

Engaging Knowledge Users in Basic Science

Tips, Tricks and Lessons Learned

Jens Vent-Schmidt, PhD

Get to know your audience – who is listening?

What is your level of KT experience?

- A. I have heard the term
- B. I have considered engaging in KT
- C. I have engaged in some KT
- D. I have extensively engaged in KT
- E. I am a KT expert

What is your research area?

- A. basic lab science related to human health
- B. translational/applied lab science related to human health
- C. mixed-method/qualitative research related to human health
- D. basic science not related to human health
- E. Other

How do you typically disseminate knowledge (=research findings)?

Audience/Partner

disciplinary community

Objectives/Goals

raising awareness

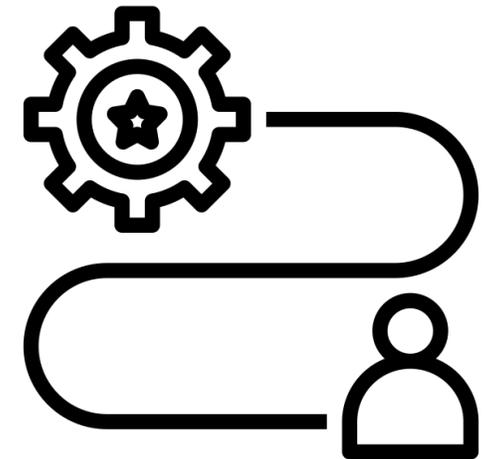
Strategy

conference presentations and peer reviewed publications

Let's move beyond these strategies

After this webinar, you will be able to:

- Identify knowledge users for your research findings
- Plan strategies for sharing research findings with knowledge users
- Consider ways to integrate knowledge users' insights and knowledge into your research program



Why should we pursue KT in basic science?

- Non-researchers are interested in current research findings, especially since 2020
- Patients are interested in research trends and new discoveries related to their condition
- Patients have vested interest in shaping research priorities
- Researchers in other fields might build on your discoveries
- Research is publicly funded and the findings should be communicated



Do we need to include KT strategies for all our findings?

Think bigger than individual papers.

- Did you find anything particularly surprising, exciting, ground-breaking?
- What is the overarching goal of your research program?
- How do individual findings support that goal?
- What drives you to perform your research?
- What excites your non-science friends/family when you talk to them?



Created by Aenne Brielmann
from Noun Project

A brief discourse on knowledge – what is knowledge?

1. Propositional knowledge – knowing that
 - information, explicit
 - communicable by reading and writing
2. Procedural/practical knowledge – knowing how
 - competence, partly implicit
 - acquired by training and practice
3. Experiential knowledge – knowing by acquaintance
 - implicit
 - acquired by personal or bodily experience



<https://goo.gl/BSRbqN>

Why should you care about this?

Knowledge users hold valid knowledge that could inform your research

Who holds and generates knowledge?

knowledge genesis

Scientists

propositional knowledge

- through external sources
- generated through experimentation and observation

practical knowledge

- through practical training

experiential knowledge

- years of professional experience

“The public”

experiential knowledge

- through living with an illness
- through awareness of one’s body and environment

practical knowledge

- e.g. coping strategies

experiential propositional knowledge

- through reflection on own experience
- conversations with other’s who experience something similar
- reading external sources



Guiding questions and principles for your KT strategy?

Audience/Partner

- Who is interested in your findings? What do you know about your “public/s”?
 - scientific community beyond own discipline
 - policy makers, funding agencies, journalists, patients, etc.

Key message

- What is your key message?

Objectives/Goals

- What goals do you have for translating your knowledge?
 - raising awareness
 - initiating action (e.g. policy, coping mechanisms, research projects in other disciplines)

KT strategy

- What knowledge translation strategies could you employ? Are they appropriate for your public?
 - workshops
 - plain English news outlets, podcasts, infographics, interviews, etc

Appropriateness

Evaluation

- How do you know your knowledge translation strategy was effective?
- What can you learn from your “public”? Can you translate back?
 - identify new research questions aligned with stakeholder needs

Guiding principles with examples from my own research – KT 1

Audience/Partner

scientific community

- IBD researchers
- immunologists

Key message

CAR-Treg works with clinically relevant antigen

Objectives/Goals

continue research on CAR-Treg

KT strategy

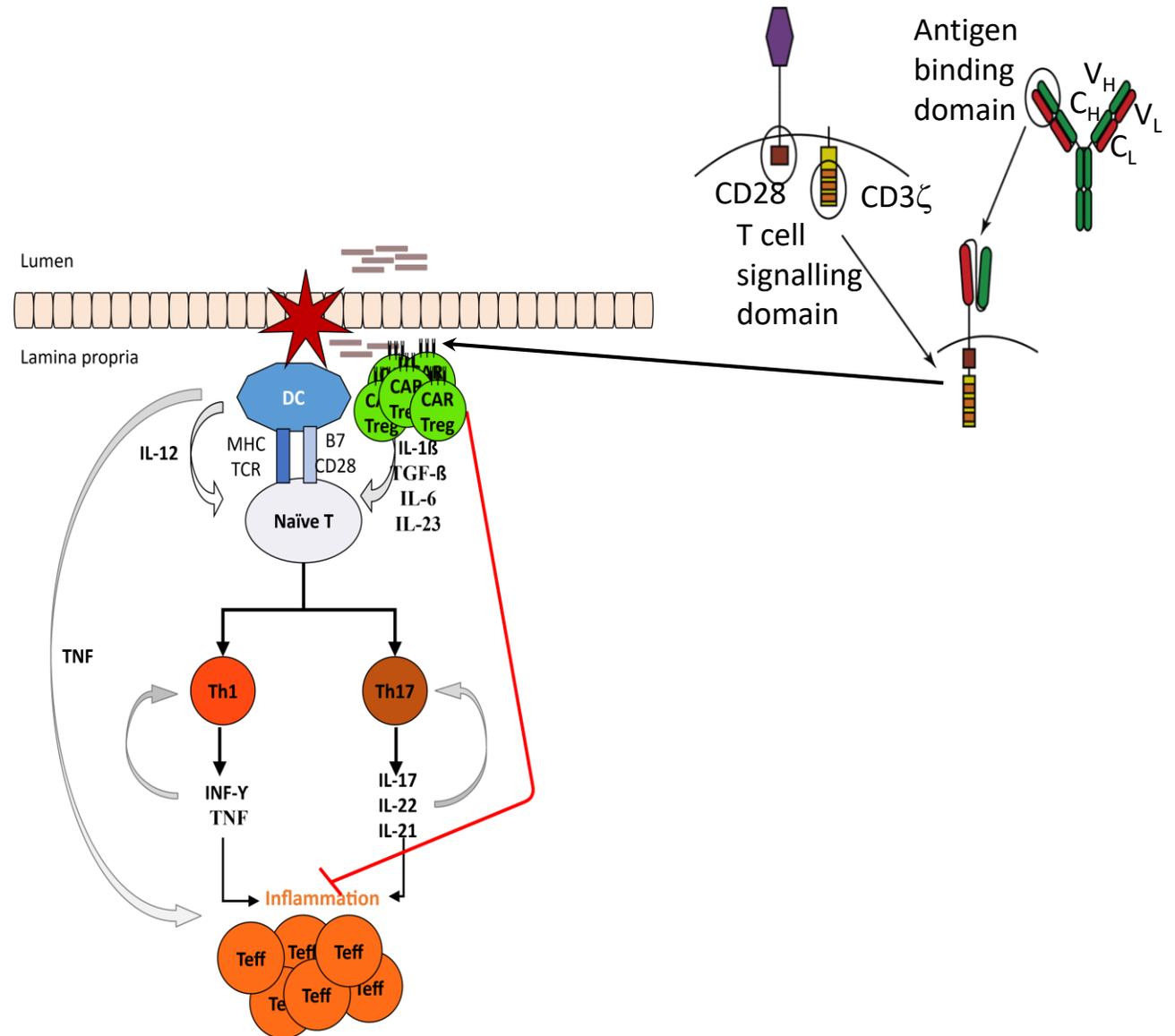
conference presentation

Appropriateness

disciplinary expertise

Evaluation

feedback and conversations



Guiding principles with examples from my own research – KT 2

Audience/Partner

people living with IBD

Key message

new possible therapy could specifically reduce flares without side effects

Objectives/Goals

gauge willingness to try

KT strategy

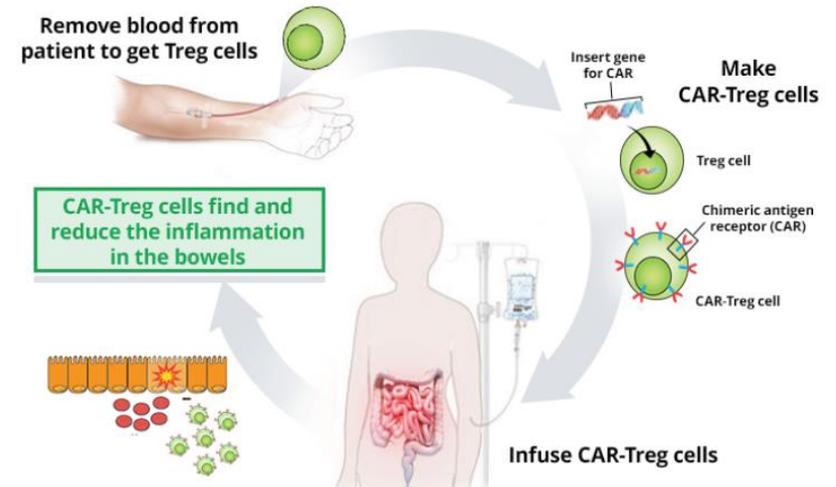
- storytelling using an analogy
- online survey

Appropriateness

iterative focus groups to include patient voice in analogy and survey questions

Evaluation

analysis of survey responses



Guiding principles with examples from my own research – KT 3

Audience/Partner

scientific community

- IBD researchers
- immunologists

Key message

people with IBD are willing to try this therapy in two hypothetical scenarios

Objectives/Goals

- continue CAR Treg research
- address areas of concern through research and/or educational materials

KT strategy

- peer reviewed publication
- conference presentation

Appropriateness

- disciplinary expertise
- peer review

Evaluation

- personal communication
- future research developments

OBSERVATIONS AND RESEARCH

Patients' Willingness and Perspectives Toward Chimeric Antigen Receptor T-Regulatory Cell Therapy for Inflammatory Bowel Diseases

Jens Vent-Schmidt, *Dipl-MolMed*,*[‡] Laurie J. Goldsmith, *PhD*,^{1,†,§} and Theodore S. Steiner, *MD**^{§,¶}

Background: Inflammatory bowel disease is a life-changing disease resulting from recurrent intestinal inflammation. Current therapies (eg, steroids and biologics) are associated with mild to severe side effects, and none provide a cure. Recent research has focused on genetically engineering gut-specific anti-inflammatory T-regulatory cells (CAR-Tregs) to control intestinal inflammation, a logistically and conceptually complex approach. The purpose of our study was to understand patients' willingness to try CAR-Treg given 2 hypothetical scenarios—in a clinical trial or as a new treatment.

Methods: We surveyed people living with inflammatory bowel disease about their willingness to try CAR-Treg. The online survey was developed using patient focus groups and associated literature. We recruited participants through email and social media. We used descriptive and inferential statistics to analyze closed-ended questions and inductive thematic analysis to analyze open-ended follow-up questions.

Results: Survey participants indicated high willingness to try CAR-Treg therapy in both a clinical trial and as a new treatment. Willingness to try was not correlated with disease state or medication history. Women were less likely than men to indicate willingness to participate in a clinical trial. Participants' reasons for being willing to try CAR-Treg therapy included the wish to change their current treatment and the calling to participate in research. Participants that were not willing to try CAR-Treg mentioned the lack of long-term data and the success of their current therapy.

Conclusions: This is the first study to our knowledge to investigate patient willingness to try CAR-Treg therapy. Our results demonstrate the promise of moving this therapy into clinical practice as most patients indicated willingness to try.

Lay Summary

We surveyed people living with inflammatory bowel disease about their willingness to try a new therapeutic approach currently developed in several research laboratories—chimeric antigen receptor-expressing T-regulatory cells—and found high willingness to try, independent of disease state or medication history.

Key Words: IBD, patient preference, regulatory T cell, chimeric antigen receptor, willingness to try

INTRODUCTION

Inflammatory bowel disease is the umbrella term for Crohn disease (CD), ulcerative colitis (UC), and indeterminate colitis (IC; also known as IBD unclassified or IBDU). While disease presentation differs between the conditions and etiology is unclear,^{1,2} disease symptoms are ultimately caused by recurrent flares of intestinal inflammation. IBD symptoms can

include chronic diarrhea, bleeding, weight loss, and abdominal pain. Furthermore, patients with UC are at increased risk for colorectal cancer.^{1,2}

In IBD, the balance between conventional T cells, which target pathogens, and regulatory T cells (Treg), which maintain tolerance to commensal bacteria, food- and self-antigens, is disrupted. This loss of balance results in a proinflammatory

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Guiding principles with examples from my own research – KT 4

Audience/Partner

people living with IBD

Key message

high willingness to try “CAR-Treg”,
a new possible therapy

Objectives/Goals

share survey results with respondents and
offer the opportunity to ask further questions

KT strategy

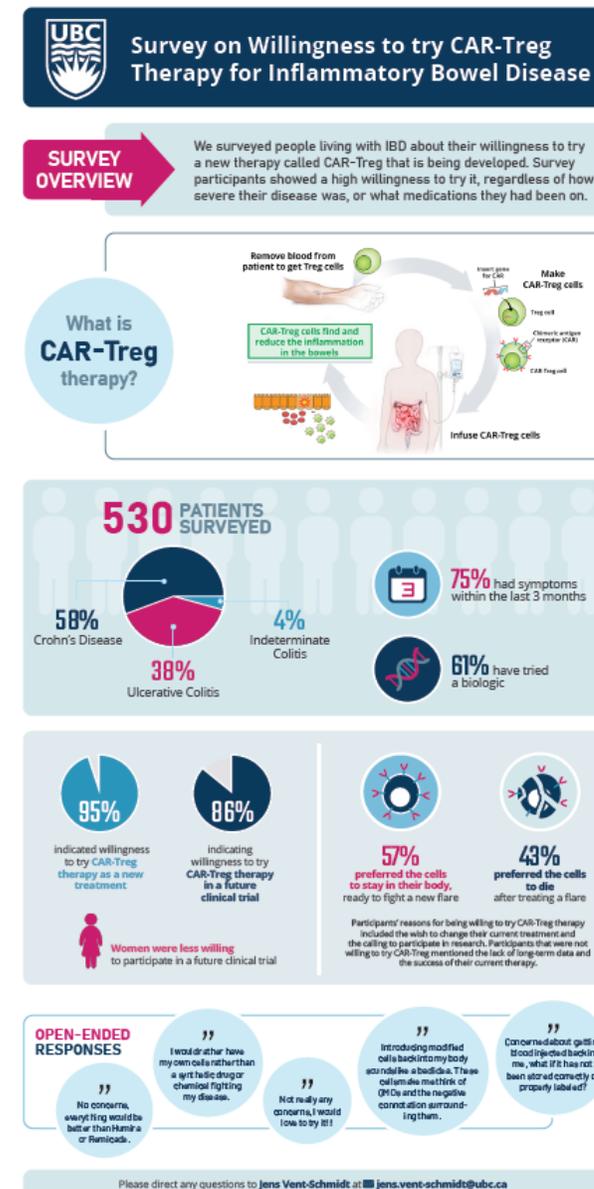
infographic with results of online survey

Appropriateness

collaboration with organization specialised
in communicating with patients

Evaluation

no evaluation strategy



Your turn – jot down answers to these guiding questions and start developing your own KT strategy?

Audience/Partner

- Who is interested in your findings?
- What do you know about your “public/s”?

Key message

- What is your key message?

Objectives/Goals

- What goals do you have for translating you knowledge?

KT strategy

- What knowledge translation strategies could you employ?

Appropriateness

- How do you know your KT strategy is appropriate for your public?

Evaluation

- How do you know your knowledge translation strategy was effective?
- What can you learn from your “public”? Can you translate back?

Lessons learned

- Start small
- Plan your approach well
- Seek help early if you move beyond your disciplinary expertise
- Get feedback from your “public” before rolling out your strategy
- Be open to feedback and learning from your “public”, they hold valid knowledge relevant to your research
- Consider KT as ongoing and throughout your research not as an afterthought or a thing to do in the end

Take-away message

- Keep your audience and goal in mind when designing your KT strategy
- Be open-minded to learning from your audience
- Take risks and accept feedback
- Engaging in KT is worth your while, good things will happen
- You can do it 😊

