What is this thing called Knowledge Translation?

Integrating scientists and end users in a knowledge translation experiment

Susan J. Elliott University of Waterloo, Canada

Jenna Dixon University of Waterloo, Canada

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What is Knowledge Translation?

What we **know**
(information gathered from research)

What we **do**
(actions of end-users)

What is Knowledge Translation?

CIHR:

"a dynamic and iterative process that includes **synthesis**, **dissemination**, **exchange** and ethically sound **application** of knowledge….

…This process takes place within a complex system of **interactions between researchers and knowledge users** which may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user."

What is Knowledge Translation?

2 types of Knowledge Translation

1) End-of-grant KT

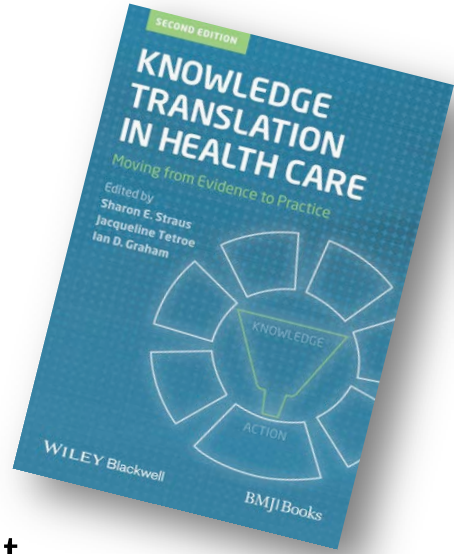
- Focus is on dissemination activities
- After the knowledge has been 'created'

2) Integrated KT (iKT)

- Applies KT principles throughout the research cycle
- Knowledge users as equal partners alongside researchers
- "will lead to research that is more relevant to, and more likely to be useful to, the knowledge users" (CIHR)

What is Knowledge Translation?

Many research gaps in iKT:



1) Used in "some fields for some problems"
   - Seldom applied to basic science research

2) How do we make this work in a practical sense?
   - Little "empirical research on the actual or potential knowledge translation roles, responsibilities, and activities of the different actors" (Tetroe et al. 2008)
   - Other iKT studies: lack of consensus on project goals

Our “grand experiment”

End users and scientists, integrated together on this research project – painting a more comprehensive picture of food allergy in Canada.

GET-FACTS

Genetics, Environment and Therapies: Food Allergy Clinical Tolerance Studies

GET-FACTS

Food allergy: a serious public health problem

- Anaphylaxis is a potentially life-threatening condition affecting people of all ages
- 7.5% of Canadians self-report at least 1 food allergy
  - 50% of households directly or indirectly
- Substantial compromises to quality of life for individuals & families
  - Unpredictable in nature
  - Need for extreme dietary vigilance
  - Rely on rescue therapy with epinephrine

- **There is no cure & causes are complex and poorly understood**

GET-FACTS

4 *equal* pillars of research:

1. Genetic determinants of food allergy and tolerance
2. Environmental impact on functional and immunological tolerance to foods
3. Novel biomarkers to assess allergy and tolerance
4. An end-user driven research agenda through Knowledge Translation

GET-FACTS

GET-FACTS Steering Committee

- Representatives from patient oriented and not-for-profit **organizations**
- Representatives from **policy**
- Representatives from the GET-FACTS **researchers**

Food Allergy Canada

Allergy Asthma information association 50th ANNIVERSARY 1964-2014

Allergies Québec

THESANDBOXPROJECT

Public Health Ontario PARTNERS FOR HEALTH | Santé publique Ontario PARTENAIRES POUR LA SANTÉ

Health Canada Santé Canada

CANADIAN CLIMATE FORUM LE FORUM CANADIEN DU CLIMAT

GET-FACTS

What we have been doing:

- In-person meetings once a year (often more)
- Monthly updates, electronic contact
- Terms of Reference for Steering Committee
  - Series of deliverables: understanding the nature of science

- Quantitative data, after all meetings
- Qualitative data (in-depth interviews) with Steering Committee AND project scientists at T1

GET-FACTS

Deliverables – for example:

- Steering committee members better understanding of and feel more empowered to contribute to the scientific process.
- Steering committee members feel they have shaped the research, can point to concrete changes from their input.
- Researchers agree that the steering committee has shaped the GET-FACTS research process and can identify concrete changes from their involvement.
- Researchers feel more empowered to contribute to the knowledge translation process.

Objective

To explore the baseline views of scientists and end users on iKT before embarking on a 5 year basic science research agenda to address the growing epidemic of food allergies in Canada.

Methods

- **GET-FACTS Scientists**
  N=16 semi-structured 1 hour interviews (100% response rate)
  - Summer 2014
  - multi-discipline, located across Canada
  - Thematically coded and analyzed

- **GET-FACTS Steering Committee members**
  N=9 semi-structured 1 hour interviews (100% response rate)
  - Spring 2015
  - Representing social science, policy & advocacy
  - Thematically coded and analyzed

Methods

- Digitally recorded, transcribed verbatim
- Theme code set developed
  - Deductive and inductive reasoning skills
- Text coded & organized using Nvivo
- Inter- and intra-rater reliability tests
- Review:
  - Relative frequencies of key themes
  - What HAS been said, but also what has NOT been said

Results

When I say the term "*Knowledge Translation*" what does that mean to you?

Scientists

- Centered around communication, interpretation and education *at the end of the grant.*
- Thought about during grant writing
- Sometimes a 'buzz' word or trendy term, lots of ambiguity
- Emphasis on practical medical use E.g. "From the bench to the bedside"

Steering Committee

- Starts at *knowledge creation*, repackaging and dissemination of information
- A key part of the work that they do on a daily basis
- Important to their organizations
- Emphasis on making information understandable and actionable for end users (general public)

Results

What do scientists think of KT?

It's not part of the scientific model...

- "There's always that end goal to translate knowledge into new therapies, but it's not directly what we do."
  (GET-FACTS Research Scientist)

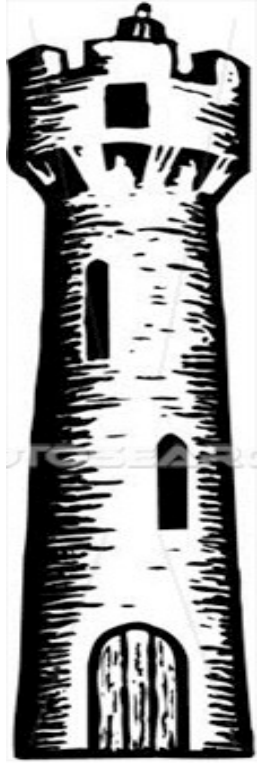
- "In my experience, [scientists are] all fully in favour of [KT] and want their knowledge to get out there, but they are pretty entrenched and focused in their research world and can't do it all."
  (GET-FACTS Steering Committee Member)

Results

What do scientists think of KT?

Openness for a new model…

- "We need to get out of our ivory towers and understand that our findings have no meaning unless the lay public knows about them and they are translated into practical strategies."
  (GET-FACTS Research Scientist)



Results

Very little training on *how* to do KT…

- "We've never received any formal training in that area. Certainly, when I trained that was a term that never really existed… so we tend to believe it's merely getting that information out there in the normal scientific channels, but clearly it's much more than that"

(GET-FACTS Research Scientist)

Results

The GET-FACTS iKT model: End-Users

Research that matters

- "I think it's a win-win for everyone. I think that scientists will be able to do a little less wheel spinning and maybe target more on areas that are of major concern"

  (GET-FACTS Steering Committee Member)

Results

The GET-FACTS iKT model: End-Users

Change the way we do research

- "I think if the model plays out, it could be really powerful… if we can really find a way to positively influence the way work is done, the way that things are published … just by getting scientists to think about the end-users all the way through. I think we can really improve their ability to be full serve. Their ability to conceive of and do the research and analyze the findings…"

  (GET-FACTS Steering Committee Member)

Results

The GET-FACTS iKT model – Scientists

Changing the scientific process

- “in a sense it is asking for the end-users to become scientists, and to become more involved in the scientific process. It could, in many ways, potentially improve that scientific process.

(GET-FACTS Research Scientist)

Results

The GET-FACTS iKT model – Scientists

Paradigm altering

- "So even though Joe Schmo doesn't know anything about [the science], but says, '*well it doesn't make sense that X, Y, Z*' and I say, '*well you know the data is this, this and this*' and he says, '*well yea but you know this, this and this*' and he comes up with an idea that my little brain has not considered...
  ...You take that little piece and you put it into the box, and you go, huh, that is an interesting way of looking at it. I had not considered that. That is where these free exchange of ideas could be potentially paradigm altering, because people do get stuck in their paradigms."

  (GET-FACTS Research Scientist)

Results

The GET-FACTS iKT model – Challenges

Scientists

- Time constraints (not given 'credit' for time investment in KT, especially iKT)
- Will end users understand how science really works? (Slow and incremental – no quick cures)

"our advances happen over a 10 year span…"

Steering Committee

- We're not a fully cohesive group yet

"Right now it's all abstract…we're just in a meeting and then everyone goes back to their science and back to their organizations a we don't interact."

Results

What will success look like?

Doing things differently…

- “I think we would recognize it if, at the end of the day, the scientists and the stakeholders can point to things that they now see differently, do differently, because of the participation in the project, that would be great.”

  (GET-FACTS Steering Committee Member)

Discussion

Biomedical scientists have little exposure to iKT

- Scientists: KT only thought of during grant writing, conceptualized as end-of-grant output
- Steering Committee: KT as daily practice, deeper understanding of iKT as comprehensive throughout research process

Discussion

Willingness of Scientists to engage more in iKT

- Challenge of institutional environment (little credit for time spent on iKT activities)
- Little to no exposure to iKT as concept, training
- Need to see a successful iKT project to fully embrace model as viable

Discussion

Red Flag: Both Scientists and Steering Committee members felt disconnected from each other

- Scientists were wary of disclosing early results
- Steering committee members unsure of scientists willingness to invest time and communicate clearly
- Not enough communication between groups
- Saying “it’s still early” → but 2 years in to 5 year project
- Challenges the very mandate of iKT project…

Discussion

We responded: More touch points between groups

Webinars

- A digital solution to keep Steering Committee and Scientists regularly talking and teaching
- 3 times per year with each of the three scientific streams

Embarked on the creation of a Performance Management Framework

- Ensure deliverables are on track
- Participation of both Scientists and Steering Committee
- Will be finalized by the end of September

Discussion

iKT involves a substantial commitment

- Time
- Financial resources (e.g. full time post doc, meetings)

→ diverted resources from classic biomedical research

- Have the commitment within the GET-FACTS team…
- BUT only time will tell if we reach the deliverables identified in our guiding terms of reference

Concluding thoughts

This research

1) Looks at iKT in new forms of research

2) Advances our practical understanding of ‘how iKT works’

Concluding thoughts

The results of this grand experiment have the potential to empower a role for end users in shaping the basic science research agenda in Canada for not only food allergy but for other chronic diseases as well

Thank you

& GET-FACTS participants

Visit our site:
uwaterloo.ca/get-facts-knowledge-translation/

Contact us:
jenna.dixon@uwaterloo.ca