CTSI Career Development Seminar

Designing Research from Inception to Dissemination

Incorporating design thinking to improve biomedical research

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Objectives

• Define design thinking and describe its advantages for biomedical research

• Use rigorous scientific principles to incorporate design thinking and stakeholder input into research

• Describe current research studies incorporating design thinking

• Discuss how biomedical researchers can collaborate with designers as part of your research team
Design Thinking

Sue Chu, PhD
Design: Definitions

• Plan from which something is to be made.
• Design is the planning and patterning of any act toward a desired, foreseeable end.
• Design is the deliberate and intuitive effort to carry out meaningful order.
• Design is problem solving.
• Design is changing existing situations into preferred ones.
• Designers make ideas into things.
Design Thinking

• Design thinking is a model that uses the designer’s sensibility and methods to match people’s needs (Brown).

• The Design Thinking process defines the problem and then implements the solutions, always with the needs of the user demographic at the core of concept development. This process focuses on needfinding, understanding, creating, thinking, and doing (d.school).

• Instead of feeling that you know it all, that you’re the expert in the subject, design thinking also means being humble and questioning it (Kelly, 2015).
Koberg and Bagnall

Design Process Model

Stages in the Design Process

Accept the Situation
Analyze
Define Problem
Ideate
Select
Implement
Evaluate
IDEO /d.school Design Process Model
Four Big Changes / Growth

• The types of problems that designers are engaging has expanded.

• The role of the user has become increasingly prominent.

• Prototyping, especially quick prototyping has gained greater currency (e.g. 3D printing).

• Social impact design, public interest design, design for social innovation, etc. has gained great interest.
Advantages in Biomedical Research

• Thoughtful design is increasingly expected in healthcare organizations.

• Clinical and Translational research must focus on meeting the needs of the user.

• Complex biomedical solutions benefit from prototyping and iteration.

• Funding agencies understand that designing for communities involves complex stakeholder groups.
Scientific Principles and Ethics in Design Research

Marilyn Bruin, PhD
Ensure Rigor and Ethics in Research

• Evolving conceptual model
• Self, peer, and participant reflections
• Bring strengths from multiple perspectives
• Document procedures as well as share data and findings
Mixed Methods Research

• “The pragmatic stance focuses on research problem and allows multiple methods to address” (Creswell & Plano, 2007, p. 173)

• Mixed methods has grown into a field of study with pragmatic philosophical roots

• Current procedures for conducting this form of inquiry (designs, standards for evaluation)

Creswell’s Breeze presentation
Mixed Methods Research

- Combine the advantages of quantitative and the advantages of qualitative?
- Does not eliminate the limitations of either methodology
- A stronger study, overall, than if we used only quantitative or qualitative research by itself
- Need expertise in two forms of research methodology as well as how and when to combine
- Mixing – questions, data, analysis, and interpretation

Creswell’s Breeze presentation
Participatory Action Research: Definition

Participatory research co-constructed through partnerships between researchers and people affected by, and/or responsible for action on, the issues under study (Jagosh, et al. The Milbank Quarterly, Vol. 90, No. 2, 2012).

The integration of participation, inquiry (research) and action to bring about meaningful change.
Problem solving as a series of iterative steps that involve fact-finding, planning, action, and then more fact-finding, planning, and action as a result of the previous action.

Education for liberation, highlighting the need for communities to engage in dialogues that facilitate their own issue understanding and resolution.

Participatory Action Research: Historical Underpinnings

Kurt Lewin (1940)

John Dewey (1920-30s)

Paulo Freire (1970)

Participatory Action Research

Democratization of education, including educator involvement in community problem solving and integration of knowledge and action.
Participatory Action Research: Core Values

- Inclusion
- Integration of strengths
- Appreciation of multiple understandings through dialogue
- Equity (shared power)
- Transparency
- Accountability
- Positive change and mutual benefit
Participatory Action Research: Ethical Considerations

• Commitment and skills to develop and sustain an inclusive partnership
• Important Protections (e.g., Institutional Review Board)
  • Respect for people – informed consent
  • Beneficence – do no harm, maximize benefits
  • Justice – fairness, demographic and access considerations
• Balancing needs and protections
Examples of Current Research

Cory Schaffhausen, PhD
Nothing is more dangerous than an idea when it is the only one you have.
- Emile Chartier
Patient Centered Organ Transplant
HCMC / UMN Fairview

Crowdsourcing Unmet Needs
CTSI and Supporting Research
C. Transplant Information

Table C6. Adult (18+) 1-year survival with a functioning graft
Single organ transplants performed between 01/01/2013 and 06/30/2015
Deaths and retransplants are considered graft failures

<table>
<thead>
<tr>
<th></th>
<th>MNHC</th>
<th>U.S.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of transplants evaluated</td>
<td>92</td>
<td>39,220</td>
</tr>
<tr>
<td>Estimated probability of surviving with a functioning graft at 1 year (unadjusted for patient and donor characteristics)</td>
<td>97.83%</td>
<td>95.08%</td>
</tr>
<tr>
<td>Expected probability of surviving with a functioning graft at 1 year (adjusted for patient and donor characteristics)</td>
<td>96.10%</td>
<td>--</td>
</tr>
<tr>
<td>Number of observed graft failures (including deaths) during the first year after transplant</td>
<td>2</td>
<td>1,820</td>
</tr>
<tr>
<td>Number of expected graft failures (including deaths) during the first year after transplant</td>
<td>3.28</td>
<td>--</td>
</tr>
<tr>
<td>Estimated hazard ratio*</td>
<td>0.76</td>
<td>--</td>
</tr>
<tr>
<td>95% credible interval for the hazard ratio**</td>
<td>[0.21, 1.60]</td>
<td>--</td>
</tr>
</tbody>
</table>

* The hazard ratio provides an estimate of how Hennepin County Medical Center (MNHC)'s results compare with what was expected based on modeling the transplant outcomes from all U.S. programs. A ratio above 1 indicates higher than expected graft failure rates (e.g., a hazard ratio of 1.5 would indicate 50% higher risk), and a ratio below 1 indicates lower than expected graft failure rates (e.g., a hazard ratio of 0.75 would indicate 25% lower risk). If MNHC's graft failure rate were precisely the expected rate, the estimated hazard ratio would be 1.0.

** The 95% credible interval, [0.21, 1.60], indicates the location of MNHC's true hazard ratio with 95% probability. The best estimate is 24% lower risk of graft failure compared to an average program, but MNHC's performance could plausibly range from 70% reduced risk up to 60% increased risk.

Figure C3. Adult (18+) 1-year graft failure HR estimate

Figure C4. Adult (18+) 1-year graft failure HR program comparison

The data reported here were prepared by the Scientific Registry of Transplant Recipients (SRTR) under contract with the Health Resources and Services Administration (HRSA).
Creating a Patient-Centered Report Cart

AHRQ Funded R01

Understanding Stakeholder Needs
• Qualitative: Interviews (~50), Focus groups (~24)
• Online Surveys / Crowdsourcing

Testing Solutions
• Usability Studies / Design Iterations
• Randomized Controlled Trial
Creating a Patient-Centered Report Cart

Collaborators

- Transplant Clinicians (HCMC / UMn)
- Epidemiologists (SRTR)
- Graphic Designers (College of Design)
- Qualitative / Social Science (College of Design)
- Plain Language / Literacy (College of Education)
- Health Care Quality Reports (U. of Oregon)
- Web/Mobile/IT Development (Nerdery)
After 3 months:

Redefining the Need

What Does Dissemination Look Like?
Please describe a challenge or experience ... that might be improved
Hypotheses

H1
High Quality

H2
High Quality

Needs/Person

Time Spent
Evaluate Quantity and Quality

Quantity Phase → Rapid, High Volumes of Need Statements

Quality Phase → Simple Screening of Quality + Automation
Measuring Quality

Quality = Importance + (6 - Satisfaction)

High Quality

IMPORTANCE

EXISTING SATISFACTION

1

5

1

5
Recruiting

Mechanical Turk is a marketplace for work.
We give businesses and developers access to an on-demand, scalable workforce.
Workers select from thousands of tasks and work whenever it's convenient.

370,050 HITs available. View them now.

Make Money by working on HITs

HITs - Human Intelligence Tasks - are individual tasks that you work on. Find HITs now.

As a Mechanical Turk Worker you:

- Can work from home
- Choose your own work hours
- Get paid for doing good work

Get Results from Mechanical Turk Workers

Ask workers to complete HITs - Human Intelligence Tasks - and get results using Mechanical Turk. Get Started.

As a Mechanical Turk Requester you:

- Have access to a global, on-demand, 24 x 7 workforce
- Get thousands of HITs completed in minutes
- Pay only when you're satisfied with the results

Learn more about being a Worker
Results

Quantity: 341 Users
1,735 Need Statements
1,246 Stories

Quality: 21,841 Quality Ratings
Results

H1: Confirmed

H2: Not Confirmed
Research and Design
Thinking Collaboration

Allyosn Hart, MD, MS
Traditional Scientific Exploration
Path to a Career Development Research Proposal

Supporting the transplant community with statistical analyses to improve patient outcomes.
Creating a Calculator for Transplant Waiting List Outcomes

- Dead or Too Sick
- Other Removal
- Living Donor Tx
- Deceased Donor ECD Tx
- Deceased Donor SCD Tx

Years since listing
Probability
0.0
0.2
0.4
0.6
0.8
1.0
0 2 4 6 8 10 12
The Effect of Communicating Risk on Medical Decision Making

“The median wait time for an individual’s first kidney transplant is 3.6 years and can vary depending on health, compatibility and availability of organs”

– National Kidney Foundation website
The Effect of Communicating Risk on Medical Decision Making

Understanding Outcomes (Risks/Benefits)

Clinical Decision Making:
Seek a living donor vs. wait on the list
Insights from Stakeholder Input

Overestimated risk to donors

- Living donor outcomes
- Understanding Outcomes (Risks/Benefits)
- Recipient outcomes

Overestimate risks of surgery

Underestimated risk dialysis

Clinical Decision Making:
Seek a living donor vs. wait on the list

1. Risk of not getting transplanted
2. Risk to living donor
3. Risk of transplant

Family is pivotal – insight from family members interesting!

Social Support

Burden of Dialysis

Fear

Belief system
Translational Science: Traditional Model

FIGURE 1-1 Operational phases of translational research (T0–T4).
SOURCE: Adapted with permission from Macmillan Publishers Ltd.: Nature Medicine (Blumberg et al., 2012), copyright 2012.
Translational Research Evolves

“...sharing at each stage ensures that researchers are meeting patient and community health needs and that progress in the clinic and community, in turn, informs the work in the laboratory. As a result, the impact of translational research on health improvements hinges on an integrated and responsive research infrastructure...”
Translational Research Evolves

"Radical Collaboration"

The CTSA Program at NIH: Opportunities for Advancing Clinical and Translational Research (2013)
Radical Collaboration

“The design thinking process becomes a glue that holds teams together, allowing students to unleash intuitive leaps, lateral thinking, and new ways of looking at old problems.”
Community Engagement and Citizen Science

Research Enterprise
Includes CEnR

- PI Expertise
- Science Question
- Aims and Methods
- Implement Study
- Collect and Analyze Data
- Publish and Disseminate

Citizen Science:
Researcher(s) collaborate with community members to share data that each have collected.
Goal: Answer research question, AND address community concerns

Crowdsourcing:
Researcher solicits community involvement to find creative solutions to complex questions.
Goal: Answer research question or meet a research need

Gaming & DIY:
Researcher solicits community involvement to find creative solutions to complex questions.
Goal: Answer research question or meet a research need

Translate for Public Health Action
Review Results
Collaborative Research
Engaged Scientific Questioning
Concern/Question
Exposure/Disease Awareness

Citizen Science Enterprise
DRIVING TOMORROW
Our ten-year plan to lead and innovate

To be preeminent in solving the grand challenges of a diverse and changing world
Thank you.

Questions?