people live in your household and what are their ages?

    d. How many members live(d) with the patient and what are their ages?

    e. Can you think of an instance when you shared with someone outside of this group? Why do you think you shared with them but did not include them on this map?

f. Who do you share with the most in this group? Where do these people live? Why do you think you communicate most with this group?

g. Who do you share with the least in this group? Where do these people live? Why do you think you communicate least with this group?

Section 2: Health information

1. What role do/did you have in this health crisis? (caregiver/communicator, recipient)
2. Tell me how you felt when you first received news about <health condition>.
   a. Do you remember the first person you contacted? How did you contact them?
   b. Describe some of the activities you did in the first month following the diagnosis.
   c. Have you sought help online from any support groups? Which ones?
3. Looking at your family map, describe the types of health information you currently share/receive with certain individuals.
4. Tell me about how you share health related information with <group from map>. What type of information do you share and how do you share it?
5. Tell me about the most difficult time you shared health related information? Who was it with and how did you share it? How did you feel afterwards? The diagnosis day. It was shared by telephone. It relieved the burden. It also felt horrible because we were just diagnosed, but it helped.
6. Describe some ways that your family members/friends have helped during this time.
7. Describe a particular moment in which you felt someone was especially helpful/considerate. Why?

8. Describe a time when you felt helpless and unsupported by a family member.
9. Describe a time when you felt you should've supported a patient but didn't. What are some of the barriers you faced in offering help?
10. Describe how you coordinate/manage household activities and tasks. Which tools do you use?
11. Has the health condition impacted your schedule in any way? Tell me more. Explain how your time management behaviour changed since the diagnosis, if at all.

Section 3: Technology use (understand proficiency in existing tools)

1. Do you currently use email to share health information? Do you have a separate email account specifically for this purpose?
2. Which social media accounts do you have set up, if any? (Skype, Twitter, Facebook, Tumblr, Flickr, etc.) Describe how often you use these accounts (list frequency for each one). Do you use any of these to share health information? Why (or why not)?
3. Of all the communication methods available to you, identify the tool you prefer to use in receiving/sharing health information? Why?
4. Describe any frustrations you have with technology as it relates to sharing/receiving health information.
5. Do you have any concerns with privacy issues with online tools such as email or social media? Explain.
6. Do you have any concerns with privacy issues offline, for example, in doctor's offices or how people you share health information with might handle what you share? Explain.
7. Can you recall a time when you felt your trust in someone was compromised because they shared health information you confided in them?

Section 4: Sketch designs (ideas that show important health information management)

1. Think for a moment about some common web pages, systems or devices you access (can be smartphones, computers, tablets, digital picture frames, eReaders, etc.). Now I'll ask you to draw a sketch of a single screen dedicated to sharing health information about <patient>. List or draw any items you'd like to see or tools that you would use to facilitate communication within your map.

Section 5: Evaluate the following designs (show snapshot of 1-2 pages with main functionality for each of the 5 listed above)

1. Are you familiar with the following sites that provide families with tools to help during a health illness?
   a. Lotsahelpinghands (http://www.lotsahelpinghands.com/)
   b. Patientslikeme (http://www.patientslikeme.com/)
   c. CaringBridge (http://www.caringbridge.org/)
   d. Microsoft HealthVault (http://www.microsoft.com/en-us/healthvault/)
   e. Telus HealthSpace (http://telushealthspace.com/)
2. Circle what you like in green and what you don't like in red. Feel free to mark it up in any way, cross things out, make notes. [THIS WILL BE DIFFERENT FOR VIDEO CONFERENCE]
3. What stands out most to you? What is your first impression?
4. What don't you like about it?

Section 6: ABC-Q

Have them fill out the questionnaire. Run through it twice, once for <M> (email), and again for <L> (telephone).

<P>   = communication partner/group from family map
<M>   = communication tool used most often (asynchronous)
<L>   = communication tool used least often (synchronous)

We're now going to finish off with a questionnaire that evaluates how you felt using <M> with <P>. (For Skype interviews, hold up paper with these 6 options). Please respond to each statement with:

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not Applicable

Affective Benefits and Costs of Communication Technology (7 scales – 26 items)

Directions: Substitute the name of the communication medium for <M> and the name of the communication partner for <P> at the appropriate places in the survey. Participants should respond to each statement with: "Never," "Rarely," "Sometimes," "Usually," "Always," or "Not Applicable."

Benefits (4 Scales – 14 items)

Emotional Expressiveness

1. Communicating with <P> using <M> helps me tell how <P> is feeling that day.
2. Communicating with <P> using <M> helps me let <P> know how I am feeling.
3. Communicating with <P> using <M> helps me see how much <P> cares about me.

Engagement & Playfulness

4. I feel that contact with me using <M> is engaging for <P>.
5. I am excited about using <M> with <P>.
6. I have fun with <P> while using <M>.

Presence-In-Absence

7. Communicating with <P> using <M> helps me feel closer to <P>.
8. After we are done communicating, I still keep thinking back to something <P> shared using <M>.
9. Communicating with <P> using <M> helps me feel more connected to <P>.

Opportunity for Social Support

10. Communicating with <P> using <M> helps me provide <P> with social support.
11. <P> makes me feel special in our contact using <M>.
12. Communicating with me using <M> helps <P> be there for me when I need them.
13. Communicating with <P> using <M> when I am having a bad day helps me feel better.
14. Communicating with <P> using <M> helps me feel less worried about something.

Costs (3 Scales – 12 items)

Feeling Obligated

15. I worry that <P> feels obligated to contact me using <M>.
16. I have to talk to <P> using <M> even if I don't want to.
17. I feel guilty if I don't answer a contact <P> makes using <M>.
18. I have to answer when <P> tries to contact me using <M> even if I don't want to.

Unmet Expectations

19. I feel sad when <P> isn't around when I try to contact <P> using <M>.
20. I feel sad when <P> takes too long to respond when I try to contact <P> using <M>.
21. I worry that I am not meeting <P>'s expectations for our contact using <M>.
22. I feel sad when <P> doesn't pay enough attention to me when we use <M>.

Threat to Privacy

23. I worry that <P> might learn something using <M> that I want to keep secret.
24. I worry about my privacy while <P> and I were using <M> together.
25. I worry that others may overhear or see something that <P> and I share using <M>.
26. I worry that I am violating <P>'s privacy during our contact using <M>.

Close the study with the participant.

Thank you very much for your help with the study. I really appreciate your time and effort. If you should think of anything else you'd like to tell me, please don't hesitate to contact me by email.

As well, if you know of anybody else who you think would like to participate, please forward them my email address.

Benefits (4 Scales – 14 items)   **Costs (3 Scales – 12 items)**

Emotional Expressiveness

Engagement & Playfulness

Presence-In-Absence

Opportunity for Social Support

Feeling Obligated

Threat to Privacy

Unmet Expectations

Communicating with <P> using <M> helps me tell how <P> is feeling that day.

I worry that I am not meeting <P>'s expectations for our contact using <M>.

I have fun with <P> while using <M>.

Communicating with <P> using <M> when I am having a bad day helps me feel better.

After we are done communicating, I still keep thinking back to something <P> shared using <M>.

I have to talk to <P> using <M> even if I don't want to.

I feel that contact with me using <M> is engaging for <P>.

<P> makes me feel special in our contact using <M>.

I worry about my privacy while <P> and I were using <M> together.

I have to answer when <P> tries to contact me using <M> even if I don't want to.

I feel sad when <P> doesn't pay enough attention to me when we use <M>.

I worry that <P> might learn something using <M> that I want to keep secret.

I am excited about using <M> with <P>.

Communicating with <P> using <M> helps me feel closer to <P>.

Communicating with <P> using <M> helps me provide <P> with social support.

I worry that <P> feels obligated to contact me using <M>.

Communicating with <P> using <M> helps me see how much <P> cares about me.

I feel guilty if I don't answer a contact <P> makes using <M>.

Communicating with me using <M> helps <P> be there for me when I need them.

I worry that I am violating <P>'s privacy during our contact using <M>.

I feel sad when <P> isn't around when I try to contact <P> using <M>.

Communicating with <P> using <M> helps me let <P> know how I am feeling.

I feel sad when <P> takes too long to respond when I try to contact <P> using <M>.

Communicating with <P> using <M> helps me feel more connected to <P>.

I worry that others may overhear or see something that <P> and I share using <M>.

Communicating with <P> using <M> helps me feel less worried about something.

What is the big picture of what you want to accomplish? Why are your questions relevant to anybody?

Within group design. IV feelings, DV - video conference, Facebook, email, telephone

How are you planning to structure your study? Are you planning to do a survey? Are you planning to do an experiment where you assign them to do tasks and observe responses? Are you involved in what people will do?

Semi-structured interviews followed by ABC-Q questionnaire. Hypothesis test can be a comparison of tests

What are you measuring? How are you measuring it? What sorts of numbers will you gather? Are you measuring yes/no answers? Are you gathering data on a scale? Scope of info that you will gather in the experiment? Are they ordinal categorical values (Likert scale)? Are they actual numbers (37 degrees)?

<mark>**Spearman Rank Correlation – allows you to assess whether there appears to be some correlation between Question A and Question B.**</mark>

<mark>**How much of a difference are you looking to detect? What is a meaningful difference to me?**</mark>

<mark>**How much variability is there in the measurements you're about to take?**</mark>

<mark>**How much of a chance do you want to take in being wrong? (Failing to detect what you are looking for)**</mark>

Stratified sampling – break your sample into groups that you think are representative.

Before-After Control-Intervention [BACI] Study

Anything you can turn into a number, you'd be using an ANOVA.

20 participants

<ol style="color:red">
Family map & social groups
Health information
Technology use
Affective benefits and costs of communication
Benefits

Emotional expressiveness (IV)
Engagement and playfulness (IV)
Presence-in-absence (IV)
Opportunity for social support (IV)

Costs

Feeling obligations (IV)
Unmet expectations (IV)

- Threat to privacy (IV)
Summarize it cross the 20 . Trying to understand relationships among certain questions. Competing interested – benefits and costs. Bendits and costs.

  Assessment of costs separately
  Assesmenet of benefits separately

  Measurement of cost – measurement of benefit. Sum of 3 costs

  Of those 3 items that relate to costs, in my mind, for my purposes, is something more important than others.

  Tale 3 things – add them
  Take 4 things – add them

  Quantify their relative merits.
  M1 vs m3
  M1 vs m4
  M2 vs m3
  M2 vs m4

  M1, 2 – sync
  M3, 4 – asyncr

  Paired t-test. (mode 1 c1 , mode 3 c1 – take the difference between them.)
  Then check to see if the averaged difference is different than 0.
  7 * 4 = 28 paired t-tests – means.

  Too many tests – type 1 error rate. Inflated type 1. Try to arrange the testing procedure so that I'm less likely to have this error. (A true mull hypotheses was incorrectly rejected)

  Take level of alpha I was going to start with (0.5). Shrink alpha. Bonferroni – instrument. Take alpha and divide it by # of tests im planning to conduct and call that my new alpha. Do all of my tests at new alpha,

  H1. Synchronous provides higher benefits for people than asynchronous for sharing health information. [Casablanca related work, interpersonal, serena's paper, ASTRA paper]

  H2. Sync has higher costs for people than asynchronous. [show any paper that explains sync takes time and obligation. My Family Window paper. Serena's paper. ASTRA paper]

  H3. Real-time video creates more benefits than not seeing the person. vs not. Video

chat to telephone. Only thing you're adding is the face (video).

H4. Real time creates more costs than phone.

People prefer synchronous

Look for patterns
Look for trends
I

	M1C1	M1C2	….	M1B4	M2C1	…	M2B4	…	M4B4
1									
2									
3									
4									
5									
6									
7									
8									
9									
10									
11									
12									
13									
14									
15									
16									
17									
18									
19									
20									

COSTS (C1, C2, C3)
BENEFITS (B1, B2, B3, B4)

M1C1 VS M3
Memorability is key.

JMP

1. **Communicating with <P> using <M> helps me tell how <P> is feeling that day.**

   Phone   [   ] Never [   ] Rarely [   ] Sometimes [   ] Usually [   ] Always

   Email   [   ] Never [   ] Rarely [   ] Sometimes [   ] Usually [   ] Always

   Video Chat (i.e. Skype)   [   ] Never [   ] Rarely [   ] Sometimes [   ] Usually [   ] Always

   Facebook   [   ] Never [   ] Rarely [   ] Sometimes [   ] Usually [   ] Always

2. **Communicating with <P> using <M> helps me let <P> know how I am feeling.**

   Phone   [   ] Never [   ] Rarely [   ] Sometimes [   ] Usually [   ] Always

   Email   [   ] Never [   ] Rarely [   ] Sometimes [   ] Usually [   ] Always

   Video Chat (i.e. Skype)   [   ] Never [   ] Rarely [   ] Sometimes [   ] Usually [   ] Always

   Facebook   [   ] Never [   ] Rarely [   ] Sometimes [   ] Usually [   ] Always

3. **Communicating with <P> using <M> helps me see how much <P> cares about me.**

   Phone   [   ] Never [   ] Rarely [   ] Sometimes [   ] Usually [   ] Always

   Email   [   ] Never [   ] Rarely [   ] Sometimes [   ] Usually [   ] Always

   Video Chat (i.e. Skype)   [   ] Never [   ] Rarely [   ] Sometimes [   ] Usually [   ] Always

   Facebook   [   ] Never [   ] Rarely [   ] Sometimes [   ] Usually [   ] Always

Why are you doing the experiment this way? Are there constraints that you are concerned about? Are there logistic restraints?

There are always extraneous factors. You want your study to be designed in a way that accounts or eliminates as many as possible.

5 x 2 factorial treatment method (5 levels x 2 treatments)