TRIO STUDIO: Increasing Clinical Research Follow-Up Survey Rates with an Elderly Population

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TRIO STUDIO: Increasing Clinical Research Follow-Up Survey Rates with an Elderly Population

By: Mary Harris and Laura Magda, Section of Hospital Medicine, University of Chicago
Facilitator: Santosh Basapur, IIT Institute of Design

Attendees:
Anjan Unni, UChicago; Divya Jain, IIT; Sai Godha, IIT; Sigi Zhang, RUMC; Drew Simon, RUMC; Raj C. Shah, RUMC; Keiichi Sato, IIT; Nurie Dervishi ITM, UChicago; Gerald Stacy, ITM, UChicago; and Sherry Robison, ITM UChicago.

Summary
Mary Harris and Laura Magda, Section of Hospital Medicine, introduced the Comprehensive Care, Community, and Culture (C4P) Program at the University of Chicago. Subjects who will be asked to participate follow-up phone calls every three months. Mary and Laura requested the studio audience to ideate solutions for three questions:

1. How do they increase timely patient participation in follow-up surveys over long periods of time?
2. How do they decrease survey refusals, particularly in the non-intervention group?
3. How do they better understand the barriers surrounding participation of vulnerable populations in longitudinal research?

Design Thinking approach was used to solve the problems faced by Mary and Laura.

Top 3 Actions Proposed by the Studio Participants to Mary Harris and Laura Magda:

1. Newsletter/Annual Picnic:
   Regularly connect with participants, acknowledgement of participant efforts, motivation of participation, non-compliant to compliant surveys.

2. Increase Motivation of Participants:
   Create a report to show study participants results. Make personal notes and follow up on these prior to jumping in to the surveys. Give small tokens of appreciation like stickers, pins, gifts, personalized cards that are hand signed. Offer a monetary incentive for every survey.

3. Stratified Patients and Research Team:
   Attempt to have the same researcher, coordinator or volunteer contact the same patients. This will help establish a relationship. Increase motivation of surveyors.
TRIO Studio Problem Description:

Mary Harris and Laura Magda, Section of Hospital Medicine, introduced the Comprehensive Care, Community, and Culture (C4P) Program. In 2012, the Comprehensive Care Program study (CCP) was started with recruitment goals being met in 2016. Subjects enrolled were at high risk of hospitalization. The ability to receive care from the same physician in the clinical and the hospital setting leveraged the power of a sustained doctor-patient relationship to improve outcomes for a highly vulnerable group of patients and also reduced the cost of their care. In four years, 2,000 subjects were enrolled on this study.

The Comprehensive Care, Community, and Culture Program study (C4P) was started in 2016 and was built on the CCP study. It addresses the social determinants of health by focusing on better understanding the nature of unmet social needs (through follow-up survey analysis) and offering interventions to better meet these needs, including a community health worker and arts and culture program. C4P offers an innovative solution to not only defragment medical care but to also effectively meet a range of social needs that are particularly concentrated in disadvantaged communities. Addressing the economic and psycho-social needs of patients creates stability and increases the likelihood of engagement in their healthcare. Mary and Laura explained that since most of their outcomes are measured primarily by patient reported data, the ability to obtain high quality longitudinal data will better help them fulfill the long-term aims of the study.

CCP and C4P are single-centered-prospective cohort studies. Subjects that are enrolled have Medicare A and B who are at high risk of hospitalization (hospitalized at least once in the past year and those who are actively identified in the emergency department). Patients currently undergoing cancer treatment, LVAD placement or certain advanced heart failure services, are in a nursing home or hospice are excluded from the study. CCP recruitment is completed with 2,000 subjects enrolled and follow-up phone calls still being performed. C4P recruitment is currently active with 528 enrolled and follow-up phone calls also being performed.

C4P subjects are randomized into one of three groups: (1) Standard of Care, (2) Comprehensive Care Physician or (3) Comprehensive Care, Community and Culture Program with Artful Living Program and Community Health Worker. Follow-up surveys are done by phone every 3 months, after initial intake, for each of these groups. Research assistants and coordinators complete follow-ups seven days a week (mornings, afternoons and evenings) up to three times a day. There is an option to complete in person follow-up surveys if subjects have more than 2 outstanding follow-up calls and presents at UCMC (bias prevention). There is no incentives offered to subjects participating in this study.

Laura explained some problems with the study which include difficulty getting subjects to complete follow-up surveys in a timely manner which impacts data quality. There is a 2.3% drop out in the CCP study at the 3 month follow up, 4.6% at the 6-month follow-up, 6.8% at the 9-month follow-up, 8.5% at the 12-month follow up and 15% at the 24-month follow up.
There is a progressive increase in refusals over time, particularly in the standard of care group. At the 3-month follow up there is a 4.3% drop out, 6.7% at the 6-month, 9.8% at the 9-month follow up, 12.9% at the 12-month, and 21% at the 24-month. There also is a limited understanding of targeted population and how to customize research efforts towards this group.

Laura explained the current barriers of the study:

- Elderly population (changes in acuity, research stereotypes and willingness to participate, changes in caregivers/proxy, etc)
- Subject fatigue, length of C4P survey average 45-90 minutes to complete
- Low income population (less than $20,00 a year) which results in temporary cell phone numbers, move frequently, limited phone minutes, non-incentivized research participation, etc.
- Long term follow-up is difficult as subjects move to different nursing homes, mortality rates, acuity changes, proxy changes, etc.
- Standard of Care group not seeing benefits of long-term participation

Current efforts include calling subjects at various times of the day and different days of the week, attempts to build relationships between research staff and patients by assigning groups of patients to designated research coordinators, seasonal greeting cards sent to all patients (including standard of care), EPIC and white pages search for updated contact information and assistance from AmeriCorps members of various ages to help engage targeted population.

Mary and Laura requested the studio audience to ideate solutions for:

1. How do they increase timely patient participation in follow-up surveys over long periods of time?
2. How do they decrease survey refusals, particularly in the non-intervention group?
3. How do they better understand the barriers surrounding participation of vulnerable populations in longitudinal research?
Figure 1. Mary and Laura presenting their study
**TRIO STUDIO: Increasing Clinical Research Follow-Up Survey Rates with an Elderly Population**

Main problem for the studio participants to solve:
The goal is to increase timely patient participation in follow-up surveys over long periods of time, decrease survey refusals, particularly in the non-intervention group (standard of care) and to better understand the barriers surrounding participation of vulnerable populations in longitudinal research.

Mary and Laura’s call to action: “How do we increase clinical research follow-up survey rates with an elderly population?”

**Studio Methodology**
Quality Science’s DMAIC approach used as part of the studio to solve this problem.

**Quality Science DMAIC Method**
We used the Quality Thinking approach with five steps:

1. Created a problem definition
2. Map out the flow and figure out problematic areas with in that flow
3. Generated ideas to address issues noted
4. Synthesized solutions that can be trialed by team
5. Assess changes needed and build change management plan if necessary
6. Solutions were proposed and were rated by the team on implement-ability (0-4 scale)
Quality Science Based Solutions:

Problem visualized with Insights

The group first discussed the problem and its context yielding the following context diagram as well as the stakeholder map:

1. Problem Definition

**Current State**
- CCP calls are 15-30 minutes long
- C4P calls are 40-60 minutes long
- Difficult to get patients to complete the follow up timely
- Increase in refusal rate over time
- Waiting longer to follow up increases dropout rates
- No incentives offered to patients for taking surveys
- Data available for list of outstanding calls
- New individual calls
- Existing individual calls
- More surveys are needed to complete the data set
- If the study fails, it costs money
- Patients taking part are from low income group
- Surveys include personal and sensitive questions-patients are hence hesitant
- Elderly patients could be cognitively impaired
- Different times of the day are divided in time slots and list of patients to build relationships
- Heavy reliance on volunteers
- Recruitment goal is way higher than it needs to be
- Study fails costing money because the data required is not collectable-lack of patients taking survey

**Goal State**
- Increase timely patient participation in follow-up surveys over long periods of time
- Decrease survey refusals, particularly in the non-intervention group
- Better understand the barriers surrounding participation of vulnerable populations in longitudinal research
- Increase patient compliance to complete surveys
- Train volunteers to develop personal relationships with patients
- Be able to host events for the patients to share compliance stories
- Catch patients in “Daily” and “weekly” list of outstanding calls before they become outstanding for longer

**Who’s experiencing the problem?**
- Researchers
- Research coordinator
- PI
- Elderly patients-under served communities
- Nursing homes
- Care givers
- Volunteers (Ameri Corps)

**What is the scale of the problem?**
- The outstanding calls - daily and weekly keep increasing exponentially
- If the study fails, it costs a lot of money

**Why does the problem exist?**
- RA’s have to stick to the script, but they don’t want to sound robotic-it’s important to develop a relationship w/ patient
- Long term research
- No incentive
- A lot of follow up phone calls
- Patients do not see benefits of the survey
- Calls are very long and go on forever-every 3 months
- Patient are surveyed both are fatigued because of long calls
- Physicians in C4P are not in the control group for patients
- Patients have changing phone numbers sometimes
- Limited understanding of targeted populations

Figure 2 Problem Definition

High level insights:
Following the context discussions, insights were generated as follows:
**Ideation for solutions**

- **Lack of Incentives to participants**
  - No money is given in the form of incentive for participating in the research.
  - No updates are sent to the participants at any time, other than seasonal greetings.
  - No acknowledgments are consciously communicated for participating in the study.

- **Need to train volunteers/Research assistants to conduct impactful research**
  - Busy Under-Grads, co-ordinators who conduct the research are usually busy with their schedules and work on voluntary time basis.
  - Experience Gap between researcher and co-ordinators conducting the research.

- **6 months, commitment of 8hr/week**

- **Keeping good rapport with the research participants will help keep the participants from losing interest over longer periods of participation**

- **Rapport relationship**
  - No other modes of communication used, other than phone calls.
  - Seasonal greeting cards are sent to participants addresses as a token of gratitude.

- **Length of interviews is long**

- **for short calls - the call should be exactly the same for all 5 min calls, dictated by protocol – for consistency of data**

- **Keeping in mind Behavioural aspects of Human beings, the interviews, questions asked, participant involvement should be kept in mind in the phase of design.**

Figure 4 Ideas as listed during discussion
Solutions Generated by Design Thinking Approach Team:
Six relatively implementable solutions were created to solve the issues of recruitment. They are as follows:

1. **Newsletter/Annual Picnic**: Regularly connect with participants, acknowledgement of participant efforts, motivation of participation, conversion of non-compliant people into compliant participants.

2. **Increase Motivation of Participants**: Create a report to show study participants results. Make personal notes and follow up on these prior to jumping in to the surveys. Give small tokens of appreciation (stickers, pins, gifts, personalized cards that are hand signed). Offer a monetary incentive for every survey.

3. **Stratified Patients and Research Team**: Attempt to have the same researcher, coordinator or volunteer contact the same patients over time. This will help establish a relationship as well as prevent people from being unresponsive to surveys. Also if there is a recognition that a group of people is more likely to be non-compliant or who would have difficulty completing the surveys on time then there should be a trouble shooting team that has skilled study coordinators or assistants than just the work-study students. Another idea could be to increase motivation of surveyors by showing effectiveness of their work on a regular basis.

4. **Conference/Webinar**: Have a conference or a webinar for internal learning on longitudinal studies.

5. **Incentives for Participants for Time Used**: Incentives can be non-monetary. Arrange events such as picnic, bingo, BBQ, and come up with non-monetary incentives which also includes the standard of care participants.

6. **Ways to Reach out to Patients**: Could part of (or full) survey be sent over mail so that the phone calls become shorter. Can surveys be conducted at home via a home visit. Can emphasis be on messaging of the survey and study design so that it is obvious how participation helps generate scientific knowledge. Can there be some focus groups and or surveys to know more about patients’ perspective on these surveys and volunteers’ experiences tendering these surveys. Analytics on feedback from participants could be run to know who answers when and schedule calls or visits accordingly.
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1. Newsletters and Annual Picnics
   - Regular Connections, Acknowledgements, Motivation from non-compliant to compliant surveyors
   - All participants to be invited
   - Maybe separate between Intervention and Non-Intervention participants

2. Incentivizing participants for time used
   - Non monetary ways
   - Arrange events-Picnic, Bingo, BBQ

3. Different ways to reach to patients
   - Survey via mail and email, at home interview, etc.
   - Emphasis on messaging of the survey: conversation, elderly genetics expert
   - Quality check on volunteers
   - Analysis on feedback from participants

4. Increase intrinsic motivation of surveyors
   - Make personal notes and follow up on personal lives for a couple minutes before jumping into the survey
   - Stickers, pins, small gifts, hand signed personalized cards, reports to show them survey summary, calls from physician or important power people
   - Offer a small $ amount for every survey

5. Stratification
   - Stratified patients
   - Stratified Researchers, volunteers, coordinators

6. Online Outreach
   - Conference or webinars for inter institute learning on longitudinal studies

Figure 5 Solutions as visualized on whiteboards
Appendix 1.
Slides from Mary Harris and Laura Magda

Appendix 2.
Session Pictures
Appendix 3.
Actual pictures of white board from the studio session.
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Addendum 1 - 30 Day Follow-up

Suggestions Proposed by the Studio Participants:

1. **Newsletter/Annual Picnic:** Regularly connect with participants, acknowledgement of participant efforts, motivation of participation, non-compliant to compliant surveys.

Implementation and Results:

Since Design Studio on January 9, 2019, the research team and PI are looking at the budget to see if they can build something in it for a picnic.

2. **Increase Motivation of Participants:** Create a report to show study participants results. Make personal notes and follow up on these prior to jumping in to the surveys. Give small tokens of appreciation like stickers, pins, gifts, personalized cards that are hand signed. Offer a monetary incentive for every survey.

Implementation and Results:

Since Design Studio on January 9, 2019, the research team has received approval to order calendars and will pass them out to participants with their follow-up phone call date circled.

The research team is working on an Amendment to add text messages to send to patients asking them about any goals they have and to remind them on their follow up calls. They can then follow up with the goals during their calls.

The research team is also adding notes to RedCap so when the Research Assistants call, they can follow up on any notes from the previous call.

3. **Stratified Patients and Research Team:** Attempt to have the same researcher, coordinator or volunteer contact the same patients. This will help establish relationships. Increase motivation of surveyors.
Implementation and Results:

The research team is currently working at assigning some of the same research assistants or volunteers to call the patients.

**Misc:** A new group of AmeriCorps members are calling the research patients. The research team is getting positive feedback, from their patients, on the age mix of AmeriCorps members. Patients are commenting that they like when someone that is familiar with their neighborhood/community call them or they are older and may understand some of their concerns.

Addendum 2 – 90-Day Follow-Up

1. **Newsletter/Annual Picnic:** Regularly connect with participants, acknowledgement of participant efforts, motivation of participation, non-compliant to compliant surveys.

Implementation and Results:

Since the 30-day follow up, the research team and PI are creating a newsletter and welcome packet for subjects who enroll in the program.

2. **Increase Motivation of Participants:** Create a report to show study participants results. Make personal notes and follow up on these prior to jumping in to the surveys. Give small tokens of appreciation like stickers, pins, gifts, personalized cards that are hand signed. Offer a monetary incentive for every survey.

Implementation and Results:

Since the 30-day follow-up, the research team is designing a calendar to give to subjects. They are also ordering greeting cards to send out for holidays.

The research team is adding notes to RedCap so when the Research Assistants call, they can follow up on any notes from the previous call, for example if they aren’t feeling well, ask them the next call if they are feeling better.
3. **Stratified Patients and Research Team**: Attempt to have the same researcher, coordinator or volunteer contact the same patients. This will help establish relationships. Increase motivation of surveyors.

Implementation and Results:

The research team is currently working at assigning some of the same research assistants or volunteers to call the patients.

4. **Conference/Webinar**: Have a conference or a webinar for internal learning on longitudinal studies.

Implementation and Results: Due to some transitions being done within the department, the study team has not established any webinars. They are looking at opportunities for internal growth and have divided up their volunteers and Americorps members into teams with the four study coordinators. This has established a more team-based approach and has shown some positive feedback with volunteers and Americorps members.

5. **Incentives for Participants for Time Used**: Incentives can be non-monetary. Arrange events such as picnic, bingo, BBQ, and come up with non-monetary incentives which also includes the standard of care participants.

Implementation and Results:

The study team is currently looking at the budget to see if this can be implemented.

6. **Ways to Reach out to Patients**: Could part of (or full) survey be sent over mail so that the phone calls become shorter. Can surveys be conducted at home via a home visit. Can emphasis be on messaging of the survey and study design so that it is obvious how participation helps generate scientific knowledge. Can there be some focus groups and or surveys to know more about patients’ perspective on these surveys and volunteers’ experiences tendering these surveys. Analytics on feedback from participants could be run to know who answers when and schedule calls or visits accordingly.

Implementation and Results:

The study team is currently working on ways to reach out to the patients. They have shortened the follow-up surveys and are currently updating RedCap with the updated survey.
About the Institute for Translational Medicine (ITM)

The ITM is a partnership between the University of Chicago and Rush in collaboration with Advocate Health Care, the Illinois Institute of Technology (Illinois Tech), Loyola University Chicago, and NorthShore University HealthSystem that’s fueled by about $35 million in grants from the National Center for Advancing Translational Sciences at the National Institutes of Health through its Clinical and Translational Science Awards (CTSA) Program.

We’re part of a network of more than 55 CTSA Program-supported hubs across the country working to slash the time it takes to develop and share new treatments and health approaches. We work with you and for you to make participating in health research easy, so that together we improve health care for all.

Join the movement and learn more about how we help researchers, physicians, community members, industry, government organizations, and others. Visit us at chicagoitm.org and connect with us on Facebook, Twitter, Instagram, YouTube, and LinkedIn @ChicagoITM.

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