

Definitions

- Advice: recommendation regarding a decision or course of conduct
- Advocacy: the act or process of supporting a cause or proposal.

Text related to informed consent

- The purpose of this research project is to learn more about participants views on what constitutes advocacy and what constitutes objective advice on the part of researchers working with policy makers.
- This is a research study being conducted by P. Alison Paprica and Walter Wodchis at the University of Toronto and Kimberlyn McGrail at the University of British Columbia.
- You are invited to participate in this research study because you have chosen to attend this session at the 2018 Canadian Health Services and Policy Research (CAHSPR) Conference.
- Your participation in this research study is voluntary.
- You may choose not to participate. Nobody will know whether you elect to participate or remain in the room as a non-participating observer. You will not be paid for participating in this study.
- The procedure involves responding to online polls at multiple points during the session. There are no right or wrong answers to the polls. The study will take approximately 30-40 minutes. Your responses will be confidential, and we will not collect identifying information, such as your name or email address.
- The online polling questions will be about your perspective on whether the behaviour of a fictional researcher in a fictional scenario constitutes mostly advocacy or mostly objective advice.
- There are no known harms or risks for this study. The expectation is that most participants will find the study interesting and thought-provoking. However, if you feel uncomfortable in any way during the session, you may stop responding to the online polls or leave the session.
- If you decide not to participate in this study, or if you withdraw from participating at any time, you will not be penalized.
- We will not be collecting any identifying information. All data that we do collect will be stored in a password protected electronic format on encrypted computers. To help protect your

Part 1

- A researcher is conducting a pilot study funded by the provincial ministry of health (MOH) of an intervention to improve coordination of care for rural residents with multiple chronic conditions.
- At the request of a Manager within the MOH, with whom she has a personal relationship, the researcher presents preliminary results to a group including an Assistant Deputy Minister (ADM), Directors and Managers within the MOH.
- The researcher presents the findings, emphasizing that the study won't be completed for three months, but the MOH representatives make a point of saying how impressed they are with the findings.
- Online poll: At this point in the fictional scenario (Part 1), how would you characterize the researcher's behaviour/activities?
- Online poll: Why did you make that selection for Part 1 of the fictional scenario?

Part 2

- The ADM asks the researcher to prepare a modified version of their intervention focused on rural residents with diabetes alongside a budget with the cost to study the new diabetes intervention.
- The researcher's first response is to present evidence that a multiple chronic condition approach is more appropriate for the population that the MOH wants to serve, but when the MOH representatives respond that their focus, at this time, is exclusively on diabetes, the researcher agrees to revise the intervention to focus on diabetes and then submits a proposal for a study of the revised (diabetes-focused intervention) to the MOH.
- Online poll: At this point in the fictional scenario (Part 2), how would you characterize the researcher's behaviour/activities?
- Online poll: Why did you make that selection for Part 2 of the fictional scenario?

Part 3

- The researcher is informed by the ADM that the ministry is planning to fund a five-community study related to diabetes and has narrowed it down to two diabetes interventions, the one developed by the researcher and one developed and implemented in four US states.
- The researcher is asked to provide information about the strengths and weaknesses of the intervention that the researcher has proposed relative to the other option being considered.
- The researcher agrees and submits the information.
- Online poll: At this point in the fictional scenario (Part 3), how would you characterize the researcher's behaviour/activities?
- Online poll: Why did you make that selection for Part 3 of the fictional scenario?

Part 4

- The researcher's diabetes intervention is implemented in a five-community study using a cluster randomized pragmatic trial.
- The results are favourable.
- The ADM informs the researcher that they want to build a case for full scale implementation of the diabetes intervention in rural communities, and that the MOH has funds for the diabetes intervention OR a program aimed at increasing childhood vaccinations in hard-to-reach sub-populations.
- The researcher is asked to join the ADMs in presenting the diabetes intervention to the MOH senior management committee chaired by the Deputy Minister so that the senior management committee can make an informed decision between the two options.
- Online poll: At this point in the fictional scenario (Part 4), how would you characterize the researcher's behaviour/activities?
- Online poll: Why did you make that selection for Part 4 of the fictional scenario?

Part 5

- The MOH decides to implement the researcher's diabetes intervention across rural Ontario.
- At the province's request, the researcher agrees to lead the evaluation of the province-wide implementation.
- Online poll: At this point in the fictional scenario (Part 5), how would you characterize the researcher's behaviour/activities?
- Online poll: Why did you make that selection for Part 5 of the fictional scenario?

Participant#	Entering "A" for "I consent to participate" indicates that: (i) you have read and understood information about the study, (ii) you voluntarily agree to participate and (iii) you are at least 18 years old.	Of the choices below, which is the primary role/perspective that you'll be using when you respond to online polls?	Do you have a second role/perspective which you feel will influence your responses?	At this point in the fictional scenario (Part 1), how would you characterize the researcher's behaviour/activities	Why did you make that selection for Part 1 of the fictional scenario?	At this point in the fictional scenario (Part 2), how would you characterize the researcher's behaviour/activities	Why did you make that selection for Part 2 of the fictional scenario?	At this point in the fictional scenario (Part 3), how would you characterize the researcher's behaviour/activities	Why did you make that selection for Part 3 of the fictional scenario?	At this point in the fictional scenario (Part 4), how would you characterize the researcher's behaviour/activities	Why did you make that selection for Part 4 of the fictional scenario?	At this point in the fictional scenario (Part 5), how would you characterize the researcher's behaviour/activities	Why did you make that selection for Part 5 of the fictional scenario?
1	I consent to participate	Researcher	No	Completely, or almost completely, objective ADVICE	They presented results, with appropriate caveats. Whatever the manager said is not their fault.	Completely, or almost completely, objective ADVICE	Activity 1: researcher offered some evidence-based advice, which was ignored. Activity 2: researcher agreed to evaluate whatever the ministry insisted on	Mostly objective ADVICE	Almost impossible to say without knowing to what extent the researcher provided a balanced and full assessment of the two options. It's certainly possible	More objective ADVICE than advocacy	The researcher has been compelled to advocate for the program, but is doing so on the basis of evidence, and one hopes not going beyond the evidence in a	NO RESPONSE	NO RESPONSE
2	I consent to participate	Researcher	No	Completely, or almost completely, objective ADVICE	Results Preliminary in nature, responding to a request from the ministry	Mostly objective ADVICE	NO RESPONSE	More objective ADVICE than advocacy	Still giving advice as researcher not asked to assess other intervention	More objective ADVICE than advocacy	Researcher not asked to comment or assess other option	More objective ADVICE than advocacy	Still advice despite potential ethical conflict on ability to be objective
3	I consent to participate	Trainee (graduate student or fellow)	No	Completely, or almost completely, objective ADVICE	Researcher states it is preliminary findings. Personal relationship appears to have minimal influence on the reaction of the MOH which consists of multip	Mostly objective ADVICE	Adm is interested in diabetes only. The researcher does not know how their research will be interpreted, but the request on diabetes may cause the resear	Completely, or almost completely, ADVOCACY	F. (note F: corresponds to "Completely, or almost completely, ADVOCACY" so was entered as the response for the previous question) Researcher must directly compare their intervention with the other intervention with the direct knowledge that the use of their work is dependent on w	More ADVOCACY than objective advice	Need to advocate for their work as to why it should be adopted.	More ADVOCACY than objective advice	NO RESPONSE
4	I consent to participate	Trainee (graduate student or fellow)	No	Completely, or almost completely, objective ADVICE	NO RESPONSE	More ADVOCACY than objective advice	Although the research itself may still be conducted objectively, the focus (diabetes) is now dictated by MOH. Positive findings would presumably support	Mostly ADVOCACY	Presumption about the researchers motive - receiving funding would be beneficial for professional advancement, so researcher would be incentivized to adv	Completely, or almost completely, ADVOCACY	At this point, regardless of objectivity of data collected/findings, purpose of presenting the research is to "build a case" for implementing their inter	More ADVOCACY than objective advice	NO RESPONSE
5	I consent to participate	Researcher	Trainee (graduate student or fellow)	Mostly objective ADVICE	Because there is nothing she has done that not objective but I didn't choose the first option since she has a personal relationship. So I went with mostly objective	Mostly objective ADVICE	She is a researcher and working with the criteria needed by the client. It would only be unobjective if she says they should focus on diabetes when the evidence didn't show it. But if she's simply presenting a proposal without overselling it and using the evidence, it could still be objective.	More ADVOCACY than objective advice	It will be hard to be objective when the researcher's reputation is at stake	More objective ADVICE than advocacy	Because she is making a claim that she can back. It is based on objective evidence	More ADVOCACY than objective advice	because in implementing they will want to foster adoption too and that becomes advocacy

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6	I consent to participate	Researcher	Clinician or another individual who makes decisions that affect the care and services for individual patients	Mostly objective ADVICE	Presenting at request of MOh, presenting actual results, emphasis on preliminary nature of results. But could also have refused until final results in to ensure complete objectivity	Mostly objective ADVICE	This is neither, it is really just executing the request to evaluate a MOh intervention. But as such, it is more like advice in that the researcher will provide results	More ADVOCACY than objective advice	Can't be objective since she created her intervention, yet she can still try to remain as objective as possible	More ADVOCACY than objective advice	She is still presumably trying to be objective but is being placed in a very difficult situation. She could have refused to attend, but that might have meant a poor understanding of her research results, and poorer decision making	More objective ADVICE than advocacy	If intervention study properly designed results can be as objective as other studies. Very common for researchers to develop an intervention, pilot it, the evaluate a larger roll out
7	I consent to participate	Researcher	No	Mostly objective ADVICE	NO RESPONSE	More objective ADVICE than advocacy	Need more info	Mostly objective ADVICE	NO RESPONSE	Mostly objective ADVICE	NO RESPONSE	Completely, or almost completely, objective ADVICE	Biased
8	I consent to participate	Researcher	No	Mostly objective ADVICE	The research was presented as preliminary and there was no evidence to suggest it was anything other than advice.	More objective ADVICE than advocacy	The researcher has allowed their research to be shaped by the ADMs focus. Still providing objective advice about the best approach they are subject to their funding model.,This feels like ministry advocacy not researcher advocacy	More ADVOCACY than objective advice	You're taking is down a slippery slope. The researcher shouldnt be asked to self evaluate their own strengths and weaknesses.	More ADVOCACY than objective advice	Im assuming that a parallel researcher will be presenting a case for childhood vaccine program. Sharing the information from relevant experts so policy makers can make informed decisions still feels like advice	Mostly ADVOCACY	Its inappropriate for the researchers to self evaluate this program
9	I consent to participate	None of the above	Policy or decision maker who makes decisions that affect the care and services for individual patients	Mostly objective ADVICE	In practice, relationships are sometimes leveraged in sharing information,Researcher acknowledged the results are preliminary and study is not yet complete	More objective ADVICE than advocacy	The researcher had a position to focus on chronic disease however was open to the focus of the ADM	More ADVOCACY than objective advice	It is important to acknowledge the power dynamic at play. The researcher is being asked to submit by the MOH as opposed to taking their own initiative to submit on his or her own accord. Because the researcher is responding to the request I feel this is more advocacy as compared to completely advocacy	More ADVOCACY than objective advice	The MPH is putting the researcher in a compromising position with their invitations. Acknowledging power dynamics and past relationships it may be challenging for the research to decline. Nonetheless I consider this to be more advocacy	Mostly ADVOCACY	I assume the researcher will acknowledge their bias and decline being the evaluation lead. MOH is being unethical with their request and is placing the research in a position of conflict of interest. It would be advocacy if the researcher accepts

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10	I consent to participate	NO RESPONSE - FLAG SOME PARTICIPANTS HAD TECHNICAL DIFFICULTIES. THIS PERSON MAY HAVE INTENDED TO ENTER PATIENT AS THEIR PRIMARY PERSPECTIVE.	Patient (an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends)	Mostly objective ADVICE	There does not appear to be support from the researcher to use these findings in policy (advocacy), rather is presenting research more as guidance in this scenerio.	More objective ADVICE than advocacy	The researcher is still looking to offer recommendations on a more specified area, and is not yet supporting that this study's outcomes should be put into practice.	More ADVOCACY than objective advice	Depends on if the researcher is going out of their way to highlight more strengths than weaknesses. They believe evidence supports another route and is now standing beside this diabetes only intervention, which contradicts their original, objective stance.	Completely, or almost completely, ADVOCACY	The researcher is defending an intervention where they know evidence supports another intervention type. The alternate option may be fully supported by the research community. The support from the researcher does not provide an 'informed decision'.	Completely, or almost completely, ADVOCACY	This is support, rather than guidance, for a particular policy or in this case, intervention.
11	I consent to participate	Researcher	No	Mostly objective ADVICE	Reasonable to share preliminary results with caveat that they are indeed preliminary. No evidence of particular position/stance to suggest advocacy. Personal relationship seems relevant... but doesn't suggest advocacy position necessarily.	More ADVOCACY than objective advice	Researcher flexed her objective (presumably evidence-informed) advice of what was best for the population to accommodate ministry priorities (which are politically based it seems)	More ADVOCACY than objective advice	Presume researcher has some stake and interest in the intervention they designed - asked to compare to one they may not know as much about — there is potential for advocacy for their own design. I don't think this is necessarily a bad thing. But leans toward advocacy	More ADVOCACY than objective advice	I think to "advocate" for something it requires choice over another thing. I don't think the researcher is taking that position here necessarily, but sharing what they know about their project. That said - given knowledge that it is up against another funding option it leans toward advocacy... but it's difficult to know without knowing what info presented	More ADVOCACY than objective advice	NO RESPONSE
12	I consent to participate	Researcher	Patient (an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends)	Mostly objective ADVICE	The topic was chosen by the MOH, and presumably they had some input regarding the methods. Therefore it is somewhat advocacy right away.	More ADVOCACY than objective advice	The researcher is piloting an intervention the MOH believes will work.	Mostly ADVOCACY	It's a bias d universe of options, and the evaluator is inherently biased.	NO RESPONSE	Technical issues. Was not able to choose in time.	Completely, or almost completely, ADVOCACY	The researcher cannot objectively evaluate the program.

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13	I consent to participate	Policy or decision maker who makes decisions that affect the care and services for individual patients	No	Mostly objective ADVICE	Prelim findings only.	NO RESPONSE	NO RESPONSE	More ADVOCACY than objective advice	Assumption that advocacy and bias are somewhat correlated here. But it would be hard for the researcher to be 100% unbiased if being asked to recommend his or her approach vs another approach.	Mostly ADVOCACY	Researcher is being put into a position to advocate for funding for one sub population/topic (diabetes) vs another (children)	Completely, or almost completely, ADVOCACY	Can the researcher be unbiased if being asked to evaluate a program they helped develop?
14	I consent to participate	NO RESPONSE - FLAG SOME PARTICIPANTS HAD TECHNICAL DIFFICULTIES. THIS PERSON MAY HAVE INTENDED TO ENTER RESEARCHER AS THEIR PRIMARY PERSPECTIVE.	Researcher	More objective ADVICE than advocacy	NO RESPONSE	Completely, or almost completely, objective ADVICE	NO RESPONSE	More ADVOCACY than objective advice	The researcher would try to be objective but would have an interest in the continuation of their own study.	More ADVOCACY than objective advice	It depends on the level of objectivity/subjectivity in the presentation	More ADVOCACY than objective advice	NO RESPONSE
15	I consent to participate	Researcher	No	More objective ADVICE than advocacy	No solid evidence at this point	Completely, or almost completely, objective ADVICE	Person does is not working from their personal position	Completely, or almost completely, ADVOCACY	Researcher has a position (I'm assuming they want their own intervention to succeed)	Completely, or almost completely, ADVOCACY	Researcher has a clear position that they are pushing for	Mostly objective ADVICE	Evaluating yourself is risky but if they can remain objective then I rate this as advice as there is no position
16	I consent to participate	NO RESPONSE - FLAG SOME PARTICIPANTS HAD TECHNICAL DIFFICULTIES. THIS PERSON MAY HAVE INTENDED TO ENTER PATIENT AS THEIR PRIMARY PERSPECTIVE.	Patient (an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends)	More objective ADVICE than advocacy	Assuming the researcher did put sufficient caveats and emphasize the incomplete data. And it is in the spirit of promoting collaboration between knowledge users and researcher	Mostly objective ADVICE	To be responsive to knowledge user needs	More ADVOCACY than objective advice	Because now researcher is working to secure additional funding and cannot be entirely objective in assessing merits between own intervention and other. Depends in part on individual integrity but definitely conflict of interest in response from researcher	More ADVOCACY than objective advice	Researcher is again put in position of advocating for funding against a rival bid. May present actual data but likely to generate arguments that favour own bud	More ADVOCACY than objective advice	Same as before. Researcher is naturally inclined to work in self interest because of funding. Scenario also speaks to need for ministry knowledge users to know how to handle these relations with researchers
17	I consent to participate	Researcher	No	More objective ADVICE than advocacy	The researcher was presenting research findings. Although the fact she or he knows the audience certainly influences how results are presented, it does not suggest that the researcher will primarily be advocating	Mostly objective ADVICE	The researcher did not go very far to convince the MOH staff, but simply re-adjusted to meet their conditions	More ADVOCACY than objective advice	I would think it's quite difficult to remain objective under these circumstances	More ADVOCACY than objective advice	The researcher seems increasingly put in a position where they must advocate over time. The more they invest, the more likely they are to advocate.	NO RESPONSE	The more the researcher invests the more difficult it is to remain objective. This is like a technology vendor evaluating their own technology

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18	I consent to participate	NO RESPONSE - FLAG SOME PARTICIPANTS HAD TECHNICAL DIFFICULTIES. WE CANNOT KNOW THIS PERSON'S PRIMARY PERSPECTIVE.	NO RESPONSE - FLAG SOME PARTICIPANTS HAD TECHNICAL DIFFICULTIES. WE CANNOT KNOW THIS PERSON'S SECOND PERSPECTIVE.	More ADVOCACY than objective advice	Risky to present preliminary results. Difficult to manage the message afterwards.	Mostly objective ADVICE	Relevant evidence to the condition just not the fully appropriate applicability.	NO RESPONSE	Likely to advocate for own research - depends on the researcher!	More objective ADVICE than advocacy	Unless the researcher has information about the potential impact of both interventions, and is completely objective herself, will likely stick with knowl	Completely, or almost completely, ADVOCACY	Should be separation between implementation study and evaluation.
19	I consent to participate	None of the above	Patient (an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends)	More ADVOCACY than objective advice	Researcher is reliant on funding from MoH and wants to demonstrate that the work is progressing,The advocacy is for the results to date	More objective ADVICE than advocacy	The researcher has clearly provided advice to broaden the focus to multi morbidities	Completely, or almost completely, ADVOCACY	The researcher is naturally biased towards their intervention; they are an expert in that particular intervention	Completely, or almost completely, ADVOCACY	The prospect of implementing the researcher's intervention biases the researcher	Completely, or almost completely, ADVOCACY	Again the researcher is biased towards their intervention and increasing its uptake
20	I consent to participate	Patient (an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends)	Trainee (graduate student or fellow)	More ADVOCACY than objective advice	Agreeing to present incomplete results to senior policy makers (who sound super receptive) tips the balance away from objective science.	More objective ADVICE than advocacy	The advice took place (and was disregarded) when researcher suggested multi disease approach. Moving on to respond to MOH request for diabetes only is separate response.	Completely, or almost completely, ADVOCACY	Conflict here- making the case for their own intervention. Should be independently assessed.	Completely, or almost completely, ADVOCACY	Again, presumably advocating for their own intervention.	Completely, or almost completely, ADVOCACY	As per the last two questions, researcher is in conflict and advocating for their own intervention's success.
21	I consent to participate	Trainee (graduate student or fellow)	Patient (an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends)	More ADVOCACY than objective advice	Common sense	Completely, or almost completely, ADVOCACY	Management is doing this all the time	More objective ADVICE than advocacy	Common sense	Completely, or almost completely, ADVOCACY	Common sense	Completely, or almost completely, ADVOCACY	In the movies,From the movies

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22	I consent to participate	Trainee (graduate student or fellow)	Researcher	Completely, or almost completely, ADVOCACY	It's preliminary results from an incomplete study. There is no clear indication of the basis on which one is to be impress.	Mostly objective ADVICE	Not enough info about the background of the researcher.	Completely, or almost completely, objective ADVICE	Not enough information about the reasons for the researchers decision and what is contained in the submission	More objective ADVICE than advocacy	I am a bit confused	More objective ADVICE than advocacy	Advice descriptor does not make sense

‡ In this table, participant responses are presented in order of increasing perception of advocacy, i.e., responses were sorted in order of increasing advocacy for Part 1, participants that had the same response to Part 1 are presented in order of increasing advocacy for their Part 2 response, and so forth