CLOSING THE LOOP: Sharing Research Results with Participants

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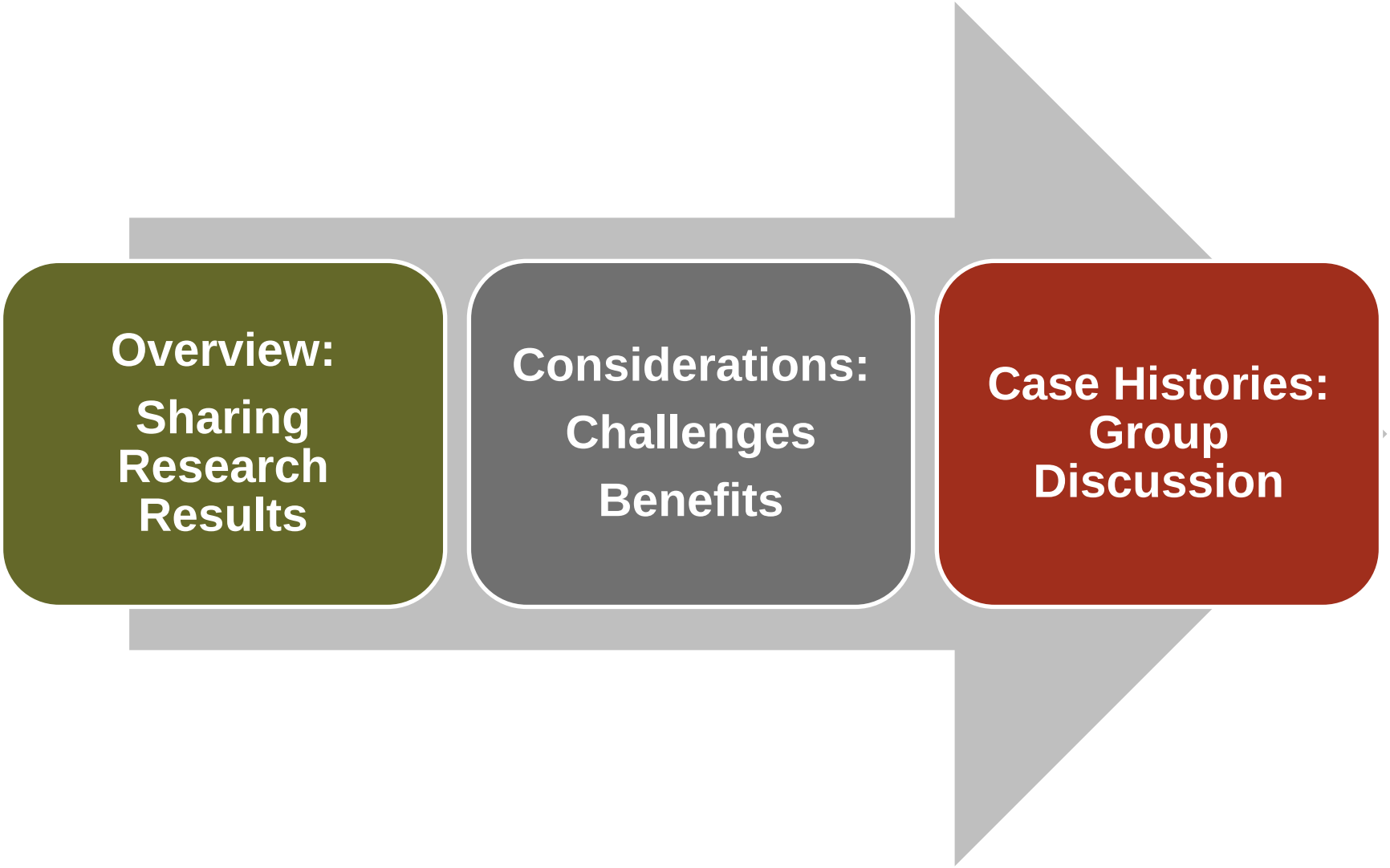
Session Outline



OVERVIEW
Sharing Research Results

- Studies show that overall, people who participate in research want to know the results of their participation
- Generally not considered as part of the study process, unless it's anticipated that there will be clear clinical relevance
- This type of engagement is getting increasing attention, with a range of arguments in support

CONSIDERATIONS

- Type of study
- Health condition
- Participant population
- Is there relevance to their ongoing health?
- What type of results, individual or aggregate?

CONSIDERATIONS

- Timing
- Type of communication
- Should participants consent in advance?
- Do the benefits outweigh the risks?

CONSIDERATIONS
Challenges

- Length of time between study participation and data analysis
- This is new for IRBs, too
- Logistics

CONSIDERATIONS
Benefits

- Way of showing respect to participants that their participation has value
- Transparency promotes trust
- Retention
- Continued engagement with research

CONSIDERATIONS
Sharing beyond the participants

Recruitment Network

The NEW ENGLAND JOURNAL of MEDICINE

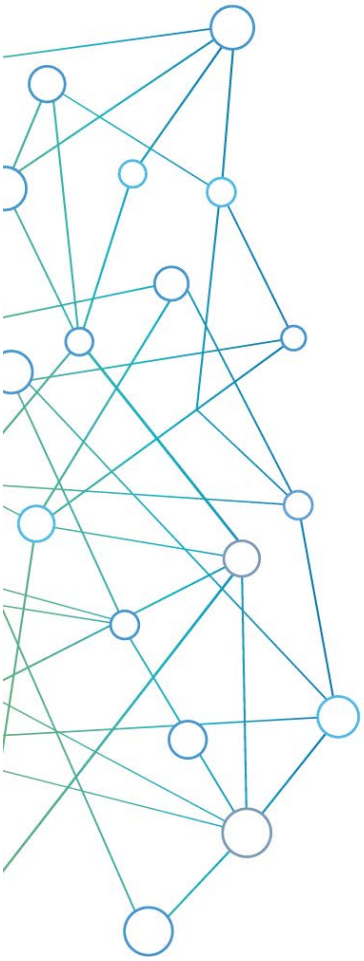
ORIGINAL ARTICLE

Robot-Assisted Therapy for Long-Term Upper-Limb Impairment after Stroke

CASE HISTORIES
Discussion

- Study population and type of study
- Type of results
- Relevance to ongoing health
- Timing and method (lay language!)
- Should consent be obtained?
- Participant response
- Risks of disclosure

Case Study: Dietary Self-Monitoring



Population

People interested in losing weight

Purpose

Test which method of tracking food intake facilitates greater weight loss

Procedures

Randomized to tracking food intake by one of three methods:

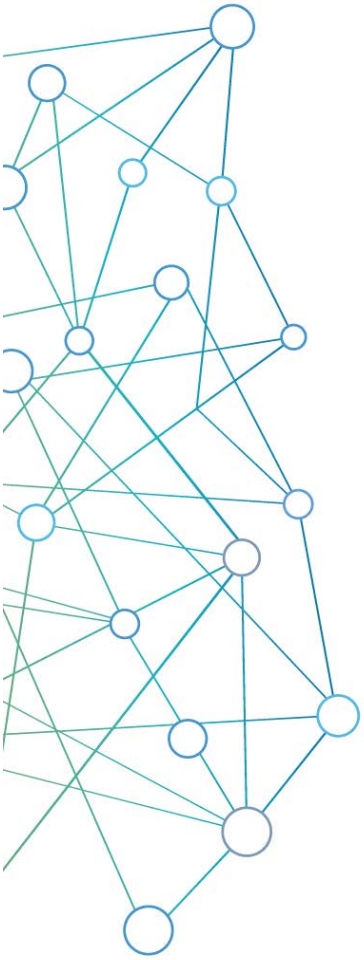
- *Paper and pen*
- *Smartphone memo function*
- *Specific smart phone app*

Results

No difference in weight loss between groups

The app and memo users tracked more consistently

Case Study: Autoimmune Proteins



Population

People with lupus, rheumatoid arthritis, or other autoimmune diseases

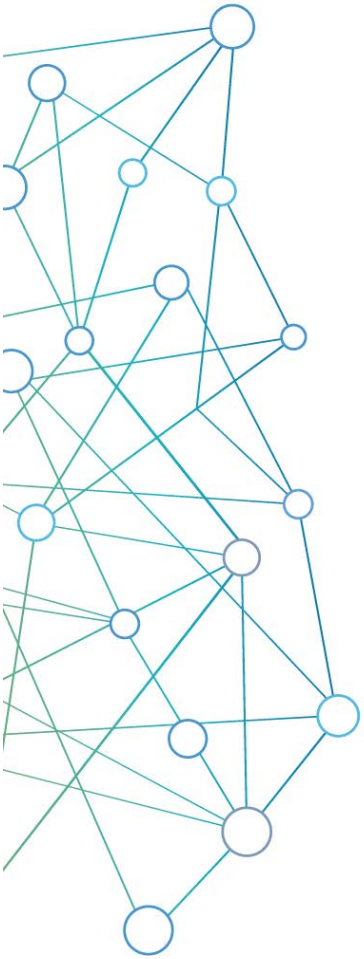
Purpose

Laboratory based studies of immune cells (proteins, lymphocytes)

Procedures

Blood draw piggy-backed on a clinical draw
Medical records review
Consent form allows for subsequent blood draws (> 3 months)
Participants are told there isn't any direct clinical benefit to them

Case Study: Sensory Sensitivity



Population

Children ages 6-9, with or without Autism Spectrum Disorder

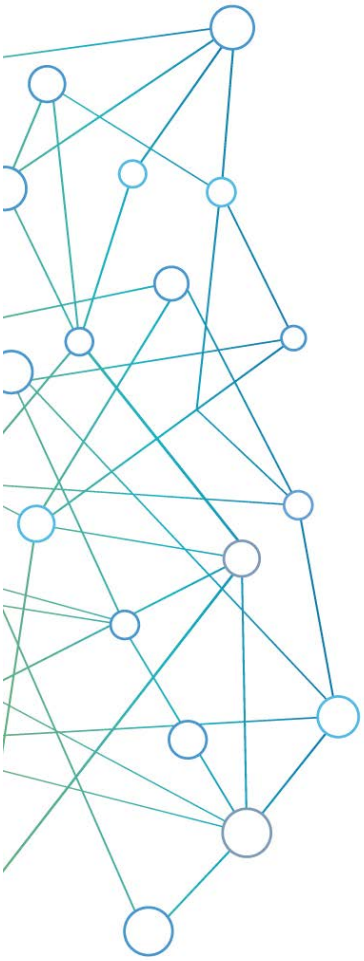
Purpose

Better understand sensory sensitivity in Autism Spectrum Disorder

Procedures

fMRI doing different tasks, such as smelling different substances and playing games
Diagnostic autism evaluations

Case Study: Managing Hot flashes



Population

Perimenopausal women

Purpose

Test whether yoga or exercise will help reduce the frequency or intensity of hot flashes associated with menopause

Procedures

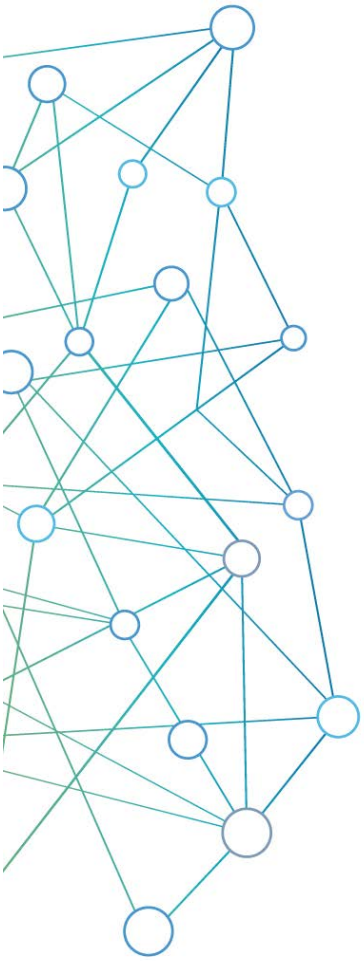
Three treatment groups for 12 weeks:

- *Yoga*
- *Exercise*
- *Usual activity*

Results

No difference seen among treatment groups

Case Study: Healthy Relationships in Youth



Population

Teens and young adults, 15-21, currently or previously in foster care

Purpose

To learn about their norms, attitudes, and behaviors around romantic and sexual relationships in order to develop interventions

Procedures

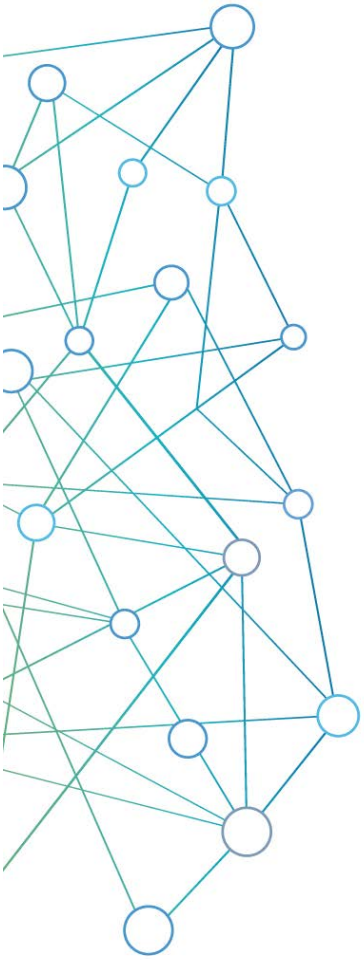
One-on-one interviews and questionnaires

Results

Participants' attitudes

- *Saw pregnancy as inevitable*
- *Normal to have sex at a young age*
- *Lack of knowledge about STDs*

Case Study: Continuous Glucose Monitoring



Population

Diabetics

Purpose

Feasibility of using a continuous glucose monitor (CGM) in a hospital setting, during and after surgery, to monitor glucose levels

Procedures

Participants wear the CGM two days before surgery and until hospital discharge after surgery

- *Monitor is FDA approved*
- *Finger stuck glucose values are entered into the monitor every 12 hours for calibration*
- *Participants and clinicians are blinded to the glucose values the device is recording*

Summary

- We can get better about letting participants know how they've helped other people
- There's no one-size-fits-all plan
- Research Coordinators are positioned to make a difference