

SPEAKING STOMA

Developing a Health Communication Guide for People
With Ostomies

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Team Members



Ivatury



Dailey



Hughes



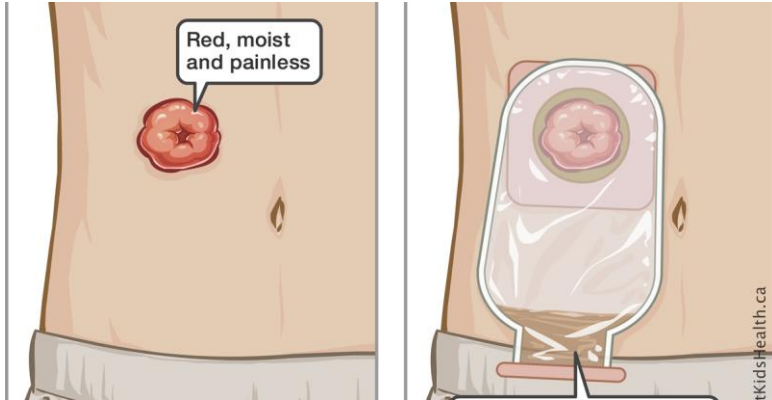
Romo



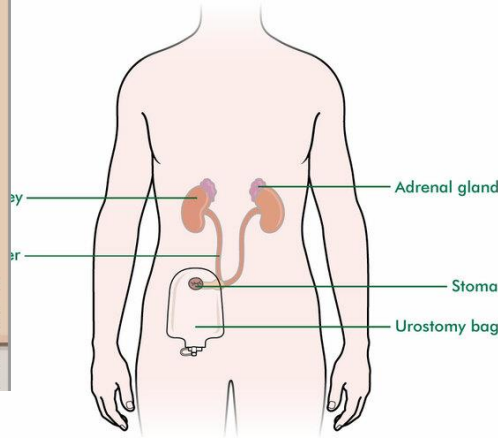
Donovan

Stoma. What Does That Mean?

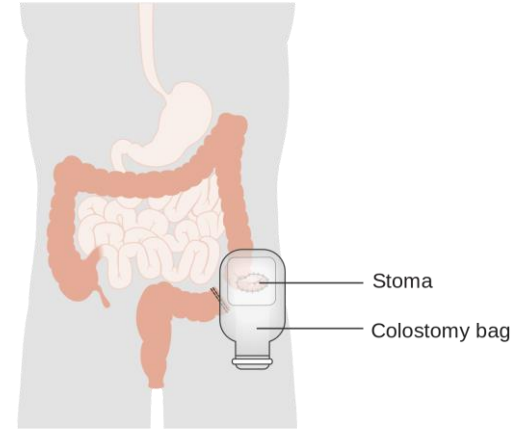
Ileostomy



Urostomy



Colostomy



Stoma = Mouth

Some Part of the Body (Usually Intestine) Brought Up To the Skin

Stomas Treat Many Health Conditions and Diseases



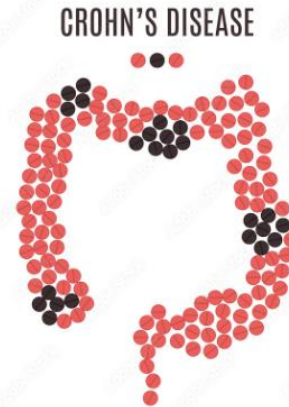
TRAUMA



ulcerative colitis



CANCER

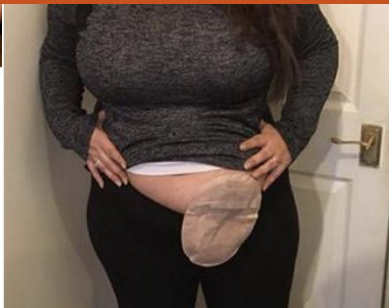


incontinence





1,000,000 People Live With A Stoma in the United States



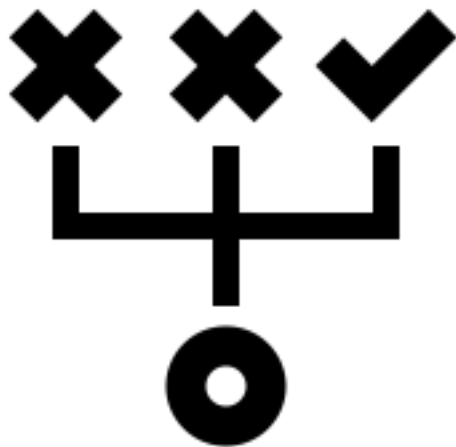
Everyday Social Interactions Are A Key Factor to Health



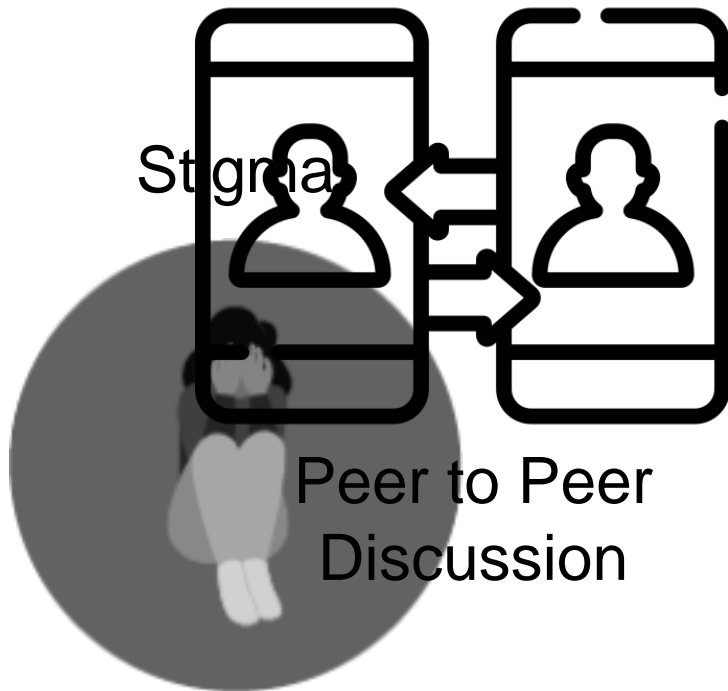
For People with Ostomies...

- Differences in How Much To Share
- Social Support Is Important
- High Uncertainty in How to Manage Stigma and Stoma-related Communication

Current Communication Strategies



Trial and Error



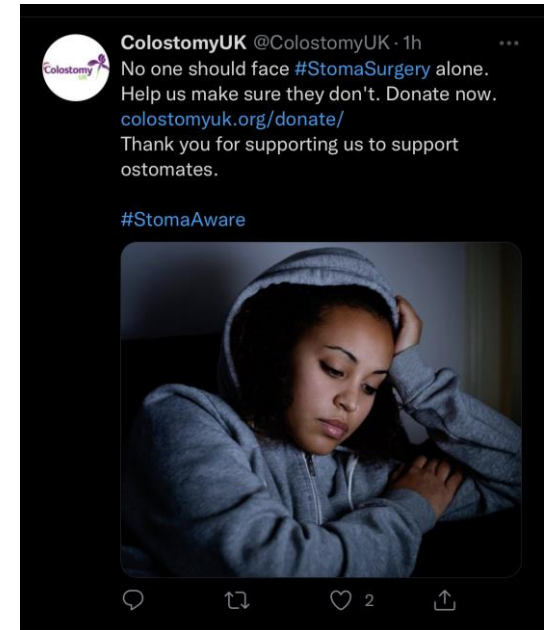
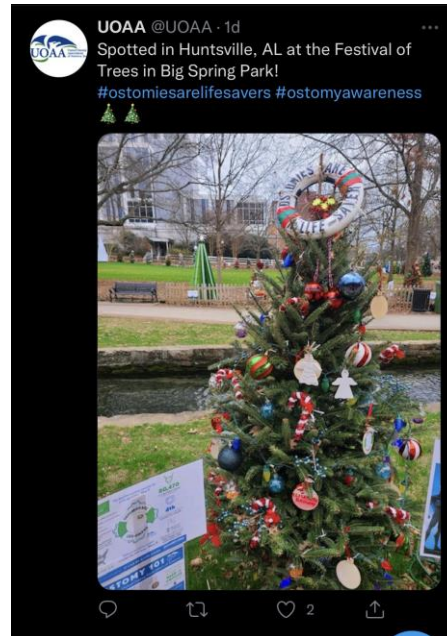
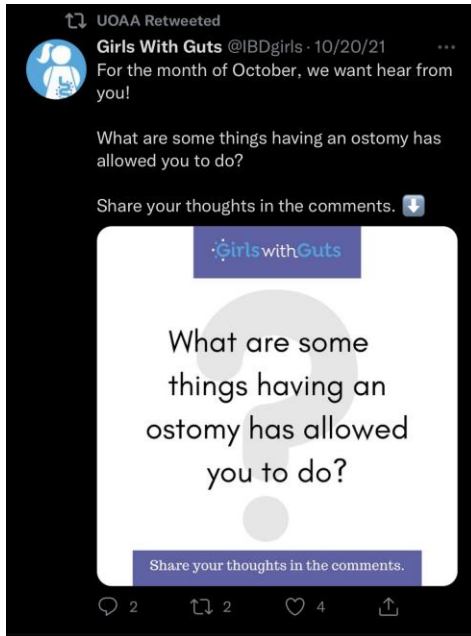
Peer to Peer
Discussion

Cannot Find
a Peer

Misinformation

Imposters


Online Communication Support Underwhelms



Current Communication Guides

EMOTIONAL SUPPORT: A Crucial Component of Quality Care for Ostomy and Continent Diversion Patients

United Ostomy Associations of America, Inc. (UOAA) is committed to providing resources to those who are in need of emotional support as well as promoting recommended standards of care across the nation that is supportive of both the physical and emotional well-being of people living with an ostomy or continent diversion.



Important research findings¹ show evidence that a high percentage of patients did not receive these recommended standards of care as outlined within the Ostomy and Continent Diversion Patient Bill of Rights².

When asked what patients struggled with most following discharge from their ostomy or continent diversion surgery, a survey of 412 respondents revealed "lack of emotional support/depression" to be in the top 3 most commonly reported answers.

60% Did not receive resources to organizations who support and advocate for patients living with an ostomy or continent diversion

68% Did not receive information about support groups

70% Were not provided the opportunity to talk with someone who has been through ostomy or continent diversion surgery

78% Were not provided the opportunity to discuss the emotional impact of surgery

"It would have been great to speak to someone who had the surgery and was living with the ostomy."

"We had to search out an ostomy nurse, our hospital only had one at the time of surgery. They hold classes for knee replacements, diabetes, etc. but nothing for a urostomy."

"I'm still shocked at how we felt so alone and abandoned after we left the hospital."

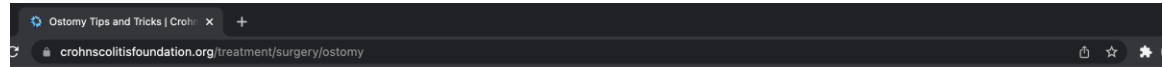
"It really is crucial to join a support group and see a psychologist."

¹Survey of 412 patients surveyed in 2018 in a national survey published in the Journal of Ostomy, Wound Care and Rehabilitation, Volume 52, Number 2, February 2018. ²United Ostomy Associations of America, Inc. (UOAA) (2015). OSTOMY AND CONTINENT DIVERSION PATIENT BILL OF RIGHTS. Available at: <http://www.uoaa.org>

DO YOU OR SOMEONE YOU KNOW NEED EMOTIONAL SUPPORT?

UOAA has 300 Affiliated Support Groups (some with visitor programs), a mental health provider finder, ostomy nurse finder, and an online discussion board.

FOR MORE INFORMATION PLEASE VISIT WWW.OSTOMY.ORG OR CALL 800-826-0826



a drastic improvement in how you feel immediately, but it's important that you take time to learn your new body and the adjustments you need to make in your daily life.

Eating +

Clothing +

Bathing and showering +

Exercise and sports +

Travel +

Intimacy +

Fertility, pregnancy, and delivery +

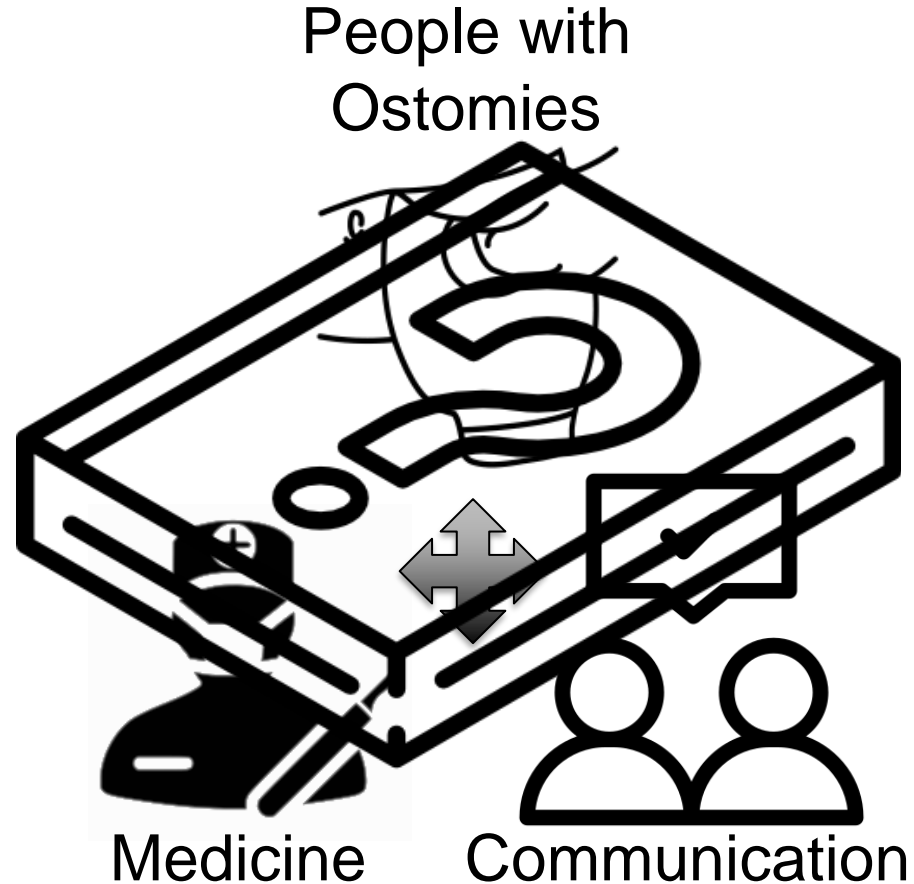
At the workplace +

The Key Gap

The need for a broadly applicable tool to help people with ostomies communicate in common social situations

Overall Objective

To produce and iteratively craft a patient-informed health communication guide for people with ostomies



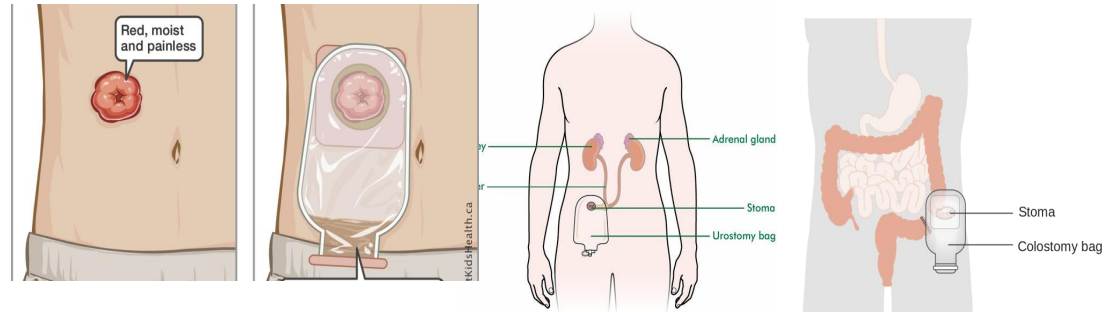
Research Questions

RQ1: What are the most salient social situations that people with ostomies face?

RQ2: What are communication strategies that experienced people with ostomies use in each situation?

Project Population

People with current ostomies (ileostomy, colostomy, or urostomy) agnostic to the disease/reason for ostomy.



Aims

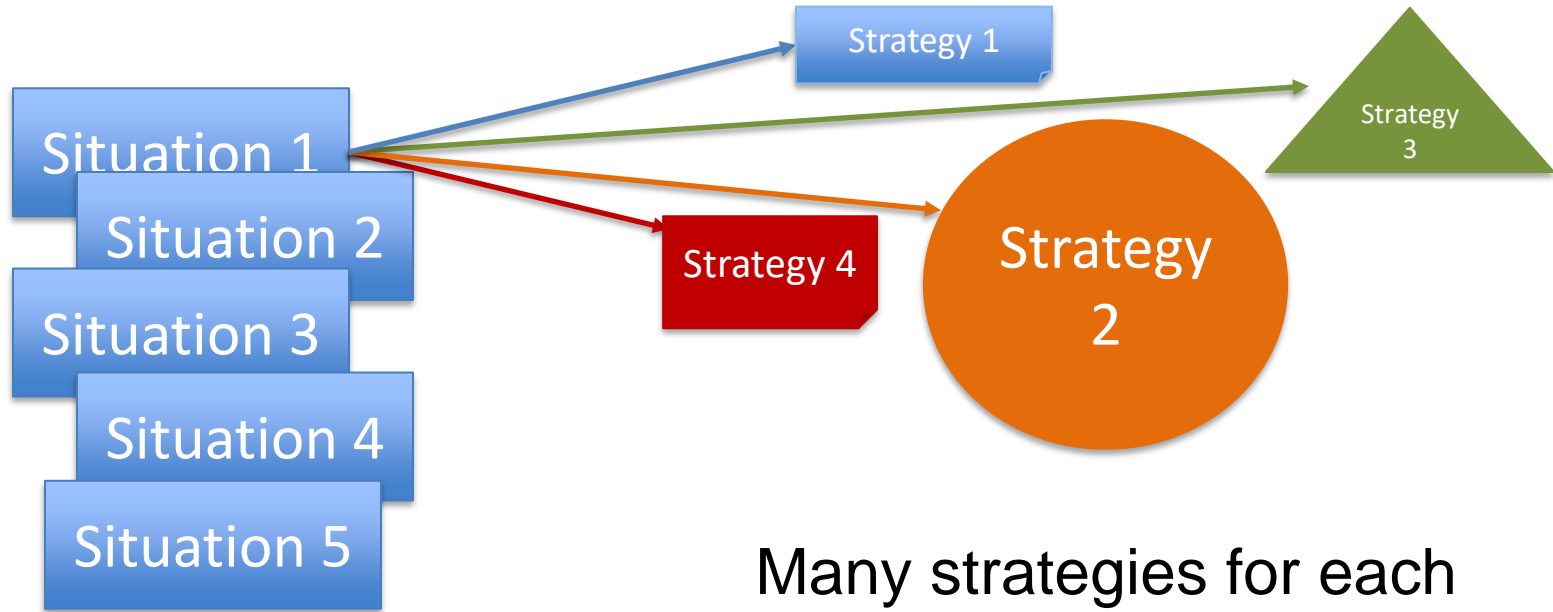
Aim 1: Identify the most salient social situations encountered and communication strategies employed by people with ostomies

Aim 2: Coproduce a health communication guide for people with ostomies for the top social situations encountered

Aim 1: Identify Salient Situations

- Focus Groups/Semi-Structured Interviews of People with Ostomies, Inductive Thematic Analysis
 - Recruited through Social Media, Clinical Practice, and Snowball/Network Sampling
 - Sampled for Age, Sex, Type of Ostomy
 - Target – 60 Participants

Aim 1: Identify Salient Strategies

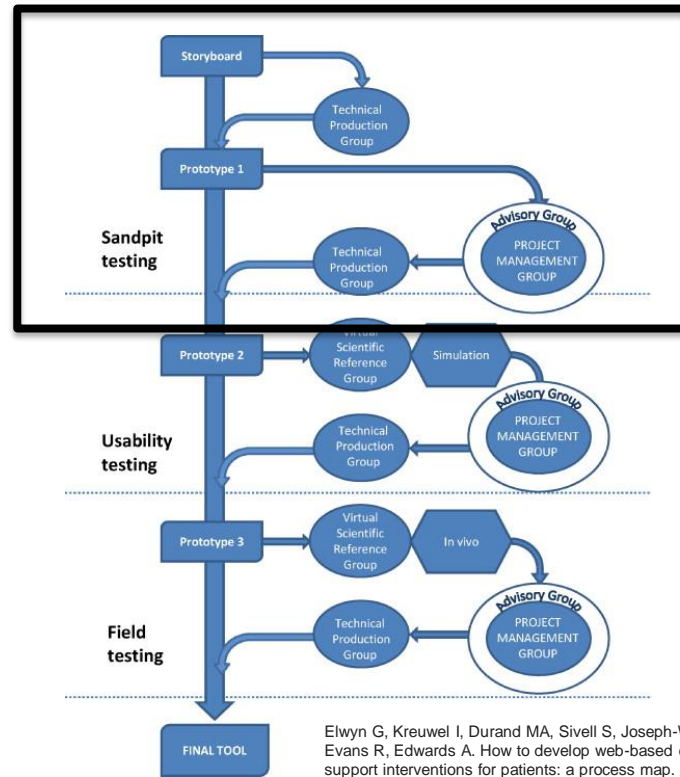


Many strategies for each salient social situation

Aim 2: Health Communication Guide

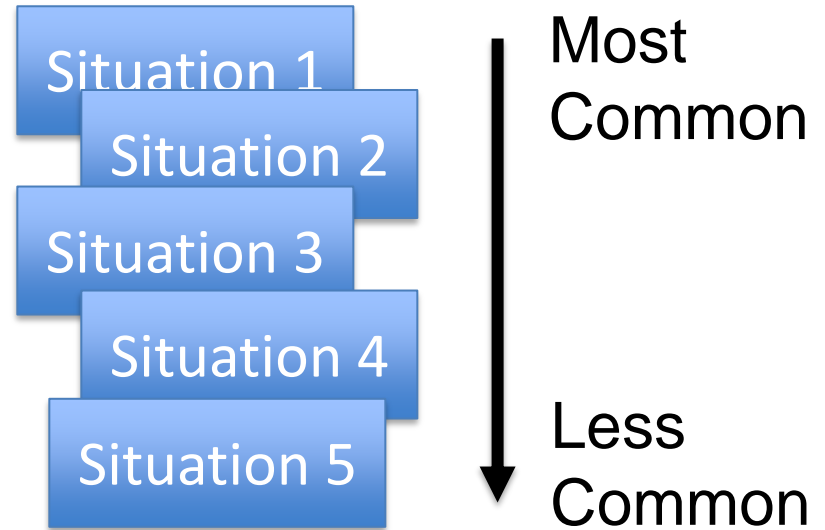
- Assemble an Advisory Board of People with Ostomies (~5 members)
- Iteratively Create Guide Based on Appearance, Readability, Understandability, Actionability
- Conduct ~6 Focus Groups

Aim 2: Health Communication Guide

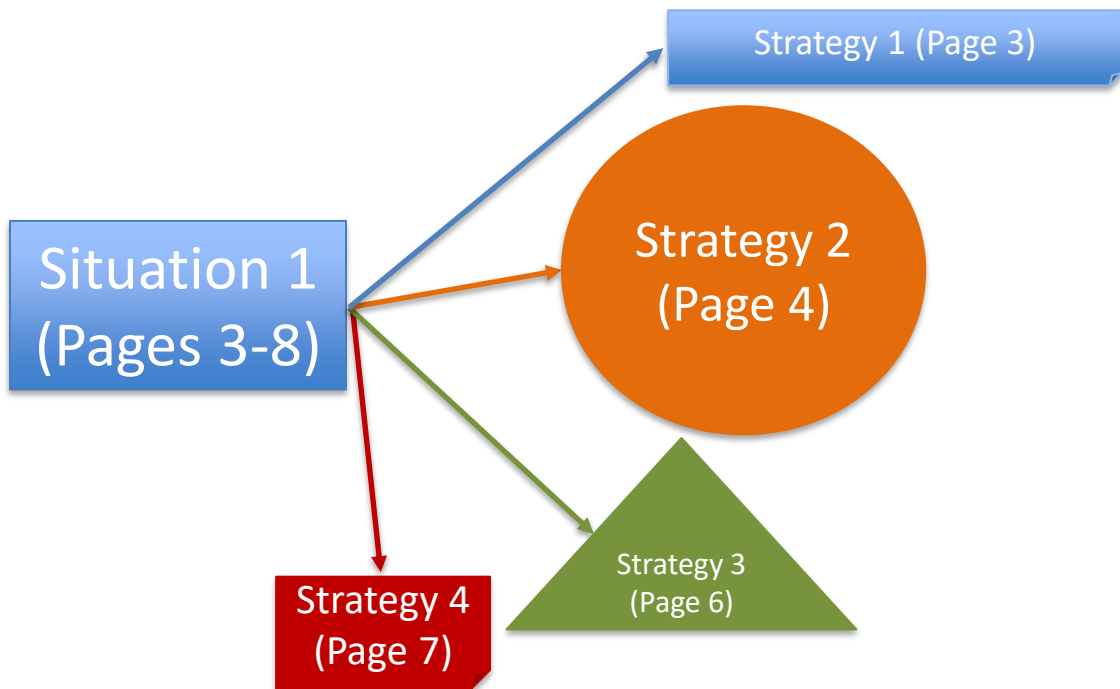
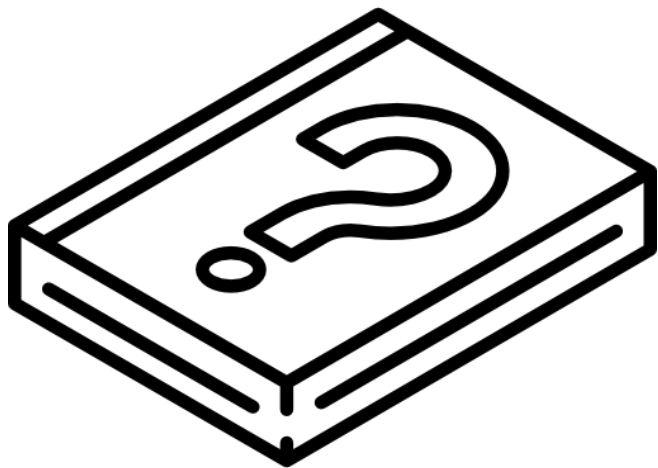


Elwyn G, Kreuwel I, Durand MA, Sivell S, Joseph-Williams N, Evans R, Edwards A. How to develop web-based decision support interventions for patients: a process map. Patient education and counseling. 2011 Feb 1;82(2):260-5.

Aim 2: Health Communication Guide



Aim 2: Health Communication Guide



Construction of Communication Guide

Results:

- 27 Participants
 - 5 countries
 - Ages 18-91 ($M = 55$, $SD = 18$)
- 8 Major Themes/Difficult Situations

Guide Format:

- Problem – Solution Format
- Multiple recommendations based on disclosure and difficulty
- Links to real testimonies from real experiences



Leaks



Public
Restroom



Travel



Disclosing



Patient-
Clinician



General
Advice



Being
Prepared

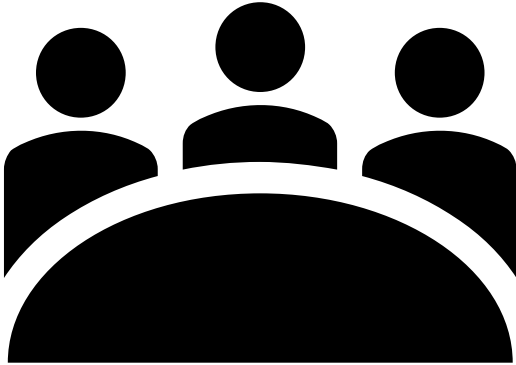


Friends and
Family

Organizing Results

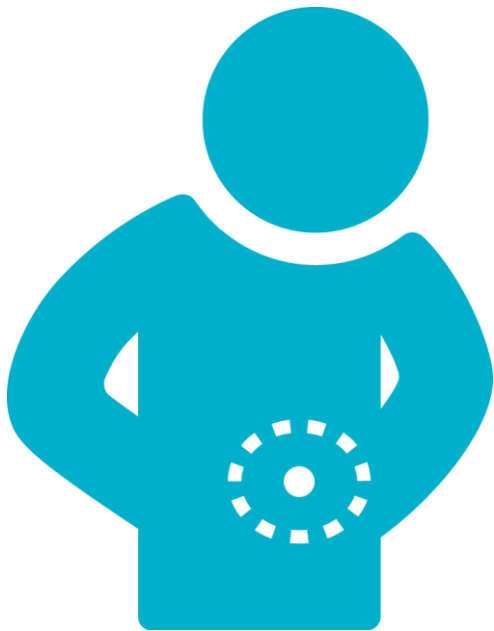
Code/Situation:	Example:	Script:
Leaks	At a restaurant with a friend – Low Disclosure	"Would you mind asking the waiter for our check? I need to go to the restroom, and we may need to leave."
Public Restrooms	Asking to jump ahead in line – Medium Disclosure	"I'm sorry to bother you, but would it be possible for me to jump to the front of the line? I'm dealing with a sudden health problem."
Patient-Clinician	Clarifying information – High Disclosure	"I have an ostomy and received a proctocolectomy, so this procedure does not apply to me. Would it be helpful if I told you more about my ostomy?"

Next Steps:



- Focus groups
- Returning and new participants
- Revision, design, distribution

Limitations / Remaining Questions



- Influence of participants who are comfortable and confident speaking about their ostomy
- Lack of discussion surrounding intimate relationships
- Predominately White/Female sample

Conclusion

Managing difficult social situations can be an unexpected burden for people with ostomies. Resources such as communication guides can be helpful to manage these difficulties.

For further information, contact: SpeakingStoma@gmail.com

