PITFALLS IN HEALTH POLICY REPORTING A WORLD CAFÉ

FINAL REPORT



HELD ON FRIDAY, SEPTEMBER 27th, 2013 FROM 9:30 AM TO 4 PM CONCORDIA UNIVERSITY, LOYOLA CAMPUS HTTP://PEP.CONCORDIA.CA











1 November, **2013**

Report: 'Pitfalls in health policy reporting: A world café'

Dear Reader,

The following pages encompass a report summarizing the event 'Pitfalls in health policy reporting: A world café'. The report attempts to remain true to what was said during the invited presentations and subsequent afternoon sessions so as to reflect the group deliberations that occurred during the event. While composing the report, we tried to use the words of participants as much as possible, partly to make sure we stayed true to their words, meanings and values, but also to allow some reflection of each individual attending the event.

We welcome your feedback on this report. Please send comments via email to:

Dr. David Secko

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Thank you to all those that attended and those helpers that made the event a success. With the imminent expiration of the Canada Health Accord in 2014, the conversations started at this event are important to future discussions of health care in Canada. We look forward to continuing these conversations in the future.

Best Wishes,

Dr. David Secko Associate Professor

Concordia Journalism

www.csjp.ca

Executive summary

On Friday September 27th, 2013, 47 people attended the World Café "Pitfalls in Health Policy Reporting." The event's primary goal was to generate discussion from the viewpoint of journalists, health practitioners, scholars, students and citizens about how to raise the bar on health policy reporting in Canada.

Research has shown the media both shape consumer expectations and interpretations of health interventions and influence how people think about their need for care and the sustainability of the system. Thus, given that the majority of the public obtain information about health care policies from the popular media, understanding and improving knowledge transfer from health care professionals/scientists, government officials, publics and the news media is critical.

The primary goal of the event therefore encompassed a wider set of objectives on the part of the organizers, who saw the World Café as an initial step to (i) discuss strategies for addressing pitfalls in reporting health policy issues; (ii) encourage public discussion of how we consume media coverage of medical issues; and (iii) to increase participant understanding of health policy debates.

The organizers realize that these objectives require multiple and diverse discussions, for which one World Café can only provide a starting point. With this in mind, the event raised five important themes regarding the responsibility of journalists, researchers and the audience for future consideration and discussion:

- 1. Participants identified as current shortcomings of health care reporting that most journalists do not seem to read scientific studies, they read press releases. This affects the quality of reporting because the journalists are handicapped in verifying the results and in consulting with other experts about studies. They also mentioned that reporters tend to use the same sources and this increases the risk of getting wrong or biased information to be accepted as general knowledge.
- 2. Participants said that in order to improve health policy reporting journalists should:
 - ➤ add value to the information they are giving by providing context;
 - be transparent about their biases; do advocacy journalism as opposed to passively giving information;
 - talk to people with real examples, real facts, as opposed to just numbers;
 - think about the audience, what they need, what they care about, and what will impact their life;
 - include 'how to element', "what to do about it;"

¹ Soroka Stuart, Public Perceptions and Media Coverage of Canadian Healthcare, CHSRF Commissioned Research, November, 2011.



- get training on how to read the studies and be able to assess the validity and impact of the results;
- > consult with other experts instead of relying on one source; cite more sources and add links to studies; and
- reduce influence from powerful groups by not affiliating themselves.
- 3. Participants, however, did not lay all the responsibility on journalists, but also mentioned that researchers, health care providers, and the public are responsible. They suggested that scientists should make their information available and package it for the media, and audiences should get their information from various news outlets and should be able to evaluate their credibility.
- 4. Participants mentioned that journalism should be a bridge between experts and the public and that it is necessary to rethink the current model of journalism to re-establish the relationship between journalist and audiences.
- 5. Participants concluded that important issues are usually not debated by the public and suggested bringing together different stakeholders, such as citizens, community members, journalists, bloggers, health practitioners and scholars, to discuss health policy issues. They considered that public engagement is good for sharing ideas but not for taking action, and that a partnership could fund putting ideas into action.

These five themes and the others discussed in this report arose from the presentations of five invited speakers and the input from a world café involving 33 participants that stayed for the afternoon discussion. Their conversations were diverse and are not all captured in this report. But it is hoped that this brief report stimulates another round of "conversations" in the near future.





The organizers would like to thank Concordia University, EvidenceNetwork.ca, Fulbright Canada, the Canadian Institutes of Health Research – Institute of Health Services and Policy Research, and Axe Éthique et Santé des Populations. We also acknowledge the hard work of the staff of the *Concordia Science Journalism Project*.

Report produced on November 1, 2013.

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Report

Event Title: Pitfalls in health policy reporting: A world café **Participants:** 47 people begun the day, 33 joined the world café

Host: David Secko

Speakers: Trudy Lieberman, André Picard, Charlie Fidelman, Daniel Weinstock, Amélie Quesnel-

Vallée

Table Hosts: Trudy Lieberman, Charlie Fidelman, Bryn Williams-Jones, Marie-Josée Potvin, Hawa

Kombian, James Falcone

Note takers: Haluk Dag, Geoffrey Tobin, Olivier Crête, Desirée Hostettler, Nana Yeboah, Deirdre

Keane, James Gibbon

This report summarises the "Pitfalls of Health Policy Reporting; A World Café" that took place on Friday September 27th 2013 at Concordia University. It notes the event's general organization, major discussion points and participant report-backs from the world café sessions. It concludes with some brief points from the organizers for future consideration.

The report is meant capture major discussion topics for future consideration and to stimulate reader feedback and reflection. No sessions during the workshop were tape recorded, so the report was constructed from notes taken during the day. The organizers welcome any additional reader comments.

Agenda

Time	Session
9:30-10:00	Registration and refreshments
10:00-10:15	Welcome & Introduction to the World Café
10:15-11:00	Keynote Address by Trudy Lieberman, Columbia Journalism Review.
	"Health Reporting: Balanced but Broken"
11:00-Noon	Pitfalls in Health Policy Reporting: Reporting, evidence and health
	Panel discussion with:
	Charlie Fidelman, The Montreal Gazette
	André Picard, The Globe and Mail
	Daniel Weinstock, McGill Institute for Health and Social Policy
	Amélie Quesnel-Vallée, McGill University
	Moderator:
	Bryn Williams-Jones, Directeur, Programmes de bioéthique, Département
	de médecine sociale et préventive, École de santé publique de l'Université
	de Montréal
Noon-1:00	Lunch
1:00-2:30	World Café: Building new knowledge
	Café table discussion on the future of health policy reporting and how to
	deal with evidence and the debates raised during the day
2:30-3:00	Report Back and Summary
3:00-3:30	Wrap up and fini



Morning Session

The event was designed to discuss pitfalls in health policy reporting by asking participants to consider where health policy information comes from, what it is founded on, whether it represents the best knowledge and who is responsible for determining and communicating the answers to these issues. Participants were asked to read an event primer prior to attendance (Appendix 3) and the event was framed as follows:

Research has shown the media both shape consumer expectations and interpretations of health interventions and influence how people think about their need for care and the sustainability of the system. But is health policy reporting based on sound evidence? Some critics say not enough evidence on health policy is reaching the public's awareness. If so, and with the imminent expiration of the <u>Canada Health Accord</u> in 2014, it is time to look at pitfalls in health policy reporting with fresh eyes. Join us for a public conversation with leading experts on how to avoid pitfalls in health policy reporting.

The morning session started with event convenor Dr. David Secko welcoming the participants and the speakers to the event and explaining them the agenda for the day. After this brief introduction, the morning session was devoted to the keynote speech and a panel with invited experts. This session was live streamed online:

https://www.youtube.com/watch?v=OnOBKEvdwHo&feature=em-upload_owner.

Trudy Lieberman (*Columbia Journalism Review*) gave the keynote speech "Health Reporting: Balanced but Broken." Lieberman talked about the difficulties encountered by health and science journalists in the United States, including the lack of interest of editors on "new", "different" stories about health and health care systems. As an example, she referred to the press coverage of the Affordable Care Act in the United States (Obamacare). This health care system reform will bring in 24 to 25 million new people under health insurance, about half of the 51 million of people uninsured when the reform was passed. According to recent polls, 50% of Americans oppose Obamacare, and although 81% have heard about Obamacare from the news media, only 8% trusted the coverage. So why, Lieberman asked, are people not trusting theses sources of information? Lieberman related her experience hearing many Americans say "I've heard a lot about Obamacare, yes, but I didn't know what was involved." At the same time, most of those who oppose the health reform are afraid that all the doctors are going to pull out and "that we're going to be like Canada." Lieberman argued that some of the opposition is based on the public's own misconceptions.

Lieberman said that although there has been plenty of media coverage on Obamacare, it has not efficiently explained what the law is about or who it will affect. The press has played "follow the leader" by quoting and reporting what others are reporting. This reflects reporters' lack of initiative and tendency to play it safe and not "connect the dots." Lieberman also pointed out that President Obama briefly mentioned moral reasons to support the law but did not "make the case"



for Obamacare. Instead of changing the current discourse, Lieberman argued, he talked about superficialities; for example that young adults would stay on a parents' plan; preventive care benefits; and talked about affordability. However, according to Lieberman, nobody talked about what "Affordable Quality Healthcare" meant.

Health insurance is expensive. With Obamacare, middle-income people will be the most affected, as they will receive a subsidy for health insurance but, Lieberman noted, it will be far too small compared to cost. Some people may therefore opt to pay a penalty fee used Obamacare instead of paying for insurance itself.

Lieberman called Obamacare a "republican, conservative" plan," and explained it was crafted by the Heritage Foundation, a group with considerable media influence. Lieberman explained that a lot of coverage had 'faux-balance,' where different sources were given the same importance although they do not have the same level of expertise. Coverage was also characterised by "he said/she said" statements, quoting sources in favor and against without providing enough context to ensure that people understand the arguments and law. Lieberman said that reporters have made the argument that Obamacare is a political story and justified the lack of context in their stories with a need to be impartial. Lieberman added that by quoting sources without providing context, journalists are "writing for the sources." She also pointed out that the media have demonized insurance companies instead of analysing the role of health practitioners: "We have to demonize somebody. Everybody loves their doctors."

At the end of her talk, Lieberman posed a series of questions for participants to consider in the afternoon session: What are the journalists' obligations here? Is it okay for this 'faux-balance' to continue, and for journalists to continue going back to same sources? Do we need a new model of journalism? What is it that we expect to the press to tell people about Health Care?

After Lieberman's talk, an invited panel was introduced by the moderator Bryn Williams-Jones. The panel began with Charlie Fidelman (*The Montreal Gazette*), who highlighted the importance of journalists knowing their own biases when reporting on policy, so that they can provide an informed story. She then identified "faux-balance" as the major pitfall for health policy reporting and recommended journalists to be mindful of who is funding their medium and how this can create conflicts of interest.

The second panelist, André Picard (*The Globe and Mail*), said he does not think journalists write about health care in the same way as how people view its importance. Regarding health care in Canada, Picard said that Canadians embrace a myth about health care being a public system when in reality 70% of health costs are out-of-pocket costs. He also mentioned that 10 million Canadians do not have private insurance while the rest do, so the Canadian health care system is a mixed one. Picard said that journalists do not talk enough about the data and numbers regarding health care in Canada, and that it is necessary to report on how much public money is going into the system.



The third panelist, Daniel Weinstock (*McGill Institute for Health and Social Policy*), argued that health policy is sometimes covered by health reporters, and sometimes it becomes big news. However, the ideas that get the most play are those that sell the most papers. He also mentioned that when addressing issues related to health and health policy, journalists tend to focus on the 'sexier' aspects of stories, e.g. whether to change laws. These aspects are the "red flags" or "silver bullets" for reporters, who often focus only on these points. Finally, Weinstock mentioned that health policy generates large amounts of research and vast opportunities for broader coverage; however, journalists tend to focus only on the most attractive aspects of stories instead of digging into more important issues.

The last panelist, Amélie Quesnel-Vallée (*McGill University*), pointed out that journalists have the responsibility to cover health care and health policy stories. She also mentioned some difficulties when covering this topic, such as the vast amount of scientific information or the difficulty to provide context to complex health issues and health policy discussions, but she stressed that it is the journalists responsibility to pull out all the information that the public needs. At the same time, she said it was the responsibility of academics to package this information for the media and be more accessible to reporters.

The panel session was followed by a Q & A session with participants, where questions were asked regarding agenda setting for health policy in the media, research funding, reporting on the medical costs paid by citizens, the impact of social media in health policy reporting, drug advertisement, and research-based medicine. A participant also referred to making researchers' press releases more attractive to journalists and asked the panel if they "have any tips on how to convince your peers (i.e. other researchers) that the human element (in press releases) is important?" Amélie Quesnel-Vallée replied that it would suppose asking researchers to think in a different way, asking them "how would explain that to your mom?" Another participant asked the panel "how do you understand that crossing off ideas, from one "elite" source or another, how do you determine what's best for the audience?" Daniel Weinstock replied that it is not enough to just provide information, but it is also necessary to consider your audiences' needs and how people will respond to the information.

Afternoon Session

In the afternoon, a world café on health policy reporting was held. Based on the work of Juanita Brown (See: www.theworldcafe.com), world cafés are participatory processes that aim to enable diverse conversations while sitting at "café-style" tables. This method is both a fun and practical way to enhance the group's ability to collaboratively work through problems. The world café sessions were meant to be conversational and open, with the intention of sharing knowledge and generating potential solutions.



In total, 33 people were involved in the world café. There were a total of five café tables in which groups of between 5-7 individuals took part in three rounds of conversation. Each round of conversation lasted 30 minutes; after each round participants were asked to join a new table. At the start of each round of conversation, a new goal for the discussion was announced to the participants.

The world café was directed towards building on the points raised during the morning session. Table hosts were asked to maintain the discussion at the tables as needed, but to otherwise allow participants to lead. The tables did not need to reach consensus as respectful disagreements were seen as equally valuable. General table etiquette at the world café included:

- Everyone can speak, but there is no requirement;
- Be respectful and listen to others;
- Be open, honest and frank with your views and ideas;
- Challenge one another but be open to change your views.

Goals for each round of discussion were defined as:

ROUND 1: Based on the morning session, what are the three most important things that journalists and their publics need to do to improve the field? (Table-defined starting points)

ROUND 2: Why are the issues from Round 1 important? What are we placing value on by saying they are important? (Digging into the issues)

ROUND 3: What solutions can we provide based on our discussions today? What should a follow up event do to help make these solutions possible? (Next steps)

Below are brief summaries of the discussion that occurred in each table. These summaries are drawn from notes taken during the world café. They reflect the attempts of the participants to cooperatively decide on answers to the goals for each round of discussion.

TABLE 1

Host: Marie-Joseé Potvin Note taker: Haluk Dag

Table 1 discussed the responsibility of journalists to get the right information and communicate it to all audiences, thereby acting as a bridge between sources and the audience. For some this was linked to objectivity, with one participant saying that journalists should always be neutral and not express opinions. The table discussed the need for timely information during health crises and argued that the government should protect its citizens by providing information to the public and the media, thus ensuring that there is no information gap or confusion among public about health decisions. As an example, the table referred to the bird flu outbreak and argued that the



government decided not to provide any further information about the epidemic in order to lessen the economical damages. As a result, people were unsure of what measures to take and doctors felt abandoned by journalists and the government. This means that any informational bridge provided by journalists is very sensitive to inclusivity. Some participants thereby considered that health policy reporting should include more stakeholders to avoid how certain issues are overrepresented, while other important issues are disregarded. The table discussed solutions such as journalists providing more detailed information with correct terminology instead of oversimplifying scientific information, and following up on stories. However, they recognized that journalists do not have the necessary time to always provide detailed information and context, so they pointed to the need for complimentary sources such as government and community websites with information for citizens who want to get more and deeper information. Participants in this table also argued that health practitioners, health institutions and pharmaceuticals should be accessible to the media, accountable and transparent. Table 1 proposed, in order to improve health policy reporting, to hold more public engagement events in public venues and to increase collaboration between professional journalists and bloggers.

TABLE 2

Host: Trudy Lieberman

Note takers: Geoffrey Tobin and James Gibbons

Table 2 discussed journalistic practices that could improve health policy reporting. They addressed, for example, the need for journalists to know their sources very well, before they write, and to know where any funding of sources is coming from. They discussed the importance of understanding why health policy reporting is political in nature and the role for politicians in this debate. The table built on this to suggest that health reporters should do advocacy journalism as opposed to passively giving information. This would involve being proactive and pushing back against common narratives in the news, thereby taking a leadership role, rather than waiting for the public to put pressure on them to cover health issues. The table saw self-reflexivity as important to journalists seeking understand the importance this role and thereby assuming some responsibly for increasing media literacy. The table linked this idea to the need for reporters covering health issues to include a 'how to element' in their stories that could guide their audiences, and to focus not only on negative aspects but also positive ones. Participants in this table also argued that journalists should seek to change the perception of science that has led to much suspicion, and create a model of journalism that re-establishes the relationship between journalists and audiences.. Table 2 proposed, in order to improve health policy reporting, that journalists should prioritize reaching out to the public with a clear focus on building trust and appealing to the audience's value system.

TABLE 3

Host: Bryn Williams-Jones Note taker: Desireé Hostettler



Table 3 discussed that health policy reporting tends to be either too broad or too specific. Journalists therefore have the difficult task of needing to provide more information while not overwhelming or driving people away. The table linked this need to the need for new health policy stories to be told, instead of quoting the same repetitive sources and stories. They referred to the need for this additional reporting to include what went right, not only what went wrong. The table recognized that such stories create tension, but participants said journalists should not let this dissuade them and they should go out and ask questions. The table did not believe journalists could do this with complete objectivity, necessitating they use and present a wide variety of sources. Participants argued that audiences also have a responsibility to look at a variety of sources of information, but felt people usually just look for the news that interests them and ignore other information. When discussing why these issues are important, the table said that public awareness of health policy is necessary because policy decisions have an impact in their lives and journalists should educate people on this topic. In this sense, they argued that reporters should not only provide information but also challenge it and make suggestions for policy improvement. Participants, however, mentioned that the difference between people is a challenge for journalists as each person consumes news and learns differently. Table 3 proposed, in order to improve health policy reporting, public forums be held involving people with different backgrounds and different sectors of society as a way to come up a practical solutions.

TABLE 4

Host: James Falcone and Hawa Kombian Note takersa: Nana Yeboah and Olivier Crête

Table 4 discussed the importance of health journalism to inform the population about research as not everyone reads scientific papers or the latest evidence. The table asked how journalists can make research results more clear and enjoyable to read. Discussions touched on news selection and how some stories are given more attention, for example, how breast cancer receives more coverage than other health topics. But the table recognized that health policy is hard to cover as there is not always a strong human interest angle to make it relatable to audiences. This discussion was related to the table noting the issue of reporters using the same sources and arguing that quoting the same experts over and over can get questionable information presented as general, accepted knowledge. This was linked to some journalists only seeking personal prestige from their coverage, as well as the concentration of media ownership which was argued as leading to the homogenization of coverage and powerful groups gaining influence over the media. Here, the table discussed the issue of responsibility, with responsible journalists seen as fair and unbiased and responsible audiences seen as seeking access to wide range of sources and verify information for themselves. Table 4 proposed, in order to improve health policy reporting, that the media, health institutions, government, and the private sector need to work together and find common goals regarding health policy. It was proposed this should be combined with a focus on improving relations between journalists and health policy researchers.



TABLE 5

Host: Charlie Fidelman Note taker: Deirdre Keane

Table 5 discussed the responsibilities of journalists. They argued that reporters should be advocatse for the public interest when covering public health. This advocate role was discussed with regard to objectivity and journalists knowing their biases and being clear about them. The table considered it a journalist's responsibility to explain whether there is scientific evidence or not regarding a health policy discussion. This required that journalists get scientific training to be able to understand studies and assess results, while also using expert sources to assess the validity of results. They said giving equal weight to all sources is problematic, and that balance means doing justice to the topic. The table linked their discussion of responsibility to maintaining public trust, arguing that journalists need to educate people, offer more sources of information and add links to studies. Readers should also work to connect their own dots, filtering information and arriving at their own conclusions. For the table, this all added up to editors and journalists asking themselves what do people need to know and what do they care about knowing for health policy stories. Table 5 proposed, in order to improve health policy reporting, that health reporters must put provoking discussion front and centre, because debate sensitizes people and increases awareness. Understanding that there are pitfalls, or biases, or vested interests, or knowledge deficits must form an essential part of this debate.

Conclusion

In conclusion, the event "Pitfalls in Health Policy Reporting: A World Café" elicited discussion about the need for more honest, public discussion on health policy reporting. Among the diverse topics covered, five themes stand out:

- Participants identified as current shortcomings of health care reporting that most
 journalists do not seem to read scientific studies, they read press releases. This affects the
 quality of reporting because the journalists are handicapped in verifying the results and in
 consulting with other experts about studies. They also mentioned that reporters tend to
 use the same sources and this increases the risk of getting wrong or biased information to
 be accepted as general knowledge.
- 2. Participants said that in order to improve health policy reporting journalists should:
 - ➤ add value to the information they are giving by providing context;
 - ➤ be transparent about their biases; do advocacy journalism as opposed to passively giving information;
 - talk to people with real examples, real facts, as opposed to just numbers;
 - ➤ think about the audience, what they need, what they care about, and what will impact their life;



- include 'how to element', "what to do about it;"
- > get training on how to read the studies and be able to assess the validity and impact of the results;
- > consult with other experts instead of relying on one source; cite more sources and add links to studies; and
- reduce influence from powerful groups by not affiliating themselves.
- 3. Participants, however, did not lay all the responsibility on journalists, but also mentioned that researchers, health care providers, and the public are responsible. They suggested that scientists should make their information available and package it for the media, and audiences should get their information from various news outlets and should be able to evaluate their credibility.
- 4. Participants mentioned that journalism should be a bridge between experts and the public and that it is necessary to rethink the current model of journalism to re-establish the relationship between journalist and audiences.
- 5. Participants concluded that important issues are usually not debated by the public and suggested bringing together different stakeholders, such as citizens, community members, journalists, bloggers, health practitioners and scholars, to discuss health policy issues. They considered that public engagement is good for sharing ideas but not for taking action, and that a partnership could fund putting ideas into action.

It was clear that participants were interested in supporting independent, evidence-based health journalists who tell important stories about health policy issue that matter to audiences. It was also clear that participants had reservations about whether current journalism practice makes effective use of credible sources and holds experts to account for their opinions. Future work that builds on this event could focus on developing practical and testable solutions for improving health policy reporting based on the five highlighted themes to emerge in this report. Participants suggested a future event should have longer periods of table discussion with questions and objectives built from this event, include more diverse citizens, and be held outside of an academic environment in a community space.

We noted during the discussions several tensions over whether journalists have the responsibility to find all the information or if researchers should also package content for the media; whether journalists should educate the public or if it is the audience's responsibility to look for more sources of information; and how to involve different groups in discussions over health policy. There is still much to discuss and we look forward to continuing these conversations.



Appendix 1

Participant Evaluations of the Event (Aggregate Comments Only)

Maximum attendance = approx. 47 Starting the world café = 33 Total evaluations received = 16

Question 1: Global Satisfaction (How would you rate the overall success of this event?)

4.3 out of 5 (scale: 1 = poor, 5 = excellent)

Question 2: Speaker Satisfaction (How would you rate the morning panel session?)

4.3 out of 5 (scale: 1 = poor, 5 = excellent)

Question 3: World Café Satisfaction (How would you rate the world café?)

4.4 out of 5 (scale: 1 = poor, 5 = excellent)

Question 4: Descriptors (What words best describe your feelings about this event?)

informative 16 organized 12 enjoyable 11 14 stimulating well-balanced 8 inspiring 5 challenging 3 repetitious 1 0 too short too long 0 0 poorly balanced overly complex 1 other: disorganized 1 boring 0 overly simplistic 0



Appendix 2

Summary of table discussions.

What are the three most important things that journalists and their publics need to do to improve their field?

Table 1 1. Lack of information in the news. What is needed to communicate?

- 2. The news media should include more stakeholders.
- 3. News reports should be objective and include factual and objective information.
- 4. The government should protect citizens, especially during disease outbreaks. There should not be any confusion about health decisions.
- 5. Journalism has to build a bridge between sources and the public/ audience.
- 6. Some issues are overrepresented in the news media, such as bird flu, and others are disregarded.
- 7. People are more informed and educated; journalists can provide more detailed information.

Table 2 1. Journalists should know their sources very well and where the funding is coming from.

- 2. Journalists have to do advocacy journalism as opposed to passively giving information.
- 3. Increase communication with audience; the public has to know who they're listening to.
- 4. Encourage the formation of student newspapers and reach networks of older persons.
- 5. Journalists have to be proactive and push back against common narratives in the news.
- 6. Providing reporting that appeals to 'value system' of audience.
- 7. Include 'how to element', "what to do about it."

Table 3 1. Think about the audience, what they need, what they care about, and what will impact their life. Have to get the public pumped up to care, use personal stories.

- 2. Journalists have to give more information and respect that audiences get knowledgeable, but not overwhelm with details.
- 3. Responsibility to assignment editor. Not copy from one source, but find stories.
- 4. More reporting on what went right, not only what went wrong. Stories create tension, journalists should not care about that but go and ask questions.
- 5. People just look for news that are of interest to them.
- 6. Many people read headlines and think that makes them experts. Eg. social media.
- 7. Many journalists and media corporations think audiences are dumb.

Table 4 1. Journalists sugar-coat information and make populist selection of news.

- 2. Science journalism is necessary to inform the population about research because audiences don't read scientific papers. How can journalists make it more digestible for readers? Should universities' PR departments make their press releases "sexier" for the public?
- 3. Journalists have professional, ethical and social pressures. How do they select which story to cover? E.g. Breast cancer big seller compared to other health topics. Journalists should think critically, and select stories and frame them according to who their audience is.
- 4. Health policy is hard to "translate." Journalists should give the information a twist, human interest to make it relatable.



- 5. If you use the same experts over and over you risk getting erroneous/biased information to be accepted as general knowledge.
- **Table 5** 1. Journalists should advocate for public interest when covering public health.
 - 2. They should know their biases and be clear about them.
 - 3. Equal weight to all sources is problematic, but ignoring "fringe" groups is also dangerous.
 - 4. Journalists should explain whether evidence is scientific or not.
 - 5. Medical reporting can be improved by citing more sources and adding links to studies.
 - 6. Journalists read press releases and then they distort the results. Journalists should be more science literate. Journalists should get scientific training to understand studies and assess results.
 - 7. Journalists not always connect different events that are related and in that sense don't offer a complete picture.
 - 8. When writing stories they should consult with other experts so that they can assess the validity of results instead of just reproducing a press release.
 - 10. Editors and journalists should ask themselves what do people need to know?

Why are these issues important, why are we placing value on it?

- **Table 1** 1. Media should inform better about health issues, gain the public's trust, be more objective.
 - 2. There are government websites for more educated audience. Traditional media don't have time to give detailed info/context.
 - 3. Journalists tend to be lazy; they don't do their homework properly. There are also constrains: lack of resources, space/time limitations.
 - 4. Pharmaceuticals and health practitioners should be accessible, accountable and transparent.
 - 5. Journalists have a hot topic one day and a completely different topic the next day. The public does not always understand this change and gets frustrated. Journalists should finish their job.
 - 6. We should increase public engagement outside academic settings.
- **Table 2** 1. Journalists should understand the power behind sources of information, and give audiences chance to make informed decisions. Understand how to challenge power.
 - 2. Audience disapproval of journalism they don't agree with as 'bad' journalism.
 - 3. Changing perception of /discussion of 'science'; suspicion of science, thanks to conservatives: i.e. global warming, evolution. Existing affinities influence how people take the news.
 - 4. Ineffectiveness of "he said/she said" coverage.
 - 5. Rethink the model of journalism that re-establishes the relationship between journalist and audience.
 - 6. Health policy gets misconstrued as political battleground, need to understand role of politicians.
 - 7. Less advocacy, more self-reflexivity, and the journalist might state their position and how their experiences inform their work.
 - 8. Journalists need to be more independent from the media.
 - 9. Additional role for journalism as educators in science literacy.
- **Table 3** 1. It is important to also cover positive stories.
 - 2. Policy debates could be covered live. Some difficulties like people not being interested.
 - 3. Things can be left behind. If some interests are pushed forward, others are pushed behind.



This creates trust issues.

- 4. The media should make suggestions, and challenge.
- 5. Some sources are used too often. Where can people get reliable information on health?
- 6. There is a limit on reporting because there is responsibility; people do not want to be responsible. Different publics make it more challenging for journalists, different education process.
- 7. Recognizing where we stand as a person and where others stand.
- **Table 4** 1. Both journalists and readers have responsibility. Audiences should read a wide range of sources and verify the information. Journalists should attempt to maintain fairness and limit biases.
 - 2. Media corporations own news networks and homogenize reports. Funding from powerful groups can influence coverage. Journalists can mitigate these influences by not affiliating themselves.
 - 3. Many journalists look for prestige. Balanced articles may not incite limbic reactions.
 - 4. Contradictory information in the media makes messages confusing.
- Table 5
 1. Journalists shouldn't report on topics without scientific evidence.
 - 2. Balance means doing justice to the topic. There aren't just two sides, all sides are not equal.
 - 3. Journalists need to educate the public, offer more sources of information.
 - 4. Readers should also connect the dots, the user is also responsible for filtering information.
 - 5. Many people don't evaluate the sources. People look only for the information that interests them.
 - 6. Journalists should try to provide context, be fair and provide examples. They have the responsibility of gaining the trust of readers, shouldn't just transmit information but add value, context.
 - 7. Researchers also have the responsibility to communicate all aspects of their research.

What should the next event do, what is there left to do, what could the next thing look like?

- **Table 1** 1. The media does not want to publish negative results, only positive ones. Conflicting interests.
 - 2. Specialization of journalists could be part of the solution, including more science training.
 - 3. Collaboration between professional journalists and bloggers.
 - 4. Discussion between citizens, community members, journalists, bloggers, and scholars.
 - 5. People don't trust science/scientific terms, no matter the evidence.
 - 6. Citizens should learn how to read through journalism. Media literacy should be increased.
 - 7. People don't trust journalists because today anyone can be a writer/journalist.
- **Table 2** 1. More solution-oriented stories focus more on moving forward.
 - 2. Few health reporters, not as attractive or valued as sports reporting.
 - 3. Educate people about differences, failures of previous reporting (avoid generalization)
 - 4. Understanding the role of advocacy, the pitfalls of objectivity, and the role of self-reflexivity.
 - 5. Separating the information from the journalist.
 - 6. Understand why health policy reporting is very political in nature.
 - 7. Reconsider the journalist-audience relationship.
 - 8. Being aware of our roles as community members
 - 9. Focus on audience reception.



10. Push back against the capitalist drive of publications.

Table 3

- 1. Communication through public forums. Involve people with different backgrounds and different sectors of society to come up with something practical. Ask people what is important to them.
- 2. The public also has responsibility. There has to be an outreach section where journalists act as mediators.
- 3. Journalists need to reach all sorts of audiences. Poor people need to be included as well.
- 4. Journalists should not be afraid to take a position and be transparent about it.
- 5. Both journalists and public health agencies are responsible to get their message out. Need support of the media to present and evaluate information.
- 6. Journalists have a responsibility because people make decisions based on media messages.
- 7. Bridge different departments together: Journalists, private sector, doctors, etc.
- 8. Public engagement is good for sharing ideas but not for taking action. A partnership could fund putting ideas into action.

Table 4

- 1. Health institutions, government, private sector need to work together towards common goals.
- 2. The media should provide the public with more information with panels and public discussions.
- 3. Academics distrust the media and don't communicate their research. This leads to possible distortions of information. There should be better relations between scientists and the media.
- 4. In trying to make stories more relatable journalists can miss important points or throwing stories out of context. They usually only use the 'juiciest' part of studies to make the front page.
- 5. There should be assignment editors who are well versed in health issues and research. Journalists have time constraints so they cannot do the necessary research.
- 6. Journalists should be better educated in order to interpret health research. Academics shouldn't be doing the journalists job in packaging the information for the media.

Table 5

- 1. It is up to individuals to be curious and search out the information, from different sources.
- 2. Journalists should provide as much information as possible and relate it to their audiences.
- 3. Give access to information to people with all levels of income and education.
- 4. Media should rely less on sensationalism and hype and just do the digging.
- 5. Include various sources. Journalists who have expertise in a topic could also be interviewed.
- 6. Facilitate information flow between different platforms and media.
- 7. Knowing the science jargon to be able to translate to the public.
- 8. Not just inform but give suggestions about what to do.
- 9. No easy solution, keep provoking discussion. Debate is important, it sensitizes people and increases awareness.
- 10. Understanding that there are pitfalls, biases, vested interests, and knowledge deficits are all part of it.



Appendix 3

Primer on the Pitfalls in Health Policy Reporting

This primer is intended to stimulate your thinking before the World Café. As an accessible introduction, it is not intended to encompass all available information, viewpoints and opinions. Instead, we expect you to bring your expertise, your views on missing but vital topics, and your energy to the event to build new knowledge on the topic.

1. Introduction

A key element of our lives is our health and the health of our loved ones, because without our health, other aspects of our lives are not as easily enjoyed. Much of what we do is motivated by our desire to maintain good health. People use seatbelts and install child seats in their cars, people avoid smoking, excessive sun, and junk foods, people take vitamins and buy gym memberships, all to get healthy, and stay healthy.

Whether we realize it or not, everything we believe about healthy living, we learned at some point. It may have been while we were younger and in school, or later in life from newspapers, magazines and television, or on the internet. Even the things our friends and family tell us usually come from somewhere, some outside source of information.

The key questions are: How accurate and up to date is this information? What is the information founded on? Does it represent the best knowledge, the latest findings? Or is it outdated, inaccurate, even false? And who is responsible for determining and communicating the answers to these questions?

2. Medical research creates evidence

Our understanding of health isn't static. It's constantly changing. A food that was considered healthy in 1993 may be called unhealthy in 2013. A drug that was commonly prescribed just last year may be considered dangerous today. Medical researchers are continuously adding to our understanding of what is safe and unsafe, healthy or harmful. Every year, thousands of tests and studies are conducted on everything from foods, drugs, toys and activities, and the results of these studies are published in journals, where they are read and discussed by experts in each field.

This is where most of our knowledge of health comes from. Medical research produces evidence that tells us what foods, drugs and other products are considered safe and beneficial, and informs



how doctors treat their patients. This evidence potentially informs how people think about their own health care and the sustainability of the health care system.

3. Evidence informs policy

This continuous flow of new medical evidence also informs our governments and institutions. When a chemical is found to be dangerous, the government can ban its use. When a pharmaceutical drug is shown to cause serious side effects, doctors can stop prescribing it to patients. When a food is found to be unhealthy, school boards can decide to stop serving it to children. These are examples of how new evidence changes policies: the laws, rules and other guidelines that govern what happens in every area of our society.

But how do Canadians find out about this new evidence, and the new policies that are based on it? The general public can't be expected to read all of these studies. People might not have the time or the interest to read them, or the specialized education and training to effectively use them. What if I have gallons of that chemical sitting in my garage? What if I'm still taking that drug? How will I know when my own understanding of what's healthy and safe is out of date?

4. Journalism informs the public (and policy makers)

At its best, journalism is one system that informs the public about new health information and policies. Journalists find out about the latest studies and interview researchers, and they present the results to the public in a way that's clear and understandable. Journalists also read policy documents, attend government press conferences, and tell the public about new laws and policies. Their work often produces good journalism.

Many expect health journalism to function as a bridge between medical experts and lay people, between government departments and citizens, and often journalists do just that. (Although, not everyone agrees this is the proper role for journalists who can produce a wide variety of storytelling and reporting for a wide variety of business, political and personal reasons.) But fulfilling this role requires much more of the journalists than simply receiving and transmitting health and policy information. It also puts journalists in the difficult position of navigating between powerful competing agendas.

For example, ambitious universities and medical journals can issue hyperbolic press releases trumpeting 'cures' which might only amount to minor advances. Academics may oversell their expertise on a topic to get airtime, headlines, and funding for a future project. On the policy front, think tanks will push ideological agendas, politicians will pitch a popular idea which is not based on evidence to win votes, pharmaceutical and insurance companies will fund advertising campaigns to sway the public and benefit their bottom line. These competing interests of ambition, profit and popularity are the minefield that a health journalist has to pick their way through to find the evidence and seek the balance. Journalism is also consistently evolving as



new forms of media and technology (for example) intertwine with a long history of debate over journalistic practices, differing expectations, story choices, deadline pressures, framing, context, omissions, and hype.

5. Journalism isn't perfect

But even when good evidence is available, journalism doesn't always function well. Sometimes, journalists fail to recognize the significance of a particular study or policy, and as a result, the public doesn't find out about it. Other times, journalists misunderstand the finding and misrepresent them to the public, causing confusion. In some cases, journalists even sensationalize, exaggerate, or dismiss the information, causing either too much concern, or not enough. When the topic is sports or Hollywood, this might not be a big deal, but when the topic is health, journalism's failures can have very real consequences.

Example 1: The SARS outbreak

News coverage of the 2002-2003 SARS outbreak, which killed 774 people around the world including 44 in Canada, provided some clear examples of Canadian journalists struggling with a public health story. Journalists can have no advanced scientific or health training, and can be no more knowledgeable about Severe Acute Respiratory Disease than the average person. However, when a major health story such as SARS breaks, many non-specialized journalists are pressed into service, tasked with reporting on every facet of the outbreak.

Not surprisingly, their stories may lack the context necessary to give the public a realistic assessment of the risks. When they do try to provide context, they might accidentally generalize about infectious diseases and epidemics, further muddying the waters. They might make apples-to-oranges comparisons, such as lumping SARS in with H5N1 bird flu, which can result in an exaggerated sense of alarm.

Deadline pressures only add to the confusion, as journalists scramble to be first, even if they're less accurate. Social media can exacerbate this problem, as news is delivered in a series of rapid-fire, bite-sized, snippets that can be little more than a provocative headline, an alarming quote, or a scary number.

Example 2: The Chaoulli decision and the public/private debate

At its best, health journalism is a source of robust and comprehensive health information, while at its worst it forsakes health evidence for profit and easy stories. Health policy reporting is particularly sensitive to this flux, since the news media play an influential role in determining the broad policy agenda and how both the public and politicians perceive health policy issues.

The 2005 Chaoulli decision is a good example of a major policy event which can impact the public's understanding of the health care system depending on how it's reported. In a 4 to 3



decision, the Supreme Court of Canada ruled that Quebec's prohibition of private medical insurance violated Quebecers' rights to life and security of person under the Quebec Charter.

What did this ruling mean, exactly? The essential message was that Quebec can't fail to deliver necessary medical services in a timely manner on the one hand, and then prevent Quebecers from paying for those services themselves on the other. If Quebec wasn't willing to pay Dr. Chaoulli for his house calls to bedridden patients, it should allow his patients to pay for them.

While the case itself was relatively clear-cut, the policy implications were anything but. Much of the debate split along ideological lines, with free-market advocates touting it as proof that private health care was necessary, and supporters of the public system arguing that Medicare was under attack. Even as they refrained from choosing sides, most journalists' reporting presented the ruling and the ensuing debates in political terms.

What was often missing from the coverage was an analysis of the evidence of efficiency, affordability and health outcomes between the different health care systems. In the same way journalists may lack the medical understanding to deal with the complexity of a SARS outbreak, they can lack the understanding of medical systems and economics to assess the validity of the various policy positions. There are strengths and weaknesses in every variation of public and private health systems, but if journalists fail to present accurate evidence on these options, the public might be left with plenty of opinions, but little understanding.

6. Citizens also inform policy

In a democracy, the government is supposed to reflect the will of the people, and its policies are supposed to serve the interests of the citizens. The citizens elect the government based on their policy proposals, and Canadians take health policies very seriously.

But citizens can only make decisions based on what they know. If citizens aren't well-informed about health issues and policies, they're not in a good position to determine what's in their own interests before they vote. And once the government is in power, citizens need the facts to enable them to judge the health policies that are proposed, and whether to support or oppose those policies. Citizens who know about health policies can't influence them very effectively.

7. Now, you are the expert

Journalism plays a key role in several areas of the health policy framework, for better and for worse. The goal of this World Café is to encourage you and your fellow citizens to reflect on journalism's impact on how we understand health issues, to discuss and debate it amongst yourselves, and to provide recommendations for future improvement.

This World Café puts you in the position of knowledge-builder. Here you are invited to provide your own evidence, drawn from your own education, expertise and life experience as an



informed citizen. The knowledge you produce together can inform how journalists cover health issues, and hopefully, it will help them avoid the Pitfalls in Health Policy Reporting.

8. Further reading

Canadian health care policy:

http://www.lib.sfu.ca/help/subject-guides/health-sciences/healthcare-reform

Public vs. private health care:

http://www.cbc.ca/news/background/healthcare/public_vs_private.html

The Chaoulli ruling:

http://umanitoba.ca/outreach/evidencenetwork/archives/7807

The SARS outbreak:

http://www.ehatlas.ca/sars-severe-acute-respiratory-syndrome/case-study/sars-outbreak-canada

Five things every journalist should know about the health care system:

http://j-source.ca/article/five-things-every-journalist-should-understand-about-canadian-health-care-system

EvidenceNetwork.ca 'tools for journalists' section:

 $\underline{http://umanitoba.ca/outreach/evidencenetwork/resources/tools-for-journalists}$

Tips for understanding studies:

http://www.healthnewsreview.org/toolkit/tips-for-understanding-studies/

The future of health journalism:

http://www.resoundinghealth.com/static/Schwitzer%20health%20journalism.pdf



Appendix 4

Speakers' biographical information.

Trudy Lieberman, Columbia Journalism Review

Trudy Lieberman, a journalist for more than 40 years, is a contributing editor to the *Columbia Journalism Review* where she blogs about health care and retirement at www.cjr.org. Her blog posts are at http://www.cjr.org/author/trudy-lieberman-1/. She is also a fellow at the Center for Advancing Health where she blogs about health at http://www.preparedpatientforum.org/. Her blog posts are at http://blog.preparedpatientforum.org/blog/category/author/trudy-lieberman/. Lieberman has had a long career at Consumer Reports specializing in insurance, health care and health care financing. She was also the director of the Center for Consumer Health Choices at Consumers Union. She is a contributor to https://www.preparedpatientforum.org/. Lieberman has had a long career at https://www.preparedpatientforum.org/. Lieberman has had a long career at https://www.preparedpatientforum.org/ health care and health care financing. She was also the director of the Center for Consumer Health Choices at Consumers Union. She is a contributor to https://www.preparedpatientforum.org/ health care and health care financing. She was also the director of the Center for Consumer Health Choices at Consumers Union. She is a contributor to https://www.preparedpatientforum.org/ health care and health care financing. She was also the director of the Center for Consumer was a consumer writer for the https://www.preparedpatientforum.org/ health care and health care fin

Charlie Fidelman, The Montreal Gazette

Charlie Fidelman is the health reporter for The Gazette. She's won recognition for her health coverage including The Canadian Medical Association/Canadian Nurses Association Award and a National Newspaper Award for Beat Reporting for breaking news stories of secret practices: patients bribing doctors for care. A transplanted Francophile from Vancouver, B.C., she's a keen dog-walker and squash-player and a fan of science #longreads.

André Picard, The Globe and Mail

André Picard is The Globe and Mail's health columnist and the author of four books. He has received much acclaim for his writing, including being honoured as the top public health reporter in the 17 countries of the Americas by the Pan-American Health Organization and named Canada's first "Public Health Hero" by the Canadian Public Health Association. André is a seven-time finalist for the National Newspaper Awards, Canada's top print journalism prize. In 2012, he received the Queen Elizabeth II Diamond Jubilee Medal for his lifelong dedication to improving healthcare. André is a graduate of the University of Ottawa and Carleton University, and holds an honorary doctorate from the University of Ontario Institute of Technology. He lives in Montréal.

Daniel Weinstock, Director of the McGill Institute for Health and Social Policy



Daniel Weinstock is a Professor in the Faculty of Law and the Director of the Institute for Health and Social Policy at McGill University. Before coming to McGill, he was a Professor in the Department of Philosophy and Director of the Centre de recherche en éthique at the Université de Montréal. His published work has dealt with a wide range of ethical issues in public policy in the area of health, education, multiculturalism, to name but a few. He has also taken an active part in a number of consultative bodies created by different levels of government. In particular, he was the Founding Director of Quebec's Public Health Ethics Committee, and a member of the advisory committee of the Taylor-Bouchard Commission. Most recently, he was co-author of a report written by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making, whose arguments and recommendations have been cited around the world, from Quebec and British Columbia to Tasmania.

Amélie Quesnel-Vallée, Departments of Sociology and Epidemiology, McGill University

Amélie Quesnel-Vallée is Associate Professor at McGill University with a joint Appointment in the Departments of Sociology and Epidemiology. She holds a career award from the Fonds de recherche du Québec - Santé and is also the Director of the International Research Infrastructure on Social inequalities in health (IRIS) at McGill. With funding from the Canada Foundation for Innovation and the Canadian Institutes for Health Research, she currently studies the impact of public coverage and private health insurance regulation on health inequalities in select OECD countries. Her work received numerous awards, including the 2005 American Sociological Association Dissertation Award, and appeared in a book she co-edited, Le privé dans la santé: Les discours et les faits (Presses de l'Université de Montréal, 2008), as well as in journals such as the Canadian Medical Association Journal, the Journal of Epidemiology and Community Health, the American Journal of Epidemiology and Social Science and Medicine.



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About EvidenceNetwork.ca:

The Evidence Network of Canadian Health Policy, commonly known as

EvidenceNetwork.ca is a non-partisan web-based project funded by the Canadian Institutes of Health Research and the Manitoba Health Research Council to make the latest evidence on controversial health policy issues available to the media. This site links journalists with health policy experts to provide access to credible, evidence-based information. For more details about our project, see the recent articles about EvidenceNetwork.ca in the BMJ's Evidence-Based Medicine, Healthcare Policy, and in University Affairs.

About Fulbright Canada:

The mandate of Fulbright Canada is to enhance mutual understanding between the people of Canada and the people of the United States of America by providing support to outstanding individuals. These individuals conduct research, lecture, or enroll in formal academic programs in the other country. In doing so, Fulbright Canada aims to grow intellectual capacity, increase productivity, and assist in the shaping of future leaders. The Foundation administers the prestigious Canada-U.S. Fulbright Program. Educational exchange allows for the development of our future leaders, it encourages a more nuanced appreciation of each other, and it contributes to a more thoughtful and more reasoned public policy debate in both countries.

About Concordia Science Journalism Project:

The Concordia Science Journalism Project (CSJP) is an endeavour initiated in 2008 to establish a science journalism research and teaching platform in the <u>Department of Journalism</u> at <u>Concordia University</u>. CSJP sees science journalism as a vital endeavour that helps people make better decisions about public matters concerning (for example) our health, our environment and our safety. As scientific research accelerates its discoveries, becomes more intertwined with the media, and crosses boundaries into politics, law and ethics, it is increasingly important for citizens to have access to digestible scientific content, lest we be left with a lack of public involvement in the governance of science. The project therefore looks to actively support, better understand and improve the role of science journalism in Canada.

About Canadian Institutes of Health Research – Institute of Health Services and Policy Research:

The Canadian Institutes of Health Research (CIHR) is Canada's major federal funding agency for health research. Its objective is to excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products, and a strengthened Canadian health care system. The CIHR Institutes support individuals, groups and communities of researchers for the purpose of implementing, within its mandate, the objective of the CIHR.



Since its inception, CIHR's Institute of Health Services and Policy Research (IHSPR) has attempted to respond to the myriad of challenges entailed in its broad mandate. This has meant moving rapidly and simultaneously on a number of fronts, to address problems and opportunities relating to:

- health services and policy research capacity in the country
- the research resources needed to undertake high quality, relevant research
- research gaps and emerging issues
- the CIHR-wide priority being placed on timely knowledge translation

About the Ethics and Population Health Branch (Axe Éthique et Santé des Populations, AESP):

The AESP, a branch of the Quebec Population Health Research Network (RRSPQ), brings together researchers and practitioners interested in public health ethics, with the goal of 1) Improving research capacity; 2) Promoting collaboration among researchers; and 3) Transferring knowledge from research to practice settings. Through these objectives, the AESP aims to support the creation of a critical mass of multi- and interdisciplinary researchers concerned with ethical issues related to research and intervention in public health. Through the organization of and support for various activities (e.g., workshops, contests, the dissemination of resources), the AESP participates in discussions and facilitates exchanges between diverse stakeholders interested in ethics and public health, stimulates the interest of young researchers in public health ethics, and develops innovative knowledge transfer mechanisms.

