#### CTSI Career Development Seminar

## Designing Research from Inception to Dissemination

Incorporating design thinking to improve biomedical research

Allyson Hart, MD, MS, Asst. Professor of Medicine, KL2 Scholar

Marilyn Bruin, PhD, Professor of Housing Studies

Cory Schaffhausen, PhD, Postdoctoral Researcher, Minneapolis Medical Research
Foundation

Sauman Chu, PhD, Professor of Graphic Design

## 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

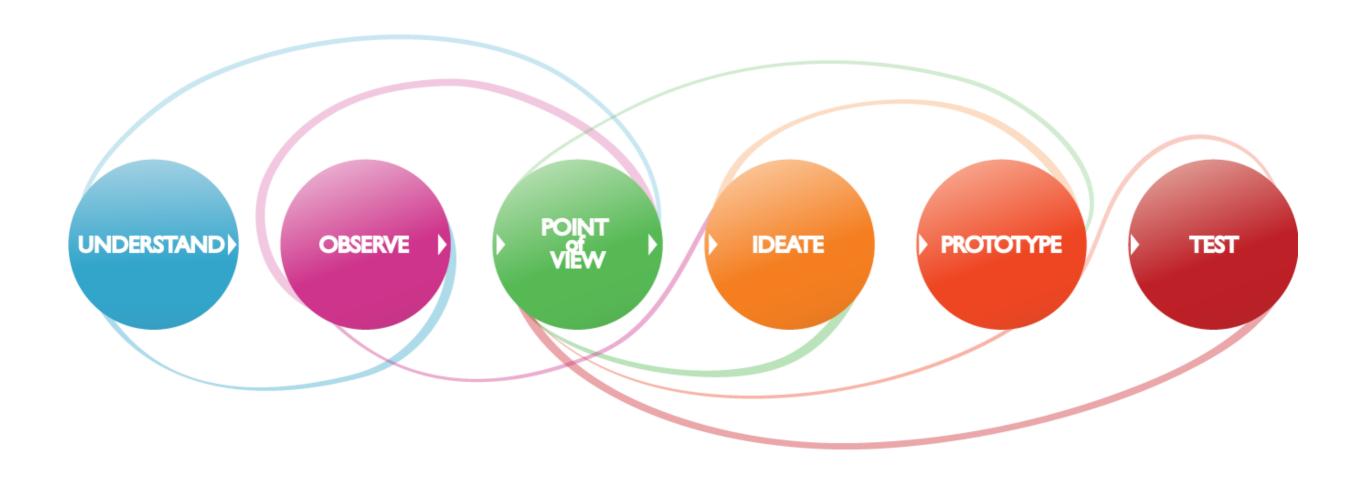
- Design thinking is a model that uses the designer's sensibility and methods to match people's needs (Brown).
- The Design Thinking process defines the problem and then implements the solutions, always with the needs of the user demographic at the core of concept development. This process focuses on 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 health care 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 coconstruction of research 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



## Participatory Action Research: Historical Underpinnings

Democratization of education, including educator involvement in community problem solving and integration of knowledge and action

Kurt Lewin (1940)

Problem solving as 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

John Dewey (1920-30s)

Participatory
Action
Research

Paulo Freire (1970)

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

#### Participatory Action Research: Core Values



## Participatory Action Research: Ethical Considerations

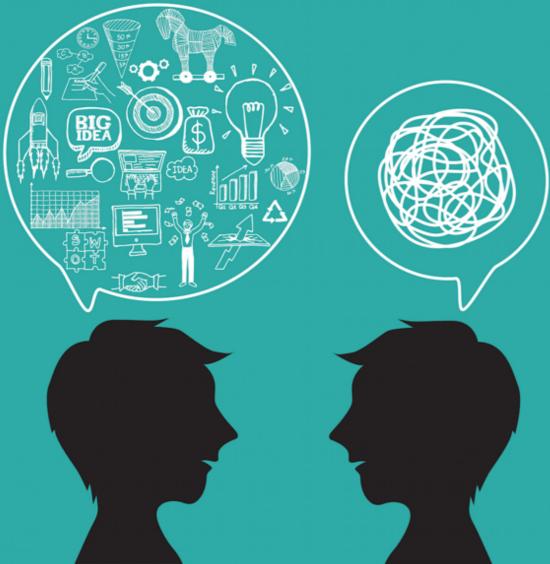
- Commitment and skills to develop and sustain an inclusive partnership
- Important Protections (e.g., Institutional Review Board)
  - Respect for people informed consent
  - Beneficence do no harm, maximize benefits
  - Justice fairness, demographic and access considerations
- Balancing needs and protections

# Examples of Current Research

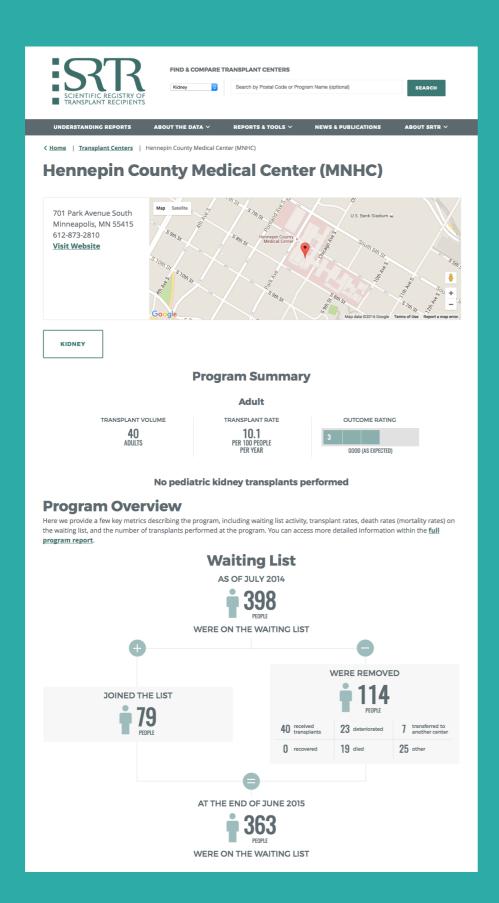
Cory Schaffhausen, PhD

Nothing is more dangerous than appear when it is the only one you have.

- Emile Chartier



### Patient Centered Organ Transplant HCMC / UMN Fairview



### Crowdsourcing Unmet Needs CTSI and Supporting Research

#### COMMUNITY DISCOVERY PROGRAM FOR CHILD HEALTH INNOVATION.

"Discovery consists of seeing what everybody has seen and thinking what nobody has thought." – Albert von Szent-Gyorgy

Researchers are always working to find cures for pediatric diseases and solutions to improve child health, but we don't want to overlook challenges related to caring for children's medical needs at home or in the hospital. Kids, and the adults who care for them, understand best what it is like to experience health conditions, hospital stays, and home health care.

#### WE ARE LISTENING...

Have you ever thought, "There must be a better way...?" Kids, parents, caregivers and other members of the community are invited to submit descriptions of challenges related to caring for children's medical needs that may be improved with new medical device solutions.





University of Minnesota

Clinical and Translational Science Institute Driven to Discover\*



Descriptions of challenges and experiences submitted through:

www.pdic.org/community



Pediatric Device Innovation Consortium (PDIC) evaluates the need for a new product, and the potential impact on child health



PDIC works with University of Minnesota researchers and medical device experts on selected projects to develop new products that address challenges described by the community

#### EXAMPLES OF CHALLENGES AND EXPERIENCES:

[Hospital-based care]

"I found it difficult to hold and comfort my child when he was connected to the IV pole. The tubes and wires were constantly tangled or were too short to allow for normal movement."

[Home health care

"My child's colostomy bag falls off several times a day and severely irritates his skin."

The Community Discovery Program for Child Health Innovation is sponsored by the Clinical and Translational Science Institute, Office of Discovery and Translation.

#### PLEASE DESCRIBE YOUR EXPERIENCE

Please describe a challenge or experience related to hospital stays, health conditions or home health care that might be improved through the development of new medical device solutions.

NAME (optional)	
EMAIL (optional)	
ARE YOU A (CHECK BOX):	
ARE YOU A (CHECK BOX):  Patient Parent	
☐ Patient	
Patient Parent	

Submissions are reviewed within three months of receipt

☐ I Agree (required) to the <u>Terms and Conditions</u>

Description of the challenge or experience

Please note that the content of your Submission will be kept confidential and will be used for program review purposes only. <u>Privacy Policy</u>

SEND MESSAGE



#### Hennepin County Medical Center

Center Code: MNHC Transplant Program (Organ): Kidney Release Date: June 16, 2016 Based on Data Available: April 30, 2016 SRTR Program-Specific Report Feedback?: SRTR@SRTR.org 1.877.970.SRTR (7787) http://www.srtr.org

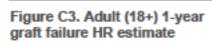
#### C. Transplant Information

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

Deauts and retransplants are considered graft failures	MNHC	U.S.	
Number of transplants evaluated	92	39,229	
Estimated probability of surviving with a functioning graft at 1 year (unadjusted for patient and donor characteristics)	97.83%	95.08%	
Expected probability of surviving with a functioning graft at 1 year (adjusted for patient and donor characteristics)	96.10%	-	
Number of observed graft failures (including deaths) during the first year after transplant	2	1,820	
Number of expected graft failures (including deaths) during the first year after transplant	3.28	-	
Estimated hazard ratio*	0.76	_	
95% credible interval for the hazard ratio**	[0.21, 1.66]	_	

<sup>\*</sup> 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, 1.66], 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 79% reduced risk up to 66% increased risk.



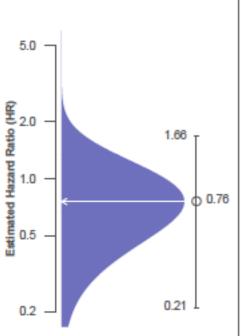
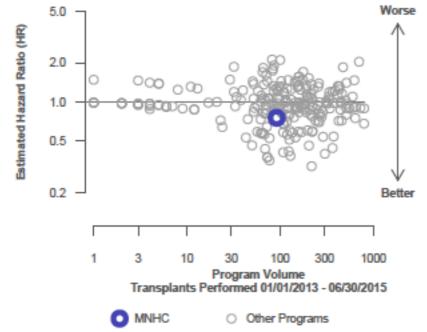


Figure C4. Adult (18+) 1-year graft failure HR program comparison



Page: 23

The data reported here were prepared by the Scientific Registry of Transplant Recipients (SRTR) under contract with the Health Resources and Services Administration (HRSA).

## Transplant Center Performance

"graft failure"

"unadjusted"

"expected probability"

"hazard ratio"

"95% credible interval"

**Unmet Need** 

# Creating a Patient-Centered Report Cart

AHRQ Funded R01

Understanding Stakeholder Needs

- Qualitative: Interviews (~50), Focus groups (~24)
- Online Surveys / Crowdsourcing

#### **Testing Solutions**

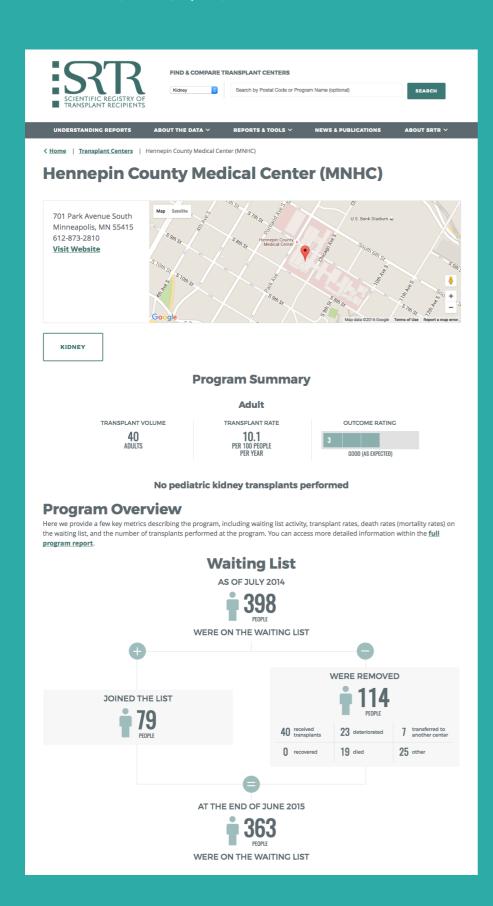
- Usability Studies / Design Iterations
- Randomized Controlled Trial

# 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)

### Patient Centered Organ Transplant HCMC / UMN Fairview



After 3 months:

Redefining the Need

What Does Dissemination Look Like?

#### **Crowdsourcing Unmet Needs** CTSI and Supporting Research

### Please describe a challenge experience ... that might be improved

COMMUNITY DISCOVERY PROGRAM FOR CHILD HEALTH INNOVATION.

erlook challenges related to caring hospital. Kids, and the adults who to experience health conditions.

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University of Minnesota

Clinical and Translational Science Institute Driven to Discover®

#### PLEASE DESCRIBE YOUR EXPERIENCE

Please describe a challenge or experience related to hospital stays, health conditions or home health care that might be improved through the development of new medical device solutions.

NAME (optional)

**Visit Website** 

EMAIL (optional)

ARE YOU A (CHECK BOX):

Patient

Parent

Health care provider

Community member

Other caretaker

WOULD YOU LIKE US TO FOLLOW UP WITH YOU ABOUT YOUR SUBMISSION?

Yes

○ No

Submissions are reviewed within three months of receipt

Description of the challenge or experience

I Agree (required) to the <u>Terms and Conditions</u>

Please note that the content of your Submission will be kept confidential and will be used for program review purposes only. Privacy Policy

SEND MESSAGE

ct, and the

medical device experts on selected projects to develop new products that address challenges described by the community

aled or were too short to

WERE ON THE WAITING LIST

Submissions are reviewed within three months of receipt

## Hypotheses



## 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)

## Recruiting

amazonmechanical turk

Artificial Artificial Intelligence

Your Account

HITs

Qualifications

Already have an account? Sign in as a Worker | Requester

Introduction | Dashboard | Status | Account Settings

#### 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. <u>Find HITs now.</u>

#### As a Mechanical Turk Worker you:

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



or learn more about being a Worker

#### **Get Results**

#### from Mechanical Turk Workers

Ask workers to complete HITs - *Human Intelligence Tasks* - and get results using Mechanical Turk. <u>Get Started</u>.

#### 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



FAQ | Contact Us | Careers at Mechanical Turk | Developers | Press | Policies | Blog | Service Health Dashboard ©2005-2015 Amazon.com, Inc. or its Affiliates

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### Results

Quantity: 341 Users

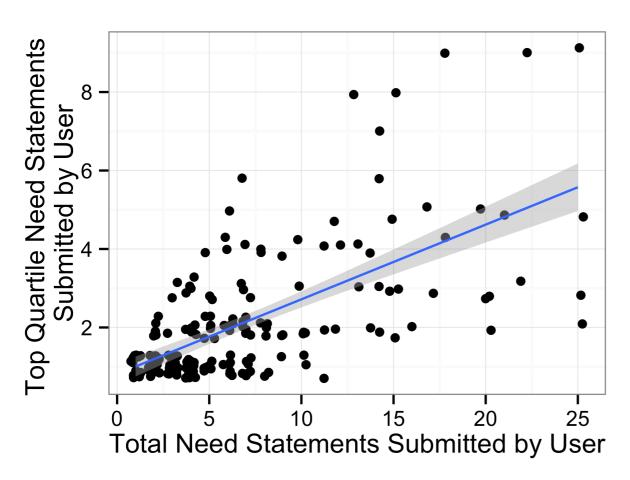
1,735 Need Statements

1,246 Stories

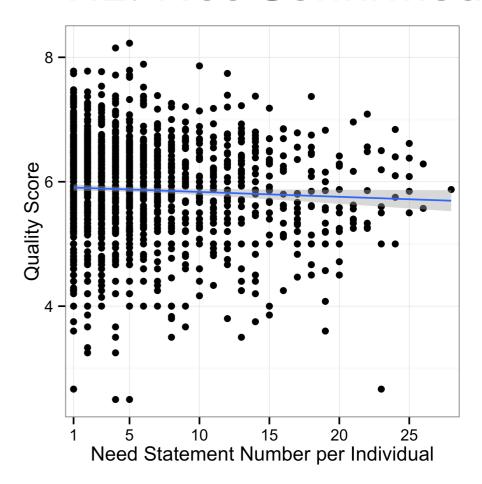
Quality: 21,841 Quality Ratings

### Results

H1: Confirmed



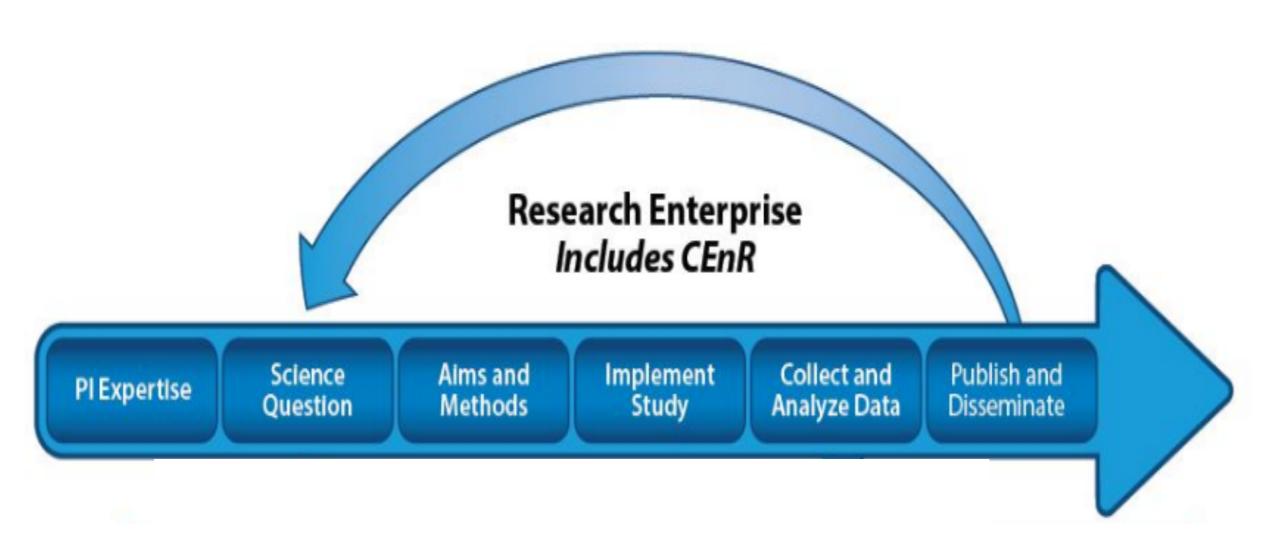
#### **H2: Not Confirmed**



## Research and Design Thinking Collaboration

Allyosn Hart, MD, MS

# Traditional Scientific Exploration



NIH: National Institute of Environmental Health Sciences E-News Volume 7, Issue 1: January 2016

PRINTIPAL ARTITICAL ARTITUTA A

#### Path to a Career Development Research Proposal

Home | Contact us SCIENTIFIC REGISTRY OF SPLANT RECIPIENTS Annual Data Reports ▼ | Tools ▼ Transplant Program Reports ▼ | OPO Reports ▼ For Researchers ▼ PSR Quick Links Supporting the transplant community with statistical analyses to improve patient outcomes. Transplant Program Reports Methodology Risk-Adjustment Models (Transplant Programs) Risk-Adjustment Models (OPO) Transplant Report Timeline OPO Report Timeline Past Notices Organ Procurement Organization (OPO) Reports Transplant Program Reports FAQs Contact the SRTR 914 South 8th Street Suite S-4.100 Minneapolis, MN 55404 Tel: 877-970-SRTR Organ Allocation Publications, Presentations. **FAQs** Fax: 612-873-1644 & Posters <u>Summaries</u> Email Us Now Released: Spring 2016 Program Specific Reports and OPO-Specific Reports Find the Transplant Program Specific Reports (PSRs) here, and the OPO-Specific Reports here. Posted: 6/16/2016



For the spring 2016 cycle of the program-specific reports (PSRs) starting in April 2016, SRTR will use new risk-adjustment lung models to assess transplant program performance. More information can be found here: <u>Upcoming Changes</u>.

Posted: 2/4/2016

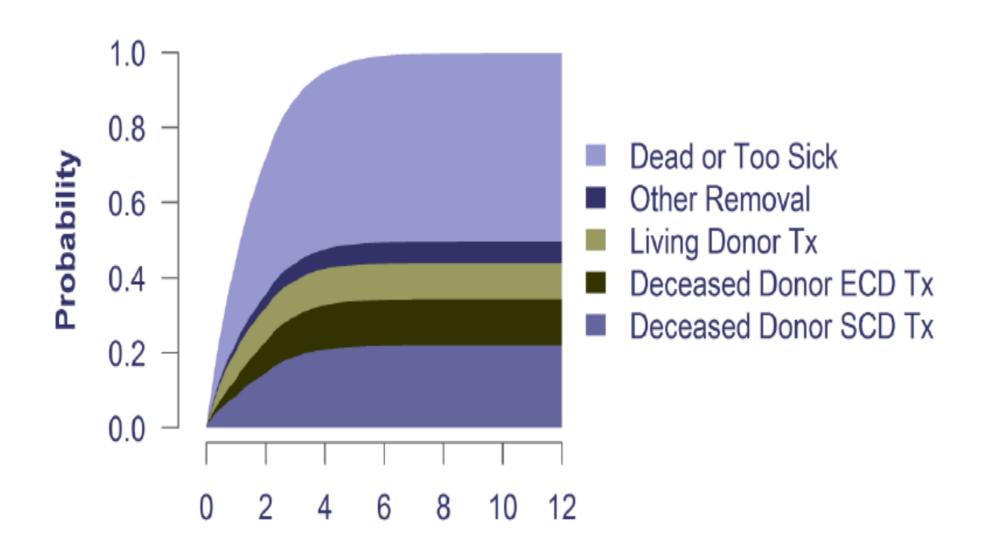








### Creating a Calculator for Transplant Waiting List Outcomes

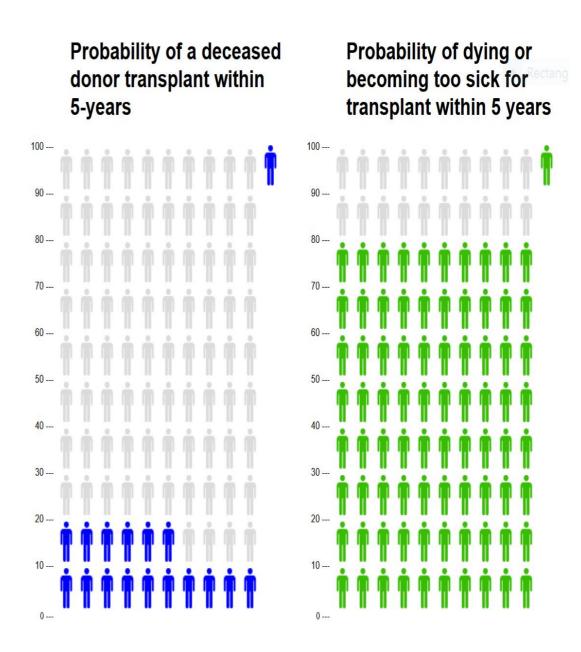


Years since listing

## 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

Family is pivotal – insight from family

1. Risk of not getting transplanted

2. Risk to living donor

3. Risk of transplant

members interesting! Overestimated risk to donors Burden Social Living Support donor Dialysis outcomes Clinical Decision Making: Understanding Seek a living **Outcomes** donor vs. wait (Risks/Benefits) on the list Recipient outcomes Belief Fear system Overestimate risks of surgery

**Underestimate** risk dialysis

## Translational Science: Traditional Model

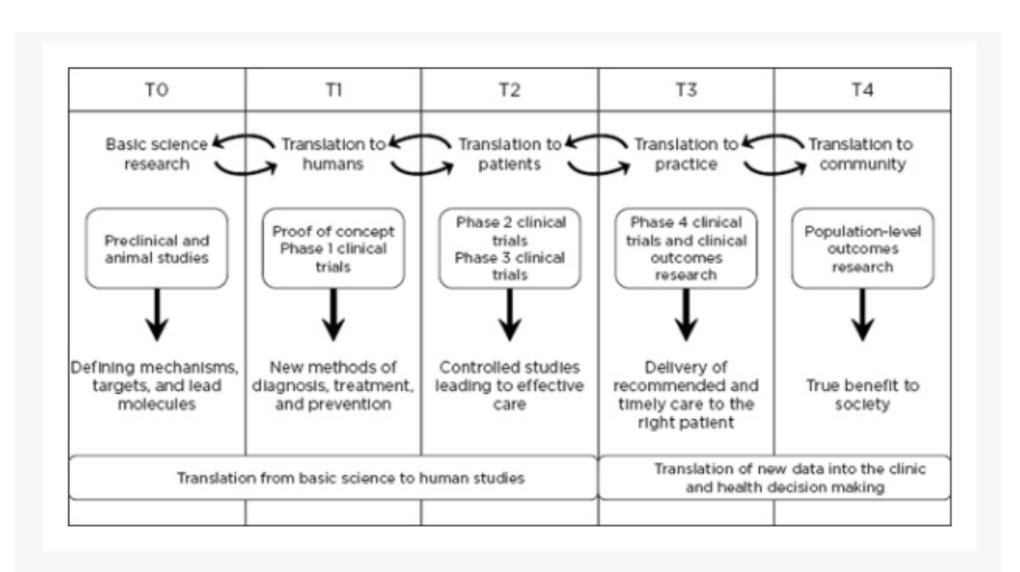


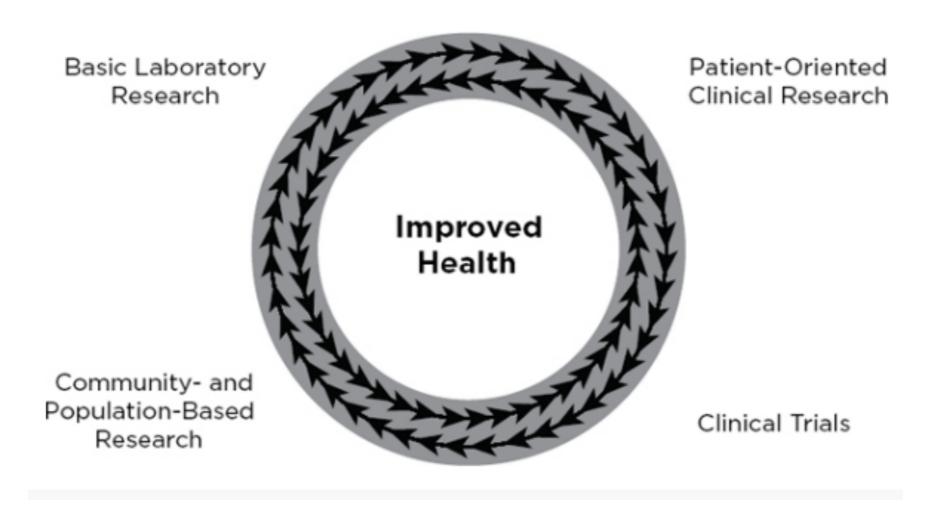
FIGURE 1-1 Operational phases of translational research (T0-T4).

SOURCE: Adapted with permission from Macmillan Publishers Ltd.: Nature Medicine (Blumberg et al., 2012), copyright 2012.

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

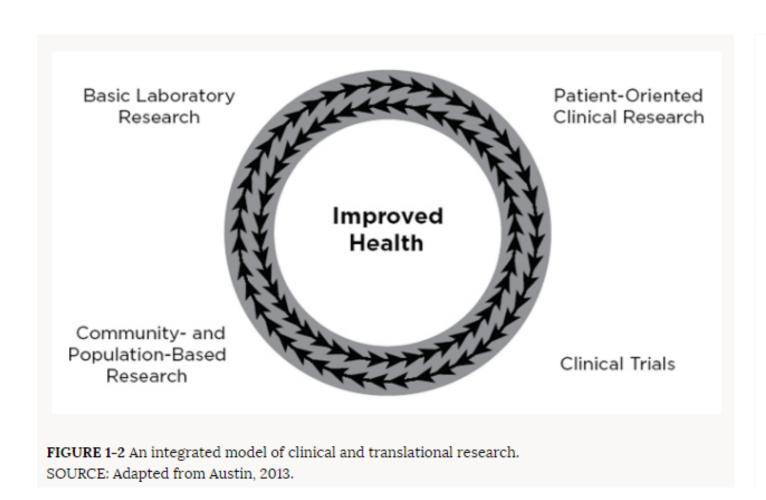
## Translational Research Evolves

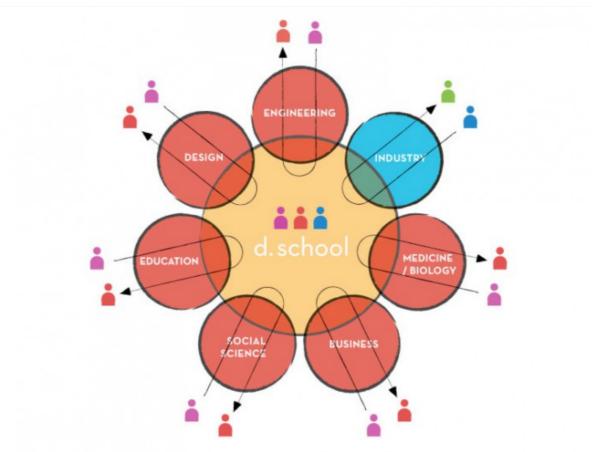
"...sharing at each stage ensures that researchers are meeting patient and community health needs and that progress in the clinic and community, in turn, informs the work in the laboratory. As a result, the impact of translational research on health improvements hinges on an integrated and responsive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



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

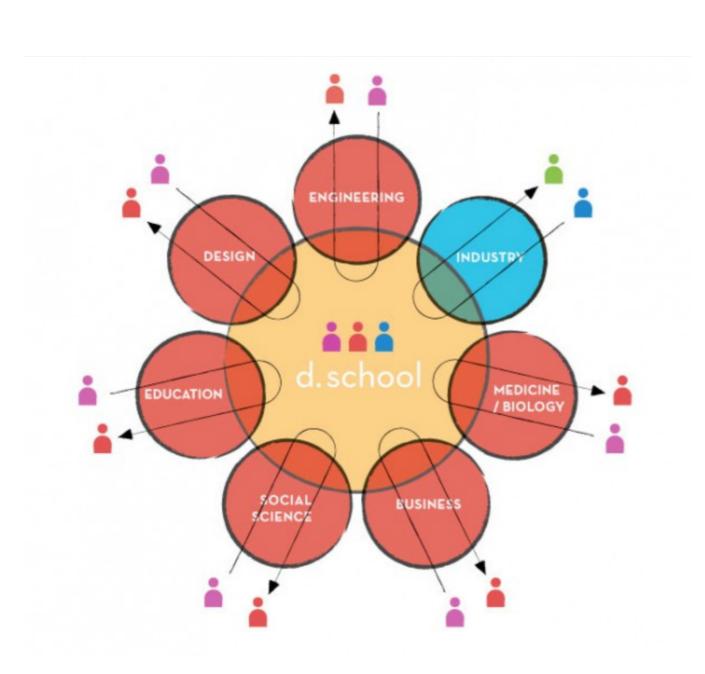
# Translational Research Evolves





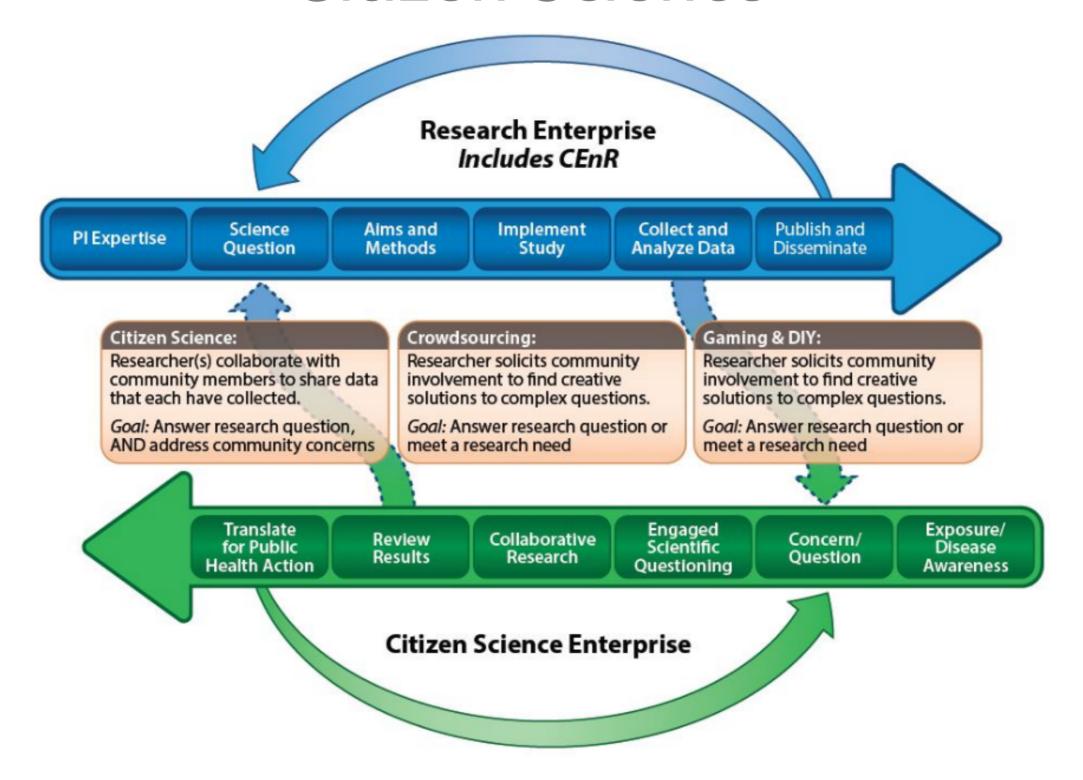
"Radical Collaboration"

### 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





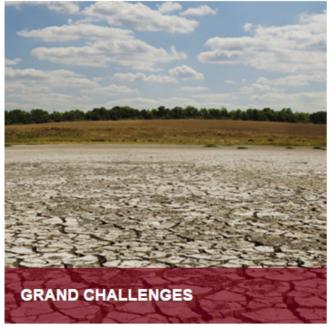
#### **DRIVING TOMORROW**

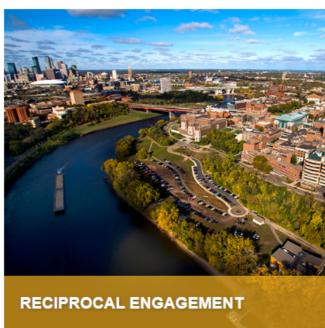
Our ten-year plan to lead and innovate

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









Thank you

## Questions?