# 2018 KT Conference Questions and Answers

## Introduction

We were very pleased about the lively participation of attendees at the 2018 Online KT Conference. Attendees of the live event may recall that not all their questions received responses. KTDRR staff reviewed the “chat pod” and followed up with presenters about these questions posed by conference attendees. Below is a list of the questions and responses from conference presenters.

**Engaging With Health System Leaders: Strategies for Effective Research Partnerships – Sarah Bowen**

**Question:** Type and definition of research is so important. There remains huge barriers to clinical research re: program improvement, survey, medical record data and tying interventions to health care outcomes very challenging. Many with no infrastructure to obtain IRB approval so gap in valuable evidence that does not make it to publication. Ideas for bridging that gap? New standards needed to protect data and subjects rights but enable ease for often exempt projects?

**Response:** This is an extremely important question that touches on a number of important issues. One of the challenges that many face in conducting health services research is lack of clarity in definitions of Quality Improvement, evaluation, and research activities. Generally only “research” requires IRB review, but this does not mean that QI and Evaluation activities do not also have important ethical implications. Some health leaders report that they sometimes begin a quality improvement activity only to find that it has larger research implications and are ‘left scrambling’ to see if they can obtain approval midstream. Others find that ethical requirements are not necessary a good fit for services improvement research and pose unacceptable delays and requirements within the rapidly evolving healthcare environment.

Some initiatives are attempting to move away from the often arbitrary distinctions between QI, evaluation and research, by looking at what ethical requirements may be recommended for any “knowledge generating activity”. One example you may want to check is the ARRECI Ethics Screening tool: <https://albertainnovates.ca/our-health-innovation-focus/a-project-ethics-community-consensus-initiative/arecci-ethics-guideline-and-screening-tools/>

**Question:** How important is it to include nonacademic partners as co-authors of reports and articles? *Follow up question from participant:* I think it really depends. I would frame is slightly differently - how can researchers assist nonacademic stakeholders in publishing in ways that are useful for them? Publishing reports and academic journals tend to advance researcher interests, mainly...

**Response:** It is very important.

You raise some interesting issues here. First, you are correct that the focus on publishing is often driven by academic researchers, and is of less importance to health system partners (it is also true that publication in peer-reviewed journals is a time-consuming activity that many working in the system cannot find time to undertake). However, I think it is important to consider what we mean by “publication”. Determining the best way to share findings with the organizations involved, in my mind, should take precedence over thinking about journal publication. I have often found that the best way to do this is to prepare an internal report - geared to organizational decision-makers - as a first step. This report should be authored by those leading the research, but be responsive to what is of importance to the organization and how best to present it. This ‘report’ can also serve to further engage internal partners in interpreting findings and exploring implications. Development of an article for submission to peer-review journals can follow this report. It will often have a very different focus and format, but should be consistent with the internal report.

 This approach means that all ‘publications’ are produced by the team together, rather than having the non-academics publish alone. A tricky issue may sometimes be: how are authorship issues dealt with? This is something that should be discussed at the early stages of the project - not delayed until there is push to get findings in print. Academic guidelines require that the person(s) who make the largest contribution are listed first in any article. This does not always have to mean that the principal investigator always gets top billing. There may be ways to “slice” the findings that facilitate a few separate publications. If, for example, one publication focuses on issues related to implementation of findings, or a commentary on relevance to practice, it may be appropriate to have an organizational decision-maker be lead author on such a publication.

Often stakeholders may not be that concerned about whether they are lead author. But the contribution of the nonacademic partners should be recognized. While at times this may be done in the acknowledgements section, it is often more meaningful (and respectful) to list all team members (academic and non-academic) as authors. Where the list becomes too long, it may also be appropriate to the list as an author the name of the group to which the non-academic partners belong (e.g. one article I published listed the WRHA Language Barriers Committee as an author).

**Question:** Are there resources to learn how to regain that respect in the event of negative experiences with partners or consumers in research?

**Response:** I am not aware of any resources that deal specifically with the issue of breakdown of research partnerships, and would suggest looking for general resources on this topic. What is always important to keep front of mind, is that partnerships are about **relationships**, not simply a means to completing a task. A couple of quick suggestions: raise the problematic issues directly and in a non-judgemental fashion; explore the potential of having an individual trusted by both sides facilitate a frank discussion; be prepared to apologize for any missteps you may have made, and work together to come up with a plan for going forward.

 But, one thing to always keep in mind is that prevention is always better than cure, and there are resources to guide establishment of partnerships. Be clear about expectations; negotiate understandings - and document them - before beginning; keep lines of communication open; and deal directly with concerns as soon as they arise.

**Question:** What could be considered examples of internal reward systems and how do you get an academic institution to change or introduce new rewards systems?

**Response:** Historically academic reward systems (promotion and tenure) reflect accomplishments in two main areas, success in obtaining research grants (with an emphasis on those for which the researcher has been the principal investigator, and from major funders) and publications in peer-reviewed journals - particularly those that have a high ‘impact factor’. These contributions are generally more heavily weighted than “teaching” or “service”, and usefulness to stakeholders may or may not be valued at all.

While some departments, and some universities, are attempting to implement changes that reward ‘engagement’ with communities (including health/social systems and organizations) and alternate strategies for disseminating research, this is a slow process. Some of the work done in this area can be found under the heading “team science”; others under the heading of “engaged scholarship”. There are initiatives underway in many countries - in Canada for example, a recent report of the Canadian Academy of Health Sciences published a report “Academic Recognition of Team Science” that includes recommendations.

**Question:** Would you comment on whether there are particular partnership criteria that you subscribe to/recommend as a starting point in trying to be more proactive.

**Response:** I am not sure if this will address the intent of the question, but the following article does include some guidance for researchers, funders, and organizations. Beyond Two Cultures: Guidance for Establishing Effective Researcher/Health System Partnerships - Open Access at: <http://www.ijhpm.com/article_3221_a8429c6cc30e1aef2a43c438ce1dcb33.pdf>

**Question:** Sarah, you mentioned token engagement, how can funders and reviewers better discern authentic engagement of stakeholders vs. token engagement? I know PCORI in USA has criteria about engagement. Other ideas?

**Response:** The word ‘token’ has two potential meanings here. The first is selection of few specific individuals to suggest broader involvement (for example, does a research team bring on just one ‘patient’ to justify patient engagement). The second interpretation is the extent to which stakeholders have meaningful - decision making - input. In the health services realm, token engagement might includes things like one or two meetings to have stakeholders ‘rubber stamp’ previously-made decisions.

I will add a few suggestions focused specifically on engagement of health organizations (patient engagement is a specialized area of engagement for which there are more resources). First, what is the evidence of a prior relationship and organizational input? A ‘letter of support’ for an initiative does not necessarily speak to engagement. As a reviewer, here are some of the questions I might be asking: What activities have researchers and the organization been involved in to develop the proposal? What evidence is there that the topic is a priority for the organization? Is it an organizational priority or a researcher interest? Is the organizational participant at the appropriate level?(e.g. if system wide, should be a senior decision-maker). Has senior management demonstrated support from what a manager or clinician is committing to? What structure and processes are in place to support joint planning and decision-making (or has this even been considered)? Have dates and events for joint review and interpretation been built into the timeline? Does the budget reflect the costs that stakeholders will shoulder to be involved (e.g. data extraction; release time)? Does the budget include costs of joint planning and interpretation sessions?

One key strategy that many funders are using is to establish review committees that include both research, and health system expertise. Having decision-makers around the table helps assess not only whether the research is important and ‘doable’ , but also whether the proposed partnership is appropriate and appears authentic.

**Question:** Do you only have one patient, or multiple? And if only one, is there a risk that you get someone acting as a "token" for the group instead of just a perspective from one person?

**Response:** There is a very rich, developing literature on patient engagement, which is a specific form of stakeholder involvement. The question of ‘who’ to engage is quite complex in patient partnerships. There is a risk of ‘tokenism’ - how can one person “represent” the diversity of patient experiences? (The answer is that they cannot). How to best address this challenge often depends on what the activity is. I have found that it is important to look at this question from two perspectives (1. Who is around the table making decisions about the research? and 2. How does the research activity itself ensure participation?)

As far as research team make-up is concerned, It is useful to know whether patient ‘representatives’ have been hand-selected, or whether existing patient groups have selected them. I have found that sometimes organizations are happy to select a “patient rep” but want to choose someone they feel is easy to deal with and is accountable to them.

If there is an existing patient organization, or expert patient group, the members of that group can select someone who they feel will speak for the diversity of experiences, and not simply represent their own point of view. Requiring broader consultations in which representatives participate in and from which they bring back perspectives to the research team is another strategy. Having a “Position Description” (for any representative position) that lists both the responsibilities and required qualifications (e.g. ability to reflect the breadth of patient perspectives) can help.

In addition to having a patient voice on a research team, it is also the responsibility of the entire team to ensure that the research design helps ensure that patient experience is truly heard - this recognizes that one or two representatives cannot do the job. This affects the selection of methods (e.g. including initial consultations, more qualitative methods; methods that are accessible to most patients); and sample selection (to ensure that the breadth of patient perspectives and experiences are included).

**Lost in Translation: How to Manage Multiple Stakeholders and Communicate Research Effectively in an Era of Competing Facts – Mark Bayer**

**Question**: Do you have people from different stakeholder segments review what you write for clarity and acceptability?

**Response:** Yes, if I have trusted contacts/colleagues within the stakeholder segment and such review is possible under prevailing time constraints.

For example, if I were presenting to a group of cancer patients, I would make an effort to discuss my material with a patient or family member touched by cancer. Such review can help avoid non-obvious landmines (using outdated terminology, omitting practical information) and also help create buy-in for your talk/presentation among stakeholder segments before you even deliver you remarks - when members of a segment have a hand in helping to shape your comments, there more likely to be supportive.

**Question: :** I think it's tricky to define what counts as contribution warranting compensation. Is anyone aware of any contribution/funding models for clients/patents?

**Response:** I don’t have any experience in this area. However, it seems reasonable to me that travel costs associated with advocacy efforts should be reimbursed.

**Question:** Is some of "tokenism" also a result of the academic environment? An environment that doesn't appreciate taking time to build meaningful stakeholder relationships because it may delay publish, etc. Is some of this a needed change in the system/environment?

**Response:** While I don’t operate within an academic environment per se, I strongly suggest building stakeholder relationships early in your process. There are so many benefits associated with it - new resources and information, contacts that can assist your process, increased credibility (what I call “gilt by association”), and others. Moreover, relationship-building can sometimes make your process more time-efficient, as you access and uncover resources you otherwise may not have encountered as quickly, if at all. Because relationship-building is an investment that doesn’t always produce short-term returns, you may be tempted to downgrade its importance among other priorities of more immediacy (publishing deadlines, etc.). Resist this temptation!

**Disability Rights in Science: Community-Engaged Research With People With Disabilities – Katherine E. McDonald**

**Question:** How do you go about changing research parameters or questions to be more relevant or updated, when people in power want to keep the same questions "so it is comparable over time with what has been done"? So we don't have to keep making new research projects to get new data?

**Response:** These are difficult decisions to make. As you note, there are advantages to “keeping the questions the same” AND advantages to making changes. Changes might be motivated by, for example, the desire to show greater respect (a great example of this are questions about sex and gender – see for example <https://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf?fbclid=IwAR39cw1KRwYwigknJtOSyF42tkKDrR0mieVKI8jB0iHAshtRPAgyN4PXElk> and [https://medium.com/@dr\_eprice/bad-gender-measures-how-to-avoid-them-23b8f3a503a6](https://medium.com/%40dr_eprice/bad-gender-measures-how-to-avoid-them-23b8f3a503a6)), new evidence, new theories or conceptual theories, or changing research needs. Thoughtful and respectful conversations about what is motivating the desire for change, sharing and discussing evidence about what is gained and what is lost by the change, and ultimately an analysis about what is gained and what is lost have helped my research teams make these difficult decisions, including identifying ways to reach comprises that weren’t initially considered. A great example of the theory and empirical evidence considerations that informed decisions about how to identify people with “disabilities” in national surveys is available and can be a useful case study to help a team appreciate a decision to make changes that did indeed cause concern but was ultimately decided to be an important and needed change.

**Question:** How do you address work culture in an environment where people are afraid of any kind of perceived conflict? e.g. What didn't go so well, how can things be improved, etc.

**Response:** Working on relationships – professional and personal – has helped my teams develop more trust and willingness to speak up over time. I have seen great success in getting to this outcome when a team shows willingness to change based on feedback – seeing or experiencing that has been transformative for members who were initially reluctant to speak up. Finding ways to receive that feedback anonymously can be important to, maybe using technology or a neutral or external party. Another strategy is for leaders to point out something they thing might not be working well, and to encourage a conversation about whether that is a shared perspective, and if so what do about it. Also offering why don’t we try X and see how it goes can be an easy way to decide to make change.

**Supporting Implementation Through Engaged Evaluation – Anne Bergen**

**Question:** Can you share some art-based tools?

**Response:** There are many arts-based evaluation tools and toolkits out there. The list below is a helpful starting place, and remember to look for local examples.

* Charlton, M. (2007). Art-based evaluation 101. Prepared for ArtReach Toronto <https://artreach.org/toolkits/artbasedevaluation/>
* Coholic, D. (2016) Using arts-based activities to collect program evaluation data. YouthREX Research and Evaluation Exchange. <https://www.exchange.youthrex.com/blog/using-arts-based-activities-collect-program-evaluation-data>
* Daykin, N. (2015) Creative and arts-based evaluation methods. Creative and Credible. <http://creativeandcredible.co.uk/wp-content/uploads/2015/07/CreativeCredible_Creative-and-arts-based-evaluation-methods.pdf>
* Simons, H., & McCormack, B. (2007). Integrating arts-based inquiry in evaluation methodology: Opportunities and challenges. Qualitative Inquiry, 13(2), 292-311. <https://journals.sagepub.com/doi/10.1177/1077800406295622>
* Yung, H. (2016). There’s an art to it: exploring creative evaluation. Ontario Nonprofit Network. <https://theonn.ca/theres-an-art-to-it-exploring-creative-evaluation/>

**Co-creating With Stakeholders: A Case of Engaging Through Concept and Design for Program Development – Tracy Boehm Barrett and Tannis Hargrove**

**Question:** Are you willing to share the proposal that you used for the grant.

**Response:** Thank you for your interest in our work on the Healthy Community Living Project. We are happy to share our knowledge and experience and would like to connect to learn more about the specifics interests you have. You can contact Principle Investigator, Dr. Craig Ravesloot, at 406-243-2992 or craig.ravesloot@mso.umt.edu

**How Do You Know Stakeholders Have an Impact on Research? – Thomas Concannon**

**Question:** In our IKT strategies, SH analysis is the very first step of the IKT strategy which is then followed by understanding the purpose for engaging with each SH, the message, the medium, the channel, the messenger, resources needed as well as monitoring of success of the IKT strategy.... would love to hear if it’s done differently?

**Response:** This sounds very much like the approach I have advocated for in recent publications. A recent JGIM review (see <https://rdcu.be/bdQO9> ) on this topic with my partners in the MuSE consortium set forth the following questions researchers can ask themselves as they prepare for engaging with stakeholders:

What is the rationale for engaging stakeholders?

* What are the intrinsic reasons for working with stakeholders?
* How do you expect working with stakeholders can improve your research?
* How to you expect working with stakeholders will improve relevant health care or outcomes?

Which stakeholder communities will be engaged?

* What model will you use to identify relevant stakeholders (Online Appendix B)?
* Which of the stakeholder communities in your framework make decisions the research is meant to inform?
* Which stakeholder communities are affected by decisions the research is meant to inform?
* What are the preferences of stakeholder communities for how they wish to be engaged?

How extensively will the stakeholders be engaged?

* How will stakeholders be involved in preparing for research?
* How will stakeholders be involved in conducting the research?
* How will stakeholders be involved in using the research?
* How intensively can stakeholders be involved in each activity?
* What resources and time that can be devoted to engagement activities?

What are the appropriate roles and modes by which stakeholders may be engaged?

* Will stakeholders have control over the course of the project?
* Will stakeholders help the research team carry out the research?
* Will stakeholder provide input but neither direct nor help with the research directly?
* Will activities be conducted in person or remotely?
* Will activities be conducted with individuals?
* Will activities be conducted with groups?
* Will stakeholder communities be mixed in multi-stakeholder activities?
* What conflict of interest procedures and conflict management resources are needed?

**Question:** Have these models been published?

**Response:** Yes. <https://www.ncbi.nlm.nih.gov/pubmed/22528615> this link will take you to the publication that introduced the 7Ps model for identifying stakeholders. This link takes you to a systematic review of stakeholder involvement in patient centered outcomes research. <https://www.ncbi.nlm.nih.gov/pubmed/24893581> A third publication, supported by MuSE and titled "Practical Guidance for Involving Stakeholders in Research," which is in publication at the Journal of General Internal Medicine and will be released several weeks from now.

**Supporting Sustainable Change in Large, Complex Organizations – Mark Harniss**

**Question:** Have you kept the same members of the task force, and has upper level leadership in DOC stayed consistent? In other words, how often and in what way do you need to back up for new people before going forward?

**Response:** The Task Force has been consistent so far, but it is new. We have had some transition and I foresee membership maintenance will be a challenge. We are attempting to make the Task Force very targeted in terms of its tasks, so people feel like they are attainable. In general, at DOC, leadership transition is a common event and we have had to back up several times. Luckily, our two ADA Coordinators have been our best advocates and the transition from one to the other was pretty seamless.

**Have You Selected, Connected, and Nurtured Your Stakeholders Effectively? – Tamika Heiden**

**Question:** Our project is interested in exploring options for virtual focus groups. What platforms have you guys found to work best?

**Response:**

* Online meeting - using Zoom.us meetings as the platform is stable and allows for recording and later access of the content.
* Meeting scheduling and planning - use tools like Doodle and calendar booking sites like youcanbook.me to assist in the process
* Online forum style - could use a private group on slack, LinkedIn, Facebook etc. - most importantly choose something that you audience is familiar and comfortable with or provide in depth training and support.
* Document sharing - Always easier to use something like Google docs or drop box so that all participants can access and make changes to the documents without multiple versions on one person’s computer

**Question:** How it could be possible to make relationship with stakeholder organizations independent of people?

* When building relationships, it will always be with people however, you want to ensure that you have a relationship and regular connection to at least two people within an organisation.
* Choose people at different levels across and organisation
* Attend meetings or have your involvement or the work you are doing together minuted at one of their meetings.
* Formalise partnerships with Memorandums of Understanding